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ORIGINAL ARTICLE

Understanding the strategies used by paraplegics in transfers to the bathroom and management of neurogenic bladder

Comprender las estrategias utilizadas por los parapléjicos en los traslados al baño y el manejo de la vejiga neurogénica

Compreendendo as estratégias utilizadas pelos paraplégicos nas transferências para o sanitário e manejo da bexiga neurogênica

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Abstract

The aim was to understand the adaptive strategies used by people with spinal cord injuries when performing toilet transfers and managing their neurogenic bladder. This was a descriptive study with a qualitative approach, supported by Adaptive Nursing. Seventeen community-dwelling individuals with paraplegia were included and interviewed. Qualitative data were processed using appropriate software, using content analysis. Two categories emerged: adaptive strategies for toilet transfer performance and Adaptive strategies for managing their neurogenic bladder, both inside and outside the home, even when faced with the threat of contamination. Participants are left unassisted in the community due to a lack of guidance on the safe performance of these procedures, improvising their strategies with available resources. Some have not even had access to rehabilitation programs, nor have any connection with them, as well as with primary health care services, which compromises their health and quality of life in the short, medium, and long term. In this sense, nurses can be decisive in assuming a leadership role in the care of these people, as they work in the various spheres of health services where they are treated.

Descriptors: Assistive Technology; Spinal Cord Injury; Urinary Bladder Neurogenic; Rehabilitation Centers; Rehabilitation Nursing.

Resumén

El objetivo fue comprender las estrategias adaptativas que utilizan las personas con lesión medular para trasladarse al baño y manejar su vejiga neurogénica. Se realizó un estudio descriptivo con enfoque cualitativo, con el apoyo de Enfermería Adaptativa. Se incluyeron y entrevistaron diecisiete personas parapléjicas residentes en la comunidad. Los datos cualitativos se procesaron mediante un software adecuado y análisis de contenido. Surgieron dos categorías: Estrategias adaptativas para el traslado al baño; y Estrategias adaptativas para el manejo de su vejiga neurogénica dentro y fuera del hogar, incluso ante la amenaza de contaminación. Los participantes se encuentran desatendidos en la comunidad debido a la falta de orientación sobre la realización segura de estos procedimientos, improvisando sus estrategias con los recursos disponibles. Algunos ni siquiera han tenido acceso a programas de rehabilitación ni tienen conexión con ellos, ni con los servicios de atención primaria de salud, lo que compromete su salud y calidad de vida a corto, mediano y largo plazo. En este sentido, el personal de enfermería puede ser decisivo para asumir un rol de liderazgo en la atención de estas personas, ya que trabajan en los diversos ámbitos de los servicios de salud donde son atendidos.

Descriptores: Dispositivos de Autoayuda; Traumatismos de la Médula Espinal; Vejiga Urinaria Neurogénica; Centros de Rehabilitación; Enfermería en Rehabilitación.

Resumo

Objetivou-se compreender as estratégias de adaptação que pessoas com lesão medular utilizam no desempenho das transferências para o vaso sanitário e no manejo da bexiga neurogênica. Estudo descritivo, com abordagem qualitativa, apoiado no Modo Adaptativo de Enfermagem. Foram incluídos e entrevistados 17 paraplégicos na comunidade. O tratamento dos dados qualitativos foi realizado com auxílio de *software* apropriado, à luz da análise de conteúdo. Emergiram duas categorias: Estratégias adaptativas de desempenho das transferências para o vaso sanitário; e Estratégias adaptativas para manejo da bexiga neurogênica dentro e fora de casa, mesmo diante da ameaça de contaminação. Os participantes ficam desassistidos na comunidade, por falta de orientações sobre desempenho seguro desses procedimentos, improvisam suas estratégias com recursos disponíveis para executá-los. Alguns sequer tiveram acesso aos programas de reabilitação, ou com eles mantêm vínculo, tanto quanto com os serviços da atenção primária à saúde, o que compromete sua saúde e qualidade de vida no curto, médio e longo prazo. Nesse sentido, os enfermeiros podem ser determinantes ao assumir papel de liderança nos cuidados dessas pessoas, pois atuam nas diversas esferas dos serviços de saúde onde elas são atendidas.

Descritores: Tecnologia Assistiva; Traumatismos da Medula Espinal; Bexiga Urinária Neurogênica; Centros de Reabilitação; Enfermagem em Reabilitação.

Introduction

The World Health Organization reports that approximately 2.5 to 5 million cases of spinal cord injury (SCI) occur annually worldwide. In Brazil, its prevalence has been increasing annually, corresponding to 16 to 40 cases per million inhabitants, with 80% of victims being men and the majority between 20 and 30 years of age. The economic impact of SCI in developed countries, the high mortality rate in developing countries, and its complex etiology constitute relevant issues for studies within the scope of international collective health[1,2].

SCI, a cause of long-term functional disability, is characterized by severity, complexity, extent, and irreversibility, with the most common causes being car accidents, falls, and violence[3,4]. This is a potentially catastrophic event that can affect all spinal cord functions: motor, sensory, and autonomic, leading to activity limitations and participation restrictions[5,6].

People with SCI must be referred to an institutional physical rehabilitation service or program after hospital discharge. However, many are excluded for various reasons unrelated to their purposes, causing worrying operational disruptions for public managers in high-, middle-, and low-income countries[1,6,7]. Even those who graduate from institutional physical rehabilitation programs will periodically require periodic evaluations by rehabilitation teams regarding adaptive training for the performance of transfers and management of neurogenic bladder (MNB)[8-10].

The relevance of this study lies in raising awareness among rehabilitation teams about the importance of systematically assessing these individuals' potential for improved performance in transfers from a wheelchair to a commode or directly to the toilet. Similarly, it is relevant for transfers for clean intermittent catheterization (CIC) and other MNB procedures, considering the irreversibility of SCI and the adaptation needs of these individuals[11]. Skills that involve performing four to six CIC and 15 to 20 transfers per day, moving from one surface to another, exiting, and returning to the wheelchair[12]. Both procedures must be based on technical-scientific parameters recognized by the academic community, such as continuing education technologies for MNB and transfer performance[7,9,12].

It's understood that Assistive Technology (AT) is a set of materials, equipment, and technical procedures used to minimize people's functional difficulties so that they can live in a healthy, productive, independent, and dignified way, participating in education, the job market, and social life[3,5,9,12]. In this sense, the guiding questions were: "How are people with spinal cord injuries prepared by interdisciplinary teams to carry out transfers and MNB in long-term care?", "What adaptation strategies do they use to perform such procedures in home and away-from-home environments, when many do not even have access to specialized rehabilitation programs and services?".

Therefore, the objective of this study was to understand the adaptation strategies that people with spinal cord injury use when transferring to the toilet and managing the neurogenic bladder.

Methodology

This is a descriptive study, with a qualitative approach, guided, structured, and based on the theoretical framework of Nursing, Adaptive Model (AM), by Calista Roy, based on the Physiological Modes, Functional Role, Self-concept, and Interdependence[13]. Qualitative research offers a deep understanding of the experiences of different people regarding how they experience human phenomena, such as the care received from rehabilitation nursing, and its more subjective implications and scope can be revealed[14].

The study was conducted in the cities of Rio das Ostras, Cabo Frio, Armação de Búzios, and Macaé, located in the Lakes Region and northern Rio de Janeiro State, Brazil. Participants were approached using information and communication technologies, available remotely (telephone), due to the period of social isolation caused by the SARS-CoV-2 pandemic.

Seventeen paraplegics with traumatic spinal cord injury participated in the study. To achieve this target number, we used non-probability snowball sampling, a type of sampling that aims to locate research participants from key informants designated as "seeds." Thus, each "seed" contributes to the research by indicating new contacts who meet the characteristics proposed in the study[15]. The inclusion criteria were individuals over 18 years of age, of both sexes, diagnosed with traumatic spinal cord injury, residing in the region, and using health and social support services available in the community. Anyone unable to communicate by telephone was excluded.

Data collection was conducted individually from September to November 2020 by the doctoral student responsible for the research. Participants were contacted in advance to schedule an interview at a time they chose. A semi-structured questionnaire was used to characterize the participants' sociodemographic (age, sex, education, marital status, family income) and clinical characteristics (etiology, duration of injury, level of injury, number of daily transfers, institution where the patient was rehabilitated, institutional affiliation with a rehabilitation program, affiliation with Primary Health Care (PHC), and anticipated/provision of caregivers). A questionnaire was also used to describe the guidance received by healthcare teams regarding transfer procedures and management of neurogenic bladder.

The average length of the interviews was 40 minutes, conducted via information technology and a remote system (telephone), audio-recorded digitally, and completed in a single session. Interview descriptions were sent to the study participants via personal email for approval of the transcribed content; however, no changes were requested.

The analysis of qualitative data was carried out with the help of NVivo software, considering content analysis, according to the following process steps: pre-analysis, exploration of the material and treatment of results, inference and interpretation[16,17].

Subsequently, exhaustive readings were conducted to decode the raw text into recording units and organize the analysis. Once this process was completed, two categories of analysis emerged, which were treated considering the chosen theoretical framework[17]. To preserve the anonymity

of the people who participated in the research, an alphanumeric identification system was adopted containing the letters PARA as an abbreviated form of the word paraplegic, followed by an Arabic numeral indicating the order of the interviews [PARA-1, PARA 2, (...) PARA-17].

The ethical aspects of research with human beings, recommended by the National Health Council, were complied with, in accordance with Resolution No. 466/2012. The research project was submitted to Plataforma Brasil, being approved by the UNIRIO Research Ethics Committee, with certification No. CAAE: 35995120.9.0000.5285, and opinion No. 4,263,342.

Results

The sample consisted of 17 paraplegics, between 18 and 65 years old, average age of 34 years, 15 (88%) males and two (12%) females. With a level of education between four and 11 years, 13 (71%) of the participants, 10 (59%) were single, and 11 (65%) of them reported a monthly family income between 1,000.00 and 2,500.00 reais. Regarding the etiology of the injury, 10 (58%) were due to traffic accidents, followed by six (35%) by firearms and one (6%) by a fall. Regarding the time of injury, five (29%) were between one and five years, four (24%) between six and 10 years, five (29%) were between 11 and 15 years, and three (18%) were over 16 years. Regarding the level of spinal cord injury, two (12%) were between T1 and T4; six (35%) were between T5 and T9; eight (47%) were between T10 and T12; and one (6%) provided no information. Regarding mobility, eight (47%) of the paraplegics performed less than 10 transfers per day, four (24%) between 10 and 15, and five (29%) between 16 and 20. Among the participants, 11 (65%) reported that they were rehabilitated by Specialized Rehabilitation Centers or Services, five (29%) did not have access, and one (6%) did not provide information. Furthermore, four (24%) participants maintain a link with the rehabilitation institution, 13 (76%) do not, 12 (71%) are registered with the APS, and five (29%) are not.

Two categories emerged from the data analysis procedure: Adaptive strategies for toilet transfer performance and Adaptive strategies for managing neurogenic bladder indoors and outdoors.

Adaptive strategies for toilet transfer performance

In this category, the deponents discuss their preferences for using the commode chair and the difficulties faced if it is necessary to use an improvised chair.

> *"I transfer and do everything in the commode"* (PARA-01).
>
> *"I use the shower chair"* (PARA-03, PARA-04, PARA-07, PARA-08, PARA-12, PARA-16, PARA-17).
>
> *"I don't use the toilet because I have a commode chair"* (PARA-13).

Their narratives also highlight the risks of transferring to an inadequate or improvised commode chair.

> *"My shower chair is normal, made of plastic"* (PARA-02).
>
> *"I lean against a plastic chair and transfer myself"* (PARA-05).
>
> *"I have an aluminum chair"* (PARA-09).
>
> *"So, nowadays I don't have the shower chair anymore, but the normal one"* (PARA-10).
>
> *"My shower chair is a normal plastic party chair"* (PARA-11).

Likewise, interviewees detail their fears, risks, and dangers faced when transferring to the toilet, fearing that it will break or that they will fall with unwanted complications.

> *"I'm afraid the vase will break"* (PARA-01).
>
> *"It's much more dangerous to go from my chair to the toilet"* (PARA-05).
>
> *"I'm afraid of falling off the toilet"* (PARA-08).
>
> *"The movement is a little more risky"* (PARA-10).
>
> *"I don't transfer it to the vase, because it might transfer and the vase might break. I'm a bit scared and a bit anxious"* (PARA-12).

While other witnesses expose their greatest difficulties in carrying out transfers, or total dependence on help from others.

> *"For the vase it is more complicated"* (PARA-02).
>
> *"[...] the transfer is more difficult. It's a little more difficult"* (PARA-10).
>
> *"My mother picks me up and puts me in the chair"* (PARA-14).

Some claimed that space was limited for carrying out the maneuvers:

> *"[...] my room has a suite and the bathroom in my room is very small"* (PARA-05).
>
> *"[...] my bathroom is a little tighter"* (PARA-10).

They also reported that the environment does not have the resources to support transfers.

> *"There are no bars here at home"* (PARA-11).
>
> *"The shower chair has to have support because it moves [...] it has to have some place to rest [...] because when you jump, it goes away and you end up on the floor"* (PARA-15).

Adaptive strategies for managing neurogenic bladder indoors and outdoors

The options for performing catheterizations either in bed or in a wheelchair are related to practicality, habit and convenience, as observed in the statements below.

> *"I do catheterization in the chair and in bed"* (PARA-01).
>
> *"[...] If I'm at home, I prefer to do it in bed"* (PARA-5).
>
> *"[...] I do it on the chair, if I'm in bed I do it on the bed"* (PARA-07).
>
> *"[...] when I'm too lazy to get out of bed, I do it right next to the bed"* (PARA-10).
>
> *"[...] I only do it lying down when I'm sleeping, then I wake up and do it lying down"* (PARA-11).
>
> *"[...] I do it in the chair and I do it in bed"* (PARA-17).

Likewise, participants choose to perform the procedure exclusively in their own wheelchair.

> *"I do catheterizations in the chair itself"* (PARA-03).
>
> *"I do it in a wheelchair"* (PARA-04).
>
> *"When I'm at home, I practically do it in the chair"* (PARA-11).
>
> *"I don't need to get out of the wheelchair, no"* (PARA-12).
>
> *"I'm like, I move my body towards the edge of the chair"* (PARA-13).
>
> *"I don't transfer, I do it in my chair"* (PARA-15).

Otherwise, participants reported that, even when at home, they perform their ureteral catheterizations in places with imminent risks of contracting urinary infections due to the contamination risks to which they are exposed.

> *"My catheterization is normal, I do it facing the vessel"* (PARA-06).
>
> *"I usually do catheterizations in the toilet"* (PARA-10).

When away from home, some people choose to carry out the CIC in the seat of their car.

> *"If my car is close, I prefer to do it in the car"* (PARA-5).

Depending on the circumstances of the environment outside their home, participants choose to undergo catheterizations in a wheelchair.

> *"I avoid doing it in street bathrooms [...] I do it in my chair"* (PARA-5).
>
> *"Sometimes I'm on the street, I do it on the chair"* (PARA-11).

Furthermore, other interviewees reported not using CIC, as they use Uripen©, Jontex©, diapers, or go directly to the toilet.

> *"I use Uripen© more"* (PARA-01).
>
> *"I wear a diaper and go to the bathroom"* (PARA-02).
>
> *"I don't do this transfer because I wear a diaper"* (PARA-09).
>
> *"I use Jontex©"* (PARA-08, PARA-14, PARA-16).

Discussion

The majority of single marital status, low education level, and family income indicate that the participants in this study face difficulties in meeting their needs for assistance, considering the inevitable expenses with AT resources, involving skills and preparation to better perform the technical procedures of transfers and MNB, the cost of home care, and the level of long-term functional dependence[3,6,18,19]. Therefore, the language used to guide how to properly proceed with transfers and MBN, both for those rehabilitated and for those who did not have access to institutional rehabilitation programs, must be simple and objective so that they, their families, and caregivers can understand it[7,11,12].

Furthermore, there were some participants who reported not having any links with any institutional rehabilitation programs, and others are not registered with the PHC, which exposes them to a complete lack of assistance regarding urgent care in the Care Network for People with Disabilities (RCPCD)[2,18,20].

Some narratives from the interviewees in this study corroborate the results of another investigation, particularly credited to the current ease of sharing experiences with peers through the various information technology access platforms[21]. Like the findings of this study, a study conducted with wheelchair users over 18 years of age who spent approximately 40 hours per week analyzed wheelchair transfer techniques and two different toilet configurations. Parameters from the Transfer Assessment Instrument were used, and the frontal toilet configuration was found to be more appropriate than the lateral one, in addition to determining significant biomechanical effects[12].

Similarly, the narratives of the participants in this study revealed a total or partial level of home caregiver assistance. Similar findings were observed in a study of 717 family caregivers, demonstrating that they accumulate a significant workload caring for people with SCI, the majority of whom are female, and spend, on average, approximately 13 years caring for their family member, averaging 21 hours/week[22]. Another study with findings related to this research, carried out with 19 individuals with SCI and 15 family caregivers, concluded that the stress associated with assuming the role of caregiver can influence the adjustment of individuals with SCI and their families[23].

It is known that acquiring skills to perform transfers and MBN requires a lot of physical effort, cognitive attention, determination, and predisposition to stress from people with SCI, as highlighted by the participants of this study when addressing their difficulties and doubts about how to proceed safely[7-9]. In this sense, to consolidate the Physiological Mode, the nurse needs to draw the attention of the rehabilitated person so that he or she learns to understand the signs, symptoms, and neurological responses emitted by the body itself, as relevant indicators of its adaptive potentialities and weaknesses[13,18]. Likewise, the achievement of the Functional Role Mode will occur with the nurse prioritizing care interventions focused on rescuing the roles of the person with SCI in society.

Nurses play an important role in rehabilitation and are involved in all aspects of the multidimensional rehabilitation process. Therefore, strengthening nursing in rehabilitation is a vital factor in providing high-quality rehabilitation and achieving the planned outcomes[24].

Regarding the success of essential interventions to achieve the Self-Concept Mode, as it involves psychological and spiritual aspects of the person with SCI, it is emphasized that each person experiences the experience of overcoming the phases of an acquired disability according to their ethical-moral-spiritual values[13,18], whose subjective impacts are decisive, both in the denial of the new bodily performance and in the search for resignation with self-esteem, resilience and determination to overcome

challenges and achieve their best functional performance[6,8,23].

The person we serve must be actively involved, and our interventions no longer consist solely of providing care, but of educating and training them on how to achieve the goals of the intervention[24]. This nursing care approach represents the core of rehabilitation to enable people with disabilities to achieve an optimal level of independence, which includes well-being, freedom, and an autonomous and better quality life[7,18,24]. Furthermore, the Interdependence Mode, as it inevitably involves interactions related to giving and receiving affection, respect, and value, and encompasses the interactive relationships maintained between the person and others[13,18,22].

Regarding adaptive strategies for CIC, some study participants reported preferring to perform the procedure in their bed when at home, out of habit, practicality, and comfort, while others perform it exclusively in a wheelchair. Some also report performing the procedure near the toilet, despite being advised of the risks of urinary tract infections[10,11].

When away from home, interviewees described situations in which they chose to perform CIL in the car seat or in their own wheelchair, fearing the risk of contamination when using public restrooms, findings like those in other studies. However, they also reported performing BNM using other assistive technologies and non-invasive materials, including diapers, as reported by people with SCI in other studies due to recurrent episodes of urinary tract infections[8,9].

A study with similar findings identified 34 patients from an institutional armed forces rehabilitation program in Asia. All were male, with a mean age of 31. Fifteen patients underwent CIC for bladder management, followed by a Foley catheter in thirteen patients. Those who used CIC performed the procedure every four hours and used disposable catheters[25]. Reusing disposable catheters is a common practice due to cost issues, but it increases the incidence of urinary tract infections in people with SCI[11,25,26].

Corroborating what was reported by some participants in this study, research conducted with 370 people with SCI found that, even using intermittent catheterization, most respondents had urinary tract infections, further exposing the need for solutions to empty the bladder without catheters and reduce clinical complications[9]. Similar data were also detected in a study involving 39 participants with SCI who practiced catheter reuse for an average of 10 years, 6 times a day, and who agreed to prospectively evaluate single-use hydrophilic-coated catheters for four weeks. All reused catheters collected (100%) were contaminated with debris, and 74% were contaminated with microorganisms[27].

Transitions from CIC to other less optimal strategies, such as indwelling catheters, are common, particularly in people with SCI who have not had access to specialized physical rehabilitation centers and services, as reported by five respondents in this study who reported not being rehabilitated. Paraplegic individuals with SCI who interrupt or discontinue CIC often have a higher average age, lower education and employment levels, and worse urinary tract infection symptoms[28].

The leadership role of nurses who are part of rehabilitation teams is crucial, both because of the direct relationship in the care of people with SCI, their families, and home caregivers, and because of the opportunities to guide and train them on how to proceed with care outside the institutional walls[7,14,24]. They work directly in the planning, execution, and evaluation of assistance and care for people with SCI, in all REPCD environments, focusing on achieving their best functional and psychomotor potential for performing transfers and MNB, considering that they have knowledge that supports their procedures from a technical-scientific point of view and care for these people for their physical rehabilitation[3,14,20,24,29].

The limitations of this study include the construction of results based on the experiences of people with SCI from a single region and the influence of the SARS-CoV-2 social isolation period on the rehabilitation of these individuals. Therefore, further studies are recommended in different settings and time periods, involving other conditions of the rehabilitation process for these individuals in Brazil.

This study contributes to the professional practice of teams working in the health and rehabilitation spheres of people with SCI, particularly nurses, by providing the opportunity to take the lead in interprofessional interventions for the care of these individuals. Considering the irreversibility of spinal cord injuries, the progressive incapacitation of individuals from performing self-care activities, and the effective presence of nurses in the various spheres of care and assistance provided to these individuals, in the short, medium, and long term.

Final Considerations

The findings of this study show that respondents improvise their strategies for performing toilet and MNB transfers, using available material resources, equipment, assistance from third parties, and knowledge acquired at specialized rehabilitation centers or services, or shared with peers in the community. They complain of a lack of accessibility at home and in public spaces and are at risk of falls and contamination when performing these procedures in their daily lives, both inside and outside the home.

Furthermore, some participants do not even maintain a link with the physical rehabilitation program, and others are not registered with the APS, which increases their difficulties in achieving adaptation strategies compatible with their functional needs for the safe performance of daily activities, such as transfers and MNB.

This gap can be minimized through care interventions led by nurses who are part of rehabilitation teams, based on Calista Roy's MA, considering the need for periodic assessments regarding the adaptation of these individuals to environments, equipment, and care procedures in the community, and the effective presence of these professionals in the various health care settings.

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