

Decisional conflict in patients with spinal cord injury who perform intermittent urethral catheterization

Conflito decisional de pacientes com lesão medular que realizam cateterismo uretral intermitente
Conflicto decisional de pacientes con lesión medular que realizan cateterismo uretral intermitente

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Descriptores

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Abstract

Objective: To identify the decisional conflict of patients with spinal cord injury who perform clean intermittent catheterization.

Methods: An observational, cross-sectional, quantitative study was conducted using two research tools: a sociodemographic/clinical questionnaire and the Brazilian version of the Decisional Conflict Scale. The research was carried out with a non-probabilistic sample in a public hospital specializing in rehabilitation in the Federal District. The data collected was analyzed using inferential and descriptive statistics of central tendency and dispersion using absolute and relative frequencies, mean, and standard deviation. The research protocol was evaluated and approved by the Research Ethics Committee of the Federal District Health Secretariat and all participants signed an informed consent form.

Results: The study involved 30 patients, most of whom were men, with a mean age of 32.43 years. Of these, 16 performed self-catheterization and 14 underwent assisted catheterization. Conflict of decision was identified in half of the patients, predominantly among those with a shorter period of spinal cord injury and period of catheterization. The information gap and the lack of support for the procedure were the main factors in decisional conflicts.

Conclusion: The time since the injury and the period during which the catheterization was performed seem to influence the acquisition of skills and knowledge in performing the procedure, showing a marked decisional conflict soon after the injury. Decisional support and supported self-care can contribute to better patient engagement.

Resumo

Objetivo: Identificar o conflito de decisão de pacientes com lesão medular frente ao cateterismo intermitente limpo.

Métodos: Estudo observacional, transversal, e quantitativo, que utilizou duas ferramentas de pesquisa, um questionário sociodemográfico e clínico e a versão brasileira da *Decisional Conflict Scale*. A investigação foi empreendida com uma amostra não probabilística em um hospital público especializado em reabilitação no Distrito Federal. Os dados coletados foram analisados por meio de estatística inferencial e descritiva de tendência central e de dispersão utilizando-se frequências absoluta e relativa, média e desvio padrão. O protocolo de pesquisa foi avaliado e aprovado pelo Comitê de Ética em Pesquisa da Secretaria de Saúde do Distrito Federal e todos os participantes aderiram ao termo de consentimento livre e esclarecido.

Resultados: A pesquisa envolveu 30 pacientes, sendo a maioria homens, com idade média de 32,43 anos. Destes 16 realizavam o auto cateterismo e 14 eram submetidos ao cateterismo assistido. O conflito de

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decisão foi identificado em metade dos pacientes, predominantemente entre os com menor tempo de lesão medular e período de realização do cateterismo. A lacuna de informações e a falta de suporte para a realização do procedimento foram os fatores preponderantes para a ocorrência do conflito de decisão.

Conclusão: O tempo de lesão e de realização do cateterismo parecem influenciar na aquisição de habilidades e conhecimentos na realização do cateterismo, manifestando-se com acentuado conflito decisório logo após a lesão. Suporte decisional e autocuidado apoiado podem contribuir para melhor engajamento do paciente.

Resumen

Objetivo: Identificar los conflictos de decisión de pacientes con lesión medular respecto al cateterismo intermitente limpio.

Métodos: Estudio observacional, transversal y cuantitativo, en el que se utilizaron dos herramientas de investigación, un cuestionario sociodemográfico y clínico y la versión brasileña de la *Decisional Conflict Scale*. La investigación se llevó a cabo con una muestra no probabilística en un hospital público especializado en rehabilitación en el Distrito Federal. Los datos recopilados se analizaron mediante estadística inferencial y descriptiva de tendencia central y de dispersión, con el uso de frecuencia absoluta y relativa, promedio y desviación típica. El protocolo de investigación fue evaluado por el Comité de Ética en Investigación de la Secretaría de Salud del Distrito Federal y todos los participantes adhirieron al consentimiento informado.

Resultados: Participaron 30 pacientes en el estudio, la mayoría hombres, de 32,43 años de edad promedio. Del total, 16 realizaban el autocateterismo y 14 el cateterismo asistido. Se identificaron conflictos de decisión en la mitad de los pacientes, de forma predominante en aquellos con menor tiempo de lesión medular y período de realización del cateterismo. El vacío de información y la falta de apoyo para la realización del procedimiento fueron los factores preponderantes para los casos de conflicto de decisión.

Conclusión: El tiempo de lesión y de realización del cateterismo parecen influir en la adquisición de habilidades y conocimientos para la realización del cateterismo, y se manifiesta con un elevado conflicto decisório poco después de la lesión. El apoyo en la decisión y el autocuidado con apoyo pueden contribuir para que el paciente se comprometa más.

Introduction

Including patients in the decision-making process regarding their health has become a central topic of discussion in several countries and at the most diverse levels of health care. For participation to be effective and of high quality, the determination of the options available for each case must be based on the best applicable scientific evidence, clarifying the benefits and risks of each alternative. The patient's values and preferences must also be included in the decision-making process regarding the course of action to be taken.⁽¹⁾ This clinical relationship model is based on the theoretical framework of Patient-Centered Care (PCC), which advocates health care that is respectful and responsive to the patient's wishes.⁽²⁾

Faced with multiple options, however, there may be doubts about which one is best for defining what really fits into the patient's life. This insecurity is known as decisional conflict, which is a state of uncertainty about the course of action to take, when the decision between competing actions involves risk, loss, regret, or challenges to personal life values.^(1,3) Conflict in decision-making has been recognized as a nursing diagnosis and incorporated by the North American Nursing Diagnosis Association (NANDA).⁽⁴⁾

The most frequent manifestations of decisional conflict are the verbalization of uncertainty, questioning of personal values involved, concern about the decision, distress in deciding, physical signs of emotional stress, hesitation, and delay in the decision.⁽¹⁾ Measuring decisional conflict and the factors that impact patients in the decision-making process can be useful in evaluating the impact of the decision support offered to the patient, such as health information, clarification of available options, benefits, and risks. This measurement can be decisive in better directing the actions of healthcare professionals and considering the patient's needs and preferences during the decision-making process.⁽⁵⁾

Patients with spinal cord injury (SCI) may need to adapt to meet different physical and psychosocial needs for a prolonged period of time and inadequate monitoring of these demands has been reported at various levels of health care.⁽⁶⁾ Among the main difficulties faced by patients with SCI, neurogenic lower urinary tract dysfunction (NLUTD) and the appropriate management of this alteration are frequently cited.⁽⁶⁾ In a national study, this problem was mentioned by 68.8% of the participants, emphasizing the challenge of making simultaneous decisions about treatments and procedures based on the diagnosis of SCI.⁽⁷⁾

Neurogenic lower urinary tract dysfunction makes it difficult to properly empty the urine re-

tained in the bladder, causing urinary retention and/or incontinence and, consequently, urinary infections. Clean intermittent catheterization (CIC) performed by the patients themselves is considered the gold standard for the management of NLUTD.^(8,9) CIC consists of passing a catheter, at regular intervals, through the urethra into the bladder to drain the urine, with subsequent removal of the catheter.^(8,9)

Because it is something new, invasive and which will cause changes in the patient's daily life, the adoption of CIC generates doubts, insecurity, and even refusal to perform the procedure. In this context, the following research question was formulated: Do patients with spinal cord injury who undergo clean intermittent catheterization have a decisional conflict?

Thus, the aim of this study was to identify the decisional conflicts regarding the use of CIC as a management technique for NLUTD, as well as the factors related to this conflict.

Methods

This is an observational, cross-sectional, quantitative study. It was carried out in a public hospital specializing in rehabilitation in the Federal District, with 30 people who performed CIC. The non-probabilistic sample included patients seen in the inpatient and outpatient units over a 4-month period (September to January 2018), with traumatic and non-traumatic spinal cord injury and an indication for CIC for the management of NLUTD. All individuals were over 16 years old and literate.

Two instruments were used for data collection: a sociodemographic and clinical questionnaire and the validated Brazilian version of the Decisional Conflict Scale (DCS). The *Escala de Conflito na Tomada de Decisão* (ECTD) is the traditional Brazilian Portuguese version of the DCS.⁽¹⁰⁾ When translating the instrument into Portuguese in Portugal, cultural adaptation was recommended, even for other countries using the language.⁽¹¹⁾

The DCS is a multidimensional scale used to identify the presence of conflict when making a

health decision, the factors that contribute to uncertainty, and the quality of the decision made.⁽³⁾ The scale has been translated and validated in more than 20 countries and 13 languages, and has been used in 253 studies to measure the impact of patient support interventions over the last 20 years.⁽¹¹⁾ It is described as a highly reliable tool, with a Cronbach's Alpha of 0.88 (subscale 1) and 0.89 (subscale 2), which discriminates between those who make or delay decisions and helps to evaluate different decision support interventions.⁽⁵⁾

The ECTD items are measured using a Likert scale with scores ranging from zero (strongly agree) to four (strongly disagree). The results of the responses were summed and divided by 16 and multiplied by 25.⁽¹²⁾ The scores were standardized to range from 0 (no decisional conflict) to 100 points (extreme decisional conflict). Scores of 25 or less are associated with the absence of conflict, while scores higher than 37.5 are associated with the presence of conflict and delayed decision-making.⁽¹²⁾

The ECTD has two subscales, the first is related to Decision, patient Uncertainty, and decision Support (DUS), consisting of items 7 to 16. The second refers to Information passed on and patient Values involved in the decision (INV). Both are calculated by adding up the answers, dividing by the number of items and multiplying by 25.⁽¹⁰⁾

The data collected was organized and tabulated using Microsoft Excel® software and then analyzed using the Statistical Package for the Social Sciences (SPSS) version 24. The sample was characterized by descriptive analysis of central tendency and dispersion, using absolute and relative frequencies, mean, and standard deviation. Assumptions of normality were tested using the Kolmogorov-Smirnov test. The Spearman (continuous) and Mann-Whitney (categorical with continuous) tests were used to verify the association between the variables. A significance level of $p < 0.05$ was adopted.

The research protocol was evaluated and approved by the Research Ethics Committee of the Federal District Health Department's Teaching and Research Foundation in Health Sciences under the CAAE identifier: 67372017.6.0000.5553, and protocol no. 2.080.560. All participants were informed

about the objectives and methodologies adopted and signed an informed consent form. In the case of minors, the informed consent form was signed by the legal guardian, while the minor signed an assent form.

Results

Profile of the sample studied

Thirty patients with SCI, NLUTD, and CIC participated in the study. The sample consisted of 24 (80%) men and 6 (20%) women, with a mean age of 32.43 (+11.46) years old. The majority, 22(73.3%), were single and 24(80%) did not work. In terms of schooling, there was a predominance of incomplete secondary education, 10(33.3%), followed by incomplete primary education, 7(23.3%) and complete secondary education, 6(20%). Traumatic SCI was the most prevalent in 25 (83.3%) cases. Firearm-related injuries came first with 13 (43.3%) cases, followed by car accidents with 7 (23.3%) (Table 1).

Table 1. Sociodemographic and clinical profile of patients undergoing CIC in inpatient and outpatient units

Characteristics	Divisions Classification	Inpatient Frequency	Outpatient Frequency	Total N (%)
Gender	Male	11	13	24(80)
	Female	4	2	6(20)
Marital status	Married	3	2	5(16.7)
	Single	10	12	22(73.3)
	Divorced	2	1	3(10)
Schooling	Incomplete elementary school	3	4	7(23.3)
	Complete elementary school	0	4	4(13.3)
	Incomplete high school	7	3	10(33.3)
	Complete high school	4	2	6(20)
	Incomplete higher education	1	1	2(6.7)
	Postgraduate degree	0	1	1(3.3)
Etiology	Firearm projectile	4	9	13(43.3)
	Car accident	4	3	7(23.3)
	Motorcycle accident	1	0	1(3.3)
	Shallow-water diving	1	0	1(3.3)
	Crushing	0	2	2(6.7)
	Fall	1	0	1(3.3)
	Non-traumatic	4	1	5(16.7)
	Type of sequelae	Tetraplegia	9	4
	Paraplegia	6	11	17(56.7)
Level of injury	Cervical	9	4	13(43.3)
	Thoracic	5	9	14(46.7)
	Lumbo-sacral	1	2	3(10)
Work activity	No	13	11	24(80)
	Yes	2	4	6(20)

There was a predominance of patients with paraplegia in 17 (56.70%) cases. Among patients assisted in inpatient units, however, there was a higher prevalence of those with tetraplegia. The average time of injury was 761 days, with 252 days being the average for inpatients and 1269 days for outpatients. The average length of stay in inpatient units was 156.14 days. Concerning CIC, 15 (50%) patients performed self-catheterization and 14 underwent assisted catheterization, i.e. performed by another person (family member or caregiver). The patients had been performing CIC for an average of 318.50 (+958.64) days, with the average value for outpatients being 1203.20 (+1144.99) and for inpatients 158.33 (+88.10) days. Regarding the frequency with which they performed CIC within 24 hours, the patients performed an average of 5 procedures/day. Most inpatients performed the procedure every 4 hours during the day and 6 hours at night. Among outpatients, there was a variation in the interval: some performed the procedure every 8 hours, while others used a 4-hour interval. Participants were also asked about the health professional who had advised them about NLUTD, and management options, including CIC. In 18(60%) cases, guidance was given by the physician, in 10(33.33%) by the nurse, and in 2(6.66%) they could not remember who had given the instructions. Nurses were mentioned as the professionals who most often explained the technique of performing CIC, by 26 patients (86.66%), while physicians were mentioned by 3 (10%). When asked about urine leakage in the interval between CIC, 12 (40%) patients said they did not have this problem, 11 (36.66%) reported daily leakage, 5 (16.66%) described weekly leakage (at least once a week), and 2 (6.66%) reported rare leakage, only once or twice a month. Regarding the search for additional information (internet, folders, other people), 5(16.66%) patients reported having looked for this data, being 4(13.33%) in inpatient and 1(3.33%) in outpatient units.

ECTD Scores

Of the 30 patients studied, 15 (50%) had decisional conflicts regarding CIC. In the ECTD score (Table

2), there was a statistically significant difference in the score between outpatients (22.80 points) and inpatients (41.30 points). The latter had significantly higher scores on the two INV and DUS subscales.

Table 2. ECTD scores and subscales

Dimension	Inpatient Med(IQR)	Outpatient Med(IQR)	Total Med(IQR)	p-value*
ECTD	41.30(14.00)	22.80(15.40)	32.10(17.30)	≤0.01
DUS	35.00(15.00)	25.00(25.00)	28.00(17.40)	≤0.01
INV	50.00(16.70)	29.10(50.00)	38.80(21.40)	≤0.01

DUS - Decision, uncertainty, and support; INV - Information and values; Med=Median; IQR - Interquartile Range; ECTD - Brazilian version of the Decisional Conflict Scale; * - Mann-Whitney Test. p<0.05

The correlation analysis showed that there was no significant correlation between age, gender, and the presence of work activity and decisional conflict concerning CIC (Table 3). In the total score, patients with neurological sequelae of tetraplegia had higher scores in relation to decisional conflict when compared to patients with paraplegia. This was also reflected in the DUS and INV subscale scores. The variables time since injury and time spent performing CIC (Table 3) showed an indirect correlation with conflict, i.e. the longer the time since injury and the time spent performing CIC, the lower the conflict in decision-making.

Discussion

The majority of the sample studied were men. This data corroborates national studies, which vary between 74% and 85%,^(13,14) and international studies

between 78% and 81%⁽¹⁵⁾ on people with SCI. The predominance of young adults confirms national studies which found a mean age of 39.45.^(7,14,16) Among the problems most cited by these patients is urinary incontinence due to NLUTD and the consequences for their social participation.⁽⁷⁾ They are therefore of working age and society's inability/impossibility to include them generates dissatisfaction with their right to work, directly influencing their quality of life.^(17,18)

The majority of patients had completed elementary school (up to the 9th grade) and less than a quarter had completed high school, showing a predominance of low levels of education. This profile is similar to that found in an analysis in the Northeast⁽¹⁴⁾ and Southeast regions,⁽¹⁵⁾ as well as in a study involving a sample of the Brazilian population.⁽¹⁹⁾

Traumatic injuries accounted for the majority of injuries related to SCI. Of these, almost half were caused by firearm projectiles. This SCI etiology has also been observed as the main one in studies in different rehabilitation centers.^(15,19)

The long length of stay found in the sample studied is related to the fact that the institution receives patients with acute complications, which delay recovery and the start of the rehabilitation process. With a similar profile, another study reported an average length of hospital stay of 130 days.⁽²⁰⁾

Regarding the management of NLUTD, the majority of patients with paraplegia performed CIC on their own, with only two needing help to arrange the material used in the procedure. Among the pa-

Table 3. Correlation between sociodemographic and clinical variables and the items of the ECTD and its subscales

Variables		DUS Med (IQR)	p-value	INV Med (IQR)	p-value	ECTD Med (IQR)	p-value
Gender	Male	41,60(32,30)	0,33	28,70(33,7)	0,55	33,60(33,40)	0,53
	Female	50,00(8,34)		32,50(25,6)		38,30(17,90)	
Work activity	Yes	50,00(16,70)	0,26	37,50(19,4)	0,11	32,00(26,50)	0,12
	No	41,70(29,20)		27,50(33,1)		45,30(16,00)	
Sequela	Tetraplegia	50,00(20,80)	0,20	35,00(16,2)	0,04*	40,60(16,40)	0,08
	Paraplegia	41,70(37,50)		25,00(28,7)		26,60(32,80)	
Age (CC)		0,29	0,11	0,25	0,18	0,22	0,24
Time since injury (CC)		-0,55	≤0,01*	-0,34	0,07*	-0,48	≤0,01*
Time of CIC (CC)		-0,57	≤0,01*	-0,44	≤0,01*	-0,57	≤0,01*

DUS - subscale 1 Decision, uncertainty, and support; INV- subscale 2 Information and values; Med - Median; IQR - Interquartile Range; ECTD - Brazilian version of the Decisional Conflict Scale; CC - Correlation coefficient; CIC - clean intermittent catheterization; * - p<0,05

tients with tetraplegia, the procedure was assisted, because given the alteration or loss of sensitivity and/or motor skills in the upper limbs, there is a need for other people to carry out the procedure.

Among inpatient, the intervals between CIC were regular, according to the guidelines received at the institution. In the outpatient units, the number and intervals of CIC varied. Studies corroborate the possibility of changes in the method chosen for neurogenic bladder emptying over time. These changes result from the combination of professional advice and personal preference and are related to individual needs such as incontinence, obesity, and autonomic dysreflexia.⁽²¹⁾

Urinary leakage occurred in 60% of the sample studied. This negatively affects quality of life and is a reason for adjusting schedules.⁽²²⁾ This was also reported in a study which revealed that 46% of individuals who performed CIC did so at their own intervals.⁽²³⁾

In order to make an informed decision about CIC, the patient should receive information about the pathophysiological changes of SCI, the consequences for the bladder and urination, the possibilities for managing NLUTD, and the risks and benefits of the options.⁽²⁴⁾ Together with an analysis of their own values and preferences, the patient will be able to make an appropriate decision. In this study, more than half of the cases (60%) were given advice on CIC by the physician, a finding also reported by another similar study.⁽²⁵⁾ A longitudinal follow-up identified that unspecific medical advice can motivate changes in the management of NLUTD and failure to follow the professional's instructions.⁽²¹⁾

In the sample studied, in 86.66% of the cases the nurse carried out training in the technique, which agrees with the information referenced on the role of nurse educators.^(24,26) Patient guidance is one of the most time-consuming functions of this professional in the rehabilitation area, and is among the main interventions suggested to solve the nursing diagnosis (NANDA) related to decisional conflicts.^(4,24)

The contribution of evaluating decisional conflicts through the ECTD lies in the possibility of quantifying uncertainties and revealing the factors that contribute to insecurity during the deliberation

process and after the decision has been taken.⁽³⁾ The presence of 50% of decisional conflicts in patients undergoing CIC suggests that, despite being considered a gold standard procedure, recommended by the best scientific evidence, and performed routinely, it still needs to be better explained to patients by nursing professionals who play this role in the rehabilitation context. This will allow proper understanding, reducing insecurity in the decision-making process. In the context of managing NLUTD, the inclusion of patients throughout the deliberation process is strongly recommended.⁽²⁷⁾

Regarding the average scores on the ECTD, inpatients had higher scores than outpatients. This information suggests an association between problems in understanding and deliberating on CIC and time since the SCI. The time factor is strongly referenced as influencing participation and adherence to CIC.⁽²³⁾

The DUS subscale showed lower scores for outpatients compared to inpatients. This data shows that the latter had conflicts in the effective decision and could postpone the implementation of CIC. Regarding decision-making and patient adherence to health care, in this case CIC, it is important to evaluate how the procedure is perceived by patients and the impact it will have on their life and quality of life.⁽²⁵⁾

The INV subscale showed higher values in both participant subgroups. This indicates the presence of decisional conflict related to the clarification of information needed to make a decision, as well as the clarity of values regarding the decision. Among inpatients, this value reached a high score, confirming that items related to knowledge have an impact on the conflict of these patients. Some studies confirm that providing more information about the procedure and possible outcomes, as well as taking the patient's values and needs into account during the decision-making process, reduces uncertainty and increases patient participation, generating greater adherence.^(3,27,28) Specifically, adequate information about the CIC process is related to adherence to the procedure in the short and long term.⁽²⁹⁾

The positive and inverse correlation between time since injury and time since catheterization showed that patient confidence increases as they be-

come more familiar with the technique. This association was also found in a study evaluating patient dropout in relation to the CIC technique.⁽³⁰⁾ In the present study, factors such as age and gender were not correlated with ECTD scores. These factors were also not correlated with adherence to CIC.⁽³¹⁾

The higher scores found when the scale was applied to patients with tetraplegia show that these individuals had more intense decisional conflicts than those with paraplegia. This may be related to the impossibility or difficulty of manual dexterity in the severe SCI group, which prevents or hinders people from carrying out the procedure. In addition, dependence on third parties to perform CIC was also a complaint found in the literature.⁽³²⁾

The data presented needs to be analyzed with caution since this is the first application of the Decisional Conflict Scale (DCS) in Brazil. In this context, patient awareness of the importance of participating in decisions about their own health is still incipient. New applications, in different contexts, could encourage discussion about including patients in the planning of their care.

Conclusion

Decisional conflicts were found among patients who performed CIC for the management of NLUTD, and were more evident in those with a shorter duration of SCI. Factors related to information about the procedure had the greatest influence on patient indecision. In this context, education by nurses during rehabilitation helps patients understand the proposed strategy for managing NLUTD. At the same time, it underpins the resolution of issues and the decision-making process, improving engagement with the proposed treatment and/or care. As an educator, nurses should include greater information support for patients in their care plans to improve the decision-making process regarding CIC. They should also consider the patient's wishes, values, and preferences when planning care, so that the proposal makes sense and fits the patient's daily life, making it possible to carry out rehabilitation with a focus on patient-centered care.

Collaborations

Antunes CMTB, Bampi LNS, Rodrigues LP, and Azevedo Filho FM contributed to the study design, data analysis and interpretation, writing of the article, relevant critical review of the intellectual content, and approval of the final version to be published.

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