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Internet as a Support for People with Spinal Cord Injuries: Usage Patterns and Rehabilitation

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Abstract: Information and Communication Technologies (ICT) is expanding in the health field and triggering changes in the relationship between professionals and patients. Considering the current relevance of this issue, this study was conducted to identify the usage patterns and perceptions concerning the internet of people with acquired spinal cord injuries. Statistically significant differences were found between the usage time and the influence of the internet before and after injury. Although the respondents' usage pattern is similar to that of the general population, some particularities were identified, which require the attention of specialized rehabilitation services in order to improve service routines. Further research is recommended at different levels of care delivery.

Keywords: rehabilitation, spinal cord (wounds and injury), internet, communication and technology

Internet como Suporte à Pessoa com Lesão Medular: Padrões de Uso e Reabilitação

Resumo: As Tecnologias de Informação e Comunicação (TIC) estão em expansão na área da saúde e desencadeiam transformações nas relações profissional-usuário. Considerando, portanto, a relevância atual deste tema, o presente estudo foi desenvolvido com o objetivo de conhecer os padrões de uso e a percepção sobre internet de pessoas com lesão medular adquirida. Constataram-se diferenças estatisticamente significativas entre o tempo de uso e a influência da internet antes e após a lesão. Apesar de se verificar padrão de uso similar ao da população geral, identificaram-se especificidades que requerem atenção dos serviços especializados de reabilitação, no intuito de aprimorar rotinas de atendimento. Recomendam-se mais pesquisas em diferentes níveis assistenciais.

Palavras-chave: reabilitação, lesão medular, internet (rede de computador), comunicação e tecnologia

Internet como Apoyo a las Personas con Lesión Medular: Estándares de Uso y Rehabilitación

Resumen: Las Tecnologías de Información y de Comunicación (TIC) están expandiéndose en las áreas de salud, y con eso inician cambios en las relaciones profesional-usuario. Por lo tanto, ante la relevancia actual de este tema, este estudio tuvo como objetivo describir los estándares de uso y las percepciones de la internet de las personas con lesiones adquiridas en la médula espinal. Se encontró diferencias estadísticamente significativas entre el tiempo de uso y la influencia de la internet antes y después de la lesión. Fueran identificados especificidades que requieren atención especializada de los servicios específicos de rehabilitación con el fin de mejorar las rutinas. Se recomienda seguir investigaciones en diferentes niveles de asistencia.

Palabras clave: rehabilitación, traumatismos de la médula espinal, internet, comunicación y tecnología

Since the advent of the internet, much has been discussed about its impact on human existence from two main perspectives. On the one hand, we seek to understand the consequences of the indiscriminate use of this technological resource to the extent it triggers or exacerbates social isolation. On the other hand, its benefits are also assessed to the extent it promotes integration and expands social networks. In fact, progressive use of the internet characterizes the contemporary world and many experts agree that such expansion has transformed economic and social life at the world level (Drainoni et al., 2004).

Interest in informatics and internet has increased in the health field with a view to enable and optimize access

to treatment and healthcare in situations of epidemics, chronic diseases and disabilities, extending such goals to the prevention of diseases and health promotion (Carlbring et al., 2006). Some organizations in the public and community health fields committed with the promotion of the population's quality of life and wellbeing began, in the second half of the 1990s, to restructure themselves as virtual communities and to function as social units in which their members relate as a group and interact using communication technologies (Demiris, 2006; Finnegan & Viswanath, 2008).

The relationship between health workers and patients has changed in this new scenario of electronic communication and such changes need to be understood to improve therapeutic follow-up. It is worth mentioning that some psychotherapeutic approaches have already adapted their methods and adopted technological resources (Prado & Meyer, 2006; Straub, 2005). In a recent investigation,

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more than 85% of the interviewees reported accessing the internet after a medical consultation to deepen information provided by the expert (Madeira, 2006). As a consequence of this evolution, there is increased concern with the appropriateness of information available in digital media and with the qualification of professionals supporting the inclusion of these resources in care delivery. Hence, some authors consider it crucial to discuss the regulation of the diffusion of health subjects in electronic networks (Barros, 2008; Caponeiro, 2008; Castiel & Vasconcelos-Silva, 2003).

The relevance of Information and Communication Technology (ICT) to providing health care services, disseminating technical-scientific knowledge, sharing popular knowledge, and overcoming geographic distances, and temporal and sociocultural barriers has been recently acknowledged. The relevant field for this is called Telemedicine or Telehealth, with interactions mediated in real time or not, through the internet or global social networks technologies, with the use of application software or not, are called E-health (Matusitz & Breen, 2007; Turner, 2003). It is worth noting that Eysenbach, Sa and Diepgen (2001) coined the term Cybermedicine to designate a new academic specialty aimed to study the applications and repercussions of the internet and global network technologies in Medicine and in Public Health. Rimal and Adkins (2003) stress that such an approach will be effective and efficacious only if the inter-relationships among the capabilities and peculiarities of this communication channel, its properties and content of messages, and more importantly, the characteristics of the population involved, are properly understood.

Internet and Rehabilitation: Focus on the Individual with Spinal Cord Injury

An injury of the spinal cord may result in a loss of voluntary movements and/or sensitivity of the upper and/or lower limbs, accompanied by urinary, intestinal, respiratory, circulatory and/or sexual changes that may lead the individual and his/her socio-affective environment to experience serious distress. In general, traumatic injuries are caused by traffic accidents, firearm projectiles, non-firearm weapons, falls, and occupational accidents or sport injuries. Non-traumatic injuries are less frequent and are usually caused by tumors, infections, vascular or degenerative diseases or malformations (Lianza, Casalis, Greve, & Eichberg, 2001; Pereira & Araujo, 2006).

It is estimated that approximately 20 to 40 individuals per million around the world are affected by spinal cord injuries (Meyers, 2001). In Brazil, according to the statistics reported by the Sarah Network of Rehabilitation concerning 2009, external causes (especially traffic accidents) accounted for most of the 15 to 49 years old victims, causing spinal cord injuries, predominantly

paraplegia (Rede Sarah de Hospitais de Reabilitação, s.d.). Significant changes in social life, and in the professional and affective spheres are observed, which reveals the need to evaluate these individuals' quality of life, social support and ability to cope, both in interventions and studies (Araujo, 2007). Four basic concepts ground rehabilitation: (a) patient-centered intervention, (b) emphasis on process, (c) integral care, and (d) responsibility for planning and implementing care to be shared with family members and close friends (Hammell, 1995; Pereira & Araujo, 2006). Therefore, it involves a complex decision-making process that goes from determining the nature and severity of problems, risk prediction, establishment of objectives and organization of specific actions to the point when the individual is reintegrated into the community, in addition to continuous re-evaluation. (Araujo, 2007; Bernardes, Maior, Spezia, & Araujo, 2009; Pereira & Araujo, 2006; Queiroz & Araujo, 2009). Current electronic means seem to provide an important contribution in this context and Telerehabilitation refers to the implementation the principles of Telehealth or Telemedicine in this specific context (Burns et al., 1998).

A careful examination of the most recent literature reveals a significant increase of studies addressing the subject. We highlight the interest of the National Institute on Disability and Rehabilitation Research (NIDRR). Studies designed to identify internet usage patterns of people with spinal cord injuries stand out (Drainoni et al., 2004; Goodman, Jette, Houlihan, & Williams, 2008; Hauber, Vesmarovich, & Dufour, 2002; Houlihan et al., 2003). The participants of such studies were: (a) recruited through the distribution of informational leaflets in associations (Houlihan et al., 2003), (b) identified by health workers (Hauber et al., 2002), (c) called to integrate into an extensive North-American study called Model Spinal Cord Injury System (Drainoni et al., 2004) or (d) selected from an institutional database (Goodman et al., 2008). Data were collected through questionnaires sent by email, pre- and posttest interviews (also held by telephone) and standardized scales (Satisfaction With Life Scale; Brief Patient Health Questionnaire and Craig Handicap Assessment Reporting Technique). Sample sizes were 23, 225, 516 and 2,926 individuals, respectively.

According to data gathered in these studies, email exchange was the main use made of the internet, followed by chat rooms, work, games, social connections, and the search for information about general subjects, health or information related to the individuals' disability. There is also a positive correlation with quality of life, positive self-perception and social integration, though an increase of isolated recreational activities – at the expense of contact with family – and depression were also observed. In relation to demographic variables, an association with more advanced education and marital relationships was found. Being competent in computer sciences was a predictive

factor of employability among the population with spinal cord injuries. No correlation was found between internet usage and degree of injury (e.g. tetraplegia *versus* paraplegia). Despite the contribution of these pioneering studies, we should acknowledge some limitations related to the low representativeness of the studied samples, the lack of sensitivity of some instruments used and the difficulty in estimating the real impact of this ICT.

Other studies also deserve to be highlighted and can be organized according to the focus of interest in relation to internet usage: (a) as a work tool for health workers (Calmels, Mick, Perrouin-Verbe, & Ventura, 2009), (b) as a research tool (Anderson, Fridén, & Lieber, 2009; Chelvarajah, Knight, Craggs, & Middleton, 2009; Edwards, Krassioukov, & Fehlings, 2002; Migliorini, New, & Tonge, 2009; Migliorini, Tonge, & Taleporos, 2008), (c) for health education (Brillhart, 2007; Lindsey, Kurilla, & DeVivo, 2002), (d) in the development of interfaces to access a computer and the internet (Choi, Micera, Carpaneto & Kim, 2009) and (e) the search related to the information needs of people with spinal cord injuries (Gontkovsky, Russum, & Stokic, 2007).

Telerehabilitation has been an advantageous tool in clinical follow-up and continues to be investigated (Phillips, Temkin, Vesmarovich, & Burns, 1998; Phillips, Vesmarovich, Hauber, Wiggers, & Egner, 2001; Soopramanien, Pain, Stainthorpe, Menarini, & Ventura, 2005). The study by Dallolio et al. (2008) does not report any increase in complications between patients cared for by the traditional model compared to those monitored through videoconference. Galea, *Tumminia* and Garback (2006) observed the effectiveness of audiovisual resources in controlling comorbidities (e.g. diabetes, hypertension, obesity, urinary infection, skin lesions and depression). Egner, Phillips, Vora and Wiggers (2003) obtained satisfactory results with telephone calls and the use of educational videos. Roth, Lowery and Hamill (2004) specifically studied pain events. Elliott, Brossart, Berry and Fine (2008) obtained favorable results in instructing caregivers. Cruise and Lee (2005) developed a program of exercises, training for independence and functionality, adapted to the specificities of Telerehabilitation.

Mathewson, Adkins and Jones (2000) compared two preventive methods for pressure ulcers: regular talks with a nurse through the internet and the management of contingencies performed in the outpatient clinic. Both interventions were effective and complemented each other. The authors concluded that opting for one modality over the other depends on the patient's characteristics. Halstead et al. (2003), Hill, Cronkite, Ota, Yao and Kiratli (2009) and Ho and Bogie (2007) also found positive results in the prevention of pressure ulcers with the use of some ICT. Lapierre, Blackmer, Coutu-Wakulczyk and Dehoux (2006) recommend that Telerehabilitation care protocols include information concerning pre-morbid symptoms

of tetraplegia, such as dysreflexia. It is also important to stress that when adopting Telerehabilitation resources, health workers need to rely on complete protocols sufficiently detailed to recognize the patients' symptoms and difficulties.

In summary, given the subject's scientific and care delivery relevance for the field of Psychology of Rehabilitation, this study was developed to identify the internet usage patterns and related perceptions of people with acquired spinal cord injuries.

Method

Participants

The following inclusion criteria were established: individuals of both genders, 18 years old or older diagnosed with acquired spinal cord injury. The exclusion criterion was not completing the questionnaire. Hence, the final sample included 43 participants.

Instruments

An electronic questionnaire developed with the Survey Monkey tool was used. It was composed of 60 multiple-choice questions, organized according to thematic axes (internet usage, characterization of the spinal cord injury, rehabilitation and personal data). These questions were developed based on a preliminary study; over its course, it was evaluated by professionals from the fields of rehabilitation, computer, and statistics, as well as by people with the sample's epidemiological profile.

Procedure

Data collection. The participants were recruited through the web. For that, two distinct strategies were employed: (a) a message was sent to the researcher's list of contacts informing them of the link to the questionnaire and (b) a similar message was sent to professionals, and rehabilitation-related institutions and websites, which redirected the invitation to participants or disclosed the Hypertext Markup Language (HTML) on their own webpage. It was also previously established that only one questionnaire per Internet Protocol (IP) would be accepted.

Data analysis. The database generated by the Survey Monkey was submitted to descriptive statistics analysis. Tests were performed to compare the averages of nonparametric variables with the responses related to internet usage patterns. The Statistical Package for the Social Sciences (SPSS), version 18.0, was used.

Ethical Considerations

The study project was approved by the Ethics Research Committee at the School of Health Sciences, University of

Brasília. The completion of the questionnaire was conditional upon compliance with a free and informed consent form, also available through the internet.

Results and Discussion

Sample Characterization

A total of 65% of the study's sample was composed of men and most individuals were single, with high school, college or graduate education (Table 1). There was little disparity between those working and those who did not work. The following occupations were identified among the latter: three psychologists, three professors, two attorneys, two publicists, two animal scientists, one physician, one network administrator, one salesperson, one technician in educational matters, one sales representative, one designer, one house keeper, a social worker, an accounting and computer technician, one electronics technician, and an educator. Monthly income ranged from less than one to more than ten times the minimum wage. Almost half of the sample received some type of social security benefit or pension.

In regard to their pathologies, 56% of the participants reported paraplegia caused by physical trauma, particularly traffic accidents. This data agree with international epidemiological studies (National Spinal Cord Injury Database, 2010). Vertebral fracture was reported in 31.7% of the cases. The most frequent changes triggered after the injury include urinary infections, emotional changes, pain and pressure ulcers. The average time, after the clinical condition was established, was 11 years, ranging from one to 34 years with a standard deviation of ± 8.78 years.

It is worth noting that the respondents' ages (from 18 to 61 years old, $A = 36$ years old) correspond to the epidemiological profile found in the international literature (National Spinal Cord Injury Database, 2010). According to the respondents' origins as reported in the questionnaire, the sample was composed of individuals from 11 Brazilian states; the majority lived in Brasília and São Paulo. In terms of living conditions, most homes (houses) had access to the street through a ramp. Most of the participants (64%) reported some type of treatment. Physiotherapy was the most frequently reported, followed by rehabilitation and psychological follow-up. Only five individuals did not participate in the rehabilitation program of Sarah Network of Rehabilitation Hospitals. Most participants (95%) reported the use of a wheelchair and the mother was the person who most frequently provided help, according to 61% of the respondents, though half of the respondents also mentioned the father. The average time of help provided was seven hours daily; 25 respondents reported living with their parents.

In regard to the total frequency of routine activities, comparing the periods 'before' and 'after' spinal cord injury

(Figure 1), the frequency of all the activities – with the exception of the internet – were drastically reduced. After the injury, using the internet became a routine for 83% of the participants as opposed to the 50% who reported its use was similar in the period prior to the lesion.

Table 1

Characterization of the Participants Concerning Sociodemographic Data and Spinal Cord Injury

Characteristics	<i>f</i> (n = 43)	%
Gender		
Male	28	65
Female	15	35
Monthly income (times minimum wage)		
Up to 1	9	21
Above 1 to 3	13	30
Above 3 to 6	10	23
Above 6 to 10	4	9
Above 10	7	16
Marital status		
Single/separated	33	77
Married/stable union	10	23
Education		
Elementary and middle school	4	9
High school and technical education	15	35
College and Technologist	14	33
Specialization/Master's degree	10	23
Occupation		
Employed	22	51
Unemployed	21	49
Benefit		
Social security and Retirement	21	49
No benefit	22	51
Injury level		
Paraplegia	24	56
Tetraplegia	19	44
Etiology of injury		
Traffic accident	17	40
Fall from height	3	7
Diving	7	16
Firearm injury	2	5
Tumor	2	5
Neurological problem	4	9
Other causes	8	19
Related changes		
Urinary infection	33	77
Pressure ulcer (bedsore)	19	45
Pain	27	64
Emotional change	33	79
No change	3	7
Other change(s)	7	17

The respondents reported regular social relationships with family and friends who already belonged to their social network. The number of contacts with coworkers and schoolmates was reduced. It is worth noting that most of their friendships were not associated with contacts made via the internet. Based on these data, we infer that those in the sample receive support appropriate to their needs. We assume that the use of the internet for communication activities may contribute to the provision of support, as observed in the literature (Kiesler et al., 2002; Shaw & Gant, 2002). Therefore, we observed, as opposed to the disseminated potential harmful effects of internet (e.g. isolation and compulsive use), that the studied group presents a favorable usage pattern.

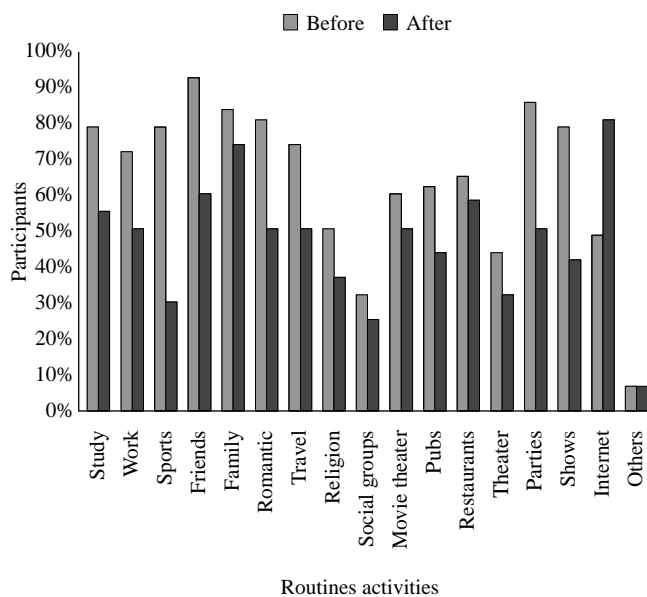


Figure 1. Routine activities performed before and after spinal cord injury.

Internet Usage Patterns and Perceptions

Access to the internet was intensified after the injury (Figure 2). The computer was indicated as the most frequently used device to connect to the internet and as access through an Asymmetric Digital Subscriber Line (ADSL) was the most frequent. After the injury, the number of users of laptops/notebooks increased from six to 24. Thirteen people did not have access to the internet prior to their injury and started using this resource after being injured. Cellular phone access was added and dialup access is no longer used. Radio access was also mentioned.

Email is the internet resource most commonly used by the studied sample, followed by search tools, message exchange and Orkut. News, sports, leisure/culture and health were the most searched topics, rather than romantic relationships and distance education courses. The items most frequently searched on

the internet were CDs and DVDs, as well as appliances, computer material and equipment, though 26% do not buy through the internet. It is worth noting that nine out of the 19 individuals with tetraplegia do not need adaptations for computer use and 90% report they do not face technological difficulties.

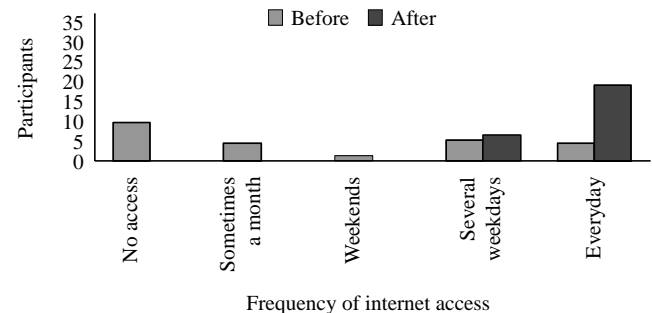


Figure 2. Frequency of access to the internet before and after the spinal cord injury.

In regard to spinal cord injuries, content most frequently found on the internet involves pathologies and research concerning therapeutic possibilities of stem cells. Clarification of doubts and emotional support were perceived as being less available. When the respondents were asked what the subjects related to their injuries were that they would like to find, they reported multiple and varied interests, from accessing results of recent research to information concerning their pathology, self-care, citizenship and social participation, and also interaction with other people affected by spinal cord injuries, as well as rehabilitation professionals. It is interesting that contacting health professionals is not a routine use given of the internet (19%) and when it occurs, it is predominantly with physical therapists.

In general, guidance concerning injuries and care are the least followed by the study's participants: the respondents favor guidance provided during face-to-face consultations with health professionals and most of the information is obtained in rehabilitation centers, hospitals, and from people with the same condition. This result differs from what was observed by Edwards et al. (2002). According to these authors, the internet is the preferred resource of individuals with spinal cord injuries to obtain information concerning their condition.

From the perspective of approximately 70% of the respondents, the internet "does not" influence or had "very little" influence on their lives in the period prior to their injury, as opposed to about 80% who reported that the internet influenced their lives "a lot" or "very much" after the injury (Figure 3).

When comparing the differences among the averages before and after injury through the Wilcoxon test, we observe that frequency of access, time of access, and influence of the internet increased significantly after injury. Moreover, there is a significant difference among

the quantity of routine activities reported, which were reduced from 11 to seven between one period and the other (Table 2). It is important to note that associations among variables and the participants' age or time of injury were not found.

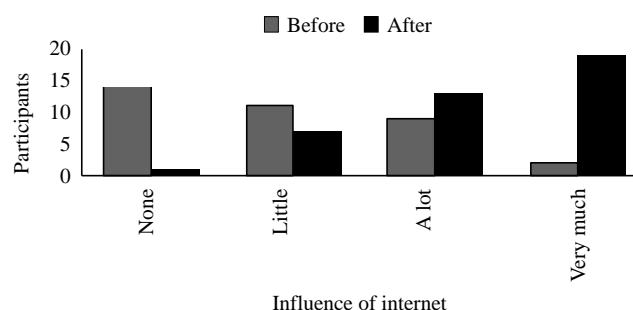


Figure 3. Influence of internet before and after the spinal cord injury.

Table 2

Wilcoxon Test to Compare Averages of Variables Before and After the Spinal Cord Injury

Variables pairs	Average	N	Z-test	Two-tailed sig.
Activities before	11	43	-3.257	.001
Activities after	7	43		
Frequency of access before	2	43	-4.613	.000
Frequency of access after	4	43		
Time of access before (minutes)	93	42**	-4.777	.000
Time of access after (minutes)	341	42**		
Influence of internet before	1	43	-4.540	.000
Influence of internet after	3	43		

Note. * $p = 0.01$, ** one of the participants did not answer the corresponding item.

The usage pattern observed in the studied sample agrees with data gathered in other studies, which also report that the home is the most frequent place from which the respondents access the internet: 95% after the injury, in comparison to 39% before the injury (Drainoni et al., 2004; Goodman et al., 2008; Hauber et al., 2002; Houlihan et al., 2003). Concomitant with this change, access from the workplace was reduced, which reflects the repercussions of limited mobility and the interruption of activities performed in this environment.

Therefore, according to the perception of the participants, the use of this specific ICT increased after the injury, while communication and attaining information related to

their current condition are a priority in their accesses and searches through the internet. The convergence of this usage configuration and the basic principles of rehabilitation is apparent (Araujo, 2007; Bernardes et al., 2009; Hammell, 1995; Pereira & Araujo, 2006; Queiroz & Araujo, 2009).

Given the previous discussion, it is essential to acknowledge that the implementation of Telerehabilitation (Burns et al., 1998) may favor the efficiency of rehabilitation programs, as well as other healthcare services provided to individuals with spinal cord injuries. It is, however, important to clarify that this study has an exploratory nature and was developed with a purposive sample of small size, which does not enable stratified inferential analyses concerning usage patterns in relation to injury level, time of injury, gender and/or age.

Conclusion

The internet usage patterns observed in this study cannot be exclusively attributed to the consequences arising from spinal cord injuries because they reflect technological, economic and social transformations experienced by the population in general in the modern world. Further research is recommended with larger samples, a longitudinal design, and the inclusion of other ICT in addition to the internet to support education and intervention programs adopting ICT – especially institutional webpages – directed to the growing contingent of people with rehabilitation needs. In summary, it is possible to assume that the internet favors rehabilitation as it promotes greater access to information and enlarges one's social network, constituting a resource to be better explored by specialized programs. For that, health professionals and institutions should be prepared to redefine their care practices and adopt new perspectives on Telerehabilitation in favor of service quality, as well as patient satisfaction and wellbeing.

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