

Assistive technology and quality of life for people with tetraplegia: bioethical approach

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Abstract

The objective of this quantitative-transversal study was to evaluate the quality of life of people with tetraplegia and, from its results, to carry out a bioethical reflection directed to the actions necessary to improve care practices and access to assistive technology resources. The WHOQOL-bref questionnaire was applied to 100 individuals with tetraplegia, whether or not users of assistive technologies, and the results were treated statistically. The highest significant scores were related to: female gender, higher educational levels, occupation, longer injury time and use of assistive technology. Bioethical reflections, based on Gilligan's Ethics of Care and Latin American Social Bioethics, have pointed to the need to improve the interrelationships around care and to formulate intersectoral public policies to protect vulnerabilities that would guarantee the following to people with spinal cord injury: clinical and sociodemographic notification, digital inclusion, home adaptation, access to technologies and special jobs.

Keywords: Bioethics. Personal autonomy. Quadriplegia. Self-help devices.

Resumo

Tecnologia assistiva e qualidade de vida na tetraplegia: abordagem bioética

O objetivo deste estudo quantitativo e transversal foi avaliar a qualidade de vida de pessoas com tetraplegia e, a partir dos resultados, refletir à luz da bioética sobre ações necessárias para aprimorar práticas de cuidado e acesso a recursos de tecnologia assistiva. Aplicou-se o questionário WHOQOL-bref a 100 indivíduos com tetraplegia, usuários ou não de tecnologias assistivas, e os resultados foram tratados estatisticamente. Os escores mais significativos relacionaram-se a gênero feminino, maiores níveis educacionais, ocupação, maior tempo de lesão e uso de tecnologia assistiva. As reflexões nesse campo, sustentadas pela ética do cuidado de Gilligan e bioética social latino-americana, apontam a necessidade de aprimorar inter-relações da assistência e a formulação de políticas públicas intersectoriais de proteção a vulnerabilidades que garantam às pessoas com lesão medular notificação clínica e sociodemográfica, inclusão digital, adaptação domiciliar, acesso a tecnologias e postos de trabalho especiais.

Palavras-chave: Bioética. Autonomia pessoal. Quadriplegia. Equipamentos de autoajuda.

Resumen

Tecnología de asistencia y calidad de vida en la cuadriplejía: abordaje bioético

El objetivo de este estudio cuantitativo-transversal fue evaluar la calidad de vida de personas con cuadriplejía y realizar una reflexión bioética dirigida a las acciones necesarias para la mejora de las prácticas de cuidado y acceso a recursos de tecnología de asistencia. Se aplicó el cuestionario WHOQOL-bref a 100 individuos con cuadriplejía, usuarios o no de dispositivos de tecnologías de asistencia y los resultados fueron tratados estadísticamente. Los mayores puntajes estuvieron relacionados con: género femenino, mayores niveles educativos, ocupación, mayor tiempo de lesión y uso de tecnología de asistencia. Las reflexiones bioéticas, sostenidas en la Ética del Cuidado de Gilligan y en la Bioética Social latinoamericana, señalaron la necesidad de perfeccionar las interrelaciones en torno a la asistencia y para la formulación de políticas públicas intersectoriales de protección a las vulnerabilidades que garanticen a las personas con lesión medular: notificación clínica y sociodemográfica, inclusión digital, adaptación domiciliar, acceso a las tecnologías y puestos de trabajo especiales.

Palabras clave: Bioética. Autonomía personal. Cuadriplejía. Dispositivos de autoayuda.

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Declararam não haver conflito de interesse.

It is known that tetraplegia secondary to spinal cord injury impairs the quality of life of the individuals affected by both sudden onset and the severe reduction of personal skills¹. The loss of motor skills generates specific vulnerabilities affecting the perception of corporeity, physical independence and autonomy of the people, besides causing social, cultural, psychological and physical deprivation². In this sense, compliance with their fundamental rights necessarily entails conditions to minimize specific vulnerabilities and ensure acceptable quality of life. Obviously, their comfort will not be the same as before the injury, but it is possible to restore their well-being, self-esteem, privacy, and expand alternatives and reinsert them in social life.

The quadriplegic individual needs care strengthening interpersonal relationships during care with more appropriate approaches to prevent comorbidities and obtain better outcomes in rehabilitation. Collectively speaking, we must emphasize the protection given by the State with cross-sector public policies contemplating their clinical and social demands.

The serious vulnerability due to the spinal cord injury and exacerbated by the condition of social violation before the injury delineates great ethical challenges in care which should be guided by issues such as freedom, intimacy, justice and wellness³. Due to the severe incapacitating neurological syndrome, and because it mainly affects young and socially vulnerable population, this type of injury must be understood as a public health problem and a social phenomenon resulting from life conditions, and not only a physical impairment caused by an undesirable event⁴.

The ethics of care is understood as a type of moral philosophy originated primarily from feminist manuscripts. Carol Gilligan⁵ proposes to reconcile the ethics of care and responsibility in the work considered as the landmark of the contemporary notion of care. According to the author, this perspective would characterize the feminine morality, whereas the ethics of the impartial principles, rights and justice would be the masculine morality. Thus, the author emphasizes two moral contents indispensable to care actions: awareness of the connections among people, and acknowledgement of responsibility for each other. These points should guide a cooperative and communicative behavior among all the agents involved so that the patient becomes the main responsible for their care.

However, tetraplegia makes it even more difficult to train patients to manage their own care,

since it imposes the separation between two forms of individual autonomy: decision which depends only on the degree of lucidity of the individuals and that most of the times is completely preserved, and executive autonomy linked to the corporal motor functionality that is invariably seriously compromised in these individuals⁶.

The ethics of care in philosophical terms is close to the Latin American bioethics and public health, since it is health care focused on integrality and humanization. In addition, it involves the State, health institutions and society in contextualizing the socioeconomic and cultural reality of the individual affected. In the case of the quadriplegic individual, care implies access to technologies to enhance executive autonomy.

The term "assistive technology" (AT) has been defined in many ways by the international literature. The present study will consider it as comprising research, manufacture, use of equipment, resources or strategies to enhance the functional abilities of people with handicaps, disabilities, or in disadvantage⁷. Although there are not many Brazilian studies approaching the subject, the importance of AT in the process of improvement of the quality of life and social reintegration of people with tetraplegia has been well documented in international studies^{8,9}. Despite the higher prevalence of cases of depression in this group^{10,11}, the use of AT may favor occupancy and functional independence⁹ and minimize depressive symptoms and suicidal ideas¹¹.

There are a number of technological resources, such as software and hardware to enable important and desired occupational activities by people with severe motor impairment, whether for academic use, work activities, entertainment or as an alternative communication resource. These resources are the result of recent technological advances, and cover various aspects of human performance from basic tasks of self-care to professional activities, as they can be adapted to the degree of incapacity of the individuals and maximize their potentialities after the injury or developed during rehabilitation.

For people in this condition, the use of computers, tablets and smartphones may represent the only possibility of access to information, work, leisure, socialization. In addition, it allows them to get in contact with the world and get back to their pre-injury activities¹², and contributes to their privacy, since most of the time they need supervision and help from third parties in their daily life. Obviously, AT accessibility is conditioned

to the allocation of resources for acquisition and distribution as well as for training, digital inclusion and home adjustments, which requires reflections and debates focused on cross-sector public policies prioritizing demands of this deficiency and guaranteeing the quality of life.

In the Brazilian context, the challenges are even greater since there is no data systematization or sociodemographic characterization of individuals with tetraplegia due to spinal cord injury in the country. However, it is known that road and work accidents, gunshot wounds, and falls are some of the most frequent causes of spinal cord injury worldwide affecting mainly socioeconomically disadvantaged groups¹³.

Therefore, access and use of AT and its impact on the comfort of individuals with tetraplegia has an obvious bioethical dimension. Article 14 of the Universal Declaration on Bioethics and Human Rights (UDBHR)¹⁴ on social responsibility and health establishes that access to quality health care and benefits resulting from the progress of science and technology is one of the fundamental rights of every human being. Unlike the hegemonic Anglo-Saxon models, the Latin American bioethics approach better understands the dialectic relations between collective and individual, as well as the core responsibility of the State in guaranteeing equity with a view to social justice, and is critically positioned in relation to technologies in health systems^{15,16}. Therefore, the problem of access to AT is a more appropriate approach in the Brazilian context.

Although it is possible to predict the positive influence of AT on the quality of life of individuals with tetraplegia, no national publications were found related to this probable correlation from the perception of the individual in this condition. Therefore, the present study aimed to evaluate the quality of life these people from the application of the WHO Quality of Life-Bref Questionnaire (Whoqol-bref) based on the individual's perspective¹⁷. The results obtained with this questionnaire made it possible to make a bioethics reflection on the actions needed involving the State, health professionals, and patients and families to improve care and access to AT resources for computer use.

Method

It is a quantitative-transversal study on quality of life based on the application of the Whoqol-bref

questionnaire to 100 individuals with tetraplegia resulting from traumatic spinal cord injury, and from the bioethical analysis of the results obtained aiming at guiding the guidelines related to care to these people, planning care, and formulating specific public policies.

The participants were recruited in a center of excellence in rehabilitation aged from 18 to 68 years (average 33.6 years). The inclusion criteria were hospitalized or ambulatory clinically-stable patients with tetraplegia due to traumatic spinal cord injuries according to the criteria of the American Spinal Injury Association (Asia)¹⁸. Patients under 18 years of age or with associated brain injury were excluded. For the quantitative analysis, the sample size was based on the total number of patients with tetraplegia hospitalized for rehabilitation during the study period, representing 83% of all adult patients with tetraplegia admitted in 2015.

A form was used to obtain sociodemographic and clinical data of the participants, and additional information obtained from the medical records was used. The quality of life assessment was made using the Whoqol-bref questionnaire, a tool validated and created by the World Health Organization Quality of Life Group¹⁷. The document contained 26 items, 24 of which belonged to the following domains: physical health (seven items), psychological health (six items), social relations (three items), and environment (eight items).

Responses followed the Likert scale ranging from 1 to 5 to measure quality of life. Whoqol-bref is considered the most accepted instrument for assessing individual comfort in case of spinal cord injury¹⁹, and the Portuguese version used in the present study showed internal consistency and high validity¹⁷. The application of the questionnaire was followed by one of the researchers, following the guidance in the manual of Whoqol-bref²⁰.

Data was analyzed by descriptive and comparative statistics. Continuous variables were synthesized by average and standard deviation; categorical variables were presented by frequency and percentiles. Comparisons between averages were subsequently tested using the Student's t-test. The chi-square test was used to compare the socio-demographic variables of users and non-users of AT resources.

Multivariate log binomial regression models were included to determine the prevalence ratios and the 95% confidence intervals for the variables associated with the use of AT. The relation between

Whoqol-bref scores and sociodemographic and clinical variables was analyzed using the Kruskal-Wallis test for non-parametric data. The significance level of $p < 0.05$, and the SPSS version 18 software were used for the analyzes. The bioethical analysis and propositions of standards and actions were developed based on the principles of UDBHR¹⁴ and the core perspectives of the Latin American school of bioethics related to the ethics of care elements of Carol Gilligan's⁵.

The idea of a Latin American school of bioethics in the current context of bioethical pluralism does not refer to the set of field productions located in this region, but rather to the school of thought proposing an ethical-political approach to moral conflicts related to the sciences of life coherent with the socio-cultural and economic contexts of the region²¹. Thus, the main foundation of the theoretical models produced by this school is critical thinking, defined herein as a philosophical position of confrontation with the ideologies of domination whose veiled production of discourses and actions deny the difference, colonize the daily life, and reduce the epistemic universe of the production of knowledge²².

No theoretical model specific to the Latin American school of bioethics was adopted in this formulation. The preference was to work with theoretical elements common to everyone, such as the criticism regarding the hegemonic thinking in the field, the need to adapt to sociocultural realities, community and dialogical construction of values that guide actions, special concern with vulnerability and social exclusion, analysis critical of the market interests in incorporating technologies to health systems, responsibility of the institutions in general and of the State, and search of equity in the sanitary actions aiming at social justice.

The project was prepared following the recommendations of Conselho Nacional de Saúde – CNS (National Health Council - NHC) by averages of Resolution NHC 466/2012²³, and evaluated and approved by the Research Ethics Committee of Associação das Pioneiras Sociais (Association of Social Pioneers). All participants formalized their consent to be part in the study by signing a free and informed consent form.

Results and discussion

Table 1 shows the sociodemographic profile and clinical data of the 100 participants in the study.

Table 1. Sociodemographic and clinical characteristics of the participants

Variables	n (%)
Gender	
Male	77
Female	23
Marital status	
Single	50
Married	41
Divorced or separated	8
Widow/er	1
Education	
Illiterate	1
Elementary School	18
High school	40
Graduated	41
Worked before injury	
Yes	99
No	1
Work after injury	
Yes	28
No	72
Social security bond	
INSS (National Social Security Institute) retirement	45
INSS continued payment benefit	32
Other	6
None	17
Motor level	
C2 – C4	23
C5 – C6	71
C7	6
Extension of the injury	
Complete	91
Incomplete	9
Causes of injury	
Car accident	31
Shallow Diving	25
Fire gun	18
Motorcycle accident	12
Fall from height	8
Other*	6

*Trauma in trampoline, surgical trauma, and run-over

Of the 57 participants who used assistive technologies, 13 used more than five types of device, with the most common being orthoses to stabilize the wrist, hand and fingers (34.5%), touch mouse and capacitive screens (30%), which were considered in the present study as AT devices due to the inability of the participants to use conventional mouse and keyboard due to muscle weakness.

The sample consisted predominantly of men of productive age, single, with high school, but who became idle after the injury (motor level between C5 and C6). The profile of the sample follows what previous studies confirmed: exposure to risk situations such as road accidents, fire guns and falls^{13,18,24-26} are common causes of this type of injury in socially vulnerable groups exposed to urban violence and informal employment. As for education, the social vulnerability to which many individuals with tetraplegia are subject besides the physical weakness of the clinical condition increases the susceptibility to accidents, and can also hamper the continuity of the studies after the injury, which explains the high prevalence of participants with elementary and high school.

In the bioethical perspective of the Latin American school as defined in the methodology of the present article, Kottowb²⁵ points out that when the human being has some inability, weakness, illness or incapacitating physical disability, they are no longer merely vulnerable but become violated and in need of protection to various aspects of their daily life.

In this sense, Schramm¹⁶ distinguishes intrinsic vulnerability of the human being from susceptibility to make them vulnerable, that is, directly affected to the point of not being able to develop their potential to have good quality of life. The physical sequelae due to the spinal cord injury along with

the low social conditions in which most of the disabled people live in Brazil and Latin America also meet the vulnerability criteria described by UDBHR, as described by Solbakk²: illness, inability, environmental conditions, limited resources, and other personal circumstances.

The lack of notification about the incidence and prevalence of spinal cord injury in Brazil prevents the correlation between the sociodemographic characteristics of the sample of the present study and the national statistics. However, data collected in this study are similar to the world epidemiological statistics on traumatic spinal cord injury, in which there is a higher prevalence of men aged between 18 and 35 years and road accidents as the main cause²⁶. In the present study, 77% of participants were males, and the average age was 33 years old. However, the incidence of traumatic spinal cord injury has increased among women, as well as the average age at the moment of injury²⁷.

The prevalence ratios for AT use according to the sociodemographic and clinical characteristics are presented in Table 2. The prevalence ratio (PR) aims to measure the relation between binary endpoint and exposure variable in studies with a transversal design, and estimates the relative probability of randomly selecting individuals who present the condition studied²⁸. The confidence intervals indicate the reliability of the estimate; the lower the interval, the more reliable the results.

Table 2. Associated factors (prevalence ratio) with the use of assistive technology

Variables	Users		Non-users		PR* (95% CI)
	n	%	n	%	
Total	57	100	43	100	
Gender					
Male	41	71.9	36	83.7	0.70 (0.58-0.94)
Female	16	28.1	7	16.3	1
Marital status					
Not married	38	66.7	21	48.8	1.39 (0.95-2.03)
Married	19	33.3	22	51.2	1
Injury time (years)					
<1	6	10.5	13	30.2	0.48 (0.24-0.96)
1 to 5	26	45.6	19	44.2	0.81 (0.58-1.14)
>5	25	43.9	11	25.6	1
Education					
High school or less	36	63.2	35	81.4	0.70 (0.35-1.40)
Graduation or more	21	36.8	8	18.6	1

continue...

Table 2. Continuation

Variables	Users		Non-users		PR* (95% CI)
	n	%	n	%	
Occupation					
No	36	63.2	36	83.7	0.67 (0.49-0.91)
Yes	21	36.8	7	16.3	1
Care service					
Ambulatory	15	26.3	1	2.3	1.58 (0.65-3.80)
First hospitalization	20	35.1	27	62.8	0.72 (0.34-1.51)
Second hospitalization	22	38.6	15	34.9	1
Motor level					
C2 to C4	13	22.8	10	23.3	0.85 (0.43-1.66)
C5 to C6	40	70.2	31	72.1	0.84 (0.46-1.54)
C7	4	7	2	4.7	1
AIS† Classification					
A	52	91.2	39	90.7	0.97 (0.31-3.06)
B/C	5	8.8	4	9.3	1

*Prevalence ration among users of assistive technology using generalized linear model with negative binomial distribution and logarithmic function; †Asia Impairment Scale to classify the extent of injury.

The lowest confidence intervals were found for the variables “gender”, “injury time” and “occupation”, demonstrating more precisely that the prevalence of use of AT resources was 70% higher among women (PR = 0.70, 95% CI 0.58-0.94), among participants who had a longer injury time (PR = 0.48, 95% CI, 0.24-0.96) and who had an occupation after injury (RP = 0.67, 95% CI, 0.49-0.91). There was no association between use of AT resources and severity of the lesion.

As shown by other authors, the term “occupation” used in the present study included paid employment, academic activities, domestic chores and voluntary work^{29,30}. Among the occupations of the participants of this study who needed devices to access computers are those related to digital arts, computer science, administration, and domestic and academic chores. At the moment of injury, 99% of participants had some occupation, and 87% had paid employment. However, among the 28 participants engaged in some activity after the injury, Instituto Nacional do Seguro Social - INSS (National Social Security Institute - INSS) did not retire only four.

As the present study is transversal, there is no way to assign cause and effect to the variables. Thus, we cannot associate the participants’ lack of occupation solely to the severity of the condition, but maybe this is the main factor so that most of them would not have any occupation after the

injury. Factors such as low education, provision of social benefits and family support or lack thereof could also explain the low rate of employed participants.

Krause and Anson³⁰ defined “work” as paid employment, and found out that 60% of individuals were working at the moment they suffered the spinal cord injury, but one year after the injury only 22% were employed. Subsequently, the study of Krause, Clark and Saunders³¹ showed that both the severity of the injury and the gender, race and education were related to the disparities in several indicators of quality of employment.

Again, the condition of social vulnerability as discussed by the Latin American bioethics is of great importance given the situation of susceptibility secondary to the social marginalization to which the disabled people are exposed in Brazil. This goes beyond the dimension of interpersonal relations regarding care, and requires a protective action by the State with the provision of rehabilitation programs and approaches to stimulate access to AT favoring the continuity of studies and access to the labor market, which is in agreement with the provisions of Article 14 of the UDBHR¹⁴. Thus, the signatory States shall develop specific programs for health promotion and social development, and the development of which should involve the participation of society³².

The specific vulnerability due to spinal cord injury exacerbated by a previous condition of social vulnerability generates major ethical challenges for caregiving based on categories such as freedom, intimacy, justice and comfort³. The same way, the connection between people and understanding responsibilities related to care as defended by Gilligan⁵ shows the need to approach family members, caregivers and health professionals

in order to share this commitment and provide humanized care with technological support and appropriate to the patients' life context.

Therefore, it is up to the State, and with the participation of society, to create special care training guidelines to be followed by institutions, professionals and caregivers. Table 3 shows the results related to the four domains of investigation of the quality of life of Whoqol-bref.

Table 3. Analysis of the quality of life according to Whoqol-bref domains and sociodemographic and clinical variables

Variables	n	WHOQOL physical			WHOQOL psychological			WHOQOL social			WHOQOL environmental		
		Average	95% CI	P-value*	Average	IC95%	P-value*	Average	95% CI	P-value*	Average	95% CI	P-value*
Total	100	54	50.7-57.4		67.5	64.1-70.9		65.8	62.1-69.6		56	53.2-58.8	
Gender													
Male	77	53.5	49.8-57.2	0.684	67.1	63.7-70.5	0.437	62.9	58.8-66.9	0.005	55.2	52.0-58.4	0.201
Female	23	55.9	48.1-63.7		68.8	59.6-78.1		75.7	67.6-83.9		58.7	52.6-64.8	
Marital status													
Single	50	56.1	51.1-61.0	0.455	67.5	62.5-72.5	0.190	65.8	60.3-71.4	0.289	55.4	51.1-59.8	0.149
Married	41	53.2	48.3-58.2		70.1	65.5-74.8		66.3	60.6-71.9		58.3	54.5-62.2	
Divorced	8	45.1	34.5-55.7		54.7	42.2-67.2		59.4	46.9-71.9		50	39.5-60.5	
Widow/er	1	57.1	-		62.5	-		100.0	-		37.5	-	
Education													
Up to high school	71	54.1	50.3-58.0	0.982	66.4	62.5-70.4	0.309	65.0	60.5-69.5	0.490	54.3	50.7-57.9	0.050
Graduated	29	53.8	47.0-60.6		70.1	63.7-76.5		67.8	60.8-74.8		60.2	56.3-64.2	
Occupation													
Yes	28	63.8	58.4-69.2	0.001	73.2	68.1-78.3	0.041	71.1	63.5-78.8	0.065	61.8	57.3-66.3	0.019
No	72	50.2	46.4-54.1		65.3	61.1-69.4		63.8	59.5-68.0		53.7	50.3-57.1	
Injury time (years)													
<1	18	47.8	41.0-54.6	0.020	62.7	52.0-73.5	0.309	65.3	59.2-71.4	0.909	57.6	51.1-64.2	0.868
1 to 5	46	51.6	46.5-56.6		66.5	62.2-70.8		65.2	59.3-71.1		54.6	50.3-58.8	
>5	36	60.3	55.2-65.4		71.2	66.0-76.4		66.9	60.0-73.8		57	52.3-61.7	
Motor level of the injury													
C2 to C4	23	53.1	45.3-60.9	0.544	67.4	60.7-74.0	0.468	64.5	54.6-74.4	0.851	55.3	49.6-61.0	0.741
C5 to C6	71	53.8	49.9-57.7		66.8	62.7-71.0		66.0	61.9-70.0		56.7	53.3-60.1	
C7	6	60.7	50.7-70.8		75.7	65.5-85.9		69.4	51.2-87.7		50.5	38.2-62.8	
Use of AT for computer													
Yes	57	58.0	53.7-62.2	0.012	71.1	66.7-75.6	0.010	65.6	60.5-70.8	0.885	57.3	53.2-61.4	0.478
No	43	48.8	43.9-53.8		62.7	57.9-67.5		66.1	60.5-71.6		54.3	50.5-58.1	
Type of resource†													
Low technology	19	50	41.8-58.2	0.068	56.4	57.2-73.5	0.343	58.8	51.0-66.5	0.359	50.3	43.4-57.3	0.209
High technology	25	55.3	48.4-62.2		70.2	64.1-76.3		66.3	58.0-74.6		59.5	52.4-66.6	
Combined use	13	63.7	56.7-70.7		72.1	62.3-82.0		65.4	55.1-75.7		58.2	54.0-62.3	
Care service													
Ambulatory	16	58.7	49.3-68.1	0.063	69.0	60.0-78.0	0.535	62.0	52.4-71.5	0.544	57.6	50.3-65.0	0.533
First hospitalization	47	49.9	45.6-54.2		65.2	60.1-70.2		65.6	59.8-71.4		54.1	49.7-58.4	
Second hospitalization or more	37	57.2	51.5-62.9		69.8	64.7-74.9		67.8	62.0-73.6		57.8	53.5-62.1	

*P-value for the Kruskal-Wallis test (p <0.05); †only users of assistive technology.

The results showed higher quality of life scores involving at least one of the four domains investigated by Whoqol-bref for female participants, with higher levels of education having some occupation with more than five years of injury and who used AT to access computers. No statistically significant differences were observed in the quality of life scores of users and non-users of AT when compared by level and extent of the injury. This result may be related to the fact that the sample comprises only people with tetraplegia, and therefore with similar motor impairment.

Women had a significantly higher average quality of life score than men ($p = 0.005$) in the social domain. In the study of Whiteneck et al.³³, women with spinal cord injury reported more difficulties in social interaction and the feeling of social exclusion. Although there is disagreement over the influence of gender on the quality of life of people with spinal cord injury and depression was not addressed in the present study, being a woman was considered a risk factor for psychological depression in the study published in 2013 by Arango-Lasprilla et al.³⁴.

Participants with more than five years of injury had higher scores in the physical, psychological and social domains, but only the first had statistical significance ($p = 0.020$). This is in agreement with previous studies in which it was observed that participants have higher levels of quality of life later on due to adaptations directed to their new reality^{33,35}.

The injury time of AT users was higher than that of non-users ($p < 0.05$), and there was a higher prevalence of users who were on ambulatory basis and who were in the second hospitalization ($p = 0.002$). These results may relate to the fact that individuals with longer injury time are rehabilitated and better adapted to their condition, so that the devices are already part of their routine. We found a lower prevalence of use of these resources among participants with less than one year of injury (PR = 0.48, 95% CI, 0.24-0.96), a result that may be associated to the clinical instability and subsequent restriction to the use of technologies in their daily life.

As expected, the results showed that the average quality of life scores were significantly higher in participants with better socioeconomic conditions - for example, the average scores in the environmental domain were higher among participants with higher education ($p = 0.05$). This

seems to be explained by the fact that in countries with large income disparities the highest levels of education are almost invariably related to better financial conditions, and consequently to housing, sanitation, urban mobility, etc.

However, it has already been shown that in Brazil and other developing countries people with tetraplegia of low socioeconomic levels face major barriers to social inclusion such as stigmatization related to physical disability, prejudice regarding working capacity, low level of education, lack of urban accessibility and adapted housing, besides the difficulties of personal and family organization³⁵.

Higher average scores on quality of life were found in the physical, psychological and environmental domains for individuals with some occupation ($p < 0.05$), which may be related to the better conditions of these individuals for physical safety and protection, access to financial resources, health services, and greater participation in several areas. This finding is similar to that of Geyh et al.³⁶, who showed that individuals with spinal cord injury and paid employment had a better quality of life, corroborating the relevance of reintegration to work and interventions in occupational rehabilitation.

These authors concluded that employment resulted not only in better financial condition, but also favored self-realization of the individual, their self-esteem, and contributed to global social integration. Achieving higher quality of life averages in three of the four domains studied shows the importance of thinking about the care of the quadriplegic individual not only by eminently clinical procedures aimed at improving physical conditions, but also by the need for cross-sector strategies and programs to their social and work reintegration. This requirement addressed to the State obviously relates to compliance with Article 8 of UDBHR regarding respect for human vulnerability and integrity of individuals¹⁴, and calls for specific vulnerabilities to be considered in the application of scientific knowledge and new technologies.

In addition, the results showed that AT users (access to computers) had higher quality of life averages compared to non-users ($p < 0.05$), which is related to the physical ($p = 0.012$) and psychological ($p = 0.010$) domains and indicates the possible influence of these equipment in their life. These results resembled those of other studies that also indicated that AT-mediated computing favors

independence in home environment, self-esteem, work ability, and social rehabilitation of people with tetraplegia^{8,9,37,38}. However, none of them was performed in Brazil.

The physical domain of Whoqol-bref addresses, among other things, the ability to work and carry out the activities of everyday life. The use of computers can help the autonomy of decision centered on the individual's freedom of choice, and enhance the executive autonomy of people with tetraplegia³⁹. Said possibility favors the maintenance of their health, psychophysical integrity and social relations, besides contributing to the perception of efficiency, and therefore to higher quality of life of people in this condition⁹.

It has been common to mistakenly relate power of self-determination and functional condition of physical independence, that is, executive and decision-making autonomy in rehabilitation publications⁴⁰. This association is extremely detrimental both for the interpersonal relationships involved in care of people with chronic disabilities and for the planning of specific health care strategies and programs aimed at this public.

The complexity of the autonomy of individuals with tetraplegia lies precisely in the frequent co-occurrence of completely autonomous decision-making autonomy and severely impaired executive autonomy, unlike that of the person affected by Alzheimer's disease, for example, whose capacity for self-determination so valued in contemporary society is lost⁴¹.

The possibility of using AT brings these two dimensions of autonomy closer, allowing the user to perform several daily tasks without the help of third parties, which obviously has positive effects on their right to privacy, their communicative and leisure possibilities, besides generating a sense of being useful provided by the occupation. It is important to mention that digital inclusion and AT programs should contemplate the training of professionals in the area, since the mere provision of resources is not a sufficient condition to promote labor and social inclusion.

The increased quality of life of participants with some occupation in three of the four Whoqol-bref domains indicates that the return to occupational activities may be a necessary condition for them to feel productive. Therefore, it would mean more than the basic need for provision, but an effective change in the construction of their identity related to changing their social position into becoming right-holders⁴².

Protection of human vulnerability designed in an integrated way with the socioeconomic contexts in which susceptible individuals are included is one of the main missions of bioethics. The large number of individuals with tetraplegia living in countries with large income disparities is therefore a social fact typical of the bioethical analysis, especially considering the theoretical perspectives and analytical parameters common to the theories of the Latin American school^{2,16,21,22,25}.

The lack of official data on the prevalence of spinal cord injury cases in South America, Africa and Asian countries¹³, as well as the difficulty to access assistive technologies in Brazil whether due to the high cost, low market supply or even lack of knowledge by rehabilitation professionals are a problem of ethical origin. In addition, the negligence of the State and society in relation to severe conditions not only from the clinical point of view, but also of the high social cost, is evident. The lack of knowledge about the profile of this part of the population prevents the formulation and implementation of contextualized programs and/or public policies to the real demands of the individuals affected and the need to prevent new cases, thus allowing the legitimate moral questioning of what may be considered negligence from the State and the health system management.

It is worth mentioning that many of the computer access resources sold in Brazil are very expensive, not only due to the complexity of these equipment, but also due to the reduced number of manufacturers and subsequent lack of market competitiveness as well as the scarce dissemination of these resources among health professionals who work with rehabilitation. It should be noted that many of the assistive technologies used by participants in the present study were simple adaptations, such as mouth sticks and plastic clips associated with tablets and smartphones.

The aspects mentioned before and the great possibility of preventing traumatic spinal cord injury by relatively simple measures such as socio-educational actions make the ethical problem even greater. Thus, epidemiological studies on this injury are justified not only by the magnitude of the morbidity, mortality and social costs, but above all by the possibility of implementing cross-sector public policies in the context of real demands of the individual affected, as well as the prevention of new cases.

Once the benefits of AT in the lives of people with tetraplegia are known, failure to include them

in the rehabilitation process implies an infringement of the right of fair and equitable access for this vulnerable portion of the population. Therefore, the possibility of providing more quality of life to individuals with tetraplegia with AT imposes the ethics of compliance with the fundamental rights of the human being, defense of equity in access to benefits, and therefore greater visibility by the State. Article 15 of UDBHR¹⁴ also corroborates this position, as it requires fair distribution of the benefits and technologies generated by science according to the needs.

Faced with physical and social vulnerability characterized by difficulties of accessibility, social reintegration, and low levels of quality of life of people with disabilities living in Brazil, the understanding of ethics of care provides, among other approaches, the conscious and contextualized use of assistive technologies to help rehabilitation, social reintegration and increase of the quality of life.

The term “assistive technology”, despite being considered by some as regards to science and technology, health, industry, education and other areas, encompasses a much broader concept, a key element for the promotion of human rights. AT helps people with disabilities have the opportunity to gain autonomy and independence in various aspects of their daily lives. In order to do so, it is necessary to adopt measures to ensure their access on an equal basis with their peers^{2,16,21,22,25}.

Final considerations

The present study considers ethical problems caused by inequities and social injustices increasing the vulnerability of people with tetraplegia in Brazil and affecting both the individual dimension of the care offered and the collective one of planning care in the health system for these people. Based on this premise, it shows that the use of AT resources for computers allowed the participants to have access to information, work and socialization, thus helping them face their vulnerabilities, empowering them in their social support networks, and generating better measurement results of quality of life.

The research findings reinforced the importance of AT as a vulnerability protection tool and as a care element ethically oriented to the quadriplegic individual. Thus, the bioethical imperatives aimed at respecting and protecting vulnerable people point to the need of recognizing the right of universal access

to assistive technologies in Brazil by pluralistic and transdisciplinary approaches.

One of the limitations of the study is the difficulty in generalizing results, as it was carried out in only one rehabilitation center. However, the sample is representative because it comes from a national reference center in rehabilitation, which is why the participants came from all regions of Brazil, thus maintaining clinical and sociodemographic characteristics similar to those of other studies. It is also the first study carried out in the country on quality of life involving individuals with tetraplegia users and non-users of AT to access computers using Whoqol-bref, an internationally recognized instrument.

The bioethical reflections emerging from the analysis of the problem and their results allowed proposing measures related to both the collective dimension of planning specific health policies and actions and the improvement of the interpersonal relationships involved in the care of people in this serious condition:

- Creation of institutional spaces for dialogue for the management of care involving patients, family members and professionals, where the limits of executive autonomy and the reduction of decision autonomy are not confused, in order to promote greater self-determination of patients in care actions.
- Development of public programs of continuing education for health professionals, and training for caregivers and family members.
- Defining the obligatory notification of cases of spinal cord injury, their cause and level, as well as clinical and sociodemographic characterization of the patient affected.
- Creation of a systematization database on the incidence and prevalence of spinal cord injury, which will allow better planning both of the rehabilitation processes and the estimation of the categories and contextualized demands of AT resources.
- Have the participation of society to create cross-sector public health equity policies with guidelines focused on specific vulnerabilities, such as improved access and quality of rehabilitation throughout the national territory; household adjustment to the comfort and care of the individual; digital inclusion; allocation of specific resources of the health budget for AT distribution adapted to individual demands.

- Creation of jobs offers to these people, recruitment of volunteers with tetraplegia for activities in social projects, including in the process of readaptation of others in this condition, creation of quota programs in universities, among other programs of social insertion.
- Programs to incentivize the national industry of components and health inputs for the production of AT, from the simplest to the latest hardware and software, in order to promote access to lower cost and contextualized resources to users' lives, besides contributing for the development of this technology in the country.

Broader studies are still needed to provide a more accurate framework of the quality of life of people with tetraplegia in Brazil. However, studies like this can help improve rehabilitation services interventions and overcome obstacles to universal access. They may also draw the attention of society and authorities to include the topic of "assistive technology" more emphatically in the context of public policies, social control initiatives, public-private partnerships, and the ideology of ethical values to guarantee the fundamental rights of people with disabilities in Brazil, as well as the development of new studies on the theoretical basis of contemporary bioethics in a field that has not yet been explored.

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Participation of the Authors

Valéria Baldassin organized and developed the study, and carried out a bibliographical collection gathering and discussing data. Cláudio Lorenzo collaborated with the methodological organization of the study. Helena Eri Shimizu was responsible for the methodological planning of the quantitative aspect of the project. All authors participated in the writing and review of the article.

