

INTRODUCTION

Musculoskeletal (MSK) complications worsen quality of life (QoL) of persons with hemophilia (PWH).

In Brazil, either by an overprotective attitude of their caregivers, or due to a lack of knowledge by their educators, many pediatric patients are still excluded from recreational and physical activities at school.



Cartoon source: <http://www.couriermail.com.au/news/were-a-risk-shy-society/story-e6frerdf-1226176700642>

OBJECTIVES



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- 1) To detect children with hemophilia with limited or no participation in physical activities at school, and
- 2) To determine the impact of school visits by a multidisciplinary team in the integration of these patients.

METHODS

From February, 2012 to December, 2013, during their scheduled routine visits to our hemophilia center at UNICAMP in Campinas, 43 children and teenagers with hemophilia were asked to answer different quality of life (CHO-KLAT) and functional assessment tools (Ped-HAL, PedsQL), according to their ages, with the main focus on their participation in recreational and/or physical education at school, as their classmates.

If any kind of exclusion was detected, the multidisciplinary team (most of time consisting of physiotherapist, psychologist, pedagogical educator, nurse and occupational therapist) scheduled a visit to that specific school, where lectures about basic concepts of hemophilia were presented (Fig. 1 A, B).



Fig. 1. School visit by the hemophilia care team. A) Staff of one school, participating during the lecture. B) Physiotherapist's lecture about hemophilia (*in loco*)

Before and after the presentation, the participants were asked to answer questionnaires, with basic concepts, in order to assess their level of prior knowledge and what was assimilated after explanations about hemophilia. A qualitative analysis was performed.

RESULTS

Forty-three children with hemophilia aged between 3 and 17 years-old were evaluated to assess their functional status and quality of life (Fig. 2).

It was detected that 8 (18.6%) children with hemophilia, including 2 siblings, did not participate of recreational activities or physical education classes as their classmates. Seven schools were contacted but only six schools were visited, despite the efforts undertaken to persuade the leaders on the importance of the visit.

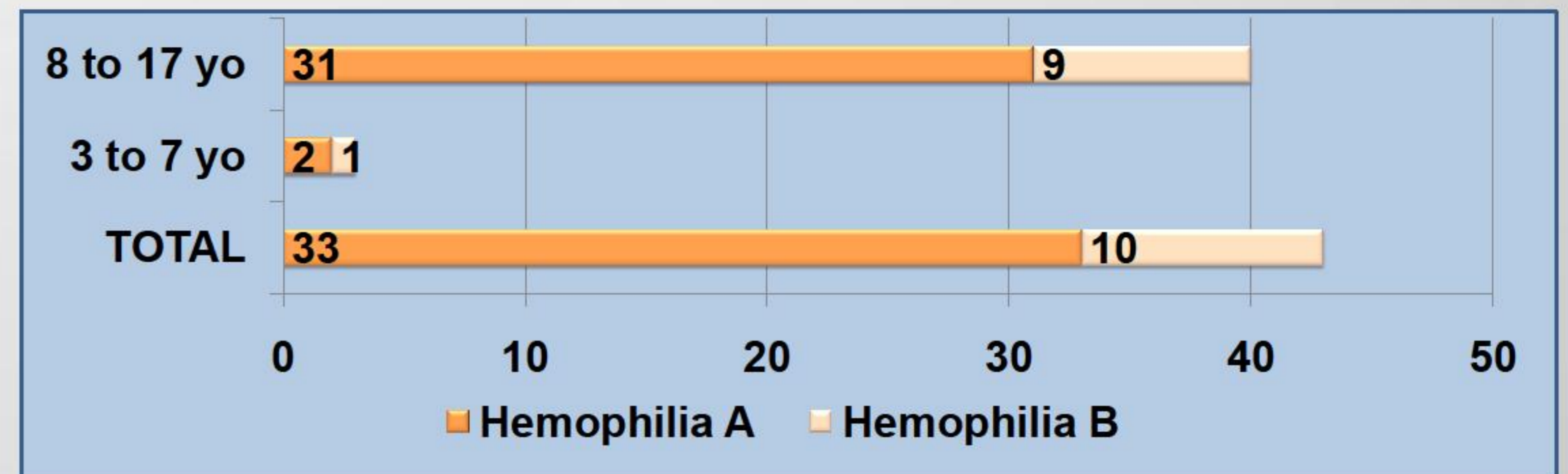


Fig. 2. Number of patients evaluated, according to age and type of hemophilia

During the school visits by the hemophilia team, a total of 48 education professionals answered the pre and post presentation questionnaires. A qualitative analysis showed that before the visits 58.4% of the professionals did not know or had wrong concepts about hemophilia, and only 9% did not find any difficult when dealing with students with hemophilia. After the visits, 96.2% felt more confident in performing regular activities with students with hemophilia (Fig. 3). All the visited schools have started to include the hemophilia patients in the physical and recreational activities along with other students.

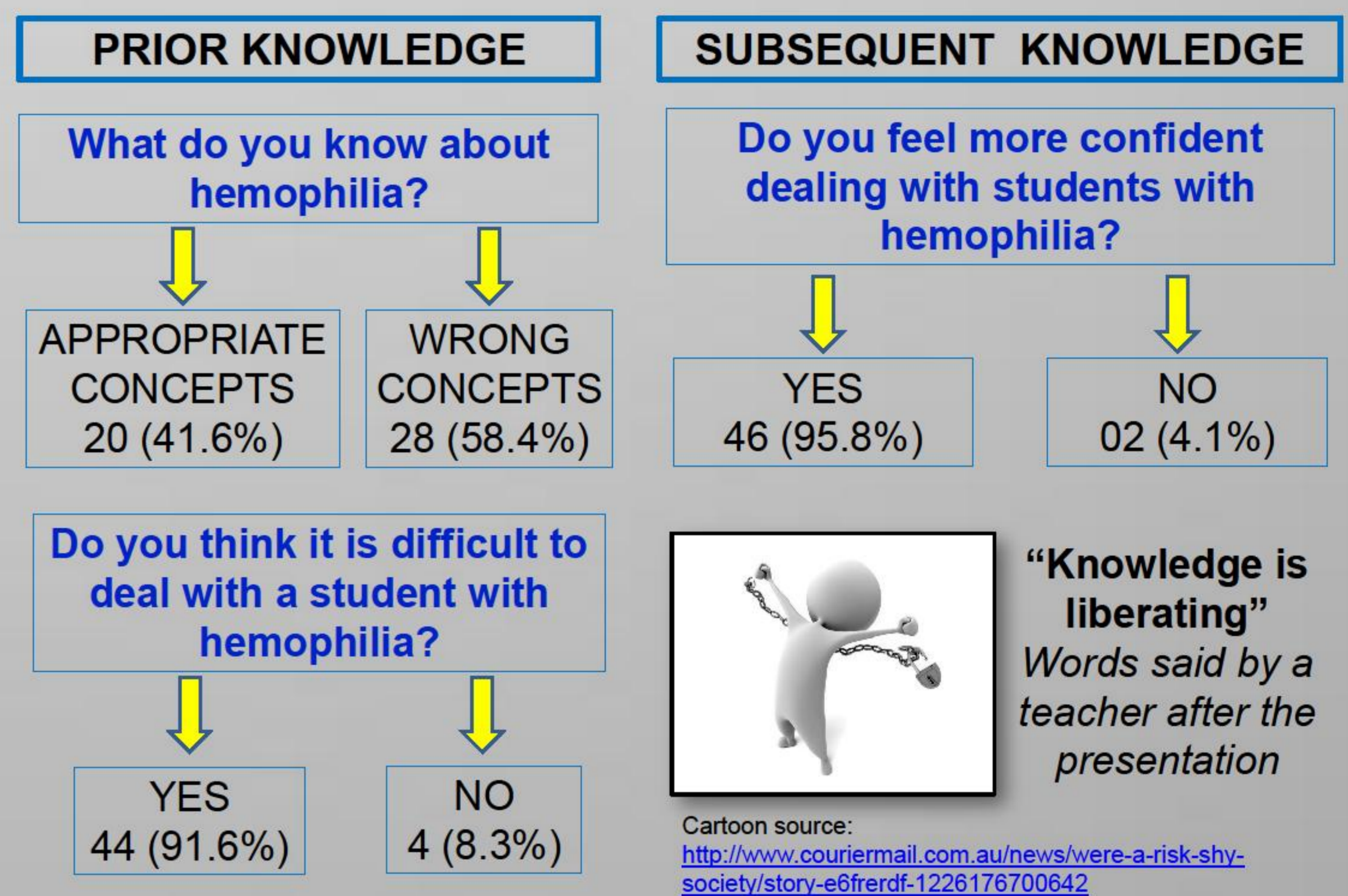


Fig. 3. Qualitative evaluation of education professionals' knowledge about hemophilia before and after the visit of the hemophilia care team.

DISCUSSION

Like many other countries around the world, MSK complications are recognized as the major cause of the deterioration in the PWH QoL in Brazil. It is common to observe social conflicts involving stigmatization by the society where PWH live, due to the lack of knowledge about the disease. Similarly, the lack of information is worse when it involves educators, who keep children apart of activities developed in their classrooms, depriving them of interacting with their classmates, because they ignore what kind of recreational and/or physical activities these children can perform.

CONCLUSION

Problems involving the social integration of children with hemophilia and their participation in recreational and physical activities can be easily minimized by disseminating educative information and developing tools, in order to allow the proper management of MSK complications in hemophilia. Sharing information through educational meetings *in loco* can constitute a powerful tool to ensure full inclusion of hemophilia patients in the educational setting.

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marcia_apm@yahoo.com.br

