



TEENS AND YOUNG PEOPLE WITH DISABILITIES PURCHASED PHYSICAL VIOLENCE: REPRESENTATIONS ABOUT DISABILITY

ADOLESCENTES E JOVENS COM DEFICIÊNCIA FÍSICA ADQUIRIDA POR VIOLÊNCIA: REPRESENTAÇÕES SOBRE DEFICIÊNCIA

ADOLESCENTES Y JÓVENES CON DISCAPACIDAD FÍSICA COMPRADO LA VIOLENCIA: REPRESENTACIÓN DE LA DISCAPACIDAD

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This study aimed to understand the representations of disability of adolescents and young people with disabilities acquired by violence. It was exploratory, descriptive, qualitative study was conducted in UBSF of Campina Grande, the period October 2011 to February 2012. In the universe of thirteen subjects, nine constituted the sample. Used as instruments form and semi-structured interviews. In the interviews we used the Content Analysis Categorical Theme ruled in the Theory of Social Representations. In the results, enunciated three categories are: representations on disability from anatomic changes; representations of feelings experienced disability and lack of representation of the term disability. The disability acquired in adolescence or youth as a result of violence brings indelible mark, representing biopsychosocial difficulties and limitations, compromising the quality of life.

Descriptors: Disabilities; Adolescent; Violence.

Objetivou-se compreender as representações sobre deficiência de adolescentes e jovens com deficiência física adquirida por violência. Tratou-se de pesquisa exploratória, descritiva, qualitativa, realizada nas UBSF de Campina Grande, período outubro de 2011 a fevereiro de 2012. No universo de treze sujeitos, nove se constituíram a amostra. Utilizou-se como instrumentos formulário e roteiro de entrevista semiestruturada. Nas entrevistas utilizou-se a Análise de Conteúdo Categorical Temático pautado na Teoria das Representações Sociais. Nos resultados, três categorias enunciaram-se: representações sobre a deficiência a partir das alterações anatomofuncional; representações dos sentimentos vivenciados com a deficiência e ausência da representação do termo deficiência. A deficiência física adquirida na adolescência ou juventude em decorrência da violência traz marca indelével, representando dificuldades e limitações biopsicossociais, comprometendo a qualidade de vida.

Descritores: Deficiência; Adolescente; Violência.

Este estudio tuvo como objetivo comprender las representaciones de la discapacidad de los adolescentes y jóvenes con discapacidades adquiridas por la violencia. Fue exploratorio, descriptivo, cualitativo, realizado en UBSF de Campina Grande, el periodo de octubre 2011 a febrero 2012. En el universo de trece temas, nueve constituyeron la muestra. Se utiliza como forma de instrumentos y entrevistas semi-estructuradas. En las entrevistas se utilizó el análisis de contenido categorial temático falló en la Teoría de las Representaciones Sociales. En los resultados, enunció tres categorías: representaciones sobre la discapacidad a partir de los cambios anatómicos, representaciones de discapacidad experimentado sentimientos, la falta de representación de la discapacidad a largo plazo. La discapacidad adquirida en la adolescencia o la juventud como consecuencia de la violencia trae marca indeleble, lo que representa dificultades biopsicosociales y limitaciones, lo que compromete la calidad de vida.

Descriptorios: Discapacidad; Adolescente; Violencia.

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INTRODUCTION

For the Health Department (HD) nowadays violence has been spread in several ways, making it almost impossible to define their causes and propose efficient measures for its extension. That question becomes more complex when the aggressions are directed to the children and youth population⁽¹⁾. Sociological and epidemiological studies have shown that especially in adolescence and youth this subject is more evident, describing these people both as aggressors as well as victims⁽²⁾.

The adolescent suffers cultural and sub-cultural influences, from the family and from his fellow mates with complex changes for his development, which characterizes this stage of life as a period of physical, psychological and social vulnerability⁽³⁾. At this age, the search for new references and experiences is common, which predisposes the people to adopt attitudes of risk and exposition to outside causes - accidents and violence⁽⁴⁾.

In Brazil, it is known that violence and accidents are the third cause of death, and among adolescents they represent the first cause of death. In 2011, the Unified Health System attended 128,316 patients between 10 and 19 years-old. From these, 16,050 died⁽⁵⁾. The victims of these violence are mainly male, in the causes of harm are the falls, the traffic accidents or the shock against still objects⁽⁶⁾.

We must also add that, among the processes of restriction and limitation imposed by physical violence we can find the physical deficiency which is shown as a non-fatal consequence of that violence⁽⁷⁾. In the cases of morbidity, the non-fatal traumatism and with consequences, represent a great impact (in a long-term time range), reverberates in the family and in society, punishing children and adolescents in their period of

growth and development. They also reverberate in social, economical and emotional costs⁽⁸⁾.

In the System of Hospital Information on the Unified Health System(SIH/SUS) the state of Paraíba registered 1,640 hospitalizations due to outside causes related to physical violence, in the period of January 2008 to May 2011, age range: 10 to 24 years old; and the main causes were: aggression, firearms, or cutting, penetrating or sharp objects⁽⁵⁾.

The impact caused by physical disability (PD) in the life a person, at any stage of life, is incommensurable, once it brings profound changes in the life of the subject and in the lives of his family⁽⁹⁾.

Among these changes we include the way the subject sees himself, that is, how he feels after the PD, constituting for himself a 'new identity', and this elaboration is influenced by the experiences and reactions manifested by internal factors (psychic structures, standards of behavior previous to the lesion, characteristics and personal traces) and external factors (socioeconomical, political, cultural conditions, schooling, among others)⁽¹⁰⁾. Thus, when the subject is socially considered different, carries with himself the marks of otherness which puts him away from the social prototype, influence his social place, his territorial space, his style of life, aspects which can jeopardize the achievement of citizenship⁽¹¹⁾.

From these premises on, the objective of the study was to understand the representations of adolescents and youths with physical disability caused by violence on the disability: So, the following question is pertinent: What is the representation of the disability of adolescents and youths who became disabled by physical violence?

We believe in the pertinence of this study, once it aims at understanding in order to contribute with the process of rehabilitation and social reinsertion of these young citizens, facing the quality of life.

METHOD

It is an exploratory, descriptive and qualitative research based on the Theory of the Social Representations (SR), which are presented as an important theoretical support in the qualitative researches. The theory of the SR 'has as starting point, the diversity of the subjects, attitudes and phenomena, in all its strangeness and unpredictability'. It has as objective 'to find out how subjects and groups can build a stable and predictable world from such diversity'^(12:79). Through the meaningfulness of these theoretical and methodological presuppositions, the choice of the referred theory to support the analysis and interpretation of the data was defined.

The scenario of the research was the county of Campina Grande, in Paraíba, and the data was collected from October 2011 to February 2012, together with Teams of Family Health, in the urban and mixed zones (urban zone covering the rural zone as well). Such strategy allowed the identification of the researched subjects, from the registered data of the Card A – referred condition – Disability (DIS) and from the knowledge of the Health Community Agents on the subjects/families residents in their micro area of acting.

A census survey was made in the 57 UBSF, composed by 85 teams (urban and mixed zone). 13 subjects were identified in 11 units of health (among adolescents and youths), who fitted the researched profile established in the criteria of inclusion. The sample from this census was not probabilistic, composed

by nine subjects who fitted the criteria of inclusion and exclusion established in the research.

The criteria of inclusion adopted were: to be a user, registered in the scope of the Family Health Basic Units of the urban and mixed zones; to be between 10 and 24 year old; to be physically disabled due to violence occurred at least six months ago. As criteria of exclusion we considered: cognitive or speech deficit which would make the interview impossible; absence of the subject in his house during the period of the data collection. Therefore, four subjects were excluded, due to the following criteria: two because they were not within the area range in the period of data collection, one for becoming physically disabled less than six months and one due to aphonia resulting from the problem suffered (brain trauma) thus making the interview impossible.

We used two tools for the data collection, a form with variables on sociodemographic data and a script of semi structured interview, with pre-established order elaborated according to the object of the research, being adapted whenever necessary at the moment the interview was recorded (digital recorder, MP4 format). The data collection was made in the patient's house, together with a Health Community Agent. The subjects and the adult responsible for a minor were asked to sign a Free Consent Form.

The data of the form were analyzed focusing on interpretation and expressivity and presented in discursive manner. For the data of the transcript interviews we used the analysis of Theme Category Content, based on the Theory of the Social Representations. At first we performed fluctuating reading of each interview, followed by a more detailed reading, pointing out key words, so considered for

representing the nuclei of the senses joined to the guiding questions. During the exploration of the material, the codification of the data in bulk was made through the choice of the units (clipping), enumeration (frequency) and aggregation to the clipped units, in order to identify the representation/expression of the content⁽¹³⁾. Therefore three categories were identified, named according to the sense within the clipping and speeches of the subjects.

From this organization the interpretation of the results based on theoretical referential occurred. We aimed at returning to the objective of the research to define clearly the representation of the subjects of the study regarding disability.

The guidelines of resolution 196/96 were followed, the Project was approved by protocol CEP no. 1912.0.000.133. To guarantee the anonymity of the subjects, they were identified by letter E followed by the number of the sequence of the interview 1, 2, 3... adding the letter A to name de adolescents and J for the youths, thus constituting: E1A, E2A, E3J until the last number of the interviewed subjects.

RESULTS AND DISCUSSION

Sociodemographic Profile

All the subjects were male, being two dark-skinned e seven white. Five subjects were adolescents being between 16 to 19 years old and four during their youths, being 23 and 24 years old. The longest period of the occurrence of the disability caused by physical violence registered was from six years and the shortest, seven months.

The subjects' schooling was considered low, once two had grade school incomplete (adolescents), four had complete grade school (three youths and one

adolescent), two had incomplete grade school (before high school) and only one (youth) was in college.

Regarding the marital status, five stated to be single. Two youths reported that they had had girlfriend and/or mates whose relationships had already finished before the occurrence of the disability. One adolescent and one youth are married; two youths are living a stable union. They reported that the conjugal living already existed before the occurrence of the physical disability and this fact had not interfered in the relationship.

In this study, most of the subjects were evangelic, followed by the catholic religion. And also a smaller number stated to have no religion. Among the subjects who declared to follow a religion only one (an evangelical adolescent) mentioned to attend the services and this practice was adopted after the occurrence of the violence.

The lack of formal technical qualification was identified among the interviewed subjects. The reported jobs were: door to door salesman, vender, police officer, mechanic, machine operator, finishing operator and animal caretaker. Two subjects reported not to work. At that time one adolescent reported to continue with his working activity (horse caretaker) and studying; another youth went back to studying five days after the occurrence (the act of violence suffered), but he still has a medical certificate which puts him away from working (police officer); both the subjects had monoparesis causing physical jeopardizing, which made possible the return to studying and working. The other subjects do not have activities of studying or working after the physical disability caused by violence, once the jeopardizing was regarding locomotion (paraplegia and tetraplegia), and now they are retired or receiving social pension.

Regarding the family income of the subjects, five reported to have an income of a minimum wage (R\$ 545.00 – at the time of the data collection), this income comes from two cases of retirement and it constitutes the family income once they are youths having a conjugal relationship. In three cases receiving social pension, for one of them, this represents the family income to support all his family. Two adolescents reported that the family income is lower than the minimum wage, and one of them started registration to receive social pension and the other one does not have an indication for such benefit (according to the report). One of the adolescents reported that the family has an income of three minimum wages and only one youth has family income of more than five minimum wages, and this is the case of the youth with the highest level of schooling.

The sociodemographic profile identified in this study confirms the several studies related to morbidity due to violence, in which the subjects have this profile: young, low income, low schooling and consequently without formal technical qualification and in most cases are involved with violent actions (fights, thefts, use of firearms), use of drugs and alcohol^(7,14).

Representations on disability

In order to know the representations of the adolescents and youths regarding physical disability caused by violence we wanted to know what they understand about 'disability' for that the following question was asked: What is disability for you?

In a certain way, the representation of the adolescents and youths on 'disability' is directly related to their singular experiences, which represents just one type of disability, the 'physical disability'. They define the term disability from the characteristics of the physical

disability presented, that is, only what one feels is noticed, this comprehension is elaborated from the type of disability thus representing an individualistic point of view. Facing the experience, the perceptions on the terms disability and physical disability are mingled in one same meaning.

This comprehension leads us to the concept of the word disability used since biblical times, in which the subject known as crippled was seen as someone sick, whose morbidity, believed to be divine punishment, was destined to the expiation of his sins, so that, and only this way, he could reach salvation. The belief that the benefit of salvation was extended to those who took care of the ill, contributed for the discrimination that was attributed to him if he mixed with the feeling of pity and the practice of charity⁽¹⁵⁾.

Although along the years many other definitions have been proposed for the term disability, currently it is observed that his colloquial use is still deep-rooted to the connotation of failure, of a physical fault of a specific part of the body, as well as of 'load, weight and prejudice' which is brought to the life of the subject, being these words identified in the speech of some adolescent through their own expressions: *For me? A fault, hum... I don't know! A fault! For me it is a fault!(E 7 A). On the first day I arrived I was called a crippled ... by my brother! (quite emphatically!). On the first day no! A few days he arrived here saying... (Stopped, continued) He arrived here saying ... and I didn't like it ... and then I got angry too! (E 9 A).*

These speeches represent the physical disability under the observation and the speech of others, which influences his comprehension of the term disability. These subjects 'feel' and 'notice to be seen' by society as a crippled faulty human being.

This comprehension confirms the socio-anthropological approach on the process of construction of the individual identity in which the subject in action

leads to learn how to deal with objective, subjective, material and symbolic elements and only then he can institute, for himself, a system of moral compensation that enables him to overcome the physical inequality, to rescue his dignity and make his social inclusion easier. So, when the person knows his difference, embodied in the appearance, form, size and functionality, he will be able to pass through adequately by the states of 'being' and 'feeling' disabled; this means that he managed to go through a metamorphosis which enables him to refuse or accept some attributes imposed socially and, consequently, break with the referential of identification during the social interactions⁽¹⁶⁾.

Nevertheless, the transformation can be presented not as metamorphosis, when the subject only reproduces the identity imposed through attributions of the social environment⁽¹⁰⁾. Therefore, it is at this point of life of the subjects that the outstanding characteristic which is presented as a reference for his identity (as he sees it) in society (as they see him) is the physical disability caused by violence, that is, the 'fault' that they presenting, influencing the representation that each one has on his own disability and in the conception of the term disability.

From the analysis of the speeches of the subjects, three expressions were identified which define the representations of the adolescents and youths on the term disability, they are described in the following categories:

Category I – Representation of the disability considering the anatomo-functional alteration

For some interviewed subjects the representation of the deficiency is attributed to a 'anatomo-functional' alteration, identified as: impairment to move; reduction and limitation of the physical capacity; and even a fault.

On this representation, they reported: *Disability is a term of locomotion which...depends on an agreement with each one, because the disability only is...only complicates locomotion and the daily experiences...it doesn't complicate anything* (E 1J). A reduction of the physical capacity and...I think you leave the automatism of some activities, to make an effort in order to perform some daily activities (E 3 J). *Disability for me it is not walking! That is all! Just that!* (E 5 J).

For these subjects, adolescents and youths, the disability constitutes the physical limitation of the person. For the reported cases, the limitations are associated to the incapacity of walking or to limitation to perform an activity which requires physical/motor effort, which was affected and/or jeopardized, according to the degree of the lesion suffered. The fact that he is not able to walk any longer implies in several limitations of life in a way that the physical limitation both anatomic as well as functional means the comprehension of these subjects on the term disability.

This representation confirms the autobiographical reports of a writer, where the first perception and concern of a person having PD was observed, especially resulting from marrow lesion, are related to the incapacity of walking and the paralyssation of the physical movements. Many times these conditions are seen as the impossibility of moving with autonomy and liberty⁽¹⁰⁾.

Category II – Representation regarding the feelings experienced with disability caused by violence

This level of representation of the term disability is only understood by those who experience it daily. The comprehension of the disability is approached from the significance (relevance, value, importance) to this subject, once just the people with disability can 'feel' what this condition really represents. This is different of the representation of disability considering anatomo-

functional alteration, where it is possible to see or touch the disability and from then on describe its representation. The representation regarding the feelings experienced with the disability caused by violence is constituted by an understanding which is only possible for those who experience disability, once it is originated in his subconscious, elaborated only for what he feels, and the identified expressions were: *Like this, boring! The person doesn't feel well... very bad... (E 2 A). Because I have seen my disabled aunt, how sad! For one who is Young this sadness is even bigger...sadness! (E 6 A). [...]The person doesn't do everything he wants! It is very bad! (E 4 J). The person has no defense, that is all, actually (E 8 A).*

So we can imply that, regarding the representation on the feelings experienced with disability caused by violence, these adolescents and youths represent the term disability with negative meanings, like something bad, boring, sad and a sensation of defenseless.

Although the meaning of the representations under this category are close to the same representation of the anatomic-functional disability once it means the 'limitation' of the human being to walk, to come and go, to be able to move everywhere he wants to, in the category of the representation regarding the feeling experienced means the castration/limitation of several possibilities and fulfillments of wishes along his life, jeopardizing his quality of life, shown in the loss of his liberty, once his capacity to walk freely no longer exists: what before was just an easy activity to perform today it 'depends' on the help of others to perform.

PD brings to the people the need to be politicized regarding the experience of disability; autonomy and support; access and rights. In dealing with the needs of health, the subjects need complete and inter-sectoral actions which assure them access; psychosocial support; autonomy and independence; dispense equipment and

assistance technological devices; information/orientation; precocious prevention/diagnosis; recognition and guarantee of rights; validation and help in the elaboration of strategies of confrontation; a link with the health professional^(17: 219).

Category III – Absence of the representation of term disability

The absence of the representation of the term disability was reported by one of the subjects. In this case, there has not yet been the acceptance/appropriation of the subjects of the condition he experiences, even preventing him from expressing his comprehension on the term presented. So, he says: *Disability for me now? I don't know anything, right now I am very Young but...It is because it's been a short time since this happened to me, I practically know nothing about disability! The answer is very difficult to find (E 9 A).*

In the cycle of life (from birth to death), the human being experiences moments of gains and losses, resulting from the processes of social relationships such as changes of school, housing, friends, independence from parents, new social relationships resulting from several changes experienced. The way a person sees what losses are and how he faces his grief is molded by the values acquired in the family, religious community, in the society and in the culture in which he lives⁽¹⁸⁾.

In the analysis of these three categories, the representations of the subjects suffer the influence of two factors, the current age and the time the fact occurred. Under the factor age the adolescents express a comprehension which is more related to emotional issues, to a representativeness turned to the negative feelings that involve the occurred fact, which can be justified by the cognitive/emotional immaturity, inherent to this period of life, while the youths report to

questions which are more directed to concepts to the fact, the anatomo-functional alteration, because they present a greater potential of cognitive/emotional growth, regarding the adolescents.

The factor time from the occurred fact contributes to a better acceptance/conformation of the situation experienced, influencing the comprehension of the subject on the term disability (even just regarding PD), as well as in the confrontation of the problems resulting from the disability. However, these two factors do not act in the same way in all the subjects.

That same inference was evident in people who had a marrow lesion, where the time between the lesion and the period of making up the study showed a possible adaptation and knowledge on the impacts generated by the marrow lesion, once it made possible for the subject the reconstruction of the reason and objectives of his own life from the way how he faces the complications resulting from PD; This time is different for each subject and it depends on factor such as: age, support of the family, previous information, causes of the lesion, among others ⁽⁹⁾.

It is outstanding that at the moment in which the health official instances aims at defining an standardizing a terminology for disability, it makes sense when we hear these people and notice that the terms to refer to disability are full of meanings resulting from an interpretative process regarding the situation^(16:112). Then, it is relevant to have the expressed knowledge of the disabled people about the term disability.

After the relevance of the data obtained, this study presents limitations due to the reduced number of participants on the research not allowing generalizations regarding the representations. It is fundamental to clarify that some Micro-areas were uncovered (without a follow-up of the Health Community Agents), making the

identification of the researched subject impossible. Besides that, the literature on this subject is insipient, jeopardizing the more profound analytical comparison of the results of this study with those from other authors.

Considering that in the venue of this study, the process of rehabilitation of the subjects as well as their social re-integrations, presents gaps related to the offer of public services for this kind of attendance. This situation may be repeated in other locations distant from the rehabilitation centers. This possibility calls attention so that similar studies are performed with a greater number of subjects in order to make generalizations possible and the consequent investment in the interiorization of the actions and the knowledge facing multi-professional rehabilitation to people with disability.

CONCLUSIONS

The adolescents and youths notice the disability and the physical disability as the same meaning, representing an individualistic comprehension. Although only the person with disability can completely describe the meaning of such work, this comprehension leads to a difficulty to make him feel as a citizen within a specific society. Considering that the situation in which the subjects are is definite, it is necessary that the comprehension provides the acceptance of his body in order to make the processes of confrontation they will experience both individually and in a group easier.

The consequences generated by a physical disability caused by violence in any period of life bring biopsychosocial repercussions. However, during adolescence and youths it becomes more severe because the subject is not yet mature enough to face such loss once this period of adventure and dreams are more present than the maturity and responsibility imposed by the adult stage of life.

The repercussions of the physical disability represented, for the subjects, from the anatomic-functional point of view, the loss of autonomy and liberty, in a moment of life when their peers are at the top of this condition. The personal rescue of this condition of liberty is not always presented as a possible horizon for these subjects.

It is up to the health professionals to practice the active reception and listen of the demands of this users, and as well as to act as agents of propulsion in orientation in the struggle to reach a better quality of life. It is up to the social and health agents to make the public policies accessible to this group of people possible, for when they loose autonomy and liberty, they also loose citizenship.

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