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VULNERABILITY IN ADULTS WITH SICKLE CELL DISEASE: SUBSIDES FOR NURSING CARE[1]

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ABSTRACT
This study was developed with the aim to get acquainted with the aspects related to the life of an adult with sickle cell disease. For this purpose, the concept of vulnerability (social, individual and programmatic) was used pointing out to the elements of nursing care. This is a descriptive study of qualitative approach whose data were collected from February to June 2011 through semi-structured interviews performed at the household of 12 adults with sickle cell disease in a municipality in Bahia. The results show that the basic analytical plans of vulnerability, although verified separately, are interdependent and in an active process showing little understanding of the people regarding the disease due to late diagnosis. Moreover, this study also indicates little power to change attitude and behavior of the patient; lower income class and little education of the patient and his/her family, difficulty to the access of health services and inadequacy of emergency care service. It is necessary the organization of care in health services acknowledging the vulnerable aspects of it as well as the improvement of the access to equipment and social, cultural and economic opportunities offered by society and the state.

Keywords: Hemoglobin SC Disease. Vulnerability. Adult Health. Quantitative Research. Nursing Care.

INTRODUCTION

Sickle cell disease in Brazil presents significant epidemiological and clinical importance because of prevalence. This one has varied from 0.1% to 0.3%, depending on the region, the studied group and the morbidity and mortality[1]. The Brazilian Government has invested in the development of policies and programs designed to offer suitable assistance to these people and to spread information about the disease. The proposed actions set changed significantly the life expectancy of the people affected by this problem.

The change in the survival profile resulted in reduction of up to 40% of premature mortality, associated with the diagnosis through neonatal screening, prevention with vaccines and prophylactic antibiotics, as well as the introduction of Hydroxyurea. Adults above 40 years old with sickle cell anemia are a unique clientele, representing therefore a new reality and a challenge for health professionals, in particular for nursing care[2-3]. In addition, present continuous care demands and are people who, by chronic illness, disability and suffering, coexist with constant vulnerability state, being of paramount importance the knowledge of these conditions for the process of care.

The studies conducted by vulnerability theorist frame have as purpose to bring elements of the process of illness, of illness and confrontation that are related to every individual and to the process of care[4-5].

The concept of vulnerability has made possible a change in the attention focus, before focusing entirely on the person, to behold it as a subject of social interaction and which it is part. Originating in the field of human rights and expressing distinct perspectives of interpretation, this concept shifts the normative character of the disease control and incorporates the individual behavior, the collective and the social context in promoting human rights[6-7]. This perspective allows the rethinking and reflection on nursing care to people with sickle cell disease.

The three basic analytical plans of

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vulnerability, although discussed separately, are active and in an interdependent process[6]. *Individual vulnerability* refers to some behaviors and attitudes that create greater chance of illness, in addition to considering the correlation between the degree of knowledge that individuals have about its pathology and daily confrontation capacity. *Social vulnerability* refers to the access to information, health services, socio-political and cultural aspects, the freedom of thought degree, social welfare conditions and citizenship among others. *Programmatic vulnerability* related to the degree of government commitment, preventive and educational actions proposed by rulers, amount of investment and financing for health care, continuity and sustainability of actions and public policies among others[6-7].

It is intended to stress that the concept of vulnerability related to sickle cell disease brings the need to transcend the individual approach, biologist, for a more magnified understanding, which consider the exchanges between the human being, society and the environment in which it is inserted.

Thus, this study aimed to meet some aspects related to adult living with sickle cell disease in relation to the three basic plans of vulnerability (individual, social and programmatic), pointing out some elements for nursing care.

METHODOLOGY

This is an exploratory study, qualitative approach, whose locus of research consisted in a municipality that comprises the metropolitan region of Salvador (BA). In this municipality were identified 12 adults with sickle cell disease which, according to the selection criteria, were subject of this study.

The insertion in the community came about by active participation in a Research Project (Quality of Life and Quality of Health Care of Adults with Sickle Cell Disease) developed with funding from the Research Foundation of the State of Bahia (Fapesb). The actions were carried out in three phases.

In the first phase occurred the active search of people with sickle cell disease on the basis of information obtained from the health professionals of the Basic Units of Family Health, from the city's general hospital and contact with the community and its residents, especially community leaders. Thus, in the period from February to July 2011, were identified throughout the municipality, including the rural and urban area, twelve adults with minimum age of 18 years, with sickle cell disease, residents of the municipality in accordance with the criteria of the survey. The small number of adults found can be justified by the early mortality, reported by community workers and families in all areas visited.

In the second step, through the communitarian agents of health took place the presentation of the researchers and the awareness of the people to carry out the interview.

In the third step of the research, the interviews were carried out guided by a script containing closed issues relating to socio-demographic data, and open questions, about health and living conditions, such as: changes and challenges occurring in life associated with the disease, how assumes the role of living with sickle cell disease, what bothers and unwanted about living with sickle cell disease, difficult to live with a genetic disease. The implementation of individual interviews occurred in the participants homes, after markup, making a total of two visits to each household. The interviews, after consent, were recorded and transcribed in full.

Data analysis was performed with the use of the content analysis technique, in its thematic analysis, which identified the units of meaning with the purpose of reaching the proposed study object, by grouping them into thematic units that will lead to the categories. From exhaustive reading material, and based on the concept of vulnerability adopted in this study were constructed categories, as the set of expressions with similar characteristics that represent the vulnerabilities of people who were part of the investigation[8]. The development of the study obeyed to ethical precepts provided for in Resolution of the National Board of Health. The Research Project has been approved by the Research Ethics Committee of the Federal University of Bahia (opinion 010/2010). The request for participation in the study was verbal

and accompanied by Free Informed Consent. In the presentation of the results, the speeches are identified by the letter E followed by the number of interview, with the objective of guaranteeing the identify preservation of the persons interviewed.

RESULTS AND DISCUSSION

Individual vulnerability of adults with sickle cell disease can be related to many aspects, however, for this study was built three categories, namely: little understanding about the disease, its implications and repercussions; late diagnosis and lack of new therapies; small power of transformation of attitudes and behaviors. It is important to consider that, although included in this analytical basics plan of vulnerability, these aspects are interdependent, influence and suffer social and programmatic influence.

In this sense, it is understandable that the main issue of living with sickle cell disease in relation to individual vulnerability is the little understanding in relation to disease. Most of the adults had late diagnosis, in spite of presenting signs and symptoms of the disease since childhood. In four cases, the diagnosis occurred in adulthood, and people have little training for self-care, difficulty of treatment adherence, besides already mingle with complications.

Most (58.3%) have diagnosis of sickle cell anemia (HbSS) followed by HbSC, 33.3%, and other 8.3% have HbS Thalassemia. At the interview time, the majority already presented more than a complication associated with sickle cell disease, pointing to an increasing complexity in the trajectory of life of these people, because they were between the ages of 29 to 39 productive years. Vasoclusion crises, followed by serious bone problems and priapism, appear as the main complications, findings that are also found in other studies with adults[9-10]. The need for blood transfusions is constant in these people, which may entail risk of iron overload, organ failure and increased mortality. One of the main challenges of caring for these patients is to reduce acute and chronic complications[10].

Thus, the care provided to these people should mainly offer information about the disease to them and their families, through educational actions, which can be performed in the waiting rooms of health units and reference units, or encouraging the formation of support groups and participation in associations. These measures may offer a change in behavioral repertoire. In this way, the deal surpasses the centralism of rationality clinic, evolving into a more global perspective, in which the human being is valued in its entirety[4].

The following statements show the late diagnosis:

> Since I was a kid I felt these pains, I was hospitalized about a month, and said it was rheumatism [...] When they found out, I had more or less twenty-six to twenty-seven years. (E7).

> I have found out already with 14 years, with problem of priapism. (E10).

> For me it was the same thing to have AIDS, I didn't know what it was. (E12).

Ignorance or late knowledge of diagnosis raises limitations and denials on both individual and family network, resulting in scarce possibilities of support. There is, on the other hand, discrimination and stigma of the disease, and often erroneously considered to be transmissible by society. Although it is a disease whose discovery date of more than one hundred years, there is little investment in research of new therapies that reduce complications and pain crises[11]. It is particularly important to note that families who cohabit with a situation of chronic disease usually experience situation of fragility and vulnerability. These families need more effective care of health professionals, who offer support according to the social context in which they live. This will make them more prepared to acquire knowledge about the disease and confront the difficulties[12].

All interviewed adults had demand continuous care at home, which requires those people and their families to domain practice that make part of the daily routine of their lives. The use of medicines and usual care with wounds, prostheses, feeding, temperature

control and pain management are often made in the home space.

In relation to the classification of domiciliary care demand, the history of admissions revealed that all respondents have been admitted to the emergency unit, medical clinic, in addition to the intensive care unit. The main reason for the hospitalizations were pain crises, referred by all respondents as one of the factors that interfere in the normal course of life. Four have already been subjected to surgery, being three of splenectomy-surgery that, in sickle cell disease, still retains a high complication rate – and one for penile prosthesis implantation, after repeated sequel crises of priapism[13-14]. So all the interviewed people make continuous use of oral medication such as painkillers (12), antibiotics (2), folic acid (12), multivitamins (4), sedatives (1), as the following fragments confirm:

> Always have to be taking medication, so ... live based on medicine and that's too bad. (E2).

> The medication you're going to have to take, for the rest of your life, always taking it. So I'm taking it and do not think anything, take and bring the day by day (E3).

It is understood that, in virtue of the little understanding about the disease, the transforming power of attitudes and behaviors, mainly for self-care practices, are compromised.

In planning nursing care are of utmost importance the exchanges of information and clarifications about clinical complications and more committed organs. The involved people need to meet and listen to their own body, facilitating and preventing the identification of crises and thereby promoting self-management of the disease.

Considering the *social vulnerability*, were also built three categories, namely: pauperization conditions and low schooling, little possibility of professionalization and impossibility of locomotion in social tessitura.

The precariousness of the social and economic conditions of individuals and families involved in the research extends the social vulnerability that the disease imposes. These people rely on individual and family low incomes, ranging from one to three minimum wages. The *per-capita* income puts them below the poverty line (*per capita* of R$ 70/month). The financial collapse has been indicated as applicant situation among people with sickle cell disease and their families[15]. In this sense, are exposed the social conditions situated with high social vulnerability. The following testimonials highlight these conditions:

> I feel difficulties, because our life doesn't have a good financial condition to be doing everything right. Everything requires sacrifice. (E5).

> I worked, today I don't. I lost all my benefits and I live with R$410,00. (E11).

About education, half of respondents have high school. Have schooling is one of the main ways to achieve better social integration and make it out of a total lack to a porch on which to obtain better quality of life.

In terms of work, 41.6% have no employment bond. In addition, 25% of these people do not have their own home, living in precarious situations and refer that, even having been included in the Social Production of Housing Program, located in rural and urban areas, were not contemplated.

This difficulty to employment of people with sickle cell disease is mainly related to: individuals with disabilities-related disease; individuals with skills to work, but unable to meet the requirements of the employer, due to recurring pain crises; and individuals without skills to work due to poor schooling. The testimony of the respondent E8 is illustrative:

> The undesirable is unemployment. Here I practically have no high school degree. I asked for a job at City Hall and I was not accepted [...] Including, handed over 200 houses in the town and I couldn't, didn't give me a house. Here the coldness is too much, is very moist.

Considering the self-declaration of race/color, 91.6% of respondents declared themselves black. Studies show that race/color are social markers that influence the degree of vulnerability of certain groups to health aggravations, like discrimination, abuse of alcohol and drugs[16]. The vulnerability related to race/color in Brazil has also been described in other chronic disease research, pointing to a situation of pauperization of these people increased by condition of illness, as

demonstrated by the following transcript fragment.

> Because of lack of support, sometimes, I play myself in drink, to see if I forget the problems. There I get a week or fifteen days without medication, and ends up getting worse.(E8).

In reference to *programmatic vulnerability*, were also built three categories, namely: actions in the face of difficulty of access to health services and drug therapy, ignorance of health professionals on disease management and implementation of Comprehensive Care for People with Sickle Cell Disease Program and quality of emergency care services.

In 2001, the Ordinance GM No. 822 created the National Neonatal Triage Program, including screening for hemoglobinopathies[17]. With the purpose of consolidating this initiative in 2005 was published the Ordinance No. 1.391, which established, in the SUS range, the National Policy of Comprehensive Care for People with Sickle Cell Disease and other hemoglobinopathies.[18] Also apprehend transformation initiatives of commitment in action, when they adopt measures that are incorporated in assistance to pregnant women with sickle cell disease, establishing standards techniques, promoting training of human resources, setting operational instruments and health education.

All the people who participated in this study were specialized monitoring in the capital state, but due to the financial situation, have difficult to perform biannual follow-up in specialized unit, as the National Policy of Integral Care referred to people with Sickle Cell Disease. The Ordinance No 55/99[19] of the Health Assistance Department provides costing expenses for transportation, meals and lodging for the patient and their accompanist, in case of need to give continuity to the off-site treatment of domicile. The deponents register this difficulty:

> If my city have an hematologist, to be taking care of sickle cell anemia, professionals, in this case, as nurses and other, it would be very good for us, you know? Very good. (E5).

> It's too bad, because it's far away and does not have transport to get there. Take the bus and I have to leave too early, it's very bad. (E1).

However, adults with sickle cell disease participants of this study do not receive the benefits provided by law, denoting the presence of restricted State intervention on diseases, health network maintained by SUS as well as the difficulty of access to government social programs.

That way, it is necessary to consider the need for public policies geared not only to the health care of adults with sickle cell disease, but also actions that promote and facilitate improve living conditions, with less fragmented public policies, that take into consideration the human being and its biological, social and psychological needs.

Despite the recognized potential of Family Health Teams, there was the presence of structural and operational factors that hinder access of these persons to Family Health Units. None of the respondents is accompanied by the health team spanning territory. Problems of articulation with other social resources, lack of training and emptying of the strategies of care, such as counseling and home visits, end up limiting the potential of the Family Health Team for programmatic vulnerability reduction. E2 's testimony makes known the terms of service to which have access in Community Health Center:

> The community Health Post, I just use to take request and the medication I take. I buy, it's hard to take into the post. (E2).

The majority of respondents reported difficulties of access to the network of complementary examinations which, as a rule, are not available in the basic services of health, prompting them to seek units with superior diagnostics and pending long deadlines for service. The search for the urgency/emergency units happens, mainly, as a result of painful crises, infection, stroke, but is also related to the unpreparedness of the basic network, the little training for self-care, the skepticism of professionals about the authenticity of the pain and to conduct about the pain crises. When these people resort to basic health services or urgency, find insecure professionals, unprepared to care people and their families[20]. The following testimonials are illustrative:

> Here had no doctor who knew what I had, didn't know how to do and didn't even know what was priapism. (E10).
>
> They have no knowledge to meet people with sickle cell disease. Ability, everyone has, but knowledge to meet the people, does not. (E5).

It is understood that the reduction of programmatic vulnerability through advancements in some points, such as: registration of people with sickle cell disease; improving the access of people in the state to the referral service with implementation of regional units, as stated in the State Program of Attention to People with Sickle Cell Disease; creation of an attention network, based on the basic care and continuing education.

So, based on this understanding, emphasizes that the guiding elements for the nursing care must contemplate listening what these people have to say about their lives, trying to see beyond what is possible to be talked about, observing the posture that the body shows, the look and the difficulty of expressing feelings.

As the experience of sickle cell disease is strongly present in the body, it is necessary to perform a complete evaluation of how the pain points are physically. It is necessary to understand what these people seek to their lives and how to make them more participants in the care of themselves and the choices they have to perform, so that care can constitute collision where the vulnerabilities are recognized.

FINAL CONSIDERATIONS

The adult with sickle cell disease coexists with difficulties inherent in people with chronic diseases, as well as those specific disease whose prevention, treatment and rehabilitation are still neglected by the Government.

Decrease the individual, social and programmatic vulnerabilities depends on effective planning, management and evaluation of public policies for people living with sickle disease and their families. Thus, the way to attend these people involves natural care of complex nature, continuous and intense. The association of vulnerabilities is revealing the urgency to undertake actions that qualify for health care services and improve access to equipment and social, economic and cultural opportunities offered by society and the State.

In this sense, it is important to rethink nursing professional action, taking into account the importance of its transformer role, because what is expected is to build a process of transformation and growth in the health care space.

This study had no claim to exhaustive, however the use of the components of vulnerability analysis can be a viable tool to signal how these issues influence the nursing care. Although small, the number of informants represented 100% of people identified with diagnosis in the municipality, and the results are similar to those found in other national and international studies.

Conformation of nursing care, it is necessary to take the patient place and their needs as a starting point for the intervention, recognizing the other as a subject of care, use the pain rating scales, see the manual of acute events, not forgetting the only human being each person is that reacts to experience quite peculiar. Therefore, the nursing care must respect the individuality and promote growth.

VULNERABILIDADE DE PESSOAS ADULTAS COM DOENÇA FALCIFORME: SUBSÍDIOS PARA O CUIDADO DE ENFERMAGEM

RESUMO

O presente estudo foi desenvolvido com o objetivo de conhecer aspectos relacionados ao viver do adulto com doença falciforme com base no conceito de vulnerabilidade (individual, social e programática), apontando elementos para o cuidado de enfermagem. Estudo descritivo de abordagem qualitativa, com coleta de dados entre fevereiro e julho de 2011, por meio de entrevistas semiestruturadas realizadas nos domicílios de doze pessoas adultas, com doença falciforme, de um município baiano. Os resultados apontam que os planos analíticos básicos de vulnerabilidade, embora abordados de forma separada, encontram-se num processo ativo e interdependente, denotando pouca compreensão das pessoas sobre a doença devido ao diagnóstico tardio; pequeno poder de transformação de atitudes e comportamentos; condições de pauperização e de baixa escolaridade do paciente e familiar; dificuldade de acesso aos serviços de saúde; e inadequação nos serviços de atendimento de emergência. Torna-se necessária a organização do cuidado e dos serviços de saúde com base

no reconhecimento das vulnerabilidades e na melhora do acesso aos equipamentos e às oportunidades sociais, econômicas e culturais oferecidas pela sociedade e pelo Estado.

Palavras-chave: Doença da hemoglobina SC. Vulnerabilidade. Saúde do Adulto. Pesquisa Qualitativa. Cuidados de Enfermagem.

VULNERABILIDAD DE LOS ADULTOS CON ANEMIA DE CÉLULAS FALCIFORMES: APOYO A LOS CUIDADOS DE ENFERMERÍA

RESUMEN

El presente estudio fue desarrollado con el objetivo de conocer aspectos relacionados al vivir del adulto con enfermedad falciforme con base en el concepto de vulnerabilidad (individual, social y programática), señalando elementos para el cuidado de enfermería. Estudio descriptivo de abordaje cualitativo, con recolección de datos entre febrero y julio de 2011, por medio de entrevistas semiestructuradas realizadas en los domicilios de doce personas adultas, con enfermedad falciforme, de un municipio de Bahia. Los resultados apuntan que los planes analíticos básicos de vulnerabilidad, aunque abordados de forma separada, se encuentran en un proceso activo e interdependiente, denotando poca comprensión de las personas sobre la enfermedad debido al diagnóstico tardío; pequeño poder de transformación de actitudes y comportamientos; condiciones de pauperización y de baja escolaridad del paciente y familiar; dificultad de acceso a los servicios de salud; e inadecuación en los servicios de atención de urgencia. Se torna necesaria la organización del cuidado y de los servicios de salud con base en el reconocimiento de las vulnerabilidades y en la mejora del acceso a los equipamientos y a las oportunidades sociales, económicas y culturales ofrecidas por la sociedad y por el Estado.

Palabras clave: Enfermedad de la Hemoglobina SC. Vulnerabilidad. Salud del Adulto. Investigación Cualitativa. Cuidados de Enfermería.

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