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Quality of life perception of people with motor disability: differences between wheelchair dependent and ambulatory patients

A percepção de qualidade de vida de pessoas com deficiência motora: diferenças entre cadeirantes e deambuladores

La percepción de la calidad de vida de las personas con discapacidad motora: las diferencias entre los con silla de ruedas y los deambuladores

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ABSTRACT | The routine of people with physical disabilities includes the use of different assistive technology resources that can aid in their physical and intellectual development, which directly affects their quality of life. The objective of this study was to evaluate the life quality perception of Wheelchair users and non-Wheelchair users living in the municipality of Itajaí, in the state of Santa Catarina. This is a cross-sectional study with exploratory and quantitative analysis. The sample consisted of 163 participants, of whom 91 were wheelchair users and 72 were non-wheelchair users. Participants responded to a structured questionnaire with socioeconomic and health information and the World Health Organization Quality of Life Instrument, WHOQOL_bref, to measure quality of life. In the evaluation of the physical and psychological domains, no significant differences were observed between the two groups. Therefore, in these two areas, the perception of quality of life was not affected by the use of wheelchair. However, by examining the social relations and environment domain the perception of quality of life was significantly lower for wheelchair users with paresis, regarding the plegias and amputation.

Keywords | Quality of Life; Disabled Persons; Biomedical Technology; Wheelchairs.

RESUMO | A rotina das pessoas com deficiência física inclui o uso de diferentes recursos de tecnologia assistiva, que podem auxiliar em seu desenvolvimento físico e intelectual, afetando diretamente sua qualidade de vida. O objetivo deste estudo foi avaliar a percepção da qualidade de vida de pessoas cadeirantes e deambuladoras com deficiência física no município de Itajaí, Santa Catarina. Trata-se de uma pesquisa descritiva de corte transversal e caráter exploratório quantitativo, cuja. amostra foi constituída por 163 participantes (91 cadeirantes e 72 deambuladores), que responderam a um questionário estruturado com informações socioeconômicas e de saúde e ao instrumento do *World Health Organization Quality of Life Instruments* (WHOQOL-bref), para mensurar a qualidade de vida. Na avaliação dos domínios físico e psicológico não foram observadas diferenças significativas entre os dois grupos, portanto a percepção da qualidade de vida não foi afetada pela utilização da cadeira de rodas. No entanto, examinando-se o domínio de relações sociais e meio ambiente, a percepção da qualidade de vida foi significativamente menor para cadeirantes com paresias, em relação às plegias e à amputação.

Descritores | Qualidade de Vida; Pessoas com Deficiência; Tecnologia Biomédica; Cadeiras de Rodas.

RESUMEN | La rutina diaria de las personas con discapacidad incluye el uso de recursos de tecnología asistencial diversos, que les pueden ayudar en su desarrollo físico e intelectual, afectando directamente su calidad de vida. Este estudio pretende evaluar la percepción de la calidad de vida de las personas en sillas de ruedas y las deambuladoras con discapacidades físicas en la ciudad de

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Study performed in the Universidade do Vale do Itajaí (Univali) – Itajaí (SC), Brazil.

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Itajaí, Santa Catarina (Brasil). Se trata de un estudio descriptivo de cohorte transversal y de tipo exploratorio cuantitativo, con una muestra de 163 participantes (91 en silla de ruedas y 72 deambuladores), que respondieron a un cuestionario estructurado con datos socioeconómicos y de salud y al instrumento *World Health Organization Quality of Life Instruments* (WHOQOL-bref) para medir la calidad de vida. En la evaluación de los dominios físico y psicológico, no se observaron diferencias significativas entre los dos grupos, por lo que la percepción de la calidad de vida no fue afectada por el uso de la silla de ruedas. Sin embargo, al examinar el dominio relaciones sociales y medio ambiente, la percepción sobre la calidad de vida fue significativamente menor a los usuarios de silla de ruedas cuanto a las paresias, plejías y amputación.

Palabras clave | Calidad de Vida; Personas con Discapacidad; Tecnología Biomédica; Sillas de Ruedas.

INTRODUCTION

The routine of people with physical disabilities includes the use of different assistive technology resources that can aid in their physical and intellectual development, which directly affects their quality of life. An equipment commonly used by people with reduced mobility is the wheelchair[1,2], since it enables their movement and, thus, a greater autonomy[1].

In Europe, the number of wheelchair users surpasses 3.3 million people[3]. In Brazil, the National Health Research (2013) estimated 200.6 million people living in permanent private households, of which 6.2% had at least one of the four investigated disabilities (intellectual, physical, hearing, and visual) and 1.3% declared having physical disabilities (0.3% were born with physical disabilities, while 1.0% acquired it due to a disease or accident). About 10% of the world population has any disability and 10% of it require wheelchairs for their limited walking capacity[4]. In the last decades, the number of manual wheelchair (MW) users has increased due to automotive accidents, which mainly cause medullar injury or the amputation of lower limbs[5].

Despite the MW being used to increase the individuals' functionality and independence, both at home and in the community, users see them as the main factor that prevents them to move around with greater ease and efficiency, limiting them more than their paralysis itself. The causes for such limitation are the environmental barriers and the bad adjustment of wheelchairs[6] due to the lack of specific training to prescribe and/or adjust the MW in most clinical centers. Pain and the commitment of upper limbs, problems that happen because of maladjustment, are reported by more than 70% wheelchair users[7].

With the use of MWs, it is expected for people with physical disabilities to become more autonomous and to find ways of dealing with their disabilities. However, health and well-being are a combination of biological, psychological, and social factors. As certain physical disabilities are permanent, it is necessary to identify the factors affecting well-being, which can be influenced by the rehabilitation team. Traditional health indicators provide a measure of the disease's impact, but they do not assess the quality of life (QoF) in the context of culture, value system, goals, expectations, standards, and concerns[7].

However, the QoF evaluates the individuals' perception of their positions in life, considering their insertion in the social, cultural, religious, and economic contexts they live. Their personal values, goals, expectations, standards and concerns also affect this perception[8].

The inclusion of QoF evaluation in healthcare promotes a comprehensive care approach and encourages health professionals to answer to their patients' perceptions and personal values. Therefore, assessing the QoF is a crucial issue for future national health planning[7].

The choice for this theme was based on the observation that there are few national studies dealing with the QoF of people with acquired physical disabilities (ambulatory and wheelchair dependent). Given that, the aim of this study was to get to know the quality of life perception of people with acquired physical disabilities.

METHODOLOGY

This study is a transversal descriptive research, with exploratory and quantitative approach, involving the quality of life of people with physical disabilities living in the municipality of Itajaí, Santa Catarina. The municipality is 90 km far from the state's capital and it has an estimated population of 216,615 inhabitants[9].

This is the first data gathering with this population in said municipality, so there are no estimations of the number of people with acquired physical disabilities.

Regarding the primary care, the city has 34 Health Units and 44 teams of the National Family Health Strategy. As the study's locations, five Health Units were selected in Itajaí, considering the researchers easy access and the fact that they count on support networks: *Associação dos Deficientes Físicos da Foz do Itajaí* (Adefi – Association of Physical Disabled of Foz do Itajaí), *Associação de Pais e Amigos dos Excepcionais* (Apae – Association of Atypical Parents and Friends); and specialized networks: Physical Therapy Clinic and the Specialized Rehabilitation Center of the Universidade do Vale do Itajaí (CER-2/Univali), both inserted in Univali and partners of the Municipal Health Secretary.

In these places, people with acquired physical disabilities were identified and interviewed. The ones attending the Physical Therapy Clinic and CER-2 were interviewed there, in previously booked hours, the ones attending the support networks were interviewed in the associations' headquarters, and the other ones at home. The interviews were performed by previously trained researchers.

The study's sample was composed by 163 participants (83 male and 81 female participants) of different age groups: teenagers (from 10 to 19 years-old), adults (20 to 59 years-old), and elderly people (60 years-old or older), from February 2015 to February 2016.

To select these individuals, the inclusion criteria considered was presenting acquired physical disabilities (paraplegia, paraparesis, monoplegia, monoparesis, tetraplegia, tetraparesis, triplegia, triparesis, hemiplegia, hemiparesis, limb lack or amputation, limbs with acquired deformity, or amputated, amyotrophic sclerosis), and they were then classified into two groups: wheelchair users and ambulatory patients. As exclusion criteria, we considered congenital disabilities or dwarfism, and ostomate and mastectomate individuals.

To obtain the intended information, two tools were used: a structured questionnaire with socio-economic and health information to characterize the sample and the World Health Organization Quality of Life Instruments (WHOQOL-bref) to measure quality of life. The first questionnaire looked for information on age, gender, schooling levels, marital status, family income (valid value for the period of study of R$ 880.00), type of disability, and presence of comorbidity. The second, WHOQOL-bref[10], is a reduced version of the World Health Organization Quality of Life (WHOQOL-100). In this research, we have used the 24 questions of the second tool, which are divided into four domains: "physical", "psychological", "social relationships", and "environment". To assess quality of life, there is no cut-off point, so that the higher the score is, better is the quality of life[8,11].

To compare the average quality of life scores for each domain, the two-way analysis of variance was used, followed by the Tukey's test, if needed. For the factors, we considered socio-economic variables, the type of disability, and using or not wheelchairs. We chose the parametric test, considering the normal distribution of the scores, using a significance level of 5%. The application Statistica v.1012 was used for the analysis.

This research was approved by the Research Ethics Committee of the Universidade do Vale do Itajaí, under the number 694.259, and it was sponsored by the *Fundação de Amparo à Pesquisa de Santa Catarina* (Fapesc – Foundation for Research Support of Santa Catarina – Universal Program), by the *Fundo de Apoio à Manutenção e ao Desenvolvimento da Educação Superior* (Fumdes – Fund for Support to the Maintenance and Development of Higher Education - articles 170 and 171).

OUTCOMES

Table 1 summarizes the main characteristics and the type of disabilities of assessed individuals. We have used the terms plegias and paresis to define if the result impairment in the motor system was total or partial, and as for the amputation, if the impairment was due to the circulatory system. Overall, there was a gender equality in the sample, with a higher percentage of women in the wheelchair user group. Most participants were adults, with an emphasis on wheelchair users, who had a higher percentage of adults than elderly people.

Table 1. Characterization of people with acquired physical disability, wheelchair and non-wheelchair users, according to socio-economic and health information in the municipality of Itajaí (SC), in 2016.

Variable	Wheelchair user				Total	
	No		Yes			
	n=91	%	n=72	%	n=163	%
Gender						
Female	41	45.1	40	55.6	81	49.7
Male	50	54.9	32	44.4	82	50.3
Age group						
Teenager	5	5.5	2	4.4	7	4.3
Adult	44	48.4	45	62.5	89	54.6
Elderly	42	46.2	25	34.7	67	41.1

(continues)

Table 1. Continuation

Variable	Wheelchair user				Total	
	No		Yes			
	n=91	%	n=72	%	n=163	%
Schooling levels*						
Illiterate	8	9.6	6	9.8	14	9.7
Elementary	41	49.4	22	36.1	63	43.8
High School	24	28.9	25	41.0	49	34.0
Higher Education	10	12.0	8	13.1	18	12.5
Income (minimum wage)						
Up to 2	51	56.0	47	65.3	98	60.1
From 2 to 4	31	34.1	19	26.4	50	30.7
More than 4	9	9.9	6	8.3	15	9.2
Physical disability						
Plegia	43	47.3	51	70.8	94	57.7
Paresis	30	33.0	13	18.1	43	26.4
Amputation	18	19.8	8	11.1	26	16.0

*Total number of 144 participants, considering that 19 research participants did not answer this item, eight non-wheelchair users and 11 wheelchair users

As for the schooling levels, most ambulatory patients had studied only until elementary school, indicating low schooling levels. In the wheelchair dependent group, it was observed a higher schooling level, in which 15.3% studied up to high school, although the difference to the ones that finished only elementary school (13.5%) is not significant. We highlight that not all participants have answered this question.

Regarding the monthly income, 60.1% received up to two minimum wages in both groups, with a percentage of 65.3% in the wheelchair dependent group.

The most prevalent disability was plegia, with a significant percentage in the wheelchair user group, as expected.

In the evaluation of the domains ("physical" and "psychological"), when the WHOQOL_bref was applied, no significant differences between both groups were observed, therefore, in these domains, the quality of life perception was not affected by the use of wheelchairs. When the domains "social relationships" and "environment" were assessed, in the first one there was a significantly lower quality of life perception for wheelchair users with paresis (between 33.4 and 52.5) in relation to the other disability types (above 56).

Table 2. Averages and confidence interval (in parenthesis) of the quality of life scores, divided into domains according to socio-economic variables and the type of disability for people with acquired disabilities, wheelchair and non-wheelchair users, in the municipality of Itajaí (SC), in 2016.

Domain	Physical			Psychological			Social relationships			Environment		
Wheelchair user	No	Yes	p*	No	Yes	p	No	Yes	p	No	Yes	p
Gender												
Female	61.6 (55.9-67.2)	57.9 (52.2-63.6)	0.4241	62.8 (58.5-67.1)	63.1 (58.8-67.4)	0.9887	61.6 (55.9-67.2)	57.9 (52.2-63.6)	0.8598	63.3 (59.0-67.7)	56.7 (52.3-61.2)	0.2400
Male	64.3 (59.2-69.5)	59.6 (53.2-66.0)		62.6 (58.7-66.5)	63.0 (58.2-67.9)		64.3 (59.2-69.5)	59.6 (53.2-66.0)		62.2 (56.2-64.2)	58.9 (53.9-63.9)	
Age group												
Teenager	67.9 (57.5-78.2)	62.5 (46.1-78.9)	0.7238	75.8 (64.6-87.1)	60.4 (42.6-78.2)	0.1251	68.3 (52.3-84.4)	75.0 (49.7-100.3)	0.5507	64.4 (51.9-76.9)	54.7 (34.9-74.5)	0.8769
Adult	58.7 (55.2-62.2)	57.1 (53.7-60.6)		65.4 (61.6-69.2)	68.0 (64.2-71.7)		66.5 (61.1-71.9)	59.3 (53.9-64.6)		64.1 (59.9-68.3)	59.3 (55.1-63.5)	
Elderly	52.6 (49.1-56.2)	48.1 (43.5-52.8)		58.2 (54.3-62.1)	54.5 (49.5-59.5)		58.9 (53.4-64.5)	56.3 (49.2-63.5)		58.6 (54.3-62.9)	55.0 (49.4-60.6)	
Schooling levels												
Illiterate	57.6 (49.4-65.7)	50.0 (40.6-59.4)	0.5205	63.0 (53.6-72.4)	57.6 (46.8-68.5)	0.8907	64.6 (51.4-77.8)	56.9 (41.7-72.2)	0.6388	66.0 (56.0-76.0)	55.2 (43.7-66.7)	0.4677
Elementary	54.5 (50.9-58.1)	54.4 (49.5-59.3)		63.7 (59.6-67.9)	64.2 (58.6-69.9)		64.6 (58.8-70.5)	55.7 (47.7-63.7)		62.6 (58.2-67.0)	60.2 (54.2-66.2)	
High School	58.6 (53.9-63.3)	57.0 (52.4-61.6)		63.5 (58.1-69.0)	z61.5 (56.2-66.8)		59.4 (51.7-67.0)	59.7 (52.2-67.1)		60.2 (54.4-65.9)	58.4 (52.7-64.0)	
Higher Education	59.3 (52.0-66.6)	51.3 (43.2-59.5)		62.5 (54.170.9)	60.4 (51.0-69.8)		63.3 (51.5-75.2)	56.3 (43.0-69.5)		64.1 (55.1-73.0)	52.3 (42.4-62.3)	

(continues)

Table 2. Continuation

Domain	Physical			Psychological			Social relationships			Environment		
Wheelchair user	No	Yes	p*	No	Yes	p	No	Yes	p	No	Yes	p
Income (minimum wage)												
Up to 2	54.5 (51.1-57.9)	53.3 (49.7-56.8)	0.8443	59.6 (56.0-63.3)	59.8 (55.9-63.6)	0.5499	60.5 (55.4-65.5)	57.3 (52.0-62.5)	0.6299	60.9 (56.9-64.9)	56.6 (52.5-60.8)	0.9546
2 to 4	58.5 (54.1-62.9)	56.2 (50.6-61.8)		66.9 (62.2-71.7)	68.0 (62.0-74.0)		65.9 (59.4-72.3)	58.3 (50.1-66.6)		63.0 (57.9-68.1)	60.2 (53.7-66.7)	
More than 4	59.9 (51.8-68.1)	54.8 (44.8-64.7)		65.3 (56.5-74.0)	73.6 (62.9-84.3)		68.5 (56.6-80.5)	70.8 (56.2-85.5)		60.8 (51.3-70.2)	57.8 (46.3-69.4)	
Physical Disability												
Plegia	56.4 (52.8-60.0)	56.2 (52.8-59.5)	0.1964	61.2 (58.0-66.2)	65.1 (61.4-68.8)	0.2002	61.4^{a} (56.2-66.7)	61.1^{a} (56.3-65.9)	0.0036	60.8 (56.7-65.0)	58.6 (54.8-62.5)	0.2422
Paresis	53.9 (49.6-58.3)	45.3 (38.7-51.9)		60.0 (55.1-64.9)	55.1 (47.7-62.5)		60.8^{a} (54.5-67.1)	42.9^{b} (33.4-52.5)		59.6 (54.6-64.6)	48.8 (41.2-56.4)	
Amputation	60.5 (54.9-66.1)	55.8 (47.4-64.2)		68.5 (62.2-74.8)	63.0 (53.6-72.4)		70.8^{a} (62.7-79.0)	68.8^{a} (56.5-81.0)		66.8 (60.4-73.3)	66.0 (56.3-75.7)	

*Probability value in the bifactorial ANOVA test for first order interaction

DISCUSSION

This study has assessed social and economic characteristics, and the disability type of wheelchair users and ambulatory patients. Regarding the gender, there was an overall similar percentage among participants (49.7% were women and 50.3% men), in opposition to the study by Felicíssimo et al.[13], who investigated the prevalence and factors related to disabilities, with 53.1% female participants. The research by Assis and Carvalho-Freitas[14] has corroborated to the results of this research, since the prevalence of people with physical disabilities was of male patients (68%).

Regarding the age group, adult wheelchair users (62.5%) has a higher percentage than elderly (34.7%) and teenager ones (4.4%). As in the study by Kirby et al.[15], the average age was of 39 years-old, that is, adults. Dolan and Henderson[16] have concluded that 53.4% of people with physical disabilities who depend on wheelchairs presented an average age of 45 years-old.

Concerning schooling levels, Gomes et al.[17] presented a sample with a schooling range varying from incomplete elementary school to complete high school, making it similar to this research. Also in the study by Gomes et al.[17], the neurologic level of injuries ranged from thoracic (T6) to lumbar (L1), which were caused by firearms, falls, and tumor, which was similar in this study, since the majority of the sample is paraplegic. The work by Schoeller et al.[18], which aimed to characterize people with medulla injuries treated in a state reference rehabilitation center, presented automotive accidents as the most frequent cause.

Pangalila et al.[22] have assessed the quality of life of 79 adult men with Duchenne muscular dystrophy and, in the WHOQOL-bref, the score in the social relationships domain was lower. The main issues were intimate relations, work, leisure, transportation and meaning of life. Seventy-three percent patients declared their quality of life was "(very) good".

The results of the study by França et al.[23] have shown that the QoL of people with medullar injuries is unsatisfactory. The limitations due to this injury affect negatively the life of patients and the domains with higher negative influence for the QoL are the physical and environmental ones. Ganesh and Mishra[7] have assessed the QoL of paraplegic people and observed low average scores for the physical health, psychological well-being, social relationships and environment domains (49.76±18.74, 48.57±17.04, 57.88±17.04 e 49.85±17.77, respectively).

However, in the quality of life evaluation by Toro et al.[24], the physical domain has improved significantly for women who received a wheelchair, and the environmental health has also improved significantly for women and men who received wheelchairs, in relation to the ones who were still on the waiting list.

Riggins et al.[25], when examining the QoL factors and the changes in mobility for individuals with traumatic spinal cord injury (SCI), concluded that individuals who began using wheelchairs within an year after the injury have had low QoL factors, including high scores for pain and depression.

Ganesh and Mishra[7] have observed low average scores for the physical health, psychological well-being, social relationships, and environment domains of the QoL (49.76±18.74, 48.57±17.04, 57.88±17.04 e 49.85±17.77, respectively). There was a strong positive association between the physical activity levels and all the domains ($P<0.050$).

The study by Martins et al.[26] has assessed the QoL of teenagers with osteogenesis imperfecta (OI) and the results have indicated that they are satisfied with their overall QoL (69.3). The religiosity/spirituality/personal beliefs and social relationships domains had the higher scores (77.6 and 73.7, respectively). The worst score was the environmental one (64.9), which was the only one with $p<10$ among the OI types.

Milioli et al.[27] have evaluated the quality of life of amputees and concluded that 36.4% subjects evaluated their QoL as not bad nor good; however, 45.50% participants were not satisfied nor dissatisfied with their health. As for the domains, the physical, social, and environmental ones, which represented 34.70%, 31.85%, and 30.30%, respectively, were assessed was neither good or bad, while 33,32% participants assessed the psychological domain as having good QoL.

Whereas the study by Chow[28] concluded that the study on the biomechanics of the wheelchair propulsion focuses on how the wheelchair user confers potency to the wheels to gain mobility and, with that, reduces the physical distress associated to the propulsion of wheelchairs in order to improve the quality of life.

CONCLUDING REMARKS

The perception of quality of life was not affected by the use of wheelchair, with the exception of the social relationships domain, in which this perception was significantly lower for wheelchair users with paresis than for other disability types.

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