Original Article

Caregiver suffering of the families of the patients with Sickle cell: a qualitative study

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ABSTRACT

Introduction: Caring for patients with sickle cell is a challenging experience for their caregivers and family members. Objective: This study was aimed at describing the caregiving suffering of the families of the patients with sickle cell anemia. Materials and Methods: In this qualitative content analysis study, 22 home caregivers and patients with sickle cell anemia (SCA) were selected through purposive sampling method. Data was collected using semi-structured interviews and managed in MAXQDA software. The steps proposed by Graneheim and Lundman (2004) were used for data analysis. Results: Four classes - 1) costly treatment, 2) overwhelming care, 3) stresses faced by the family, and 4) stigma - were obtained as a result of data analysis, which were placed in "family suffering" theme. Conclusion: The results showed that the care suffering of the families with sickle cell patients exists in all aspects of life and the families of these patients need specific and organized attention and support to reduce caregiving suffering and enhance family functioning.

Keywords: Care suffering, family, sickle cell, content analysis

Introduction

Sickle cell anemia (SCA) is a severe hemolytic anemia that is caused by the inherited sickle hemoglobin gene, leading to defects in hemoglobin molecule; therefore, in case of exposure to low oxygen pressure, it becomes crystalline leading to blockage in capillaries, veins, and vascular obstruction [1, 2]. The prevalence of this disease in Iran is high in the provinces around the Persian Gulf and Khuzestan [3, 4] and among the cities of Khuzestan, the highest prevalence is observed among the native people of Khorramshahr [5].

Sickle cell is characterized by various acute painful crises, signs, and symptoms that need daily care and sometimes aggressive drug therapy [6, 7]. Given the family-centered nature of the disease, care for a person with sickle cell is considered a challenging experience for caregivers and their family members [8-11]. A study in Nigeria indicated that the caregivers were exposed to severe stress due to caring and risk of physical problems affecting their ability in care for the affected person [12]. Disease-related care suffering is among the most significant problems considered in the field of research and treatment, which refers to a certain extent of the problems stated by the caregiver or patient's family [13]. Undoubtedly, in chronic diseases, home care responsibilities, unpredictable medical costs, and uncertainty about the patient's future cause physical, economic, mental, and psychological problems to the patients and their families along with disruption to social and educational life. This will affect how the patient and his family adapt to the disease [14].

Sickle cell leaves a profound effect on the patient life and his/her family, but the focus of health caregivers is usually on

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the patient and his/her family members are not considered as the ones helping the treatment process. This is while these individuals undergo a difficult and painful process that needs assistance and support [15] as the health of caregivers and patients are closely linked and caregivers can have an important role in the health and well-being of patients with sickle cell. Literature reviews indicate that studies on the care suffering of the families of patients with sickle cell in Iran are limited and this issue has rarely been considered in previous studies, with most of them conducted as quantitative. Thus, lack of sufficient studies in this regard renders qualitative performing of this study significant as the qualitative approach could help clarify ambiguous and deeper understanding of the phenomenon. Thus, there is a need for qualitative research in this regard. Hence, the study was conducted to describe the caregiving suffering of the family members of those with sickle cell anemia in the socio-cultural and economic context of Iran.

Method:

The study used a qualitative content analysis approach and was conducted in Shahid Baghaei Hospital 2, where the patients with sickle cell and their families visited for care and treatment and were available. The population was patients with SCA and family caregivers. The participants were 22 home caregivers and patients with SCA, who were selected using purposive sampling. The inclusion criteria were having a physician diagnosis of sickle cell, ability to communicate, and willingness to participate in the study; and the criteria for selecting home caregivers were being a member or members with at least one year of care experience to the patients with sickle cell at home, the ability to communicate, and willingness to participate in the study and stating their experiences.

The researcher visited Shahid Baghaei Hospital 2 in Ahvaz after obtaining permission and code of ethics and the written consent was completed after selecting the participants. The permission was obtained from the participants after stating the purpose of the study and the confidentiality of their information and the interview data, and interviews were conducted individually in a comfortable location if they were ready to participate in the study.

Data was collected using semi-structured interviews. Initially, the researcher asked some questions to get more familiar with the participants and to establish a sincere and comfortable atmosphere, and then more specific questions in line with the purpose of the study were asked. The caregivers were asked questions such as "What pressures have you suffered in caring for the patient?" The patients were asked questions like "How has your illness affected the lives of your family members?" Moreover, to increase the depth of the interviews, exploratory questions like "What do your entourage say?" and "What costs do you mean?" were used. Demographic information was collected from each participant as well. The length of the interviews was 45 minutes on average varying from 35 to 55 minutes depending on the conditions of the participants. During the interview sessions, all participants' verbal communication was recorded and their nonverbal behaviors like eye contact and facial changes were noted and recorded as well. Collecting and analyzing data were simultaneous and the interviews were ended when the classes appeared and the data was saturated.

Using the steps suggested by Graneheim and Lundman (2004) for data analysis, at the end of each interview session, all notes, papers, and typed material were broken into the smallest semantic units or codes after repeated review and then the initial codes were compared with similar codes placed in subclasses. Then, the notes were replaced by continuous comparisons of subclasses and based on their proportion and similarity, each one was placed within the main classes containing the main themes of the study with a degree of abstraction.

Four proposed criteria by Lincoln and Guba were considered to reach data accuracy and robustness [16]. A combination of interviewing techniques like interview and writing, time integration including reviewing at different times, reviewing the transcripts of the interviews and agreeing on the codes and classes extracted by the research team were used to increase the acceptability with regard to adequate time allocation for the interview, earning the participants' trust and long-term involvement with the data extracted for the interviews. Moreover, corrective comments of the participants were used if needed to eliminate any ambiguity in understanding what they intended.

Results:

In this study, 12 patients (6 women and 6 men) and 10 home caregivers (7 mothers, 1 spouse, 1 father, and 1 brother) participated. The mean age of the patients was 29 years and the mean age of caregivers was 47 years. The participants had bachelor's degree (n = 3), associate's degree (n = 1), diploma (n = 4), and less (n = 9). Five participants were still continuing their studies.

Four classes - 1) costly treatment, 2) overwhelming care, 3) stresses faced by the family, and 4) stigma - were obtained as a result of data analysis as follows.

1. Costly treatment

1.1. High costs of health services:

The participants talked about health expenditure as one of the problems after diagnosis:

"The hospital is so costly to us right now. We have to pay a lot when we are hospitalized and it is not free." (Mother, 42 years old)

"I was hospitalized for two nights just two days ago and they charged me a hundred and something." (A male patient, 38 years old)

"Two of his joints have been worn out and have a joint replacement. They tell us we have to take it without social security insurance. It is really expensive to us…" (Mother, 29 years old)

"We have to pay even to do MRI…" (A male patient, 35 years old)

Patients and their parents also talked about buying medicines and lack of insurance assistance.

"I have to buy hydroxyurea and folic acid pills, salbutamol, and some other drugs…. Well, how can I pay for them? I cannot buy them anymore as I have no money …" (A female patient, 27 years old)

1.2. Transportation costs:

The financial problems made the patients and their families suffer even when they visited the health center. In this regard, the families stated:

"I brought him in. I paid 150,000 tomans as taxi fare to bring him here." (Father, 62 years old)

"… I get a million tomans a month, and I pay more for the car and the taxi fare to take him here and away…" (A mother, 58 years old)

1.3. Financial poverty

Poverty and financial inability and also lack of proper housing and employment are among the major pressures for these patients and their families.

"We are financially poor, his father is unemployed, he wants assistance and needs good food, but I cannot provide him with those…" (A mother, 36 years old)

"Good nutrition is costly and my family cannot afford it …" (A male patient, 29 years old)

2. Overwhelming care

Care for a sickle cell patient imposes a significant burden on family members, which can be due to their responsibilities for patient care and interfering with the routine care of the sickle cell patient. Regarding this, the participants stated:

"My mother has three patients at home and she is bothered so much and gets tired while caring for three patients …" (A female patient, 27 years old)

"Now my dad has to do my job in the shop and cannot do his job and my mother leaves home to come with me" (A patient, 33 years old)

3. Stresses faced by the family:

A chronic illness like sickle cell causes many emotional and psychological problems that affect family members.

"… Our major problem is just this: the pain that has plagued us and has made us suffer…" (A mother, 48 years old)

"…When you see a loved one is suffering, so are you. When he suffers, I suffer more… "(A mother, 56 years old)

4. Stigma

One of the major complaints of the participants was the discrimination of the community, the different look, and the labels given to the patients by those around:

"We heard a lot… Think about it, when there was a marriage issue, they even told my grandmother that we are a disabled family…" (A female patient, 27 years old).

"Our town is very small and everyone knows each other. When someone comes to ask for her hand, they tell she is disabled and is good for nothing." (A mother, 57 years old)

Table 1: The main and sub-classes forming the family suffering

Semantic units	Subclass	Main class
High cost of hospitalization Hip joint charge financial load Costly medicines High cost of diagnostic procedures	High cost of health services Transportation costs financial poverty	Costly treatment
Difficulty of care for several patients in one family Interference of patient care with everyday life Failure to meet the needs of other children	-----	Overwhelming care
Losing family members' morale Family psychological distress in case of pain Mother's crying during pain attacks	-----	Stresses faced by the family
Disabled label by those around Disabled label by relatives Disabled human label Incompetence Label	------	Stigma

Discussion:

The results of the study showed the problems and challenges faced by family members of the patients with sickle cell in care for them. One of the results is costly treatment, showing the financial challenges faced by caregivers while receiving hospitalization services, surgery, procedures, diagnostic tests, and buying medicines. In the study by Kaoff et al., the majority of costs associated with sickle cell (80.5%) were related to hospital care [17]. Moreover, in many studies, such as the one by Adgook et al., the costs needed for surgery for children with sickle cell accounted for 5.5% of total annual costs and 16% of annual revenues had been spent on diagnostic tests [18], which is in line with the present study.

Long-term use of medicines in the patients with sickle cell and the government's non-inclusion of the disease as a specific disease, and thus, the need to pay for long-term medication purchases have increased the severity of patients' economic problems. In the study by Kaoff et al., 3.6% of the disease cost was related to the prescribed medication [17].

Another care problem of the families was the transportation cost of the patients to get health care. In the present study, as the families often resided in rural areas or small towns in the province and the only care center for these patients is located in Ahvaz and in the center of the province, they had to spend money though less to refer to the center, which could be a great

portion of the budget of these poor families. In a study by Yousefi et al., the costs associated with patient transportation to access health care constituted a significant portion of the direct costs of household health expenditure [19].

Financial poverty has been another problem for families, which results in inadequate nutrition and amenities that have made some families even to borrow from others. Similar studies have shown a relationship between caregivers' financial status and their caregiver suffering so that caregivers with low incomes or occupational status are affected by their patient care process [20-25].

Moreover, most of the duties and responsibilities of care are home-based and performed by the primary caregivers showing the overwhelming care of the family at the time of the pain attack, including activities like helping the patient to receive medication, assisting with pain relief during periods of attacks, etc. Similar results have been reported in the study by Tuel et al., which are consistent with the present study [26].

Another significant result of the study is the stress faced by the family. As sickle cell disease has a long-term process and is considered as a chronic disease, families may experience feelings of hopelessness, anxiety, anger, and guilt, and may have difficulty adjusting negative emotions [27]. In a study by Hoffman et al., post-traumatic stress disorder was confirmed in the parents of children with sickle cell [28]. The results of these studies are consistent with the results of the present study.

Another result was the stigma posed by the entourage, which verbally or non-verbally had bothered the parents or the patient, which can be due to the cultural poverty and ignorance of people with this disease, clearly observed in Iranian culture. In the study by Ola et al., the people with sickle cell had experienced negative reactions from relatives, friends, and other community members [29].

Conclusion

The results of the study showed that caring suffering exists in various aspects among the families of sickle cell patients, which can decrease the level of patient care and endanger the physical and mental health of the caregiver. Thus, it is recommended to consider the role of these people in the treatment of patients in the planning of the health system and cover them by financial support, insurance, educational, and medical counseling. Moreover, the necessity of culturing in the community and informing the public about the disease and changing the attitude of the people towards these patients and thus the reduction of these people and their families are felt.

Limitations:

Among the limitations of the study, one can cite the mental status of the subjects during the interview, which could affect the responses and was beyond the control of the researcher. Another limitation was the interruption of the interview process due to some reasons, like parents being called by the medical staff and physicians or patients.

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References

1. Adeyemo TA, Ojewunmi OO, Diaku-Akinwumi IN, Ayinde OC, Akanmu AS. Health related quality of life and perception of stigmatisation in adolescents living with sickle cell disease in Nigeria: A cross sectional study. 2015;62(7):1245-51.
2. Rahimi M, Asadi Zaker M, Kykhaii Dehdez B. The Effect of Aerobic Exercise on O2 Saturation in Children with Sickle Cell Trait. Medical science Journal of Jundishapour 2012;11(3).
3. Sehlo M G, Z. KH. Depression and quality of life in children with sickle cell disease: the effect of social support. BMC Psychiatry. 2015;15(78):2-8.
4. Brandow AM, Brousseau DC, Pajewski NM, Panepinto JA. Vaso-occlusive painful events in sickle cell disease: impact on child well-being. Pediatr Blood Cancer. 2010;54(1):92-7.
5. Ahmadzadeh A, Moghtaderi M, KH. Z. Neonatal Screening for Sickle cell Disease in South West Iran: a pilot Study. Iranian Journal of Blood and Cancer 2011;2(4):117-20.
6. Piel FB. The present and future global burden of the inherited disorders of hemoglobin. J Hematol Oncol Clin North Am. 2016;30(2):327-41.
7. Dampier C, Lieff S, LeBeau P, Rhee S, McMurray M, Rogers ZJPBC. Health-related quality of life in children with sickle cell disease: a report from the comprehensive sickle cell centers clinical trial consortium. 2010;55.
8. Olatunya OS, Ogundare EO, Fadare JO, Oluwayemi IO, Agaja OT, Adeyefa BS, et al. The financial burden of sickle cell disease on households in Ekiti, Southwest Nigeria. Clinicoecon Outcomes Res. 2015;7:545-53.
9. Ohaeri JU, Shokunbi W. Psychosocial burden of sickle cell disease on caregivers in a Nigerian setting. J Natl Med Assoc National Medical Association. 2002;94.
10. Modell B, Darlison M. Global epidemiology of haemoglobin disorders and derived service indicators. J Bull World Health Organ SciELO Public Health. 2008;86.
11. Kell RS, Kliewer W, Erickson MT, Ohene-Frempong K. Psychological adjustment of adolescents with sickle cell disease: relations with demographic, medical, and family competence variables. J Pediatr Psychol Soc Ped Psychology. 1998;23.
12. Adegoke SA, Kuteyi EA. Psychosocial burden of sickle cell disease on the family, Nigeria. Afr J Prim Health Care Fam Med. 2012;4(1):380.

13. Idstad M, Ask H, Tambs KJBPH. Mental disorder and caregiver burden in spouses: the Nord-Trøndelag health study. 2010;10(1):516.
14. Erdem E, Korkmaz Z, Tosun Ö, Avcı Ö, Uslu N, Bayat M. The burden of care in the mothers of the children with chronic disease. Journal of Health Sciences. 2013;22(2):150-7.
15. Santo EARdE, Gaíva MAM, Espinosa MM, Barbosa DA, Belasco AGS. Taking care of children with cancer: evaluation of the caregivers' burden and quality of life %J Revista Latino-Americana de Enfermagem. 2011;19:515-22.
16. Lincoln Y, Guba E. Naturalistic Inquiry,. ed t, editor. London, UK Sage Publications; 1985.
17. Kauf TL, Coates TD, Huazhi L, Mody-Patel N, Hartzema AG. The cost of health care for children and adults with sickle cell disease. Am J Hematol. 2009;84(6):323-7.
18. Adegoke SA, Abioye-Kuteyi EA, Orji EO. The rate and cost of hospitalisation in children with sickle cell anaemia and its implications in a developing economy. African health sciences. 2014;14(2):475-80.
19. Yousefi M, Assari arani A, Sahabi B, Kazemnejad A. Direct and Indirect Costs of Household Health Expenditure %J Hospital. 2014;12(4):51-61.
20. Deniz H, Inci F. The burden of care and quality of life of caregivers of leukemia and lymphoma patients following peripheric stem cell transplantation. Journal of psychosocial oncology. 2015;33(3):250-62.
21. Klassen AF, Raina P, McIntosh C, Sung L, Klaassen RJ, O'Donnell M, et al. Parents of children with cancer: which factors explain differences in health-related quality of life. International journal of cancer. 2011;129(5):1190-8.
22. Rha SY, Park Y, Song SK, Lee CE, Lee J. Caregiving burden and the quality of life of family caregivers of cancer patients: the relationship and correlates. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2015;19(4):376-82.
23. Shieh SC, Tung HS, Liang SY. Social support as influencing primary family caregiver burden in Taiwanese patients with colorectal cancer. J Nurs Scholarsh. 2012;44(3):223-31.
24. Wang J, Shen N, Zhang X, Shen M, Xie A, Howell D, et al. Care burden and its predictive factors in parents of newly diagnosed children with acute lymphoblastic leukemia in academic hospitals in China. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2017;25(12):3703-13.
25. Wang L-J, Zhong W-X, Ji X-D, Chen J. Depression, caregiver burden and social support among caregivers of retinoblastoma patients in China. 2016;22(5):478-85.
26. van den Tweel XW, Hatzmann J, Ensink E, van der Lee JH, Peters M, Fijnvandraat KJHH. Quality of life of female caregivers of children with sickle cell disease: a survey. 2008;93.
27. Wonkam A, Mba CZ, Mbanya D, Ngogang J, Ramesar R, Angwafo FFJJGCS. Psychosocial burden of sickle cell disease on parents with an affected child in Cameroon. 2014;23.
28. Hofmann M, de Montalembert M, Beauquier-Maccotta B, de Villartay P, Golse BJAJH. Posttraumatic stress disorder in children affected by sickle-cell disease and their parents. 2007;82.
29. Ola BA, Yates SJ, Dyson SM. Living with sickle cell disease and depression in Lagos, Nigeria: A mixed methods study. Social Science & Medicine. 2016;161:27-36.