

## Emotional perception of family-member caregivers regarding the clean intermittent catheterization in myelomeningocele cases

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### ABSTRACT

There are many special needs of the urinary tract of a child with myelomeningocele, who requires constant help from a caregiver who is often a family member that can face doubts, fears, and difficulties related to the clean intermittent catheterization that is necessary in these cases.

**Objective:** This study investigates the thoughts and feelings of family-member caregivers regarding their performing this technique on children, and analyzes how the caregiver feels about the possibility of the child carrying out the procedure him/herself later in life. **Method:** This observational and transversal research uses both qualitative and quantitative approaches. Also, structured interviews were made and recorded in audio with 15 family-member caregivers from a rehabilitation institution located in the city of São Paulo between April and August of 2012. Lexical and content analyses of the open questions was made using the software SPAD-T<sup>®</sup> version 1.5. **Results:** The categories found where: the caregiver's general impression of the catheterization, how long it took to get used to the procedure, the caregiver's perception of the child's general impressions, references to the professional's intervention, the caregiver's perception of the auto-catheterization, the caregiver's perception of how capable the child could be (to conduct the procedure him/herself), and references to the (in)dependence in the caregiver-child relationship. The statistical analysis was made using the software SPSS<sup>®</sup> 15.0. **Conclusion:** All caregivers showed negative feelings and thoughts about the catheterization even though some of them mentioned positive points as well. Moreover, most caregivers could not answer clearly whether the child would perform the self-catheterization by itself in the future.

**Keywords:** caregivers, child care, meningomyelocele, urinary catheterization

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Received on December 17, 2012.

Accepted on January 7, 2013.

DOI: 10.5935/0104-7795.20120035

## INTRODUCTION

Myelomeningocele is the most frequent form of Neural Tube Defect (NTD), comprising about 85% of the cases. It results in the serious functional impairment of various organs and systems in the child, one of which is urinary incontinence. Its etiology is considered multifactorial, in the world's population its incidence is 1:1000 live newborns and it is more common among females (58%).<sup>1,2</sup>

Due to the urological complications of the child with myelomeningocele, the Clean Intermittent Catheter (CIC) is frequently recommended. The CIC is described as a technique that introduces a lubricated catheter into the bladder through the urethral meatus in order to empty it, and it is recommended for reducing the incidence of urinary infection.<sup>3</sup> It can be done by the patient himself or by a caregiver,<sup>4,5</sup> which is understood as being the individual who helps the patient to perform his or her daily activities.<sup>6</sup>

As for the possibility of renal complication and its treatment indications, the families of children with myelomeningocele may feel anxious when they start using the catheter for many reasons: they worry about the clinical condition that makes it necessary to indicate the CIC, about hurting the child, and about their capacity to perform the procedure at home.<sup>7</sup>

Contrary to the vision of many health professionals that the CIC is a simple procedure, the families frequently have a different impression. Many times they describe this procedure as something that ties them to the child, due to their applying the catheter many times a day.<sup>7</sup>

The many types of care that children with myelomeningocele demand result in significant changes in the family routine, such as the need to learn specific procedures, which demands constant monitoring from the health team, as well as facing social difficulties resulting in the physical and emotional overload of the various members of the family. In addition, these children's families also learn to live with prejudice and stigmas related to motor difficulties, to urinary and fecal incontinence, which interfere with social activities.

The families of children with myelomeningocele experience doubts, anguishes, and difficulties that can discourage them and make them hopeless in relation to the treatment. Due to these difficulties and to the lack of health services that help the child as a whole, many families abandon the treatment, resulting in the aggravation of symptoms that could have been avoided.<sup>9</sup>

The literature points out that it is important that the health professional who deals with these families be sensitive when broaching the CIC questions, especially with the main caregiver.<sup>7</sup>

## OBJECTIVE

Based on the above facts, the present study aimed to investigate the thoughts and feelings of the family caregiver on performing CIC on the child with myelomeningocele, and analyze whether the caregiver visualizes the possibility of the child doing self-catheterization in the future.

## METHOD

A quantitative, qualitative, observational, and cross-sectional study was made with 15 family caregivers of children of both genders diagnosed with myelomeningocele. These children were recommended to perform a CIC and were under treatment at a rehabilitation center in the city of São Paulo.

The subjects were selected according to the nurse's agenda, and she was responsible for the CIC orientation at the institution. Included in this study were only caregivers who had already received their first orientation at least 15 days before and who were supposed to return to check the technique.

In this way, structured interviews were made in the period between April and August of 2012, arranged previously by telephone contact and made according to the caregiver's availability. Each caregiver was interviewed individually by one of the researchers, who recorded the audio and transcribed it later. All the participants read and signed the Free and Informed Consent Form.

The interview was made by sample characterization, 4 closed questions and 2 open. The sample contained 15 caregivers, all of them female, with ages ranging from 20 to 53 years (average of 35 years), 7 married with number of children between 1 and 7 (average 2). The kinship of these caregivers to the child is of 14 mothers and only one grandmother. It was also seen that 12 subjects did not work for a salary, since the most frequent level of education was incomplete junior high (5) and incomplete high school (5). The child's age varied from 1 to 12 years (average 6 years), with 9 males.

The closed questions contained questions concerning the following aspects: whether the

caregiver applied the CIC and how frequently, whether anybody helped, and whether the caregiver could visualize the child performing the CIC alone in the future. The open questions concerned the feelings and thoughts of the caregiver on the CIC, and the caregiver's reasons for visualizing the self-catheterization or not.

After the transcription of the interviews, the open answers were analyzed as to content, based on Bardin.<sup>10</sup> This analysis consisted of the careful and systematic reading of all the answers, selecting them by subject and parts of the discourse considered relevant. Later on, these pieces and words were gathered according to equivalent meanings, creating categories and subcategories of analysis for each question separately. The categories found were: "Caregiver's impressions on the catheterization" ("negative sense"/"positive sense"); "Time of adaptation to the procedure"; "Caregiver's perception on the impressions of the child" ("negative sense"/"acceptance of the catheterization"); "References to the health professional's intervention"; "Caregiver's perceptions on self-catheterization" ("negative sense"/"doubts"/"necessity"; "Caregiver's perceptions on the child's potential" ("caregiver visualizes the child's potential"/"caregiver has doubts about the child's potential"); "References to (in)dependence in the caregiver-child relationship."

The data from each open question was treated by the SPADT® software, version 1.5, to perform a lexical analysis, in which the referred software counted the frequency of words obtained in the subjects' answers. In addition, the program was responsible for gathering, for each subject, all the sentences that contained such words with the purpose of making it possible for the researchers to verify the meaning of those words in their discourses. In this way, the meanings could be compared, grouping only the words whose meaning was the same, making it possible to count them. In that context the words whose meaning was not in agreement with the referred category were excluded.

The software SPSS® 15.0 was used for statistical analysis, calculating the frequency of data collected from the sample characterization, from the closed questions, and from the content analysis categories.

Qualitative analysis was chosen due to the lack of research, scales, and tests on the emotional issues of a caregiver as to their performing the CIC, which gives the present study an eminently exploratory character. In that sense, a lexical analysis was chosen to

provide a quantitative basis for the content of the answers. However, the lexical analysis was not applied to all the categories created, for some answers could not be quantified, for they expressed their meaning in the general context of the discourse and not simply in the isolated word.

## RESULTS

Table 1 shows that 8 subjects mentioned they performed the CIC irregularly. "Irregularly" is understood as those subjects who performed the catheterization for a certain time, then stopped, and/or did it differently than what was instructed.

Table 2 shows that 7 caregivers performed the catheterization 5 times or more per day.

As shown in Table 3, 13 caregivers did not receive any help in doing the CIC. Of the two subjects who did receive help, one was helped by the child's father and the other by the child's grandmother.

In Chart 1 the categories that were created from the answers to the first open question are shown, referring to the caregiver's feelings about performing the CIC. The first category, called "caregiver's impressions on catheterization," identified answers referring to feelings and thoughts on the procedure and it was subdivided into "negative sense" and "positive sense".

"Negative sense" corresponds to the caregivers' words that evoked a potentially

negative view of doing the CIC and/or showed possible difficulties with the technique. All fifteen caregivers gave negative comments about the catheterization.

*"It is difficult. Very difficult." (Subject 2)*

*"It's kind of complicated; I think it's a little complicated to pass the tube. I'm afraid of hurting, things like that." (Subject 1)*

In the lexical analysis of this category, the most frequent words were: "difficult" (8), "complicated" (7), "fear" (6), and "bad" (meaning to feel bad) (4), since the 8 caregivers mentioned some of these words at least once.

In the subcategory "positive sense", with frequency of 9, it refers to the answers associated with viewing CIC as something necessary and beneficial to the child, denoting tranquility or a possible absence of difficulty in the caregiver performing the catheterization.

*"(...) I'm relaxed now, I saw that it wasn't as complicated as I thought it would be." (Subject 7)*

*"(...) for me it's easy, normal." (Subject 8)*

From the lexical analysis of this subcategory, a total of 13 occurrences of the following words was observed: "normal" (6), "all right" (3), "no problem" (2), "relaxed" (1), "tranquil" (1), since 5 subjects said some of these words at least once.

"Time to adapt to the procedure" identifies the caregivers' comments that mentioned a change in feelings and thoughts in relation to catheterization over time, that is, mentioning two different moments: one when they

started performing the procedure, and another at the time of the interview.

*"Today it's easy. I was apprehensive at first." (Subject 3)*

*"In the first weeks I felt bad, you know... then I saw that it was for his benefit" (Subject 4)*

The lexical analysis counted many words that made mention of time to adapt in the caregivers' comments. To be specific the words were: "at first" (8), "the first time" (2), "time" (10), "right at the beginning" (1), "in the first weeks" (1), "first" (1), "before" (1), totaling 15 times in the discourse of 9 subjects. From those subjects, only 2 talked about how they felt when they first started to apply the procedure, but did not refer to how they felt later on.

Words referring to a later period of time were: "after" (7), "now" (5), "time" (1), "today" (1), totaling 14 occurrences. In this way, 7 subjects answered with some of those words at least once.

Of the subjects interviewed, 9 had their answers included in both "positive sense" and "negative sense" subcategories. Six caregivers were also included in the "time to adapt to the procedure" category.

The third category, "caregiver's perceptions on the child's impressions" gathered the answers referring to the caregiver's perception on the feelings and thoughts of the child on doing the CIC. This category was subdivided into two subcategories. One of them, "negative sense", refers to the caregiver's negative view of what the child feels, thinks, or how it reacts to the catheterization, and 9 caregivers provided answers to that.

*"She didn't want that at all." (Subject 8)*

*"I think it bothers him." (Subject 9)*

Another subcategory, called "acceptance of catheterization", involved caregivers' answers referring to the child having accepted or gotten used to the CIC, and it was mentioned by 3 caregivers.

*"Then we kept talking for awhile, and then she let me do it, she accepted it" (Subject 8)*

The category "references to the health professional's intervention" refers to caregivers' speeches that mentioned the influence of the health professional in the performance of the procedure. These comments may offer emotional relief and serve to justify doing the procedure or not, as well as to show the hopes the caregiver places on the intervention of the health professional to resolve the caregiver's conflicts and difficulties. In this category 8 subjects mentioned the health professional.

**Table 1.** Performance of the CIC

	N	%
Done irregularly	8	53.3%
Done as instructed by a health professional	5	33.3%
CIC was not done	2	13.3%
Total	15	100%

**Table 2.** Frequency of CIC performances during the day

	N	%
5 to 6 times a day	7	46.7%
3 to 4 times a day	5	33.3%
0 to 2 times a day	3	20.0%
Total	15	100%

**Table 3.** Help received by caregivers to perform the catheterization

	N	%
No	13	86.7%
Yes	2	13.3%
Total	15	100%

**Chart 1.** Categories referring to how the caregiver feels performing catheterization

Subjects	Caregiver's impressions of the catheterization			Caregiver's perceptions of the child's impressions		
	Negative sense	Positive sense	Time to adapt to the procedure	Negative sense	Acceptance of the catheterization	References to the health professional
1	x	x	x	x		
2	x			x		x
3	x	x	x	x		x
4	x		x	x	x	
5	x					
6	x		x			x
7	x	x	x			
8	x	x	x	x	x	
9	x	x	x	x		x
10	x	x		x		x
11	x	x			x	x
12	x		x	x		
13	x	x	x			x
14	x	x				
15	x			x		x
Total	15	9	9	9	3	8

*"She (the nurse) said no, that he could feel discomfort if I went beyond a certain point, but it wouldn't hurt, he wouldn't feel pain. Then I felt more relaxed." (Subject 3)*

For the lexical analysis 24 occurrences were found of words related to the health professional. These words were used at least once in the discourse of 8 caregivers: "she" (11), "doctor" (4), "nurse" (3), "physician" (1), "professional" (2), "doctor" (1), "S." (nurse's name) (1), "young woman" (1).

As shown in Table 4, 8 caregivers (subjects 3, 4, 8, 9, 12, 14 - charts 1 and 2) could not answer whether the child would perform self-catheterization in the future, while 6 answered "yes" (subjects 1, 2, 5, 6, 7, 10, 13, 15) and 1 caregiver answered "no" (subject 11).

Chart 2, "Caregiver's perceptions of self-catheterization" included answers concerning how the caregiver sees the possibility of the CIC being performed by the child in the future, that is, what are the caregiver's feelings, thoughts, and opinions about this. *This category was subdivided into: "negative sense," "doubts," and "necessity". "Negative sense"*

*was considered for those answers that involved potentially negative effects regarding the caregiver's view on self-catheterization.*

*"I think it's going to be a little complicated." (Subject 1)*

*"I think it's strange." (Subject 2)*

The most frequent words with "negative sense" were: "complicated" (5), "strange" (1), and "difficult" (1), totaling 7 answers, with 4 subjects using some of these words at least once.

"Doubts" refer to answers that denote the caregiver's questioning and doubts on whether the child will perform self-catheterization, and for this subcategory 7 caregivers' answers were obtained.

*"It's not a certainty, but sometimes it's possible, right?" (Subject 5)*

"Necessity" is implied in answers where the caregiver mentioned the necessity of performing self-catheterization, and it was verified through qualitative analysis that, in some discourses, the caregiver viewed self-catheterization (as well as catheterization) as a chore. This subcategory was present in the conversation of 6 subjects.

*"As he needed to do it in school, as soon as he learns, he can do it in school." (Subject 13)*

*"But if it's needed, then, I think, yes." (Subject 12)*

In the second category, "caregiver's perceptions on the child's potential", were selected comments where the caregiver listed characteristics of the child that, in his or her opinion, would or would not make the performance of the CIC possible in the child's future. From that category a subcategory was created: "caregiver visualizes the child's potential", where 12 caregivers discussed the child's characteristics and gave reasons to support their belief that the child would be capable of perform self-catheterization in the future.

*I think he has the potential to do it alone." (Subject 9)*

*"He's intelligent. (...) I think he can do it alone in the future." (Subject 4)*

The words or expressions that had the highest frequency through lexical analysis were: "will power" (2), "intelligent" (2), "smart" (2), "good boy" (2), "interest" (1), "potential" (1), "dedicated" (1), "tranquil" (1), totaling 13 answers, with 6 subjects using some of these words at least once.

The subcategory "caregiver has doubts about the child's potential" included the comments of 8 caregivers who showed doubts about their children being able to perform self-catheterization, supported on the children's characteristics they considered might hinder their capacity.

*"Only if he is too insecure about it." (Subject 3)*

*"No, I don't know, he's too naughty." (Subject 5)*

In the lexical analysis, the words "insecure" (1), "naughty" (1), "stubborn" (1) were some of the ones found, totaling 3 occurrences by different subjects.

In the category "references to (in)dependence in the caregiver-child relationship" answers were grouped that denoted a possible relationship of dependence between the caregiver and the child and also the expectations, questionings, and caregiver investments in the possible independence of the child in the future.

*"I want him to be independent, the most autonomous possible. I will encourage it." (Subject 3)*

*"The nurse said she'll teach him to do it by himself, but he didn't want to because he's still too dependent on me." (Subject 9)*

**Table 4.** Caregiver's opinion whether the child will perform self-catheterization

	N	%
Does not know	8	53.3%
Yes	6	40.0%
No	1	6.7%
Total	15	100%

## DISCUSSION

As described by many authors, the analysis of results revealed that the main caregiver in families with disabled children is the mother.<sup>8,9,11,12,13</sup>

**Chart 2.** Categories referring to the child and self-catheterization in the future as seen by the caregiver

Subjects	Caregiver's perceptions of self-catheterization			Caregiver's perceptions of the child's potential		
	Negative sense	Doubts	Necessity	Caregiver visualizes the child's potential	Caregiver has doubts about the child's potential	References to (in)dependence in the caregiver-child
1	x			x	x	x
2	x	x			x	
3			x		x	x
4				x		
5		x	x	x	x	x
6	x			x		
7		x		x		
8				x		
9				x		x
10	x	x		x	x	
11	x	x			x	
12		x	x	x		
13			x	x	x	x
14			x	x		
15		x	x	x	x	
Total	5	7	6	12	8	5

Another factor verified in the present study is that most caregivers did not receive any help in doing the CIC. Thus, the caregivers do not count on anybody to care for the child, not even their partners.<sup>12,14</sup> It was also found that most caregivers do not have a job and spend a great part of their time caring for their children.

As for the CIC, most of the study's subjects answered that they did the CIC in an irregular manner. Although the frequency found had been similar to that recommended by the physician, which for these subjects was an average of 5 to 6 times a day, this does not mean that the CIC had been performed correctly. This is because, in some cases, its performance was discontinued or the caregiver's answer left doubts about the regularity of the frequency mentioned. Some of the difficulties reported that justify the irregularity were: lack of information, emotional issues, lack of material, clinical interferences of the child and of the caregiver, doubts, and unavailability of time on the part of the caregiver.

At the same time, it was observed that the caregivers were contradictory in their discourses when referring to the CIC as something "normal", "tranquil", while also expressing fear, anguish, anxiety, among other feelings and sensations that illustrated emotional difficulties in doing the CIC.

However, it was noted that, aside from this contradiction, there was also a contrast

in the caregivers' comments expressed by the category "*Time to adapt to the procedure.*" For these caregivers there was a time before the research at which they had considered the CIC application more difficult, in contrast to the time of the interview, at which they reported being more at ease with the procedure. One possible hypothesis is that necessity, adaptation, and learning to perform the CIC could, over time, have been superimposed over the negative feelings and thoughts that had been emphasized before. Thus, in some way, the caregivers had matured, become used to, and adapted to their performing the CIC, for they understood its need.<sup>4</sup>

This adaptation to the CIC also appeared in the category "*acceptance of the catheterization,*" in which the caregivers reported the child feeling uncomfortable with the procedure, but that, with time, had become used to it and sometimes even accepting it.

In the category "*caregiver's impressions of the child's perceptions,*" many caregivers reported how difficult it was for the child, who feels pain, complains, cries during the CIC procedure, while the caregivers themselves show difficulties and negative feelings about the procedure. This could also be seen in the caregivers' reports that used the word "we" when saying that both child and mother had done the CIC.

In this way, it is possible that the caregivers' emotional difficulties themselves in

relation to the procedure were in some way transmitted to the child during the catheterization. In some way, the child can also feel and perceive that this caregiver is not comfortable doing the CIC, which may influence the child's perception of it. Therefore, identifying which possible factors make it difficult or easy to perform the catheterization, would allow the development of strategies to reduce the fear of the procedure so as to promote its acceptance and increase adhesion to the treatment.<sup>11</sup>

As for how the caregivers view their children's capacity to perform self-catheterization, most caregivers could not answer this question clearly. When asked about their answer, in general, they showed frequent doubts and negative perceptions on self-catheterization, despite also showing recognition of its necessity in their comments. It is also possible to identify ambiguity in the answers for their view on the child's potential, since this subcategory showed similar frequency to the one on doubts about the child's potential. These results can illustrate how confused the caregivers feel about self-catheterization, justifying their answers.

The subjects who answered "yes" mainly justified their answers based on the need for performing this procedure and visualized the characteristics of this child that indicated its possibility of doing self-catheterization in the future.

In the course of the research, it was considered that the child's age when the CIC started being done would influence the mother imagining the possibility of self-catheterization. However, there was a caregiver with a one-year-old child who could visualize her child performing the CIC alone in the future, and another caregiver with a 12-year-old child, who could not visualize that same possibility. The age of the child, therefore, seemed not to interfere with the caregiver's visualization of the child performing self-catheterization in the future.

Thus, emotional aspects of the caregiver-child relationship, as well as the degree of dependence in the relationship, and the investment of the caregiver in the child's autonomy are factors that may interfere with the performance of the CIC and of the self-catheterization. In this way, it is understood that the information on the procedure alone is not enough for this caregiver to perform the CIC as recommended by the health professional.

According to reports, in a certain way, health professionals have some influence on the caregivers doing the CIC, as exemplified by the emotional relief reported by the caregivers after clarifying doubts, exposing their anguish, and obtaining information from

them. In addition, they support themselves on the conduct and professional knowledge of the health professional to justify whether they will perform the procedure at home. More than that, there are also expectations for the team to solve conflicts and difficulties, or even to end the child's problem with some medication, treatment, or cure.<sup>14</sup>

Considering the aspects mentioned above, it is of the utmost importance that health professionals have a different perspective and listen to the caregivers, for example, guiding and helping patients and their family members, seeking a better quality of life and adherence to the treatment. The physician-patient relationship effects the treatment,<sup>15</sup> since the comments and demeanor of the health professional have an influence on the patient.<sup>16</sup> In this context, we see the need for a psychologist working with the interdisciplinary team, so that this professional may manage the emotional difficulties with all those involved in the procedure.

## CONCLUSION

From the analysis and discussion of the results found, it is possible to verify that all the family caregivers of children diagnosed with myelomeningocele have shown negative feelings and thoughts about the CIC, despite some of them having shown positive outlooks.

In addition, most of the caregivers could not answer clearly whether they thought

it possible for their children to perform self-catheterization in the future.

For future studies on this theme, a larger number of subjects and a deeper research into self-catheterization is recommended since, through the report of professionals involved with the CIC, patients show difficulties in performing the technique by themselves.

## ACKNOWLEDGEMENTS

We thank the entire AACD team, and our family members and friends, who directly or indirectly contributed to this work.

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