

Life story of university students and the adjustment of living with motor deficiency



A história de vida de estudantes universitários e a (con)vivência com a deficiência motora
Historia de vida de estudiantes universitarios y la (con)vivencia con la discapacidad motriz

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ABSTRACT

Objective: To understand the life story of university students and the adjustment of living with motor deficiency.

Method: A qualitative research, developed with eight university students with motor deficiency. Data collect was performed between October 2016 and March 2017. Thematic data analysis was used.

Results: Two categories emerged: family as safe harbor and extra-family relationships: weaknesses and strengths. Family and friends were fundamental for facing disability, standing out for their support and affection. Friends have been encouraged to overcome the limitations and difficulties. Extra-family life was exposed to prejudice that resulted in fears and traumas.

Conclusion: The impact of motor deficiency on daily life is the result of life experiences. Healthy family relationships, along with strong bonds of friendship, made the difficulties found in the daily life of these students smoother.

Keywords: Nursing. Disabled persons. Family relations. Interpersonal relations. Universities.

RESUMO

Objetivo: Compreender a história de vida de estudantes universitários e a convivência com a deficiência motora.

Método: Pesquisa de abordagem qualitativa, desenvolvida com oito estudantes universitários com deficiência motora. Coleta de dados realizada entre outubro de 2016 e março de 2017. Foi utilizada a análise temática dos dados.

Resultados: Emergiram duas categorias: família como porto seguro e relacionamentos extrafamiliares: fraquezas e fortalezas. A família e os amigos foram fundamentais para o enfrentamento da deficiência, destacando-se pelo apoio e afeto. Os amigos apresentaram-se encorajadores para superar as limitações e dificuldades. A vida extrafamiliar foi exposta a preconceitos que resultaram em medos e traumas.

Conclusão: O impacto da deficiência motora no cotidiano é resultante das experiências de vida. As convivências familiares saudáveis, junto com laços fortes de amizade, fizeram com que as dificuldades encontradas no cotidiano desses estudantes fossem amenizadas.

Palavras-chave: Enfermagem. Pessoas com deficiência. Relações familiares. Relações interpessoais. Universidades.

RESUMEN

Objetivo: Comprender la historia de vida de los estudiantes universitarios y la convivencia con la discapacidad motriz.

Método: Investigación de enfoque cualitativo, desarrollada con ocho estudiantes universitarios con discapacidad motriz. Recolección de datos realizada entre octubre de 2016 y marzo de 2017. Se utilizó el análisis temático de los datos.

Resultados: Emergieron dos categorías: familia como puerto seguro y relaciones extrafamiliares: debilidades y fortalezas. La familia y los amigos fueron fundamentales para enfrentar la discapacidad, destacándose por el apoyo y el afecto. Los amigos se presentan como alentadores para superar las limitaciones y dificultades. La vida extrafamiliar fue expuesta a preconceptos que resultan en miedos y traumas.

Conclusión: El impacto de la discapacidad motriz en el cotidiano es el resultado de las experiencias de vida. Las convivencias familiares sanas, junto a lazos fuertes de amistad, hacen que las dificultades encontradas en el cotidiano de estos estudiantes sean amenizadas.

Palabras clave: Enfermería. Personas con discapacidad. Relaciones familiares. Relaciones interpersonales. Universidades.

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■ INTRODUCTION

According to the World Health Organization, there are over 1 billion people with disabilities in the world, or about 15% of the world's population, or one in seven people with some disability. Of this number, between 110 and 190 million adults experience locomotion difficulties. It is estimated that about 93 million children, one in 20 of which are under 15 years old, live with moderate or severe disability⁽¹⁾. In the Brazilian scenario, according to the latest demographic census conducted in Brazil in 2010, 45,606,048 million people reported having at least one of the deficiencies investigated, corresponding to 23.9% of the Brazilian population. Of these, more than 13 million people have motor deficiency, which corresponds to 6.95% of the population of the country, and in relation to biological sex, motor deficiency is more significant in females, with 6.8% of female population having motor deficiency, compared to 4.5% of the male population⁽²⁾.

Looking at the state of Santa Catarina (SC), it has a resident population of 6,248,436 inhabitants. The population of men with motor deficiency corresponds to 163,547 inhabitants (2.62%), and the population of women in the same condition is 255,646 (4.09%), totaling in the state a population of 419,193 (6.71 %) people with motor deficiency⁽²⁾.

With this, we realize that deficiency is universal, and there is every likelihood that we will all experience some disability, either directly or in a family member. In this study, the term "deficiency" is used as a general term for activity limitations and participation restrictions, denoting the negative aspects of interaction between an individual (with a health condition), and the context in which they live (personal and environmental factors)⁽¹⁾.

In response to the biomedical model on the subject, studies on deficiency emerged as a specialty of the humanities in health, whose theoretical commitment was to demonstrate that the experience of deficiency inequality resulted more from social structures barely sensitive to diversity than from a body with injuries. Thus, the social model of deficiency, the main theoretical framework of the studies on the subject, has subverted the logic of causality proposed by the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH), that is, injuries were not the main cause of the disadvantages, but social oppression for the disabled⁽³⁾.

The person with motor impairment is faced with questions and conflicts about many aspects of their lives, including changes in their body and all the social factors involved⁽⁴⁾. When we talk about the changes in someone's body, we can understand how the intimate and daily life

of the person is, and when we talk about the social factors, we enter social life and the impact caused in the daily life of the family. In this way, daily life is the basis for building a social life⁽⁵⁾.

It is indispensable to understand the person with a deficiency as an integral part of the world, influenced by the environment, both cultural, social, political, spiritual and economic⁽⁶⁾. The family is the basis and mirror for the construction of individuality as well as influences outside the family. Education and the experiences seized in the family nucleus are brought to life, such as how to observe the world, how to deal with difficulties and opportunities, how to build independence and mastery of the skills that will be necessary for inclusion in life and in the community.

We highlight one of the environments in which the person with some deficiency faces many challenges: the school environment. In this particular study we chose the university environment in which students and professionals are inserted and confronted daily with situations that challenge them in the face of deficiency.

People with a deficiency have been excluded from the school environment and, historically, the arguments underlying this exclusion would be that they would be out of the scope of the disciplinary purposes of the school and, when classified as abnormal, they should be derived to the regency of another institution which, if it did not correct them, would deprive them of social life. In Brazil and in other countries, such arguments have been displaced in the sense of seeking the inclusion of the disabled in the devices and institutions that aim to prepare them for exercising a social function, or in the labor market, often understanding that this would be the way to introduce and integrate these people into the world⁽⁷⁾.

From the foregoing, this study aims to understand the life story of university students and their coexistence with motor deficiency.

■ METHOD

The present study is about a qualitative research⁽⁸⁾ in which the aspects of human experience from the life story are emphasized. This study is a clipping of the nursing course completion work of *Universidade Federal de Santa Catarina* (UFSC)⁽⁹⁾, and the method "thematic life story", in which interviews have a specific thematic character for the study group, with the interviewer aiming to clarify the facts from the interviewees' speech⁽¹⁰⁾, was used for its development.

The inclusion criteria for the research were: young people of at least seventeen years old, undergraduate or

graduate students at UFSC, both groups with motor deficiency and who have lived with this condition for more than a year. Exclusion criteria were deficiencies classified as temporary and non-motor deficiencies.

The study participants were contacted by researchers knowledge, and through the *snowball* method, which consists in indicating new participants through the previous participant, and so on. Participants were also selected from the previous contact with the accessibility sector of UFSC, where there is a list of university students with motor disabilities enrolled and receiving follow-up. Contact with the sector was made via e-mail, and later the participants who were interested in participating in the study returned with availability. We reached a total of eight participants. The number of participants was not greater because of the difficulty they presented to participate in an interview and share their life story.

Data collection was carried out between October 2016 and March 2017, through a semi-structured interview script, containing questions related to the life story of these students, including general data and family and

non-family relationships in childhood, adolescence, youth and maturity. The interviews were previously scheduled according to the availability of the participants, in their residences or in the university, recorded in a digital recorder, and performed in a single step, with an average duration of 1 hour and 20 minutes. After collection, the stages of transcription, validation, transcription, conference, letter of assignment and filing were performed. According to the ethical aspects, participants signed the "Informed Consent Form" and the "Letter of Assignment", and the research was approved by the Ethics Committee of UFSC, under number 03932812.2.0000.0121.

We chose to identify the participants by the letter "P", plus the interview number (from 1 to 8), in order to guarantee anonymity. The main information about the research participants is shown in Chart 1. Among the eight participants, five are males and three females. The average age of participants is 26.5 years old, all being young people and mostly single. In terms of deficiency, four people were diagnosed with congenital deficiency and the other four people with acquired deficiency in adolescence.

Participant	Gender	Age	Deficiency	Nature of motor deficiency	Marital status	Course
P1	F	23	Bone dysplasia (femoral head deformity)	Congenital	Single	Nursing - 9 th phase
P2	F	22	C4 spinal cord injury	Acquired	Single	Law - 8 th phase
P3	M	18	Myasthenia Gravis and muscular myopathy	Congenital	Single	Biological Sciences - 3 rd phase
P4	F	35	Muscular dystrophy	Acquired	Married	Anthropology - 5 th phase
P5	M	26	Cervical muscle dystonia	Congenital	Single	Chemistry - 8 th phase
P6	M	27	Multiple arthrogryposis	Congenital	Single	Psychology - 5 th phase
P7	M	36	MSE Amputation	Acquired	Married	Law - 2 nd phase
P8	M	25	T3/T4 spinal cord injury	Acquired	Single	Master in Mech. Engineering

Chart 1 - General profile of the interviewees, Florianópolis, 2017

Source: Authors, 2017.

Regarding data analysis, we prioritize thematic analysis, since it is used as a unit of record to study the motivations of opinions, attitudes, values, and trends. In order to perform the analysis, we initially carried out a detailed reading of the interviews, in order to pick up the units of record that were most evident in the interviews, to identify and select the most relevant data from then on, and to conform the categories of analysis⁽¹¹⁾.

■ RESULTS

It was possible to specify several aspects of the life of the university student with motor deficiency, from his experience in family to his insertion in social life. From the testimonies, two macro categories emerged: Family as a haven and Non-family relationships: weaknesses and strengths. There were several testimonies that originated the reflections for each of these categories.

Family as a haven

Some study participants were born with some deficiency and others acquired it throughout their lives, but both brought up the family's reaction to their disability.

During early life, changes in motor, cognitive, emotional and social development can have a special impact on family interactions.

I remember my family interacting with me as a child in the best possible way, I always had support, they always supported my decisions and they helped me in these comings and goings of health, they gave all the support required (P3).

My parents always dealt very well with this; they ran after everything I needed. My father constantly tries to invent something for me, so he does a thousand things to help me, and it was a very quiet family experience, I believe that the deficiency had little impact within the family (P6).

We also perceive the figure of parents as the people who influenced the development of the personality of the participants the most, in addition to the older siblings, as expressed by the following subjects:

I see traces in me that are reflections of them. I see the seriousness of my father, how he deals with his professional life, my mother's patience and the charisma she has, and my brother's determination. I see traces of everyone in me, it is difficult for me to mirror myself in one person, we get a little from each of us, what we think is good (P6).

She [sister] is the oldest of all and has that thing of being the leader, of being also a mum in the absence of my mother, so she had this responsibility to discipline us, to say what could and could not be done. I enjoyed watching movies with her. Regarding personality, I think my sister had great influence, in her way of dealing with responsibilities, taking care of others, taking responsibility for themselves (P7).

Another issue that stood out in the testimonies was the limitations some parents realized when faced with the condition of the children during adolescence.

In adolescence, supposed to be a complicated, upsetting stage, it was calmer because I spent a lot of time away from home playing basketball, and video games with my friends, and my parents have always been cool about me leaving, they only talked for me to tell them where I was going, I never had any restrictions (P5).

It was a somewhat more conflictive relationship, because I started to go out a little more and they started to have some difficulties letting me do what I wanted. Several things happened, for example, watch-outs. I said: "I'm going to the mall with my friend!" They replied: "For God's sake, no!" So when they left the house, I would go to the mall (P6).

We also highlight the ability of parents to keep their children informed about the deficiency.

I always saw to the future; I did not cling to my childhood very much because it was not very good. They were always [Parents] very realistic with me, my neurologist always told me what could happen, always spoke openly about my diagnosis (P5).

I was always aware of what was happening to me. "If you have to take the medicine it's not because "Daddy" and "Mommy" are in charge, but because "if you do not take it, you will not get better" (P6).

Closing the first category, we have seen through the testimonies that the stories are different just like any life story, and for this reason we must understand them as unique and incomparable stories.

Non-family relationships: weaknesses and strengths

In this category, the statements about coexistence outside the family arise, and the beginning of social life occurred mostly in school age.

My mother took my brother to the nursery and I went along just to accompany her [mother], she says that I screamed and cried because I wanted to stay in the day care too, so

the next year my mother put me in the day care center, that's when I actually started having some relationships outside the family, because had it not been for that, I only socialized with cousins and uncles (P1).

I have always liked the friends I made, so today, for example, one of my best friends is from third grade (P2).

Most of it was in school. The first contact was the friends of the neighborhood. And at school I went with a friend of 5th grade because, unlike me, he was very sociable, it was through him that I made friends with other people, he was a guy who was very sociable, other people knew me through him (P5).

Living with other people was in high school. It was a complicated conviviality, I was shy as a child and the relationships I had in college were very short relationships, nothing lasted until today, it was more at high school time that I started to make friends, relationships that carry on to this day (P6).

It is from the non-family conviviality that differences begin to stand out, evidenced in the testimonies.

During my childhood, because I was different from the other children, I always suffered bullying, to such an extent I even got battered, at least once a week I came back with a bruise from school, several students, one in particular, tormented me and the class found it funny (P5).

My relationship with friends at school was always one with a certain dependency, because everything I did in the classroom was with the help of a friend, and these relationships, when they get closer, they consolidate, begin to create body, then that friend who used to take my stuff from the backpack is now traveling with me and taking care of me, taking me to the bathroom, showering me, and then relations begin to develop. These friends helped me out more, freed me more, they helped me enjoy life more (P6).

Social life comes as a major impact on one's life, and deficiency is seen through other looks.

■ DISCUSSION

From a family point of view, children are part of a developmental stage in the life cycle and have an effective mark on human beings and in social groups, and have a wide social and psychological meaning, which forces the members involved to adapt, changing roles, relationships and affective links⁽¹²⁾. These adaptations to the new reality and a reorganization of the whole family structure are changes

related to the emotional, physical, behavioral, social and economic aspects⁽¹³⁾. Thus, the birth of a child with some deficiency alters family structure in a more complex way, causing surprise and fear of the unknown⁽¹⁴⁾. And all this, as mentioned earlier, will result in innumerable feelings and changes in the daily activities of the family.

These feelings and changes are also due to the body image that is motivated by the media, and which in turn reproduce an image based on the pursuit of perfection by society, based on political and psychological factors. The patterns of strength, efficacy, beauty and perfection are highly valued in the society we live in and, in this sense, when parents wait for a child, already during pregnancy they reflect in the fetus the body image expected by social paradigms, and the coming of a child with a deficiency makes them revise projects, rethink dreams that were interrupted by the obstacles related to the limits caused by deficiency⁽¹⁵⁾.

After some reactions experienced by the family of the child with motor disability, such as denial and mourning, the family seeks acceptance, and with that they adapt to a recent reality and reorganize to face the experience of living with the child with disability. This situation involves a feeling of vulnerability and an emotional rebalancing that requires time⁽¹⁶⁾. There are families who take on the challenge, while others have greater difficulty and cannot reorganize themselves, showing hopelessness, dismay and fatigue in the journey with the child, and sometimes their structure is threatened and their capacity to react to situations of potentially destructive crises is weakened⁽¹⁶⁾.

We noticed that participants expressed good family coexistence, and that parents were willing to help and support their decisions. Therefore, the deficiency has little influence on family life, and with this, we recognize that the way the family deals with this event influences the construction of the family identity, as well as the individual identity of the person with motor impairment.

Acceptance of motor impairment begins in the way of acting, when parents acquire the ability to understand that the child is a person who has limitations, and who must overcome them in his own time, as well as all human beings who seek to overcome daily difficulties. The way of communication and the exchange of information of the family with the person with a deficiency will have repercussions in the behavior and development of this young person.

Thus, the way parents act in their care is the main element that provides autonomy, or not. How they enable adequate stimulation and how they deal emotionally with difficulties are factors that must be reflected upon and oriented to avoid feeling inadequacy, social exclusion,

excessive dependence, and lack of awareness about the real difficulties and possibilities⁽¹⁷⁾.

Like parents, siblings also play an important role in personality formation. The fraternal relationship usually arises in the individual's infancy and plays a fundamental role in determining their identity characteristics⁽¹⁸⁾. Brothers participate directly in family life. We perceive in the testimonies the influence of brothers in forming more determined people, leaders and that, in the absence of the parents, the brothers have the responsibility to discipline, and to say what can or cannot be done. Based on this, siblings are influencers of the person with a deficiency, especially in early childhood.

The role of the family in the care and development of the child is of fundamental importance, since the family nucleus comprises its first social support network, where also the most important care relationships take place, through actions of protection, acceptance, respect and empowerment of the other⁽¹⁹⁾. There are family members who stimulate the person with some motor limitation rather closely to what is demanded from other family members, as noted in an account - the person with a deficiency was always aware of what was happening in their health and illness process, and family members have always encouraged their participation and responsibility for their health. In this way, we tend to see people more inserted in society than in the families in which there is insecurity or overprotection around the person with disability⁽²⁰⁾.

As a mirror, family is the reflection of character, it is the model that the person in formation will have. From the moment the family accepts the deficiency, the disabled individuals will also accept their condition, and live well with themselves. Family health goes beyond the absence of disease, as families with people with deficiencies may be better able to be healthy, either for the time they share, for their commitment to success, for their ability to manage stress, or even for flexibility built from the disadvantage of one of the members. Thus, the development of affection with the person with a deficiency reported in the speeches demonstrates advantages for the reconstruction of a healthy family.

Family is the pillar of support and reference for its members and, when well-structured emotionally and affectively, it can stimulate the person with motor deficiency to transpose stages of suffering, contributing to their better adherence to rehabilitation and the resumption of life⁽²¹⁾. In this sense, the family as a point of support and balance of its members needs support in the technical-institutional and emotional fields to care for the disabled, a practice that presupposes so many specifics (emotional, theoretical and practical) in the different axes of the process of

rehabilitation - from high complexity to primary health care - as established in the Rehabilitation Network by Ordinance 793/2012⁽²²⁾.

Based on the above, even in a society that still does not welcome people with deficiencies, when healthy family interactions are developed, it is in the family that support and encouragement is found to live in society and to overcome existing prejudices⁽¹⁷⁾.

School and friends reflect the first contact, now, in the non-family aspect. Inclusive school education, which advocates free and unrestricted access and permanence of students with deficiencies in regular schools, has been established in Brazil, specifically in the pedagogical environment, as a legally authorized educational practice and, mainly, as an ideology.

Since the 1990s, school inclusion of students with disabilities has been daily experienced in common schools throughout the country. It should be noted that the expansion of the provision of services to students with deficiencies in the public-school system and in common classrooms was particularly marked by the launching of the National Policy on Special Education by the Ministry of Education (MEC) in 2008.

Based on the policy that aims at special education, it is necessary that the focus of teachers be directed to the particularities and needs of each student, since the person with a deficiency is unique, and must have their autonomy respected, and this transcends their deficiency. In order for the faculty to have specific knowledge of the person with a deficiency, information on the internal dynamics of the families is necessary, in order to favor an approach of the teacher with the socio-cultural environment in which the child lives. However, this extensive information must be expressed by family members, since it is them who know the children the most because they are always with them⁽¹⁴⁾.

A person who was previously living the experiences in the family nucleus begins to broaden their affective bonds, and their relationships begin to expand towards relationships outside the family; and these relationships are important for the development of the person with a deficiency in a community. The social support received is fundamental, as it alleviates the stress of family members and promotes a better bonding with their child. Thus, in addition to its traditional goal of promoting education and social integration, the school plays a key role in preventing or reversing situations of exclusion by promoting awareness-raising about the rights of people with deficiencies.

A person with some deficiency, besides being the target of the changes of daily life at the beginning of life outside the family, can also be the target of prejudice. We

can speak of prejudice when the subject-object relation no longer refers to a continuous process of mutual exchange, and the subject refuses to know the object, confined solely to his previous knowledge⁽²⁰⁾.

Based on the findings, from the moment the person with motor deficiency is a victim of prejudice and ridicule, he is blocked to the social world, socialization becomes synonymous with danger, and what was to be pleasurable becomes embarrassing, as one of the participants who reported bullying, evidenced by marks in his body, and which school comrades thought funny. When a person is victimized by classmates in the classroom, the stimulus to study and interact is impaired.

On the other hand, life outside the family brings strengths along, and also people who influence social and intellectual growth. However, we are social beings and, the more relationships we can establish, and the more different roles we play, the healthier we will be⁽²¹⁾. We can highlight these strengths in the testimony of one of the participants in the study, in which it was reported that the relationship with friends in school always existed with a certain dependence, since everything that was required in the classroom could only occur with the help of a friend. This also contributed to the strengthening of social relations.

From the participants' statements, we understand life story as an important process for the development of the person in society, as well as in university. The way students with deficiencies behave in university, whether autonomous or not, reflects the construction of their family and non-family stories, their support and the education received.

The exchange of knowledge and experiences causes difficulties and limitations to be discussed and shared among the groups, with ideas and opinions that help overcome the situation. However, a small part of these people reaches resocialization⁽²³⁾. Many of them remain in their homes because of socio-economic and cultural conditions and have not been referred to rehabilitation. Rehabilitation is responsible for enabling the training of new skills to the people who use them, making it possible to face everyday obstacles. To this end, the work of a multidisciplinary team⁽²⁴⁾ in the three levels of health care is fundamental, comprising the biopsychosocial aspects, and aiming at the autonomy and resocialization of these people.

■ CONCLUSIONS

Through this research we had the opportunity to know the life story of university students with motor deficiencies, and we were able to understand how their childhood was

and how family and non-family coexistence influenced their life perspectives. Regarding family coexistence, we understand that the family was always very present, with a fundamental role for the creation of strategies of coexistence with motor deficiency. The family is the haven and primary influence for future actions. The family was generally supportive of the choices, because the way in which it dealt with this person favored their strengthening to endure the difficulties.

Regarding relationships outside the family, it was at school and with friends that the first contacts took place. Differences in the life span of people with motor deficiency were discernible; on the one hand prejudice, the most innocent questions, even the ill-intentioned practical jokes that make a person with deficiency close to new life experiences. On the other hand, good influences symbolized by friends encourage them to develop as a person and to create affective bonds.

We understand that the impact of motor deficiency on the daily lives of university students is positive, and this is due to the favorable life experiences of support and protection that these people received. We emphasize that healthy family experiences, added to the strong ties of friendship, made it possible for the difficulties encountered in the daily life of these students be softened and overcome.

Considering the complexity of the theme "life story of university students with motor deficiency", it is observed that this study presents some limitations, among which we can mention the scarcity of articles, both national and international, related to the subject in question. The number of study participants may also be considered a limitation, due to the complexity of the interviews (the difficulty of obtaining the acceptance of some participants), and the bureaucratic procedures to reach the interviewees.

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