Original Article

Living with a chronic disease in a fishing community*

Viver com doença crônica em uma comunidade pesqueira

Vivir con enfermedad crónica en una comunidad pesquera

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ABSTRACT

Objective: To identify the elements that influence the assessment of quality of life made by people with chronic diseases living in a fishing community. **Methods:** Data collection was done through focus groups, with participation of 22 persons. The data analysis was guided by four generic processes: apprehension, synthesis, theorization and transference. **Results:** Three categories emerged, which represented the elements that influence the quality of life, according to these people, considering positive and negative aspects, strengths and difficulties, and conditions for the care of the chronic disease, in that community. **Conclusion:** Living in a fishing community within limited physical area, which has special social and cultural conditions, allows better interpersonal relations and favorable characteristics for chronic disease care; also, the quality of life of these patients can be improved.

Keywords: Quality of life; Chronic illness; Nursing

RESUMO

Objetivo: Identificar os elementos que influenciam a avaliação da qualidade de vida feita por pessoas com doenças crônicas de uma comunidade pesqueira. **Métodos:** A coleta dos dados foi através de grupos focais, com participação de 22 sujeitos. A análise de dados foi orientada pelos quatro processos genéricos: apreensão, síntese, teorização e transferência. **Resultados:** Emergiram três categorias, que expressam os elementos que influenciam a qualidade de vida, segundo estas pessoas, considerando aspectos positivos e negativos; facilidades e dificuldades e condições para o cuidado da doença crônica nesta comunidade. **Conclusão:** Viver em uma comunidade pesqueira, com uma área física delimitada, que apresenta condições sócio-ambientais e culturais próprias, com melhores relacionamentos interpessoais confere características favoráveis ao cuidado da doença crônica e à qualidade de vida destas pessoas.

Descritores: Qualidade de vida; Doença crônica; Enfermagem

RESUMEN

Objetivo: Identificar los elementos que influencian la evaluación de la calidad de vida según personas con enfermedades crónicas de una comunidad pesquera. **Métodos:** La recolección de los datos se realizó a través de grupos focales, con participación de 22 sujetos. El análisis de los datos fue orientado por cuatro procesos genéricos: aprensión, síntesis, teorización y transferencia. **Resultados:** Emergieron tres categorías, que expresaron los elementos que influencian la calidad de vida, según esas personas, considerando aspectos positivos y negativos, las facilidades y dificultades, y, las condiciones para el cuidado de la enfermedad crónica en esa comunidad. **Conclusión:** Vivir en una comunidad pesquera, que posee una área física delimitada, que presenta condiciones socio-ambientales y culturales propias, con mejores relaciones interpersonales, confiere características favorables al cuidado de la enfermedad crónica y al aumento de la calidad de vida de esas personas.

Descriptors: Calidad de vida; Enfermedad crónica; Enfermeria

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INTRODUCTION

Quality of life (QOL) is understood, from the concept of the World Health Organization, as "the individual's perception both, of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns"[1]. It is a broad concept affected, in a complex way, by the person's physical health, their psychological state, their social relationships, their level of independence and their relationships with the most relevant characteristics of their environment.

Quality of life does not only involve health-related factors, such as physical and psychological well-being, but also socio-environmental factors such as family, friends, job and housing. It is therefore a broad term that focuses on the conditions that allow individuals to live as they intend.

Health is widely recognized as the largest and best resource for social, economic and personal development, as well as one of the most important dimensions of the quality of life. In this way, health and quality of life are two closely related themes, as can be recognized in our quotidian lives, and with which researchers and scientists agree entirely.

Thus, health improves the quality of life and quality of life is fundamental for the individual or the community to be healthy. This implies an understanding that health is neither a conquest nor the exclusive responsibility of the health sector. It is the result of a range of social, economic, political and cultural, collective and individual factors that combine in a particular way in every society and in specific circumstances, resulting in societies with more or less health.

Quality of life should enhance a person's perspective in relation to the various dimensions of their life, not only in relation to the intensity of symptoms of their disease, as it is a subjective concept. Therefore, the quality of life is viewed subjectively(2), as the person's satisfaction with the life domains that they perceive as the most important.

These domains include: Family (taking care of the family being more important than taking care of oneself), "Functioning" to maintain independence (mental "functioning" - positive attitude - being more important than physical "functioning") Spirituality (to accept disease as a possibility for inner growth) Work (continued engagement in productive work); Socio-economic security (having financial resources to pay their bills and treatment being important to maintain independence) and Self-realization (to maintain personal growth and to be able to maintain the course of life, even though, for this, there is a need to make adjustments due to the symptoms - realistic goals)[2]. Combining quality of life with a chronic disease is a challenge for health professionals, for people that live with the disease and for their families.

Chronic disease is defined as a condition that affects the functions of the person, in their daily activities, for longer than three months, which can cause hospitalization of at least one month per year[3]. To experience chronic illness means living with one or more diseases that require long hospitalizations or readmissions. Moreover, they are incurable, leave sequelae that impose limitations of functions on the individual and involve all the obstacles and deviations from normal physiology, which have one of the following characteristics: they are permanent, leave residual disability, are caused by irreversible pathological changes, and require long period of supervision and observation of care[4].

Health is affected by the person's well-being, but well-being is much larger than health. To live well with the challenges of chronic disease requires an understanding of the impact this situation has on the body, mind and spirit of the person. Considering the human being as unique and indivisible, improvement in one aspect leads to improvements in the whole, or in the life of the person.

The care, in turn, can be understood as the basis of human existence, an essential way-to-be that reveals how it is to be human[5]. It is fundamental to sustaining life, being present in everything, as an instinct for preservation. To care is not an isolated act of one person, but a way of being in the world, i.e. how people structure and understand themselves in the world with other people[6].

In this world of socio-cultural relationships, people continue developing an understanding of reality and ways of caring. Like diverse human behavior, caring is also constructed at the cradle of personal and socio-cultural relationships. The environment in which people grow and develop presents situations of life and caring that will be solidified in everyday experiences.

The investment of people with chronic diseases in the achievement of a higher quality life can be constructed and consolidated, in a process that includes reflection on what is decisive for their quality of life and the establishment of goals to be achieved, taking as inspiration the desire to be happy.

In this study, the innovation is centered on the research location. Prior knowledge is focused on the more urbanized communities and so, the intension of this study was to recognize how cultural, social and environmental aspects of a more circumscribed community, especially with a common labor activity - fishing, influence or participate in the perception of people in respect of their health/disease and quality of life.

In this sense, our objective was: To identify the factors that influence the assessment of quality of life made by people with chronic diseases from a fishing community.

METHODS

This was a descriptive, exploratory study using a qualitative approach, developed in a fishing community in Florianopolis - Santa Catarina, which has about 800 inhabitants. This community is geographically well-defined, since access is only by boat or trail (walking).

The data collection technique used was the focus group[7], which is an in depth discussion group that explores a specific theme previously defined and limited. It is composed of 6 to 15 participants and conducted by a moderator. This technique has been used in different types of research and has the special characteristic of the use of interaction as part of the collection of data. This was desired in the study because it allowed a discussion

among people with chronic diseases about what quality of life is for them and how cultural, social and environmental aspects influence their health and/or the control of their chronic disease.

Data collection occurred from July to August 2006, by conducting two focus groups with 22 people with chronic health problems, from the 51 people, with chronic diseases attending the local health unit, who were invited by community health agents to participate in the research. The inclusion criteria established for the study were: being a patient with chronic disease and a resident of the community for over a year, being over 18 years of age and wanting to participate in the focus group. The selection of participants considered the variability and the capacity for expression of the subjects, so that they could provide rich and interesting data, sufficient to identify the factors that influence the evaluation of quality of life.

The data were recorded in MP3 and later transcribed for analysis. Qualitative analysis was concurrent with data collection, defining the need to return to the research subjects to interview or to make further focus groups.

Data analysis was guided by the proposal of Trentini and Paim[8] which involves four generic processes: gathering, synthesizing, theorizing and transference. The process of gathering encompassed the organization of data, its encoding and the formation of categories based on the identified codes.

The interpretation included the following processes - synthesis, in which associations and variations of information were examined subjectively; - theorization, where a theoretical framework was developed from the relationships recognized during the synthesis process, which was made considering the theoretical-philosophical foundation of the project; - transference, where meaning was sought for the research findings and an attempt made to contextualize them in order to socialize the results.

The research project was approved by the Human Research Ethics Committee of UFSC, process n° 128/2005 and obeyed Resolution n° 196/96 and the complementary principles of the National Health Council/Ministry of Health that define the Guidelines and Standard Regulations in Human Research. Approval was obtained by signature of the Free Prior Informed Consent Terms, by the subjects. In order to preserve anonymity and confidentiality, the testimonies of participants are identified in the text by fictitious names.

RESULTS

The categories listed below, express the elements that influence the evaluation of quality of life made by people with chronic diseases in the fishing community studied.

Living in the community: positive and negative aspects

We can say that the quality of life reflects the perception that people have about how their needs are being met, whether physical, psychological, emotional and eco-social vision from the environment in which they operate:

This is even good both for us and for everybody. It is not worth having a forest like this and then you, use the saw, axe or fire and destroy such a beautiful thing like this. Worthwhile for everyone. No use to set fire. Because you're losing nature. It has so much timber and water and vegetation, and I think that's what it has good, inside here. [...] The Coast has the water, the mountain, the vegetation, the green, and the fish. The fish are good for health (Ireno).

[...] Is a dish with shrimp, is a pretty girl in a bathing suit, enjoying the beach. Look at that tasty thing: a pile of fried shrimp, a cake ... These here are a few small sail boats that pass here a lot... a butterfly, which is very good for us to see. And one more little fish to finish (Iris).

In these quotes, the importance attached to the environment is stressed, relating human health to the preservation of nature. There is a concern in this aspect, expressing a local and global awareness, involving the risks of economic development and exploitation of nature in people's lives. The subjects emphasized that contact with nature provides a more natural diet, and that access to vegetation and the sea and the contemplation of natural beauty provides leisure for local people. This element points to the importance of this relationship with maintenance, recovery and the quality of life of these people.

Another factor cited as an essential value and relevant is living in families, considering that the members of the same family mostly live in the community, close to each other. This element seems to function as a mechanism for protection, support and the structuring of the lives of these people.

We have a family that represents everything in our lives. Our structure is the family [...] (Iris).

Although the study participants suggest that living in this community is good, they highlight some negative points, such as the geography of the region and the presence of many insects.

For me, the hill and mosquitoes are bad. (Maria).

Contradictory aspects are present in the quotes, because the contact with nature is positive, but also has disadvantages, such as the difficulties that the rugged terrain, with hills, creates for movement, making actions difficult, such as regular walking, as recommended in the prevention and control of diseases. The presence of insects is also described as a negative aspect of the area, bringing discomfort to residents.

The risk of urbanization and the consequent population growth is another factor of concern because, for them, this could bring harm to the environment and the local beauty, with the destruction of native forest and disappearance or death of the animals, prejudicing the quality of life.

A building. In the middle of such a beautiful forest is going to be made here (showing a picture with various buildings)? How many things are destroyed to make this? (Ireno).

I think a road here would be bad. How many animals are there in here? Would kill ... (Ireno)

The concern for environmental preservation is relevant, since the study site is a relatively isolated coastal region of an unspoiled

nature. Again, the ecological consciousness and the relationship established between the progress of the area and the destruction of nature is highlighted, where the forests and local fauna would be replaced by buildings and roads. Therefore, the place where people live with their families is one element that contributes positively to the quality of life, with emphasis on the value of the environment and the tranquility it offers.

Living with chronic disease in the community: facilities and difficulties

The people of the community surveyed reported having some facilities that help them live with their chronic health problem. Among these facilities, access to natural food was mentioned, they can fish, raise animals, and plant and harvest fruits and vegetables in the garden of the house.

The gift is a fish well done, well tasty for us to eat. A little chicken, that everyone here on the Coast has, chicken with chick. This helps to make the diet, because the chicken is the best, home reared, the eggs are good for everything. And only. (Iris)

Another factor is the possibility to perform physical activity, although the topography of the region is rugged with boulders and hills. Even with these environmental difficulties, people report that opportunities exist in the community to try to do something physical or mental, to control their chronic disease, such as walking and meditation.

[...] As I have bronchitis, I think, being in meetings here with friends, practicing a little sport, a sporting activity, for certain, greatly improves the bronchitis. I hike. Here, Mrs. A said that if we participate, on Thursdays, in the program of Doctor M who does meditation, does exercises. She thinks that, with the meditation, she feels really well. (Carla)

Clean air and a noise free environment, i.e. a low level of environmental pollution is considered favorable to health, which helps in improving the quality of life.

[...] Without pollution, without vehicle smoke, with no smell of fuel, without the noise of the car, motorcycle ... This here is enough for us to feel more at ease. (Ireno)

Living in a more isolated community has its disadvantages as well, especially considering that these people have a chronic disease and may present acute exacerbations and situations that require emergency assistance. In this sense, the deficient structuring of health services brings insecurity and anxiety.

The difficulty of reaching a hospital [...] if I had a crisis, certainly, I would have difficulty reaching the hospital, it would not be a very quick thing as well. (Carla)

The way the health services are structured, especially the local health unit is discussed by the subjects, relating the deficiencies to the public administration that, with political implications and interferences, does not consider the real needs of the community:

I also think that the health units, as they put it over there. The politics, if the politicians thought better about us, the Brazilian people [...] the money they throw away, they could invest more in health units and then people would not seek the hospitals so much. Having a health unit, which would be well equipped, with medication and first aid, I think it would be much better. (Carla)

This complaint demonstrates the importance of discussion regarding the need to define public policies, social mobilization for the structure and coverage of health services in areas of difficult access and lower socio-political appeal. Improving the service capacity and resolution of local services would bring more peace, security and quality of life for these people:

If we had more doctors, we would live more peacefully. We only have three times a week. (Olindina)

The unit, we go there and get the medicine to take. I do my walking, do my diet, don't eat sweet things, don't eat fat and without salt. (Demézia)

The influence of the local health unit (LHU) on the quality of life of people with chronic diseases can be measured by the ability of the service to resolve problems and attend to the needs presented by these subjects. Many of the people consider the availability of medicines used by them as a criterion for evaluating the efficiency of the LHU.

Care in living with chronic disease in the community

In the fishing community under study, it was realized that the care of chronic disease is more centered on the local health service. As a chronic disease requires continuous monitoring and care and, in many cases, continuous medication, the manifestation of care was more focused on the use of this, associated with medical consultation and carrying out examinations.

I always go to the unit, both to get medications and to be consulted by the doctor [...]. Suddenly, if the doctor thinks I have another problem, if he says that it is worsening, he gives a certificate to me or, sends me immediately to the emergency room of a hospital, in order to consult with another doctor, a cardiologist, to do an electrocardiogram ... It also helps, because then the doctor who sent will already see the case, will give the medicine to not make it worse. (Ireno)

The evaluation of the situation and the medical management of the professional monitoring are expressed as caring that helps control chronic disease. The people in the community seek to maintain the link with a professional they trust, especially at times when the disease manifests its symptoms and/or complications. When the relationship that is established, between health professionals and people with chronic disease, is one of trust and empathy, they begin to feel understood, which facilitates more active participation in their care.

I consult my pulmonologist since five years ago. Not always. Just when the bronchitis attacks me. (Carla)

No use having the disease and never going to the unit, check the pressure, diabetes, check the weight. If I am overweight, slimming. (Ireno)

[...] I come to the unit three times a week and check the pressure and the diet, not much fat, not much salt and Thursday we have here a class of relaxation and physical exercise with Dr. M. (Olindina)

[...] I do a diet with little salt and little fat. (Maria Luisa)

The care as a way-of-being is special for every human being. It presents general characteristics, but is particular to each. Understanding how best to care for oneself is the challenge of every person in the adaptation to the limitations imposed by the disease, given the individual characteristics and needs felt.

[...] I have a bicycle at home and cycle because I can not walk because I have a problem in my feet. So, the bike is what helps me. (Iris).

I take medication and am doing acupuncture [...] (Maria Luisa).

I'm doing treatment that is not massage, it is reflexology. So, I'm getting better with it. (Maria).

These quotes reinforce the awareness of adherence to treatment and the need to incorporate new practices in the care of a chronic health condition, with continual adjustments, evaluation and reevaluation due to the dynamics of its representation and evolution, as well as the constant search, by the person, for a solution for the disease.

DISCUSSION

Each community has its own peculiarities and characteristics, which will depend on geographical, cultural, economic and social aspects. Thus, in the community studied, the things which stood out more were the fishing activities and the verdant nature that affects the lifestyle of the people.

Among the positive aspects emphasized by the research participants, the place where they live was highlighted. For them, being surrounded by nature - forest, lake - gives them a better quality of life. To have access to fresh foods such as fish and shrimp, to see a pretty girl on the beach, to have a boat to ride, are factors that positively affect their way of living, helping them to maintain health.

The family continues to be constructed based on, culturally and historically determined, parental relationships. It is identified as a key element not only for the "survival" of the people, but also for protection and socialization of its components, such as in gender relationships and solidarity between generations. It represents the traditional way of life, operates as a space of production and transmission of cultural practices and guidelines, and as an organization responsible for the quotidian existence of its members, producing, gathering and distributing resources to satisfy their basic needs[9]. Therefore we can say that the responsibility and the social functions of the family do not lose their relevance, regardless of the level of community development.

The destruction of the environment has been identified as an aggravating factor for the increase in health problems. Man finds in nature his source of energy. This dynamic process of interconnection and exchange of energy can be associated with the integration of the systems that make up the human body, where its proper functioning requires an internal equilibrium that can not be established without an interaction with the external environment. Therefore, the body undergoes nature's direct influence[9].

The control of a chronic disease will require, from people, care that goes beyond usual care, which can be seen as an "alert" to the need for an awareness of self care. The people start to see themselves as better, becoming more attentive to their reactions, feeling the best way to care for themselves. In this sense, there is agreement with the finding that the quality of life construct seems to consolidate itself as an important variable, both in clinical practice and in the production of knowledge in the health area, specifically in nursing[10], as caring can contribute to and permeate this construction.

Care, such as diet control and performing physical activity, suggest a search for change in lifestyle, which the literature[11-13] shows to be an important issue in the control of chronic diseases. Health professionals emerge as educators concerned with the quality of life of the people they care for, thus performing group meetings to empower them for their self care.

Therefore, health education constitutes an essential activity to generate change in behavior. It is necessary that the nurse has knowledge and the ability to teach and thus contribute to the lifestyle change and improved health status of the person and, consequently, to improve their quality of life[14].

Following the line of thinking of the individuality of each human being in living with a chronic disease, we observed a tendency for caring that works with its energy, involving the person as a whole. Currently, many people are returning to a lifestyle that values nature and natural methods of healing. Acupuncture is one of the methods, that's core philosophy is based on the potential for self-healing of the human body[15].

The care in living with chronic disease in the fishing community represents a way-of-being and living in a small town, where people know each other and have a closer relationship with the local health service. All have been seeking ways of caring, according to the facilities encountered and the difficult characteristics of the area, aiming for quality of life in living with a chronic disease.

A more effective and human health care practice needs to understand that caring is carried out for people who are integrated beings, with actions and feelings. To be committed to the quality of life of these people is necessary, looking for strategies that promote healthier living, even with a chronic disease[16].

Thus, the fact of understanding quality of life, from the different perspective of the health-disease process of people with chronic disease, contributes to overcoming the eminently biomedical models of care, that discards and disregards, in the majority of cases, socioeconomic, psychological and cultural aspects which are important in the promotion, prevention, treatment and rehabilitation of health[10].

FINAL CONSIDERATIONS

Living in a fishing community, with a defined physical area,

which presents its own socio-environmental conditions and closeness in interpersonal relationships, confers favorable characteristics on the quality of life. Living with a chronic disease in these conditions provides a specific evaluation, with positive and negative aspects, being that, the lack of resolvability of problems by the local health service, insecurity and poor access to more complex health care, are relevant in this assessment.

The relationship of care between people with chronic disease and health professionals also has its specific features, with greater identification and proximity in the relationships, which contributes to adherence to care and control of the disease. In this sense, care for people with chronic disease in these conditions is related to the process of coping and personal, family and community adaptation to previous experiences, to the existence of similar situations, and to the socio-cultural aspects of this community when defining the type of care and assistance measures.

Given the understanding that quality of life is a subjective concept, it emphasizes the importance of the education process in health, in order to empower people to live their full potential. This empowerment includes developing ways to control their disease, such as: adequate diet, care for the environment, regular exercise, maintenance of social-affective relationships, readapting to work and others. It also implies the full exercise of citizenship for achievements, such as: adequate health services and public policies that address the quality of life expected.

It is for the nurse, as well as other health care professionals, to recognize this process, given the socio-environmental and cultural conditions of the people, their disease and the possibilities of caring. Thus, the focus of care and incentives to adopt positive attitudes in the face of chronic health conditions can contribute to improving the quality of life of these people.

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