






## Effect of reading an educational booklet about sickle cell disease on family members' knowledge\*

Efeito da leitura de caderneta educativa sobre doença falciforme no conhecimento de familiares

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### ABSTRACT

**Objective:** to analyze the effect of reading an educational booklet about sickle cell disease related to family members' knowledge. **Methods:** quasi-experimental study, with 20 children's family members with sickle cell disease. A form was used before and 30 days after medical consultation (pre- and post-test). The booklet was given to the family member on the day of the consultation. Analysis was performed using Statistical Package for the Social Science version 20 with the Shapiro-Wilk, Student's t, McNemar's chi-square and Odds Ratio statistical tests. **Results:** all participants were female, mostly mothers aged 20 to 30 years with high school education. The analysis revealed increase in the number of correct answers after reading the booklet with statistical significance ( $p < 0.001$ ). **Conclusion:** the reading of the booklet and the strategies used to encourage it contributed to increase the knowledge of family members about some disease aspects, enabling them to better deal with this disease.

**Descriptors:** Anemia, Sickle Cell; Educational Technology; Health Education; Child; Family.

### RESUMO

**Objetivo:** analisar o efeito da leitura de uma caderneta educativa sobre doença falciforme relacionada com o conhecimento de familiares. **Métodos:** estudo quase-experimental, com 20 familiares de crianças com doença falciforme. Utilizou-se um formulário antes e 30 dias depois da consulta médica (pré e pós-teste). A caderneta foi entregue ao familiar no dia da consulta. A análise foi realizada através do *Statistical Package for the Social Science* versão 20 com os testes estatísticos Shapiro-Wilk, t de Student, Qui-Quadrado de McNemar e *Odds Ratio*. **Resultados:** todos os participantes eram do sexo feminino, a maioria, mães de 20 a 30 anos com ensino médio. A análise revelou aumento do número de acertos após leitura da caderneta com significância estatística ( $p < 0,001$ ). **Conclusão:** a leitura da caderneta e as estratégias utilizadas para o seu incentivo contribuíram para o aumento do conhecimento dos familiares sobre alguns aspectos da doença, capacitando-os para lidar melhor com essa enfermidade.

**Descritores:** Anemia Falciforme; Tecnologia Educacional; Educação em Saúde; Criança; Família.

## Introduction

Sickle cell diseases are characterized by the presence of red blood cells that assume a different conformation, rigid and sickle-shaped, reducing their flexibility and the adequate blood flow in the vessels, which generates complications in several organs and tissues<sup>(1-2)</sup>. These diseases contribute to the low quality of life and increased morbidity and mortality of children and young adults worldwide, and the most vulnerable group is children up to five years of age, the period in which the onset of sickle cell crises occurs<sup>(3)</sup>.

In this case, family members become involved with multiple health care and monitoring, necessary for disease control. A study developed in India with family members of a child with sickle cell disease revealed that the parents' knowledge and skills are relevant for childcare, due to early perception of crisis situations. The more direct and conscious participation of these caregivers may reduce the morbidity and mortality associated with this disease<sup>(3)</sup>, but national and international literature have identified the low population knowledge about sickle cell disease<sup>(4-6)</sup>.

In order to contribute to changing this reality by using tools that facilitate family members' understanding about sickle cell disease and care necessary to prevent its crises, a booklet on the subject was developed and validated in 2018, in printed and digital format, as support to family members. This technology is the only existing one for health education for family members of children with sickle cell disease in Portuguese and has undergone a rigorous process of creation and validation of content and appearance by expert judges and target audience<sup>(7)</sup>, being chosen for the development of the present research. Based on these considerations, we aimed to analyze the effect of reading an educational booklet about sickle cell disease related to family members' knowledge.

## Methods

This is a quasi-experimental study, whose in-

tervention was the reading of the booklet "Caring for a child with sickle cell disease" and the strategies used to encourage it. Family members' knowledge about sickle cell disease was assessed pre- and post-test. Everyone was their own control and data collection took place in the period from December 1, 2017 to January 31, 2018, with application before of evaluative form on the subject and 30 days after. The booklet was given to the family member on the day of the consultation, and a text message and a phone call were also sent fortnightly, together with the same form and content, with standard verbal and written text reminding the participant about the research and the importance of reading for their learning, during the 30-day interval between the two meetings (strategies to reinforce/encourage reading).

In the two months of collection, 34 family members came to the service and were invited to participate in the study, which was accepted by 33 family members, but only 20 of them remained until the completion of the study. Inclusion criteria were being the minor's guardian and participating in his or her treatment in the health services and home care, and the child having sickle cell disease with laboratory confirmation. The exclusion criterion was family members with previous detection of cognitive deficit diagnosed by a physician.

For data collection, a two-part form was filled out: the first part contained sociodemographic data of the family member and clinical data of the child; the second part contained 16 closed questions about sickle cell disease, with four possible answers and only one correct alternative in each question. The instrument was based on the Manuals of the Brazilian Ministry of Health and on pertinent literature, including the main contents addressed in the booklet. A pilot test was carried out with five family members, with no difficulties in understanding the questions and the alternative answers. The 16 questions were applied in the first moment in person and reapplied 30 days later during a phone call made by one of the researchers. The family member was not informed that he/she

would be submitted to the same questions afterwards, to reduce the possibility of the so-called “learning effect” occurring, a situation in which the participants perform better in the post-test due to what they had learned from the pre-test experience. So, after one month, a call was made and, after reading confirmation, they were submitted to the reapplication of the form (post-test).

At the moment, there were difficulties in contacting the participants. Despite several attempts on weekdays, weekends, and different times, two participants had their phones constantly off or were absent, four did not answer the calls, three had personal problems and gave up the research, and four did not finish reading the booklet, totaling 13 exclusions for discontinuity. Thus, in the post-test, 20 family members participated.

Data analysis was performed using the Statistical Package for the Social Science® version 20 software. The descriptive analysis was performed using the absolute and percentage frequencies of the variables. In the bivariate analysis, the Shapiro-Wilk test was used to test the normality of the variables. In the parametric data, the Student's t-test was performed with a 5% statistical significance level. The knowledge per question was also analyzed, before and after the application of the booklet via McNemar's Chi-square and via Odds Ratio with a 95% confidence interval. The data were grouped and organized in tables. The research was approved by the Research Ethics Committee of the State University of Ceará in opinion No. 1,955,727/2017 and by the committee of the mentioned pediatric hospital (protocol No. 1,994,879/2017).

## Results

All the 20 participants responsible for the children were female and most of them were mothers of the children (90.0%), being 70.0% between 20 and 30 years old. As for education, the largest portion had high school education (complete and incomplete)

(70.0%). Most participants lived in cities in the interior of the state of Ceará (60.0%) and had no formal job (85.0%). Income ranged from <1 minimum wage to three minimum wages, and most had one to two wages (75.0%).

Regarding the information about the child, the majority were female (60.0%). The age ranged from nine months to 11 years and half of them were up to three years old. About the types of sickle cell disease, 55.0% were Hemoglobinopathy (Hb) SS (sickle cell anemia), 30.0% HbSC (SC disease) and 15.0% Hb S/ beta-thalassemia. It was identified that 60.0% of the children had already undergone more than 10 follow-up visits to the pediatric service, with a hematologist. Table 1 shows the correct answers of the participants in the pre- and post-test.

**Table 1** – Percentage of correct answers in the pre- and post-test. Fortaleza, CE, Brazil, 2018 (n=20)

Participants	Pre-test	Post-test	Difference (%)
	n (%)	n (%)	
1	13 (81.2)	15 (93.7)	+ 12.5
2	12 (75.0)	15 (93.7)	+ 18.7
3	6 (37.5)	16 (100)	+ 62.5
4	8 (50.0)	14 (87.5)	+ 37.5
5	14 (87.5)	16 (100)	+ 12.5
6	5 (31.2)	11 (68.7)	+ 37.5
7	12 (75.0)	15 (93.7)	+ 18.7
8	5 (31.2)	15 (93.7)	+ 62.5
9	12 (75.0)	16 (100)	+ 25.0
10	9 (56.2)	14 (87.5)	+ 31.2
11	12 (75.0)	14 (87.5)	+ 12.5
12	7 (43.7)	14 (87.5)	+ 43.7
13	8 (50.0)	15 (93.7)	+ 43.7
14	3 (18.7)	4 (25.0)	+ 6.2
15	5 (31.2)	9 (56.2)	+ 25.0
16	13 (81.2)	14 (87.5)	+ 6.2
17	3 (18.7)	12 (75.0)	+ 56.2
18	5 (31.2)	11 (68.7)	+ 37.5
19	9 (56.2)	16 (100)	+ 43.7
20	10 (66.6)	12 (75.0)	+ 8.3
Average	8.55 (53.4)	13.4 (83.7)	30.31

Based on this analysis, an increase in the number of correct answers after reading the booklet was noticed among all participants. The difference in this increase ranged from 6.2% to 62.5%, the average being 30.1%.

On average, the number of hits after reading the booklet (Mean = 13.40, Standard Error = 0.659) was higher than the number of hits before reading (Mean = 8.55, Standard Error = 0.796), with statistical significance ( $p < 0.001$ ).

In the following table, you can see the percentage of correct answers in the pre- and post-test, more specifically, for each of the questions asked.

The questions with the highest percentage of correct answers in the pre-test were questions 3, 10, 11, 12, 14, and 15. The questions with the highest number of correct answers in the pre-test were 1 and 2 (90.0%). The McNemar's  $\chi^2$  analysis showed statistical significance in the differences between the pre and post-test scores on questions 11, 12, 14, and 16 (Table 2).

**Table 2** – Correct answers to the form questions in the pre- and post-test. Fortaleza, CE, Brazil, 2018 (n=20)

Questions	Pre-test	Post-test		p* value	Odds Ratio (CI95%)
		Wrong n (%)	Right n (%)		
1. What is sickle cell disease?	Wrong	2 (66.7)	1 (33.3)	1.000	0.61 – 14.86
	Right	-	17 (100.0)		
2. How is sickle cell disease acquired?	Wrong	-	2 (100.0)	1.000	0.84 – 1.06
	Right	1 (5.6)	17 (94.4)		
3. What is sickle cell trait?	Wrong	11 (64.7)	6 (35.3)	0.130	0.68 – 5.28
	Right	1 (33.3)	2 (66.7)		
4. What are some of the symptoms of sickle cell disease?	Wrong	1 (12.5)	7 (87.5)	0.020 <sup>†</sup>	0.88 – 1.49
	Right	-	12 (100.0)		
5. Which item shows complications of sickle cell disease?	Wrong	2 (20.0)	8 (80.0)	0.010 <sup>†</sup>	0.92 – 1.70
	Right	-	10 (100.0)		
6. What care is important to prevent pain?	Wrong	1 (11.1)	8 (88.9)	0.010 <sup>†</sup>	0.89 – 1.42
	Right	-	11 (100.0)		
7. How is sickle cell disease diagnosed?	Wrong	2 (28.6)	5 (71.4)	0.060	0.88 – 2.24
	Right	-	13 (100.0)		
8. What is hydroxyurea?	Wrong	1 (12.5)	7 (87.5)	0.020 <sup>†</sup>	0.88 – 1.49
	Right	-	12 (100.0)		
9. What care is needed for the teeth of the child with sickle cell disease?	Wrong	3 (50.0)	3 (50.0)	0.630	0.82 – 4.19
	Right	1 (7.1)	13 (92.9)		
10. What is the care with feeding these children?	Wrong	1 (9.1)	10 (90.9)	0.010 <sup>†</sup>	0.73 – 1.32
	Right	1 (11.1)	8 (88.9)		
11. What is the importance of vaccination?	Wrong	5 (33.5)	10 (66.7)	<0.001 <sup>†</sup>	1.05 – 2.15
	Right	-	5 (100.0)		
12. Are health rights.	Wrong	4 (36.4)	7 (63.6)	0.020 <sup>†</sup>	1.01 – 2.46
	Right	-	9 (100.0)		
13. What is the care of the school child with sickle cell disease?	Wrong	-	7 (100.0)	‡	‡
	Right	-	13 (100.0)		
14. What is bone marrow transplantation?	Wrong	6 (46.2)	7 (53.8)	0.020 <sup>†</sup>	1.12 – 3.07
	Right	-	7 (100.0)		
15. Are complications of sickle cell disease (mark correct)	Wrong	3 (25.0)	9 (75.0)	0.070	0.60 – 1.68
	Right	2 (25.0)	6 (75.0)		
16. What is the treatment like?	Wrong	4 (40.0)	6 (60.0)	0.030 <sup>†</sup>	1.01 – 2.77
	Right	-	10 (100.0)		

\*McNemar's  $\chi^2$  test; <sup>†</sup>Values of  $p \leq 0.05$ , the number of correct answers in the pre- and post-test differ significantly; <sup>‡</sup>No statistics were computed because question 13 post-test is a constant; CI: Confidence Interval

## Discussion

Among the limitations presented in this research, we highlight the difficulty of telephone contact with the participants to continue the research and the discontinuity of 13, which led to a reduction in the final sample size. In addition, the same data collection instrument was used in the pre- and post-test, and although the family member was not informed about it in the first collection, trying to avoid the “learning effect”, these aspects may have influenced the findings. Another limitation concerns the inability of the study to establish a cause-and-effect relationship with other clinical variables.

Despite the obstacles, the study brings contributions to the practice, to the extent that it was noticed that the reading of the booklet by family members and the strategies for its encouragement contributed to the improvement of learning, which reveals the applicability of the booklet as a technology that can be used in health education processes in this group.

Regarding the characterization of the participants, corroborating the evidence found in the literature, there is a predominance of caregivers who are mothers of chronically ill children<sup>(8-10)</sup>. Regarding the profile of mothers of children with sickle cell disease, the present study identified that most mothers had high school education, results like those found in a research in Oman (Arabian Peninsula), which revealed that most parents had high school education<sup>(11)</sup>.

It was observed that those with higher education achieved higher scores in the post-test, as a probable consequence of the greater ease of understanding of the issues exposed in the booklet, which was also seen in research on educational activity with mothers of children with sickle cell disease in Egypt<sup>(12)</sup>. However, it is noteworthy that all participants increased their scores on the form about sickle cell disease after reading the booklet, among the different levels of education (Table 1).

As for income, it was noticed a low family socioeconomic level and the importance of financial be-

nefits provided by the government, given the constant demands of care for these children, both at home and in monitoring in health services. Moreover, most needed to travel long distances to get proper health care for the child, since in their municipalities there was unavailability of resources for this treatment, which also demanded costs for these families. On the other hand, it is noteworthy that no relationship was observed between socioeconomic status and learning the contents of the booklet.

In this context, a study carried out with 164 family members of children with sickle-cell disease pointed out as one of its main results the caregivers' precarious socioeconomic conditions, highlighting the lack of employment ties for most of the mothers (79.4%)<sup>(13)</sup>. On the other hand, a research showed financial difficulties for family members of children with chronic diseases in dealing with the continuous health care imposed by the disease<sup>(9)</sup>.

As to the profile of the children, there was a predominance of females, like another cross-sectional study with 668 medical records of patients with sickle cell disease, 53% of whom were women<sup>(14)</sup>. Sickle cell anemia (HbSS) has also been evidenced as the most prevalent type of sickle cell disease, corroborating the results of the present study<sup>(14-15)</sup>.

Regarding the number of outpatient appointments, it was initially believed that family members with more access to these appointments could present more knowledge about sickle cell disease due to increased chances of having been oriented by a specialist. However, statistical analyses did not show any such association.

A research developed with 48 children and adolescents with sickle cell disease identified that 87.5% had irregular outpatient follow-up visits, which was also found in the present study<sup>(16)</sup>. However, the small sample size (20 participants) and the differences that may exist, depending on the type of sickle cell disease and its complications, should be highlighted, since the more severe the disease, the more consultations may be necessary.



Regarding family members' knowledge, there was a low average score of correct answers before the reading of the booklet, which was positively affected by the reading of the booklet, as well as by the reinforcement of this reading via message and phone call.

Corroborating the findings, a research that also assessed the level of knowledge of mothers of children with sickle cell disease before and after health education sessions in Egypt showed that most of them had low level of knowledge about sickle cell anemia concepts, as well as about its complications, forms of treatment and prevention. Overall, the author exposed that 55% of the total knowledge on the subject had poor understanding<sup>(12)</sup>.

Similarly, a study that assessed the practices and knowledge of family members of children with sickle cell disease about the aspects that precipitate sickle cell crises showed that they had intermediate understanding about the disease, generating discussions about the essential role of educational actions in face of this reality<sup>(6)</sup>.

It is observed that the family members' knowledge often stopped only at technical concepts, such as its definition and form of acquisition, since these concepts corresponded to the two questions with the highest level of correct answers in the pre-test. In this perspective, another study with family members of children with sickle cell disease also emphasized their low level of knowledge about the disease, regarding its general aspects and sickle cell crises<sup>(5)</sup>.

It is noteworthy that, with the increase in survival after five years of age in the last decades, discussions about child and adolescent care started to focus on situations of high risk of occurrence, such as complications of sickle cell disease, as is the case of stroke, which causes severe disabilities and may lead to death<sup>(17)</sup>.

Thus, it was noticed that the knowledge of these family members before reading the booklet about relevant issues of the disease in the child was low, especially when it comes to complications, care to prevent painful crises, importance of vaccination, ne-

cessary therapies, and care with feeding, revealing the importance of the urgent need to implement strategies that seek to reverse this situation.

A research conducted highlighted the constant yearnings of family caregivers of children with sickle cell disease to understand the different aspects that permeate this disease, especially regarding the coping and treatment required in daily life, which can, in turn, generate stressful events such as anxiety and depression<sup>(18)</sup>.

On the other hand, it is noteworthy that after reading the booklet "Caring for a child with sickle cell disease" and the strategies used to encourage it, all participants answered at least 70% of the questions in the post-test, except for the question about sickle cell trait, which only had 40% of correct answers (25% more than in the pre-test).

Similarly, to this research, an experimental study with 72 relatives of children with sickle cell disease (37 in the intervention group and 35 in the control group) evaluated the effect of educational intervention (two educational videos provided via cell phone and four orientation phone conversations) on the increase in knowledge of these relatives, by applying a 25-item questionnaire. After four weeks, the intervention group had higher knowledge scores ( $21.8 \pm 1.3$ ) compared to the control group ( $11.7 \pm 2.3$ ), with statistical significance ( $p < 0.001$ ), which reinforces the importance and effectiveness of health education with this target audience<sup>(11)</sup>.

Other studies also showed statistical significance when analyzing health education activities on sickle cell disease for children's relatives, in pre- and post-tests<sup>(3,12)</sup>. Therefore, the use of technologies in this sense has revealed important strategies to help family members and caregivers in their orientation process.

## Conclusion

The reading of the educational booklet "Caring for a child with sickle cell disease" and the strategies

to encourage such actions can positively contribute to the learning process of family members about different aspects that permeate this chronic disease. Thus, this booklet can be used as a technology in health education processes with the researched clientele.

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## Collaborations

Figueiredo SV and Gomes ILV contributed to the conception and design, data analysis and interpretation, article writing, relevant critical review of the intellectual content, and final approval of the version to be published. Moreira TMM, Campos DB, and Chaves EMC contributed to the writing of the article, relevant critical review of the intellectual content, and final approval of the version to be published.

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