Daily life of elderly people with motor deficiency in a Family Health Unit

Cotidiano de pessoas adultas com deficiência motora numa Unidade de Saúde da Família

Cotidiano de personas adultas con deficiência motora en una Unidad de Salud de la Familia

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RESUMO

Objetivo: o presente estudo objetivou compreender o cotidiano de pessoas com deficiência motora de uma Unidade de Saúde numa cidade do interior da Bahia. **Método:** trata-se de um estudo qualitativo com abordagem fenomenológico, de caráter descritivo, exploratório. Participaram desse estudo 29 pessoas com deficiência motora. A coleta de dados foi realizada através de entrevista semiestruturada, após autorização do Comitê de ética parecer nº 633.531/2014. Os dados empíricos foram submetidos a análise de conteúdo. **Resultados:** emergiram as seguintes categorias: o sofrimento no processo do viver com deficiência motora; a aceitação do viver com deficiência e o preconceito no conviver com as diferenças no processo relacional. **Conclusões:** esse estudo revelou que o cotidiano da pessoa diante de suas relações sociais é fundamental para a reconstrução do significado do viver com a deficiência motora.

Descritores: Imagem corporal; Pessoas com deficiência; Atividades cotidianas.

ABSTRACT

Objective: This study aimed to understand the daily routine of people with motor deficiency in a Health Unit in a city in the interior of Bahia. **Method:** This is a descriptive, exploratory study with a qualitative approach. 29 people with motor deficiencyparticipated in this study. The data collection was done through a semi-structured interview, after being authorized by the Ethics Committee by resolution No. 633.531 / 2014. The empirical data were subjected to content analysis. **Results:** The following categories emerged: Suffering in the process of living with motordeficiency; the acceptance of living with deficiency and prejudice when living with differences in the relational process. **Conclusions:** This study revealed that the daily life of the person in front of their social relations is fundamental for the reconstruction of the meaning of living with motor deficiency.

Descriptors: Body Image; Disabled People; Daily Routine.

RESUMEN

Objetivo: El presente estudio buscó comprender el cotidiano de personas con deficiência motora de una Unidad de Salud en una ciudad del interior de Bahía. **Método:** Se trata de un estudio descriptivo, exploratorio con un abordaje cualitativo. Participaron en este estudio 29 personas con deficiência motora. La colecta de datos fue realizada a través de una entrevista semiestructurada, después de ser autorizada por el Comité de Ética mediante el parecer nº633.531/2014. Los datos empíricos fueron sometidos a análisis de contenido. **Resultados:** Surgieron las siguientes categorías: El sufrimiento en el proceso de vivir con deficiência motora; la aceptación de vivir con deficiência y el prejuicio al convivir con las diferencias en el proceso relacional. **Conclusiones:** Este estudio reveló que el cotidiano de la persona frente a sus relaciones sociales es fundamental para la reconstrucción del significado de vivir con deficiência motora.

Descriptores: Imagen Corporal; Personas con Discapacidad; Actividades Cotidianas.

ORIGINAL

Introduction

Living with a motor disability requires adaptation to the standards imposed by society, which were socially constructed, dictated and standardized for normality in the presentation of bodies, in the relationship with activities of daily living, in self-care, at work and in the participation of life in society. The motor disability experience brings in its peculiarity a series of representations and meanings, which originate from innumerable factors, becoming part of the daily life that suffers great impacts with the new reality.[1]

Disability is considered as the loss or abnormality of a psychological, physiological or anatomical structure and / or function that results in an inability to perform activity, within the standard considered normal for humans.[2] Whereas, the congenital or acquired motor deficiency is related to the alteration or complete or partial dysfunction of one or more body segments. [3-4]

Motor disability is usually remembered with regret and considered a marker of disability, in the difficult adaptation of the person and the caregiver family. The way in which each individual deals with disabilities, limitations, possibilities of adaptation, self-image and body acceptance depends on factors such as psychological, emotional, social and spiritual. These factors can determine the impact on the new stage of life and the meanings that will be built in everyday life.[5]

The public exposure of people with motor disabilities is a major challenge in the process of re-signifying life, as it represents an impact for the individual and for society and for being able to provide a vulnerable image, making it susceptible to a set of stereotypes socially constructed by unfamiliarity.[6]

This study is justified by the need to understand which aspects related to the person's daily life have the potential to re-signify living with motor disabilities, and no other studies were found that analyzed this relationship, after a survey conducted in the Virtual Health Library database (VHL) in April 2014. However, it is important to highlight that studies on motor disabilities and investments for the inclusion of people with such disabilities have been growing, however the aspects related to the daily lives of these people still require further investigation. Thus, it is questioned how daily life impacts the reconstruction of living with motor disabilities?

In this study, we consider as daily the way of life that are shown on a daily basis, through their interactions, beliefs, values, meanings, culture, symbols, which outline their process of living, in a movement to be healthy and get sick, punctuating your life cycle.[7]

It has scientific relevance for contributing to the production of knowledge about the daily lives of people with motor disabilities, which can foster further research. It also has social relevance, as it affects reflections that can serve as a basis for the development of public policies and actions that condition improvements in the conditions for the reintegration of people with motor disabilities into society.

Thus, this study aimed to understand the daily lives of people with motor disabilities in a Health Unit in a city in the interior of Bahia.

Method

This is a qualitative study with a phenomenological approach, with an exploratory and descriptive character. The study group consisted of adults with motor disabilities who lived in a neighborhood on the outskirts of Feira de Santana, state of Bahia, and were assisted by a Basic Health Unit.

The participants were included in the study based on the following inclusion criteria: individuals of both sexes, adult age group, who had some type of motor disability and who were able to verbalize about their current health condition and about the experiences they had with disabilities in your daily life. The study did not consider people with motor impairment associated with difficulties in communicating and with cognitive impairment.

Before data collection, scholarship holders, volunteers and community health agents participated in training carried out by the tutor of PET-Redes Attention to People with Motor Disabilities on: motor disabilities, data collection techniques through semi-structured interviews and other related aspects the interview.

Data collection took place through the application of a semi-structured instrument after the participants signed the Free and Informed Consent Form. Following the design of the phenomenological study, the data collection technique allowed the free expression of the participants, based on reports of the experiences lived in their daily lives and how they faced these difficulties.[8-9]

The interviews were conducted at home, between the months of July and December 2014, by scholarship students and volunteers from PET-Networks Attention to People with Motor Disabilities. The interviews were scheduled by the Community Health Agents (CHA) of the referred UBS, who also accompanied the researchers during the interviews.

The interviews lasted an average of 30 minutes, were recorded and transcribed in full as the data was collected. After exhaustive reading, they were decoded and submitted to thematic analysis. The participants answered the question: tell me what it is like to live with a motor disability?

The thematic content analysis stages were followed, which consisted of: pre-analysis, exploration of the material or coding and treatment of the results obtained/interpretation. The pre-analysis stage comprised the floating reading, made from the reading of the transcribed data. The step of exploring the material was done by categorizing the answers based on words or expressions that indicated the same meaning, classifying them. The treatment of the results was carried out from the interpretation, making an analogy with the literature.

The ethical aspects provided for by Resolution 466/12 were observed through the favorable opinion of the Ethics and Research Committee with Humans, Protocol No. 633,531 / 2014, issued on 05/02/2014. To preserve the interviewees identity in the explanation of their reports in the text, they were identified by Interviewee (Ent), followed by ordinal numbering (01, 02, 03, ...), which corresponds to the order of the interviews.

Results and Discussion

Twenty-nine people participated in the study, 10 male and 19 female. The types of physical disabilities varied among the participants, including paraplegia, quadriplegia, amputation, cerebral palsy and others.

The results found were analyzed and organized into three thematic categories: suffering in the process of living with motor disabilities; acceptance of living with a disability; prejudice: not living with the differences in the relational process.

Suffering in the process of living with motor disabilities

Living in contemporary times with a motor disability reflects the difficulties experienced, the limitations and the inability to develop activities of daily living.[1] In the experiences of the study participants, these aspects are related to the meaning that the person attributes to the disability.

In some interviewees report, there was an expression of feelings that reflect low self-esteem, sadness, shame, discouragement, embarrassment, insecurity, incapacity and the desire for death. The difficulty in accepting the current condition, express the anguish experienced in daily life, due to the difficulty of adapting to the limitations of the body. The following reports illustrate these aspects:

I think it's bad because I can't go out (Ent 01). Terrible. (Ent 02). It is complicated, because I feel incapable (Ent 03). I have no pleasure in life, I want to die because of pain in my legs and difficulty walking. (Ent 05). I am not used to it, I would like to do everything (Ent 06). A little discouraged. (Ent 09). Embarrassed. (Ent 16). I feel bad. (Ent 17). I feel really bad. (Ent 19). I'm insecure. (Ent 26).

When asked about the difficulties they faced, the participants reported that, after acquiring the disability, they were unable to perform some activities, mainly due to physical limitations. The following testimonies exemplify these difficulties:

> *It is because I see everyone walking and I cannot walk. There's a party, there's a thing, a micareta something like that and I can't leave the house, that makes me sad. Even today I went on the street, I got there, we stayed there, right, almost an hour and a half of a clock waiting, getting there at the right time for us to be there, right, we passed the time.* (Ent 13).
>
> *I feel bad, I feel good, I'm just sick, unable to get up Ah! I have a lot of sadness. I don't get up anymore. And since I got sick, I never got up. My biggest difficulty is walking. I'm just here waiting for death and nothing else.* (Ent 20).

The testimonies portray the interviewees' difficulty in adapting to a new lifestyle, emphasizing that the current limitations are different from other situations experienced previously. The difficulties of carrying out activities such as walking, using public transport and going to parties were the most reported, compromising their self-realization and increasing the level of dependence.

Regarding the representation about the feelings experienced with the acquired disability, these people attributed, to the term disability, negative meanings as something bad, terrible, sad. This representation constructed by the interviewees, regarding motor disability, influences their way of "being and being in life".

Acceptance of living with motor disabilities

In view of the impossibility of reversing the situation of motor disability, some reports address the adaptation to this living, also revealing to experience positive meanings. Such meaning can be perceived in the expressions:

> *There are a lot of people who bother more than me. And I don't even care. I feel good. (Ent 01); It doesn't feel much of a difference. (Ent 02); At the beginning I suffered a lot, I didn't want anyone to see me. Nowadays I don't care anymore. (Ent 07); I feel very good about the situation. (Ent 20). A little sad, but do what? I have to conform, but it is very sad not to have the freedom to come and go, depending on others. He liked the life he led. At work and traveled a lot* (Ent 29).

These reports can translate a feeling of self-worth, that is, a demonstration of satisfaction and confidence in yourself. Self-worth, trust and acceptance occur after the period of adaptation to the conditions imposed by the motor disability. On the other hand, it is possible to identify in the speeches a feeling of denial, as they use the "no" to sustain their speeches, which in the symbolic field can represent a contradiction. In a study[10] carried out with 120 people with disabilities, when analyzing their perception of life with disabilities, it revealed that, in this study, people with disabilities did not perceive themselves as people with restrictions, but face life adapting, seeing themselves beyond limitations, like human beings.

In some reports, it is clear that despite the barriers found for the development of activities of daily living, in daily life, these people adapt to their condition and overcome architectural and relational barriers:

> *In the wheelchair, with my daughter, the most difficult is the cemetery slope, my girl gets very tired. Here at home I do everything, I do my food, I wash my dishes, I do my laundry I do everything. I make my coffee, my food. I do it by dragging myself across the floor. I feel happy. I go to the street with my daughter or my boy, sometimes the driver takes the elevator, when I say I don't want it, I don't like it, I drag myself up and go up.* (Ent 13).

> *So, I lead a normal life. I get out of bed, go back to bed alone, do my thing.* (Ent 21).

In the excerpt above, the participants overcame the differences and understand that the difficulties need to be faced and overcome. They value and recognize the preserved skills and place them as an exercise in autonomy. Interviewee 13 feels fulfilled by being able to choose whether or not to ride the bus lift and believes in her own body's ability to crawl up and still reports a feeling of happiness.

Thus, they demonstrate an adaptation and acceptance in the way of being and thinking, which provides energy, resilience, good humor and a good sense of perspective on life, as well as the belief in a superior being who strengthens and favors adaptation. Similar feelings are observed in the following statement:

> *It's been so long, I've gotten used to it. Be as God wants! Worrying will get even older. I feel normal, that's how God wanted me to do what ?! Lead life as God wants.* (Ent 21).

Thus, a positive life perspective is observed in the reports, even with the difficulties and barriers encountered in daily life. The ability to recognize your limitations, favors understanding for the development of a body image, through the experiences of its possibilities and the incorporation of adaptations.

Prejudice: living with differences in the relational process

Living with visible physical changes resulting from motor disabilities makes people perceive themselves as different from the standards considered normal by society, and reveal discriminatory and prejudiced behaviors. As you can see in the statements:

> *I was embarrassed, I didn't want anyone to see me ... there were people who laughed ... sometimes, I don't know, for lack of understanding, you know. They said I wasn't going to get married because I didn't have a finger, they called it a cut finger*. (Ent 07).

> *At school they call me crippled and deny black. (Ent 10); Being called a lame by people is very bad. (Ent 15); He was embarrassed by the questions asked on the street. (Ent 16); Sometimes people do not want to accept my participation in worship groups, because I am the only one who is different. (Ent 24).*

The statements portray the reflex of non-acceptance and discrimination of people with motor disabilities, which can culminate in social isolation and suffering from rejection. Although it is not the subject of this study, it is important to note that prejudice related to disease, as well as racism, increases the segregation and vulnerability of these people. However, it is worth mentioning that the participants' reports demonstrate that the acceptance of the disability and the strengthening of their autonomy help them to overcome or live with situations of oppression and violence. After years of living with motor disabilities, adaptation favors the acceptance of oneself and respect for their difference from other people, as observed in the report:

> *Outside, personal stuff, so friends, no one has prejudice. I already suffered when I was younger, but now I am not in a place. This week I argued with a creature who called me a hooligan, I said it like this - I don't accept that you call me hooligan ... If you want to call me by my name, I accept, if you don't I don't! You will call me and I will pretend that you are not talking to anyone, because I*

> *will not answer!* (Ent 06).

The prejudice related to sexuality, mystifies that the motor disability makes the person unable to have sex or that he does not arouse the desire in another person for a loving relationship. These people fear starting a relationship in order to preserve the condition of acquired emotional stability.

> *It does exist in the flirtation term. Because I am alone, I have two children, but even today since I am dating, I am not with anyone. I dated, but it's not that thing to get married. I don't know if it's my imagination, but I think it's due to my disability. Understood? So I think there is prejudice, yes!(*Ent 06).

Thus, the difficulties in the daily life of people with motor disabilities permeate the affective field, which, in order not to live with prejudice, discrimination and domination, sometimes fail to get involved in a loving relationship, building barriers at all levels of the process relational.

The inability to move freely in the environment can trigger negative feelings related to the restriction of physical mobility. Given this perspective, an acquired physical disability can mean an immediate identity crisis, since the differences that now appear in the body break with the identification framework during social interactions.[11]

In this sense, the difficulties to develop some specific activities of daily life also impose limitations to the social, such as relationship difficulties, low self-esteem and discouragement to invest in interactions.

In the process of acceptance and rehabilitation, the psychological, emotional, economic and social aspects of these individuals are relevant factors for living with the disability. Thus, when understanding the health-disease process, it is essential to include social issues in order to find the meanings and implications of this deficiency in the individual's life.[12]

Self-image and body acceptance have an influence on the individual's well-being, especially if the motor disability is acquired. The individual will have to adapt to the new body image, which has undergone aesthetic and functional changes that embarrass and demotivate. In motor deficiency of congenital origin, acceptance is different, the individual has not had a previous experience, his body image has not been altered and adaptation is worked out earlier.[13]

The meaning of the life of a person with a disability goes beyond the health condition that changes their daily lives, the feelings related to their identity and the changes and limitations. It also includes physical pain, social oppression, hope and the need for restraint, the suffering associated with the threat of projects, dreams and routines.[12,14]

A fact that can contribute to the construction of a positive self-image is the problem-solving capacity, because in everyday life there are various situations where an intense process of adaptation of people with motor disabilities is necessary to be successful when faced with obstacles, thus a way to achieve a positive emotional balance.[15]

Thus, for someone to recognize themselves as a person with a disability, the ability to perform social roles in the face of fulfilling commitments is taken into account, especially if they are fulfilled independently. In this sense, physical limitations are not obstacles to the performance of daily activities.[16]

In this context, a study carried out with people with physical disabilities identified that one of the nursing diagnoses observed was the "Impaired Social Interaction", due to the difficulty of separating the strong association between disability and negative, depreciative meanings or feelings of incapacity, which result in social devaluation. Thus, it is a challenge to ensure that people with physical or sensory disabilities have social relationships without prejudice, given the predominance of inappropriate behavior in the context of the disability, in addition to the perpetuation of feelings such as pity, shame and fear.[17]

People with disabilities can use as a strategy of adjustment and social insertion a softening of their difference, not in an attempt to address the lack of a part or function of the body, but by capable behavior. When the person with disabilities breaks their own limitations in carrying out daily tasks, they establish a system of moral compensation, revealed in the effort to overcome physical inequality, recovering their dignity and facilitating their inclusion in social relationships.[18]

Although individual actions are of great importance for the social insertion of people with disabilities, they must not be separated from the external factors that condition this process, so the conditions must be seen as individual, that is, they must not be generalized. In this context, Law No. 13,146 / 2015, which deals with the inclusion of people with disabilities, instituting the status of people with disabilities, is considered a landmark for the redefinition of the process of living with disabilities, ensuring their rights and the duties of society as a welcoming object of that citizen.[19]

Another aspect that should be considered when coping with disability is spirituality, discussed as a possible complementary resource for coping with diseases, boosting the search for meaning and coping strategies, often found in spirituality, religiosity and personal beliefs. Faith in God is a feeling rooted in our culture and is just as important as other ways of coping. The spiritual dimension occupies a prominent place in people's lives.[20]

The problems faced by people with disabilities vary, from the lack of accessibility, such as transportation, adaptation of public environments, sexuality, to the prejudice manifested by the so-called "normal" people. The various forms of discrimination tend to lead to the exclusion of these subjects, moving them away from the wider social life and depriving them of having experiences common to most people.[20]

Prejudice in relation to the sexuality of people with disabilities was observed in the statements, which leads us to the sexual construction of asexuals and people who are not interested in sex. In other words, based on a pattern of sexuality that reduces sexual intercourse and reproduction, the sexuality of people with disabilities is delegitimized without the need to exercise their sexuality. Therefore, the assumptions of the social model of disability point to the valorization of the experiences of people with disabilities in the construction of unique and creative ways of experiencing sexuality.[21]

Thus, the recognition on the part of society, that it is composed of diverse actors, is the initial part of a historical process of stigma that needs to be overcome. Recognizing human body diversity and the specific needs of different social groups, society becomes less exclusive, consequently encompassing people with disabilities, and with this there is a promotion of probable adaptations and rectifications that are indispensable for their personal and social development.

Conclusion

This study aimed to understand the daily lives of adults with motor disabilities, who were observed through suffering in the process of living with motor disabilities, manifested through low self-esteem, sadness, shame, and discouragement. Embarrassment, insecurity, disability and the desire for death also appeared in the participants' statements when they are unable to adapt to the body's limitations.

From the acceptance and adaptation of the disability, the feeling of self-worth and self-confidence was observed. The way of being and thinking, based on the testimonies, provides energy, resilience, good humor, as well as the belief in a superior being. Prejudice was observed in the social and affective / sexual relationship, making people perceive themselves as different from the standards considered normal by society.

There is a need for a paradigm shift and conceptions on the part of society to reduce the obstacles and prejudices faced, starting from the viability and guarantee of the effectiveness of public policies aimed at this population group. The study had limitations regarding its population, as people with motor disabilities of all age groups, in a single neighborhood, were considered as participating in the study, disregarding the specificities of the age groups and the race / color item, the latter being fundamental for the deeper understanding of the phenomenon studied, especially with regard to structural racism.

Finally, understanding the daily lives of people with motor disabilities and the experience of this condition through the person who experiences it, allowed to reveal the importance of social participation in order to mobilize strategies to face challenges and also instigates for the construction of a differentiated way of life. health care that is appropriate to the physical, social and cultural diversity of these social actors.

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