

# Perception of adolescents with spinal cord injury about autonomy

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## Abstract

Starting from the referential of patient's human rights and considering that bioethical aspects of relational autonomy are important in the construction of autonomy as a life project, this study analyzed the perception of the autonomy process in adolescents with spinal cord injury participating in a rehabilitation program. This is a cross-sectional quali-quantitative study that used interviews to collect data and the Iramuteq software to analyze them. Fourteen adolescents participated, 50% male, 29% living in the Federal District, 71% with paraplegia. The qualitative data analysis identified five classes: rehabilitation program (20.9%); autonomy (21.8%); family relations (16.7%); feelings and experiences (23.9%); and routine (16.7%). The mother was indicated as the main caregiver (64%) and autonomy was often related to the concept of independence. Other forms of relationships corroborated the model of relational autonomy, and intrinsic and extrinsic challenges to the condition of the participants analyzed from the perspective of patient's human rights were also identified.

**Keywords:** Adolescent. Personal autonomy. Human rights. Rehabilitation. Bioethics.

## Resumo

### Percepção de adolescentes com lesão medular sobre autonomia

Considerando que, a partir do referencial dos direitos humanos do paciente, aspectos bioéticos da autonomia relacional são importantes na construção da autonomia como projeto de vida, analisou-se a percepção do processo de autonomia em adolescentes com lesão medular participantes de um programa de reabilitação. Trata-se de estudo transversal quali-quantitativo que utilizou entrevista para coletar dados e o *software* Iramuteq para analisá-los. Participaram 14 adolescentes, 50% do sexo masculino, 29% moradores do Distrito Federal, 71% com paraplegia. Na análise dos dados qualitativos, identificaram-se cinco classes: programa de reabilitação (20,9%); autonomia (21,8%); relações familiares (16,7%); sentimentos e vivências (23,9%); e rotina (16,7%). A mãe foi apontada como principal cuidadora (64%) e a autonomia muitas vezes foi relacionada ao conceito de independência. Outras formas de relacionamentos corroboraram o modelo da autonomia relacional, sendo identificados desafios intrínsecos e extrínsecos à condição dos participantes analisadas na perspectiva dos direitos humanos do paciente.

**Palavras-chave:** Adolescente. Autonomia pessoal. Direitos humanos. Reabilitação. Bioética.

## Resumen

### Percepción de los adolescentes con lesión medular sobre la autonomía

Considerando que, desde los derechos humanos del paciente, los aspectos bioéticos de autonomía relacional son importantes para constituir la autonomía como proyecto de vida, se analizó la percepción del proceso de autonomía en adolescentes con lesión medular de un programa de rehabilitación. Es un estudio transversal cualicuantitativo, que utilizó entrevistas para recopilar datos y el *software* Iramuteq para analizarlos. Participaron 14 adolescentes, 50% del sexo masculino, 29% residentes en el Distrito Federal, 71% con paraplejía. Del análisis de datos cualitativos emergieron cinco clases: programa de rehabilitación (20,9%); autonomía (21,8%); relaciones familiares (16,7%); sentimientos y experiencias (23,9%); y rutina (16,7%). La madre fue la principal cuidadora (64%), y la autonomía estuvo relacionada frecuentemente con el concepto de independencia. Otras formas de relación respaldan el modelo de autonomía relacional, con la identificación de desafíos intrínsecos y extrínsecos a la condición de estos participantes desde la perspectiva de los derechos humanos del paciente.

**Palabras clave:** Adolescente. Autonomía personal. Derechos humanos. Rehabilitación. Bioética.

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Adolescence is the period of development delimited by Brazil's Child and Adolescent Statute as the group aged from 12 to 18 years<sup>1</sup>. It is a stage marked by great physical, psychic, and social transformations, highlighting the conquest of rights in various social contexts<sup>2</sup>. However, some factors may affect the development of individuals, such as environmental adverse events or illnesses which cause physical disability, accentuate their intrinsic vulnerability, and impair the exercise of their autonomy.

Among the negative events which may occur in this age group, physical deficiencies due to spinal cord injuries stand out, that is, injuries to the structures in the medullary canal, causing paraplegia or tetraplegia<sup>3</sup>. These lesions can generate motor, sensory, autonomic, and psychoaffective alterations, which will manifest themselves as limb paralysis or paresis; alter muscle tone and superficial and deep reflexes; change or eliminate sensitivities (tact, pain, pressure, vibration, and proprioception) and sphincter control; cause sexual dysfunction; and produce autonomic modifications, such as vasoplegia, sweating changes, body temperature control alterations, among others<sup>4</sup>.

In Brazil, spinal cord injuries are considered a public health problem given their severity, the irreversibility of its sequelae, and its productive consequence since it more gravely affects young adult individuals<sup>3</sup>. A study of the epidemiological profile of spinal cord injury, conducted in the Sarah Network, found an incidence of 21 cases per million inhabitants/year and an 8.6% prevalence of traumatic spinal cord injuries<sup>5</sup>.

Its highest incidence occurs among people aged 20 to 24 years, especially due to traumatic injuries (80%) caused by car accidents, falls, shallow dives, work accidents, sports practice, and episodes of violence, especially gunshot wounds. Tumors and infectious, vascular, and degenerative diseases feature among its non-traumatic causes (20%)<sup>6</sup>. These injuries trigger factors which directly or indirectly impact autonomy, quality of life, and social participation<sup>6</sup>.

From a historical and social point of view, it is customary to differentiate disability injuries. The first approach would be the focus of biomedical actions in coping with intrinsic conditions, whereas the second would be the

object of social justice and public welfare policies. In the latter model, disability has a relational character extrinsic to the person since it consists in the interaction of such attributes with social barriers which may hinder or prevent access to and exercise of rights on equal terms or conditions similar to other people's<sup>7</sup>.

The Brazilian Law on the Inclusion of Persons with Disabilities (Law 13,146/2015)<sup>8</sup> comprises disability as long-term physical, mental, intellectual or sensory impediment, which, in interaction with one or more barriers, may obstruct their full and effective participation in society in equal conditions with others.

Rehabilitation is defined by Martini as *educational, social, and therapeutic work in which a person suffering from some type of disability seeks to re-establish or create resources to resume the activities of their life in the best possible way*<sup>9</sup>. It is work which leads to a better discernment of limitations and possibilities to enable individuals to fulfill their social role and optimize their participation in their community.

This study was developed based on the concept of autonomy—people's ability to self-govern and make their own choices—to guide their actions. However, in the context of rehabilitation, the term "autonomy" is broad and is related to independence, functionality, mobility, social participation, decision-making, identity, ability, skills, self-management, self-determination, self-government, efficiency, etc.<sup>10,11</sup>. Social conditions bind people to decision-making about their own lives, often based on social and interpersonal demands and restrictions<sup>12</sup>.

Thus, Albuquerque conceptualizes relational autonomy based on the assumption that *people are interrelated, interdependent, and interconnected but without disregarding the notion of the individual (self), understanding it from its interactive constitution and through intersubjective relationships, relational autonomy refers to the concept of autonomy that binds the person to the social aspects of the individual's life, that is, its integral connection with politics, economy, race, gender, culture, life experiences, and interactions with others and personal desires*<sup>12</sup>.

According to Eler and Albuquerque<sup>13</sup>, the human rights of patients is considered

appropriate to protect these people since, in addition to imposing the responsibilities of respecting, protecting, and meeting patients' rights on the State, it belongs to an expanded view of healthcare, unrestricted to access to goods and which emphasizes care (among other ethical essential goods) to achieve better health outcomes and increase patients' well-being<sup>14</sup>.

The objective of this research was to analyze, in the light of such human rights framework, the perception of adolescents with spinal cord injury within a rehabilitation program about their autonomy process, based on the principle of relational autonomy. When exploring the object—adolescence and its relations with autonomy in the context of spine cord injuries (SCI)—it was found that few studies addressed this theme, which justifies the relevance of this study.

## Method

This is a descriptive and quantitative-qualitative study with data collected in interviews with a semi-structured script which was conducted from February to March 2020 at the Brasília/DF unit of the Sarah Network of Rehabilitation Hospitals. Adolescents with physical disabilities due to spinal cord injury who signed a consent form and whose guardians signed an informed consent forms were invited to participate in this research.

Inclusion criteria were a) age between 12 and 18 years; b) SCI diagnosis (traumatic or non-traumatic); and c) have attended the rehabilitation program at Sarah Hospital for at least six months. Exclusion criteria were a) other associated comorbidities, such as cranioencephalic trauma, brain injury, and moderate to severe cognitive deficit and b) rehabilitation beginning at least six months before data collection.

The instrument elaborated for this study included closed questions on participants' sociodemographic aspects (age, schooling, and family composition and income),

care (regarding bladder, neurogenic intestine, skin, and use of medications), input acquisition, and social benefits received by the family, collected from hospital electronic medical records. Finally, interviews were conducted, with 13 open questions divided into four themes: 1) patient routine and family relationship, 2) meaning of SCI for them, 3) perception about the rehabilitation program; and 4) perception of autonomy.

After participants were selected, face-to-face interviews were scheduled, associated with dates of care, such as examinations or consultations of patients in the hospital. In total, seven patients participated in the interview during their hospitalization and two at home (given their impossibility of going to the hospital). These interviews were individually conducted in a discreet space and audio recorded via a cell phone after authorization was given by the interviewees.

Descriptive statistical analyses were performed for data from the first part of the questionnaire in the Statistical Package for Social Sciences (SPSS), version 21.0. Qualitative data were analyzed via Iramuteq<sup>15</sup>, version 0.7 Alpha (2014), a tool which enables the association of text segments which research considers relevant, grouping of statistically significant words, suggestion of relevant categories and themes, and the qualitative analysis of data. Bardin's content analysis<sup>16</sup> (in its thematic category modality) was used to examine the classes of words generated by Iramuteq.

## Results

This study included 14 adolescents, male (n=7; 50%) and female (n=7; 50%), all participating in a rehabilitation program, of which 64% showed traumatic spinal cord injuries, distributed in paraplegia (n=10; 71%), paraparesis (n=3; 21%), and tetraplegia (n=1; 7%). Their age ranged from 12 to 18 years (mean=15 years); 21% (n=3) came from the Federal District; seven attended elementary school; and 43% (n=6) reported having missed a school year at least once (Table 1).

**Table 1.** Sample characterization

Adolescent	Gender	Age	Cause of injury	Injury level	Educational attainment	Origin
1	M	18	Fall from height	Paraplegia	Higher education	Brasília/DF
2	M	16	Car accident	Paraplegia	1st year of high school	Brasília/DF
3	M	17	Transverse myelitis	Paraplegia	2nd year of high school	Ariquemes/RO
4	F	14	Transverse myelitis	Paraplegia	9th school year	Brasília/DF
5	M	16	Shallow diving	Tetraplegia	2nd year of high school	Monte Carmelo, MG
6	F	16	Car accident	Paraplegia	2nd year of high school	Santa Rosa do Sul/SC
7	F	13	Transverse myelitis	Paraparesis	9th school year	Pimenta Bueno/RO
8	F	16	Cauda equina syndrome	Paraparesis	2nd year of high school	Costa Rica/MS
9	F	12	Car accident	Paraplegia	7th school year	Pontes de Lacerda/MT
10	M	12	Car accident	Paraplegia	7th school year	Campo Verde/MS
11	M	18	Gunshot wound	Paraplegia	10th school year	Araguaína/TO
12	M	15	Gunshot wound	Paraplegia	8th school year	Formosa/GO
13	F	16	Car accident	Paraplegia	2nd year of high school	Sinop/MT
14	F	12	Intramedullary tumor	Paraplegia	8th school year	Valparaíso/GO

For 64% (n=9) of adolescents, their mothers were their main caregiver or legal representative; to 29% (n=4), their father; and for 7% (n=1), their grandparents. Caregivers' educational attainment ranged from tertiary education (21%; n=3), secondary education (57%; n=8), and elementary education (21%; n=3), whereas family income, from R\$ 748.00 to R\$ 10,000.00, according to patients' reports. The mean number of people living in the same house was four, with a maximum of seven.

Our textual corpus contained 298 text segments, of which Iramuteq analyzed 234, corresponding to 78.52% of the total and representing an appropriate portion for descending hierarchical

classification. According to Reinert<sup>15</sup>, research should avoid proportions lower than 60% for this analysis. Content analysis produced five classes.

The dendrogram in Table 2 shows the relations between these five classes, indicates the initial context unit (UCI) percentage of each (regarding the entire textual corpus), and show the words with higher chi-square in each class. The chi-square index indicates the impact of these words on class formation, which we named according to the main subjects in participants' responses. We interpreted their convergence by the adopted theoretical framework. We described each class in participants' responses and illustrate them by examples (Table 2).

**Table 2.** Descending hierarchical classification obtained via Iramuteq, evincing five classes and the distribution of percentages in the corpus.

Class 5 16.7%			Class 2 21.8%			Class 1 20.9%			Class 4 23.9%			Class 3 16.7%		
Word	χ <sup>2</sup>	%	Word	χ <sup>2</sup>	%	Word	χ <sup>2</sup>	%	Word	χ <sup>2</sup>	%	Word	χ <sup>2</sup>	%
School	61.02	63.64	Autonomy	33.34	71.43	Lack	51.97	100.00	Talking	18.15	51.35	Family	37.06	73.33
Routine	56.54	86.67	Alone	32.15	76.47	Sarah	50.15	88.24	Problem	18.04	180.00	People	29.66	50.00

continues...

Research

Chart 1. Continuation

Class 5 16.7%			Class 2 21.8%			Class 1 20.9%			Class 4 23.9%			Class 3 16.7%		
Word	$\chi^2$	%	Word	$\chi^2$	%	Word	$\chi^2$	%	Word	$\chi^2$	%	Word	$\chi^2$	%
Agreement	46.80	100.00	Program	28.10	83.33	Accompanies	35.34	100.00	See	17.39	58.33	Calm	25.55	100.00
Organize	46.29	80.00	Thinking	76.92	24.54	Supply	35.34	100.00	Thus	16.86	48.78	Siblings	23.46	58.82
Afternoon	41.42	100.00	Want	52.78	23.96	A lot	27.29	70.59	Person	16.77	55.56	Especially	19.71	83.33
Sleep	40.45	90.00	Future	100.00	18.33	Learn	26.58	73.33	Moment	12.94	100.00	Mother	16.92	38.10
Go out	38.57	63.64	Choice	100.00	18.33	Get	23.71	68.75	No	11.94	31.69	Better	16.90	66.62
Watch	36.08	100.00	Clothing	85.71	17.30	Help	19.39	69.23	Catch	11.87	75.00	Normal	15.85	58.33
Room	36.08	100.00	Exercise	100.00	14.60	Here	18.91	50.00	Say	09.85	56.25	Well	15.60	50.00
Final	30.79	100.00	Decide	83.33	13.68	Service	18.26	77.78	Always	09.83	48.15	Take	05.78	71.43
Night	30.79	100.00	Rehabilitation	63.64	01.86	Because	12.62	36.51	Accessible	09.66	100.00	Grandmother	15.78	71.43
Coffee	30.79	100.00	Live	71.43	10.43	Help	12.23	40.00	Be born	09.66	100.00	Month	15.19	100.00
Lunch	30.79	100.00	Wear	80.00	10.16	Need	11.82	66.67	Improve	09.66	100.00	Discover	14.76	80.00
Take	30.46	64.71	Question	62.50	08.05	Present	11.47	100.00	Jeans	09.66	100.00	Play	14.12	60.00
Arrive	30.17	80.00	Count	66.67	07.27	Evolve	11.47	100.00	Pants	09.66	100.00	Get used to	11.08	66.62
Friend	25.55	100.00	Still	54.55	07.26	Treatment	10.76	80.00	Bullying	09.66	100.00	Father	10.19	55.56
Week	25.17	77.78	Thing	32.86	07.17	Accept	10.76	80.00	Talking	08.94	71.43	Beginning	09.97	75.90
Cell phone	20.35	100.00	Head	75.00	06.76	Need	10.76	80.00	God	08.82	80.00	Uncle	08.51	57.14
Home	17.83	47.83	Pass	60.00	04.38	Walk	08.81	45.45	Bladder	08.82	80.00	Like	06.91	60.00
Dinner	15.19	100.00	Depend	60.00	04.38	Surgery	07.60	50.00	Physician	07.47	60.00	Familiar	05.08	45.40
TV	15.19	100.00	Bath	50.00	03.87	Decision	06.77	55.56	Until	06.77	53.85	When	03.79	29.17
<b>Routine of adolescent with spinal cord injury</b>			<b>Autonomy of adolescents with spinal cord injury</b>			<b>Rehabilitation program of adolescents with spinal cord injury</b>			<b>Feelings and experiences of adolescents with spinal cord injury</b>			<b>Family relationships of adolescents with spinal cord injury</b>		

**Class 1**

**Rehabilitation program of adolescents with spinal cord injury**

By analyzing its representation in the textual corpus, we found that Class 1 occupied the third place in our hierarchy (49 of 234 words or 20.94%) and that its words with the highest chi-square were “lack,” “Sarah,” “follow-up,” “supply,” and “a lot,” as per Table 2. Most participants positively perceived the rehabilitation program, finding that it met their needs and that they had learned self-care due to the necessary adaptations to their current situation, thus promoting their independence, autonomy, and a new perspective toward their daily lives, as exemplified by the following reports:

*“It helped me a lot to understand that I am not the only one in this situation (...) and for helping me, because I basically didn’t know anything about wheelchairs” (A3).*

*“The rehabilitation program helped me to have this autonomy because they were always very present, teaching, advising, and showing me new ways. So, what I learned, like transference and self-care... I learned all that from rehabilitation, I learned to get by” (A7).*

Regarding the negative aspects of the program, adolescents reported feeling the need of greater guidance on the benefits and rights of people with disabilities, available aquatic activities, and tilt training.

*"I stayed there in 2018 for rehabilitation but I wish I'd swum or done something that could stimulate me, help me stand, improve the function in my leg, to walk again" (A4).*

*"In my opinion, I would like professionals to pass on more ideas about benefits. I didn't know about Fremec, which is about discounts on tickets, travel, and other things that benefit patients" (A2).*

## Class 2

### Autonomy of adolescents with spinal cord injury

Class 2 occupied the second place in our hierarchy (after we analyzed its representation in our textual corpus) and its words with greater chi-square were "autonomy," "alone," "program," "think," and "want" (Table 2).

Initially, participants had difficulty understanding the meaning of autonomy and we needed to briefly explain its basic concept, according to which, the term "autonomy" comes from the words *autos* ("I") and *nomos* ("law"), indicating the notion of self-legislation, self-government, and self-determination. After we explained them the concept, we found, however, that some adolescents tended to associate autonomy with a notion of independence and decision-making.

*"Autonomy is like being independent, so I don't always depend on my mother. I have to do it myself, go to school, do my catheterization, put on diapers, put on clothes, my sneakers, all by myself (...) I help move my chair. I think it's about having maturity about things, knowing how to make the right choices and not the wrong ones" (A4).*

*"Now that I'm rehabilitated, I can make my own decisions. Go, do things by myself and socialize more, right? I couldn't even get on the sidewalk" (A9).*

Another fact is non-autonomy, that is, patients' total dependence on the help of third parties. An adolescent, for example, reported lacking autonomy for understanding he was governed by his mother. Learning to take care of oneself, dealing with embarrassing situations, such as sphincter control, so as to prevent defecating or urinating on their clothes, brought a sense of mastery of the situation,

which participants understood as autonomy. Vesico-intestinal reeducation brought adolescents a better quality of life since they could maintain continence.

The interviewed adolescents mentioned situations in which they were unable to exercise their autonomy due to their age and physical limitations or because their desires were unmet. In all these situations, adolescents' saw their lack of autonomy as something negative which gave them a feeling of impotence and devaluation.

*"Spinal cord injury does not interfere with my social life (...) of course I can't do everything, for example, I can't ride the bus since it isn't adapted" (A12).*

*"When you need to do something, if you don't have an accessible place, you don't" (A7).*

Adolescents also understood autonomy as planning their future and envisioning life with another look, focused on professional and personal fulfillment.

*"About my future, I think a lot about the profession I want to have. I've thought about having several professions, being a cop, being a lawyer, being a veterinarian or psychologist" (A4).*

## Class 3

### Adolescents with spinal cord injury and their family relationships

Class 3 occupied the last place (tied with Class 5) regarding its representation size in our textual corpus (39 UCI in 234 or 16.67%). Its words with the highest chi-square were "family," "people," "calm," "brother," and "especially" (Table 2). This category evinced adolescents' relationship with their family and friends in their lives. We found a predominance of mothers as the main caregivers in participants' reports.

*"My mother has always taken care of me, so I want to give her the best I can" (A8).*

*"The relationship with my family is normal, the closest people [to me] are my family and my relatives (...) I feel supported by them, especially my mother and aunt, my mother's sister" (A12).*

On the other hand, some adolescents reported frustrations regarding their family's misunderstanding

of the diagnosis and prognosis of their disease, which generated excessive and critical charges.

*“My grandmother and some of my family members, those elderly uncles who were raised in the farm and think that ‘tough’ solves everything. Only then we explain, and they understand. When the person does not accept me or does not like to see me in the chair, I pull away, because it is better to be close to the people who are good to us” (A14).*

*“Initially, the reaction from my family members was very difficult but nowadays everyone got used to it, especially my maternal grandmother, who used to cry and be very distressed” (A3).*

*“My family helps me when my mother needs to work. Then, they come to stay with me. At first, I was surprised because I didn’t want to be like this” (A1).*

According to adolescents’ perception, families face a process of reorganization and adoption of strategies that stimulate the implementation of a social, emotional, and practical support network or financial aid. We may consider social support as a way to help family members manage problems and collaboratively act in the health care system.

Participants’ disease complicated family relationships. Thus, overwork and time spent caring for adolescents with spinal cord injury may have interfered with some family members’ daily lives, causing overload, which could be the reason for another study.

## Class 4

### Feelings and experiences of adolescents with spinal cord injury

Class 4 occupied the first place in our hierarchy (after we analyzed its representation in our textual corpus) (56 UCI in 234 or 23.93%). Its words with greater chi-square were “speak,” “problem,” “see,” “thus,” and “person” (Table 2).

However, one word drew our attention: most adolescents mentioned the term “get used to,” in the sense that they got used to the situation, as did their family members and friends. It is emphasized that, in view of the

reflection on how SCI impacted their lives, many were emotional talking about it.

*“It was actually good because it resulted in my growth from adolescent to adult, it’s not all roses, I’m saying exactly the opposite, but, when you get used to it, it’s not as difficult as people think” (A2).*

*“I was nine years old, I was in the Base Hospital, so I knew that I would not move my leg anymore. I spent a long time without wanting to talk to anyone, then I got used to it” (A1).*

A teenager mentioned the experience of having supportive people around, rather than experiencing discrimination at that time. However, not all had such an experience. Some reported situations in which they suffered prejudice and discrimination, even from those close to them, such as family members and friends. Persons with SCI need a means of locomotion and most use wheelchairs.

Another stigmatizing factor was the use of diapers since urinary and fecal incontinence embarrass patients. Skin lesions and deformities due to their injuries were also factors which limited or even moved adolescents away from social life. These adolescents felt and experienced this change in the behavior of the people around them.

*“Once no shoe fit the device. I cried in the store. So, when I came here [Sarah], they made a much better device (...) today I wear whatever shoe I want” (A8).*

*“My family members are very patient, they always try to see put themselves in others’ shoes, so they always look for different ways to change those scenarios that are not accessible” (A7).*

However, in adolescents’ view, their family have often overestimated the difficulties and failed to believe that they could overcome them, which was not always true. Thus, we found ableist attitudes from people close to these adolescents, albeit they did not aim to hurt or sadden them. Family members acted in ways which seemed to doubt that these adolescents would be capable of handling their situation. Their reports express this behavior when participants claimed having refused the help of others or being able to move by themselves.

*“For them, it’s much harder than what I go through, I don’t feel I’m in that much trouble (...) for example, my father thought that I could never wear jeans because he figured it would fit to tightly since I would have to wear a diaper all the time” (A2).*

*“They think it’s a lot harder than what I really go through, they want to protect me... they have good intentions, of course, they are parents” (A2).*

The church, the religious community, and the various ways of seeing God were important factors in people’s interrelationships. In some adolescents’ view, faith triggered feelings of hope, important to face the disease. Sometimes, however, their families’ faith has brought unrealistic expectations about adolescents’ progress. On the other hand, the way of naming SCI provided better coping mechanism for adolescents and families since it softened how they perceived the problem.

*“At the same time that I’m learning, I’m instructing other people. My family tells me to do my part since God will do his” (A4).*

*“Spinal cord injury is a strange term for me, I usually say it is a disruption of the spinal cord” (A7).*

A teenager mentioned jealousy. However, she emphasized that this feeling was absent in her family since she feels surrounded by protection and security.

*“As I was born with a condition, my mother gives me more attention. But my brother and sister were never jealous of me” (A8).*

We found that two adolescents who experienced bullying at school (the term in English has been incorporated into Brazilian Portuguese and is especially used among children and adolescents). They were mocked due to deformities in their feet and reported name-calling, nicknames due to their obesity and their need of wheelchair. Their reports showed, on the other hand, the support from the school staff and their siblings to deal with these acts. Adolescents found that independence and autonomy were means to face bullying.

*“Sometimes, someone will only look at my foot and tease me, something like that, or they will make a joke (...) I can’t wear heels and my dream is to wear them” (A8).*

*“They [brothers] have always helped me with everything at school. When I was bullied, my sister was the one who helped me (...) they always gave me the greatest support” (A8).*

Adolescents have sometimes reported negative feelings and unhappiness. At times, they reported discouragement, sadness, hopelessness, and even depression and suicidal ideation. Commonly, due to functional loss, we found a mourning phenomenon after the spinal cord injury which is accompanied by anger, guilt, low self-esteem, anxiety, and loneliness. Family support in the face of difficulties was a means of seeking strength and emotional support, improving coping to move on.

*“I tried to die, I’ve grabbed a knife... then my mother arrived on time and saw it and didn’t allow it. I’ve also asked people to buy me a knife to try it, but it did not work (...) because I don’t feel like doing nothing... I lost all the will to live. I lost the will to smile after I became like this. I saw, like, how I played ball and now I can’t” (A9).*

*“It’s not normal. I am not normal like other people” (A11).*

*“Having to get used to a new life is complicated. Like, psychologically. Low self-esteem. I’m always down, with a little bit of depression. There is a specific symptom within depression that is like a discouragement in my life” (A3).*

## Class 5

### Routine of adolescent with spinal cord injury

After analyzing its representation in our textual corpus (39 UCI in 234 or 16.67%), we found that Class 5 occupied the last place in our hierarchy (tied with Class 3). Its words with the highest chi-square were “school,” “routine,” “agreement,” “organize,” and “afternoon” (Table 2). Routine was important in the lives of these adolescents, enabling them

to organize their thoughts and tasks, which they have now incorporated into other activities related to their disease. When asked who organized this routine, most adolescents stated having done it themselves, with the exception of a young man who claimed that his mother organized his routine into slots set in his cell phone.

Adolescents' routine tend to intersperse school and social and personal tasks. When reporting their routine, they talked about school and personal care, relating family and leisure moments and showing a reality very similar to that of adolescents without disabilities.

*"I organized my routine and I think it is organized. Weekend's not the same... I go to my grandmother's house and we're there playing with each other, with my cousins"* (A12).

*"I put the schedules on my cell phone. As for leisure, I don't really like going out. I prefer to go out on weekends"* (A1).

*"My routine is based on going to school. Then, I come home at lunchtime, and I do my catheterization. I'm free in the afternoons. I watch movies and I like to go out at night"* (A7).

## Discussion

The question explored in this study was understanding, in light of bioethics, the perception of adolescents with SCI on their autonomy, especially regarding relational autonomy, shared decision-making processes, and patient-centered care within a rehabilitation program. We analyzed adolescents' reports from the five thematic classes we identified.

More than half of participants maintained expected school levels. Some failed school years due to periods of hospitalization and absence from school, impairing their academic performance. An adolescent said she needed to leave the classroom due to bladder catheterization and, when she came back, her teacher would not repeat the explanations and failed to give her the opportunity to ask questions, a fact that led her to perceive herself at a disadvantage, compared to her classmates.

According to Martini and collaborators<sup>11</sup>, WHO reports describe that children with SCI are

less likely to start or advance in their academic life, which corroborates this exemplified fact. However, it is known that education is a social good, and the importance that the State and society dispense to children serves as a parameter to promote social justice.

In view of the changes that occurred in the lives of these adolescents and their family members after SCI, participants reported the sudden and unexpected interruption of their life plans and dependence of third parties for day-to-day activities as the most impactful factors in their lives, considering that they thought of the concept of autonomy functionally, focusing more on independence. Some reported how they felt about losing autonomy: from getting out of bed, going to their wheelchair, to the bathroom, and out on the street by themselves.

Interaction with other people who experienced the same condition, family relationships, and the rehabilitation program were important to exchange experiences, feelings, and information since they were considered "different" in other environments. We observed stigmatization and discrimination, which can generate social isolation, segregation, and hostile environments at a stage in which adolescents need to be in groups with which they identify and to which they belong.

In this study, it was observed that adolescents who underwent the rehabilitation program incorporated into their routine care taught during the program, such as self-catheterization. They also described other care, such as bathing, rest, leisure, and relationships with their family and friends as important in their daily lives. Most participants described their routine as good and organized. According to what we observed in their reports, adolescents with SCI daily face several challenges limiting their autonomy. The routine of these young people is then restructured.

Reports which valued participation in decisions related to treatment, as well as shared decision-making, contributed to build a concept of autonomy. Participants referred to it as something they were conquering, even if they were small victories, such as decisions about what to eat, what to wear, bedtime, etc. Even in small daily activities, participants recognized that they were exercising their autonomy by performing such activities by themselves or making decisions.

This study showed mothers as primary caregivers. Guimarães states that *care, when analyzed, in the family context and in social relationships closer to persons with disabilities is a task performed by women (...). Some caregivers face the challenge of reconciling paid work outside the home and caring for those with disabilities*<sup>17</sup>.

The importance of parents encouraging adolescents' participation in decision-making was present in the statements, when adolescents' opinion on a given subject was valued. These reports corroborated the concept of relational autonomy, which, according to Albuquerque, *is dynamic (...) to the extent they intertwine with their personal relationships and consist of personal experiences*<sup>12</sup>. Lived experiences generate new ways of facing ethical and moral conflicts, changing their way of thinking.

Lack of accessibility prevented or hindered adolescents with disabilities from exercising their right to come and go, as did inadequate buildings and unadapted bathrooms. A young man replied that the lack of adapted buses prevented his autonomy since it was the only thing he was unable to do: get on an unadapted bus. Rather than SCI interfering in this teenager's life, the barriers he encountered in this path did. According to Barbosa, Santos, and Silva, *affordable public transportation is one of the recurring demands (...) is one of the forms of guarantee of the right to mobility (...) when this right is not guaranteed, it may also hinder access to other rights, such as the right to health and education*<sup>18</sup>.

Participants' statements were important to find that, regarding access to rehabilitation programs and basic supplies, such as medications, catheterization material, and other personal care materials, the State has partially fulfilled its role as provider of these materials. However, we still find much to be done since, even with the constant struggle for the rights of people with disabilities and against discrimination, many situations perpetuate social injustices, removing these persons' power of manifestation, participation, and access to goods and services, marginalizing them<sup>18,19</sup>.

Shakespeare<sup>20</sup> mentions a political strategy to remove barriers as a means of dismantling crippling obstacles and thus include people with disabilities as a strategy of social transformation. The author also suggests that a final answer to

discrimination could be fought by civil rights and laws on equality of opportunity and race relations. Therefore, public policies should be formulated to include this age group and enhance adolescents' autonomy from the socio-relational context in which they live.

Among the limitations of this study, we highlight the reduced number of adolescents. Moreover, we conducted this research in a single health institution, whose model of care excels in the philosophy of care, so that the reports were restricted to the care and philosophical proposal of this institution. It is suggested that, in future studies, research should include other rehabilitation centers and life contexts to compare different realities, as well as empirical studies involving relatives of adolescents and healthcare providers, which this investigation failed to address, for example.

## Final considerations

Autonomy is a socially constructed capacity, that is, its exercise by adolescents occurs by integrating the relational element. Due to their special status as vulnerable persons, it should be recognized that autonomy not only means obtaining informed consent from adolescents. More than that, health professionals should be aware of the conditions affecting adolescents' ability to make autonomous decisions, which mitigate their willingness to participate in treatment.

In the construction of the autonomy of adolescents with SCI, in addition to dealing with conflicts specific to age and those intrinsic to the disease, they still face unnecessary situations and extrinsic barriers since society itself is yet to sufficiently evolve to the point of guaranteeing their rights.

Adolescents related autonomy to independence. However, in their statements, we found other relationship forms which also refer to autonomy, expanding the concepts for their daily activities and corroborating the relational autonomy model. Therefore, we considered appropriate to use this concept in the context of adolescents with SCI.

In the analysis of adolescents' perception, it was possible to confront the bioethical assumptions of relational autonomy, from the human rights framework, as tools to build autonomy as a life project. However, progressive,

relational autonomy, built as independence, trust, and freedom levels are gained, can be considered. It is noteworthy that one should not unlink autonomy from the relational context in which adolescents live. Therefore, it is necessary to establish a safety net which prevents paternalistic relationships, a repressive social environment, and inadequate institutional policies, as they hinder the development and exercise of autonomy.

In the social model, disability fails to prevent the exercise of the human rights framework, but all barriers which impose restrictions on people with disabilities do; that is, prejudice, discrimination, inaccessible public buildings and transport systems, segregated education, among others. The human rights model covers the values for a policy that recognizes the human dignity of persons with disabilities.

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## Appendix

### Semi-structured interview script

#### Data collection instrument

##### Sociodemographic questionnaire

Teenager's date of birth: \_\_\_\_/\_\_\_\_/\_\_\_\_ Age: \_\_\_\_ years \_\_\_\_ months

Guardian's date of birth: \_\_\_\_/\_\_\_\_/\_\_\_\_ Age: \_\_\_\_ years \_\_\_\_ months

City in which they live:

Biological sex:

( 1 ) Male ( 2 ) Female

Family member who is responsible for monitoring the adolescent in the service:

( ) Mother ( ) Father ( ) Paternal aunt/uncle

( ) Maternal aunt/uncle ( ) Paternal grandfather/grandmother

( ) Maternal grandfather/grandmother ( ) Brother/sister ( ) Stepfather

( ) Stepmother ( ) Other: \_\_\_\_\_

Family members' educational attainment:

( ) Literate ( ) Elementary School ( ) Junior High School

( ) Incomplete High School ( ) Complete Secondary Education ( ) Master's Degree

( ) Incomplete higher education ( ) Complete higher education ( ) Specialization

Guardians' profession: \_\_\_\_\_

Family income: R\$ \_\_\_\_\_

How many people live in the home? \_\_\_\_\_

Family composition:

( ) Mother ( ) Father ( ) Paternal aunt/uncle

( ) Maternal aunt/uncle ( ) Paternal grandfather/grandmother

( ) Maternal grandfather/grandmother ( ) Brother/sister ( ) Stepfather

( ) Stepmother ( ) Other: \_\_\_\_\_

Grade the teenager attends: \_\_\_\_\_

Number of failed subjects: \_\_\_\_\_ Failed grades: \_\_\_\_\_

Reason: \_\_\_\_\_

Which professionals follow the teenager up at Sarah Hospital? \_\_\_\_\_

( ) Neurosurgery ( ) Pediatrics ( ) Speech Therapy

( ) Psychology ( ) Functional therapy ( ) Psychopedagogy

( ) Social Worker ( ) Nurse ( ) Orthopedist

( ) Hospital professor ( ) Physical education teacher ( ) Nutritionist

( ) Group service

Date of start of care at Sarah Hospital: \_\_\_\_/\_\_\_\_/\_\_\_\_ (file details)

Age at which diagnosis was made or date of diagnosis: \_\_\_\_\_

Medication use:

If so:

What medication? \_\_\_\_\_

How many times a day and at what dosage is the medication currently taken? \_\_\_\_\_

Do you get this medication from the government? \_\_\_\_\_

Do you receive intermittent bladder catheterization:

If so:

How many times a day? \_\_\_\_\_

How do you obtain the catheterization materials? \_\_\_\_\_

What hinders or facilitates catheterization? \_\_\_\_\_

Have you ever had pressure injuries? \_\_\_\_\_

If so:

How many times? \_\_\_\_\_

Where in your body? \_\_\_\_\_

How was the care to heal this wound? \_\_\_\_\_

Do you receive any government benefits?

If so:

- ( ) Continuous Benefit Programme
- ( ) Exemption from income tax, IPI, ICMS, IPVA, and IOF
- ( ) Interstate free pass
- ( ) FGTS and PIS withdrawal
- ( ) Home full release
- ( ) TFD
- ( ) Free pass (local)
- ( ) Young apprentice
- ( ) Electricity bill discount
- ( ) Adapted school
- ( ) Other

### Script for the semi-structured interview

Questions directed to the adolescent:

1. How is your routine? Do you consider it organized or unorganized?
2. How is your relationship with your family? Do you feel supported by them?
3. What does it mean to have spinal cord injury for you?
4. Which symptoms affect you the most?
5. How does spinal cord injury interfere with your personal and school life?
6. How do your family members react to your limitations due to spinal cord injury?
7. How does follow-up at Sarah Hospital help you?
8. How do you participate in decisions regarding your treatment?
9. In your opinion, how do nurses contribute to your follow-up?
10. What do you understand as autonomy?
12. In what situations do you exercise your autonomy?
13. How did the rehabilitation program help you have autonomy?
14. Would you like to comment on the topic?