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ORIGINAL ARTICLE

Translation of a Brazilian educational booklet concerning hydrocephalus into Spanish as spoken in Spain

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KEYWORDS
Hydrocephalus;
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Abstract
Purpose: A booklet for children with hydrocephalus and their parents was presented. This study translated the Brazilian version of the booklet ''Laura's diary: knowing hydrocephalus and its treatment'' into Spanish as spoken in Spain.
Methodology: This methodological study conducted in Spain (Universidad de Santiago de Compostela) and Brazil (Botucatu Medical School) undertook the following translation steps: translation, using two Brazilian translators fluent in Spanish; synthesis, involving a Spanish nurse with experience in education; and back-translation, using a Brazilian translator and nurse fluent in Spanish.
Findings: The two versions of the initial translation were similar, with few amendments necessary during the consensus meeting between the researchers to achieve synthesis of the translations. The two versions of the back-translation were very similar to the original.
Conclusion: A free Spanish booklet was presented to minimize the negative effects of surgery, empower families, and aid future research between Brazil and Spain. Mismanagement of a disease can affect a child's quality of life. Communication is essential for health education to help ensure greater participation of patients and families in care plans.
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PALABRAS CLAVE
Hidrocefalia;
Niños;
Rehabilitación enfermera;
Educación en salud

Traducción de un folleto educativo brasileño acerca de la hidrocefalia a español de España

Resumen
Objetivo: Se presentó un folleto educativo para niños/as con hidrocefalia, y sus progenitores. Este estudio tradujo al español la versión brasileña del folleto *Diario de Laura: Conociendo la hidrocefalia y su tratamiento*.
Metodología: Estudio metodológico realizado en España (Universidad de Santiago de Compostela) y Brasil (Botucatu Medical School), que llevó a cabo las siguientes etapas de traducción: traducción propiamente dicha, utilizando dos traductores de Brasil con amplio dominio del español; síntesis, implicando a una enfermera con experiencia en formación; y traducción inversa utilizando un traductor y una enfermera brasileños con amplio dominio del español.
Hallazgos: Las dos versiones de la traducción inicial fueron similares, siendo necesarias pocas modificaciones durante la reunión de consenso mantenida entre los investigadores para realizar una síntesis de las traducciones. Las dos versiones de la traducción inversa fueron muy similares al original.
Conclusión: Se presentó un folleto educativo gratuito en español para minimizar los efectos negativos de la cirugía, empoderar a las familias, y contribuir a investigaciones futuras entre Brasil y España. La gestión inadecuada de la enfermedad puede afectar a la calidad de vida del niño/a. La comunicación es esencial para educar en salud, y ayudar a garantizar una mayor participación en los planes de cuidados por parte de los pacientes y sus familias.
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Introduction

Hydrocephalus is a common neurological disease requiring surgery during childhood, and it is important to understand the disease, its diagnosis, treatment options, and complications.[1] The overall prevalence of hydrocephalus is 88/100,000 in the pediatric population, and prevalence rates are significantly higher in Africa and South America compared to other continents.[1]

Hydrocephalus results from an imbalance in the production, movement, or absorption of cerebrospinal fluid in the central nervous system, leading to intracranial hypertension. It is treated surgically and shunts are commonly used. However, shunts involve significant risks of dysfunction and infection requiring frequent revision surgeries.[2–5] An early diagnosis of malfunction is important to reduce the damage due to decompensated intracranial hypertension.[4]

The care of children with chronic health conditions represents a significant challenge to healthcare professionals and family members, as they encounter experiences related to treatments, successive hospitalizations, consultations, and examinations.[6–8] Throughout their lives, children with hydrocephalus often undergo multiple surgeries, and it is important that health professionals provide guidance during the perioperative period.[9,10]

Health education is focused on knowledge aimed at health promotion and prevention of disease and complications, with a view of enhancing patient autonomy.[11] Moreover, health education is an excellent tool for strengthening social bonds between a child, the family, and the health professional, since it can provide a relationship of trust, and health education has been reported to significantly contribute to better understanding and improvements in coping with the disease.[11,12]

Education in health, using printed educational material, is an approach that is well-accepted by parents of children with hydrocephalus. When well-written, easy-to-understand, attractive, and authored using publicly-accepted language, educational materials improve the knowledge and satisfaction of the reader, develop skills, promote autonomy, and can assist in decision-making.[13,14] However, there is limited research concerning the development of educational materials for children with hydrocephalus and their families.

We recently refined and validated a booklet for children with hydrocephalus and their parents. Through a children's story, learning objectives were included: the definition of hydrocephalus; recognition of signs and symptoms of shunt dysfunction; recognition of the role of parents and the surgical team (surgical center nurse, neurosurgeon, and anesthesiologist); perioperative care; the surgical environment; separation of mother and child in the surgical center; and social inclusion.[13] Some hospitals, organizations, and shunt suppliers provide their own educational material for patients with hydrocephalus and their families, such as material provided by the Hydrocephalus Association (www.hydroassoc.org) and the Spanish Federation for Spina Bifida and Hydrocephalus – SFSSH (http://www.febhi.org), which currently covers 27 associations throughout Spain. However, the authors did not describe the elaboration on these materials or whether they were validated for target audiences. In addition, the SFSSH material has a greater focus on spina bifida, whereas hydrocephalus is less well-addressed.

The development of new instruments in healthcare is complex, consuming further resources and requiring the mobilization of skills and knowledge from different areas.[15] Therefore, the translation and cultural adaptation of instruments previously developed and validated in other languages is useful for the exchange of information and dissemination of knowledge among the scientific community.[16–18]

As a major international language spoken in numerous countries by millions of people, we considered the Spanish language to be an important language for communication between researchers, and that due to the limited educational material for children and their parents, the translation of educational material may benefit many patients and families. Therefore, this study aimed to translate the Brazilian version of the booklet 'Laura's diary: knowing hydrocephalus and its treatment' into Spanish.

Method

This methodological study,[16] approved by a Research Ethics Committee in Brazil (Opinion no. 1.950.202 and CAAE: 64119917.6.0000.5411), involved the translation and cultural adaptation of printed and digital educational material developed and validated in Portuguese for use in Brazil.[13]

The study was undertaken between 2017 and 2018 at São Paulo State University and at the University of Santiago de Compostela, Spain.

In 2007, Beaton et al.[16] proposed the following steps, which were used in our translation process: (1) initial translation, (2) synthesis of translations, and (3) back-translation. The 21-page booklet translated in this study had been previously developed in Brazil and addressed hydrocephalus and its treatment. The content had been validated by experts, with a global content validity index (CVI) of 0.90, and its appearance and semantization had been validated by parents of children with hydrocephalus, with a CVI of 0.98.[13]

In step 1, the booklet was translated by two independent, bilingual translators, fluent in the language of the original version; thus, two translations (T1 and T2) were obtained. In step 2, the two translations were analyzed by the Spanish researcher who sought to provide improved terms for the booklet where possible. This process led to a synthesis of the translations (T1–2). In step 3, the synthesis (T1–2) was then back-translated into the original language of the booklet by two other independent and bilingual translators, giving rise to two back-translations, namely RT1 and RT2. This step verified equivalence and reliability between the Spanish version and the original version of the booklet. Fig. 1 illustrates the translation and back-translation process. We used Dwdiff v. 2.1.2 software to analyze the concordance rate of the versions.

Results

The initial translation was undertaken by two independent Portuguese native translators also fluent in Spanish with experience in the translation of materials related to health. The synthesis was undertaken by a nurse, who was also a nursing instructor and a native Spanish speaker. The two versions of the initial translation (T1 and T2) attained a combined concordance of 68%, and 28% of the words were changed (Fig. 2). Several terms and expressions were modified to ensure that there was consistency and adequacy of meaning to achieve a synthesis of the translations (T1–2) (Table 1).

The back-translation was performed by an independent translator with experience in health, who was a native Portuguese speaker also fluent in Spanish, and by a Brazilian nurse with experience in health education, who was a native Portuguese speaker also fluent in Spanish. The back-translations (RT1 and RT2) were checked by the authors of the educational material, and they indicated that the translations reflected the original content (Table 2). RT1 and RT2 were 63% and 60% in concordance with the original version, respectively. The rate of agreement between RT1 and RT2 was 70% (Fig. 2).

After completion of steps 1–3, the T3 version of the educative booklet was finalized (Fig. 3).

Discussion

This study described the translation steps of a playful booklet. Although there is no consensus on the translation and cultural adaptation of educational materials, studies indicate the importance of the entire process being undertaken systematically to ensure a clear and easily understood translated version.[16–19] During the translation process, modifications were introduced to terms that did not readily apply in the Spanish language, for example: ''decaimento general'' instead of ''caída del estado general,'' ''solicitar la asistencia del personal sanitario'' instead of ''buscar servicio de salud,'' and ''teléfono móvil'' instead of ''celular.'' Some terms that are used in the Spanish spoken in Latin America, such as ''celular'' and ''basquetebol,'' are not used in the Spanish spoken in Spain. Smith, et al. reported that parents develop considerable expertise in recogniz-

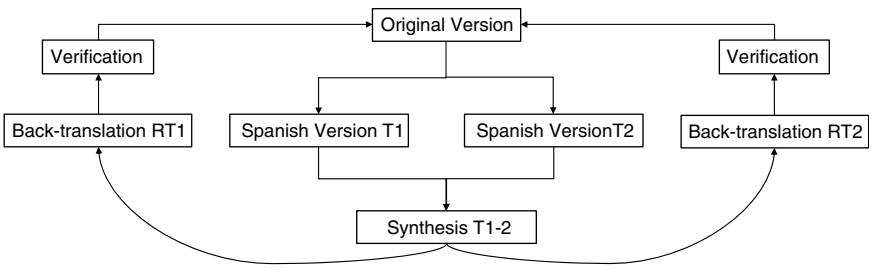

Figure 1 Flowchart of the translation, synthesis, and back-translation steps.

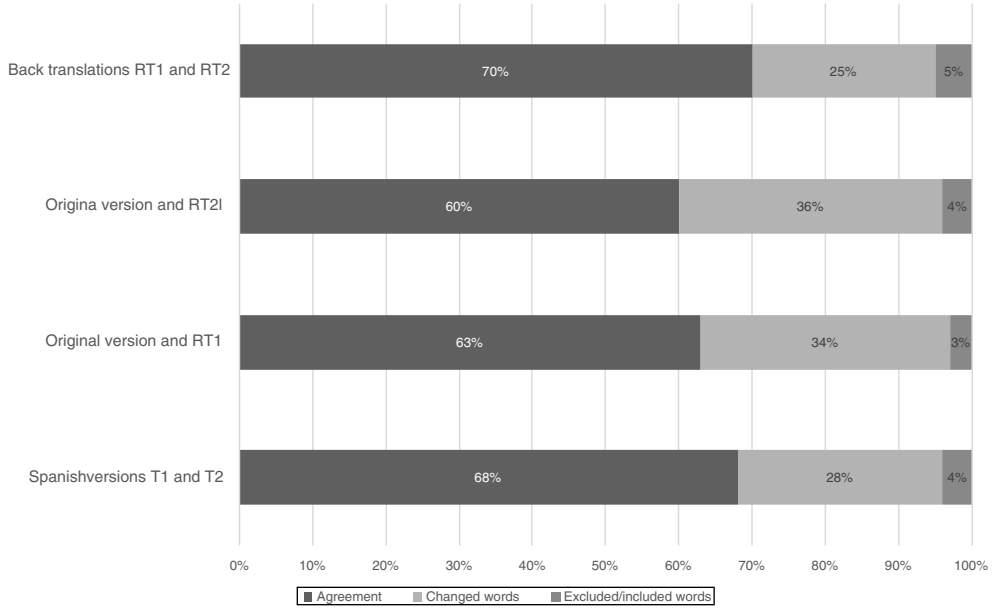

Figure 2 Rate of agreement between the versions.

Table 1 Major differences in T1 and T2 and the synthesis of the booklet.

T1	T2	Synthesis (T1–2)
la primaria	el tercer	en tercer curso
una tienda	un pequeño almacén	una tienda
Centro Quirúrgico	Quirófano	Quirófano
aula de Laura	clase que Laura	clase que Laura
ni tampoco ir a jugar con mis amigos y estaba sin hambre	no logré ir al cole ni jugar con mis amigos y no tenía apetito	ni jugar con mis amigos y no tenía apetito
Intenté almorzar, pero pasé mal y vomité después	Intenté comer, pero la comida me sentó mal y después vomité	Intenté comer, pero la comida me sentó mal y después vomité
Cuando voy a hacer cirugía	Cuando me tienen que operar	Cuando me tienen que operar
internada en el Departamento de Pediatría	internada en la enfermería de Pediatría	quedará ingresada en la hospitalización pediátrica
no voy a poder comer y ni beber nada, ni chupar caramelos y chicles	no podré comer ni beber nada, ni comer caramelos o masticar chicles	no podré comer ni beber nada, ni comer caramelos o masticar chicles
Camisón, bragas, pendientes, teléfono móvil	Bata, ropa interior, aros, celular	Camisón, ropa interior, pendientes, teléfono móvil
quizás sentiré solo un pinchazo rápido	tal vez sienta una pinchadita rápida	tal vez sienta un pinchacito rápido
muchos equipamientos	muchos equipos	muchos equipos
muchas cirugías	muchas operaciones	muchas operaciones
ella se quedará soñolienta a causa de las medicinas y que deberá quedarse en reposo	hoy estará somnolienta debido a la medicación y que deberá reposar	hoy estará somnolienta debido a la medicación y que deberá reposar
Soroche	Suero	Suero
el tamaño de la barriga	al tamaño de su abdomen	al tamaño de su abdomen
caída del estado general	caída del estado general	decaimiento general
buscar servicio de salud	buscar el servicio de salud	Solicitar la asistencia del personal sanitario
Realizar curativo de la región 2 veces al día	Realizar la cura de la zona 2 veces al día	Realizar la cura de la zona 2 veces al día
lavar las regiones de incisión con mucha agua	lavar las zonas de incisión con bastante agua corriente	lavar las zonas de la incisión con bastante agua corriente
1° día de postoperatorio	1er día tras la operación	1er día tras la operación

Table 1 (*Continued*)

T1	T2	Synthesis (T1–2)
Las enfermeras vinieron varias me auxiliaron con la ducha y le cambiaron el curativo	Las enfermeras han venido varias veces, me ayudaron a bañarla y a curarle la herida	Las enfermeras han venido varias veces también a ver cómo estaba, me ayudaron a bañarla y a curarle la herida
que mi análisis dio buen resultado, hoy voy a tener alta	que el resultado de mi examen fue bueno, hoy me darán el alta médica	que el resultado de mi examen fue bueno, hoy me darán el alta médica
no consigue anda	no puede caminar	no puede caminar
Yo, todavía, voy a tener que quedarme en reposo por un tiempo, no va a dar para jugar la rayuela y ni baloncesto, pero da para jugar a las muñecas y otras cosas	Aún tendré que reposar durante un tiempo, no podré jugar a la rayuela ni al básquetbol, pero podré jugar a las muñecas y hacer otras cosas	Aún tendré que reposar durante un tiempo, no podré jugar a la rayuela ni al baloncesto, pero podré jugar a las muñecas y hacer otras cosas

Table 2 Differences between the original version and the RT1 and RT2 translations.

Original version-Portuguese language	RT1	RT2
animada para brincar e se aventurar	animada para brincar e divertir-se	animada para brincar e divertir-se
Trabalha em uma mercearia	Trabalha em uma mercearia	Trabalha em uma loja de mantimentos
É muito divertido e tira várias gargalhadas de Laura, além de solucionar as dúvidas da Melissa.	É muito engraçado e faz Laura rir, assim como resolve as dúvidas de Melissa.	É muito divertido e faz a Laura rir, além de solucionar as dúvidas de Melissa.
enfermeira do Centro Cirúrgico	enfermeira cirúrgica	enfermeira da sala de cirurgia
Tentei almoçar, mas passei mal e vomitei depois.	Tentei comer, mas a comida me fez mal e vomitei depois.	Tentei comer más a comida não me caiu bem e depois vomitei.
sou muito ligada a mamãe	sou muito apegada à minha mãe.	estou muito apegada com minha mãe
Para falar a verdade	Para ser honesta	Para ser sincera
enfermaria de Pediatria	enfermaria de pediatria	hospital pediátrico
Centro Cirúrgico	Salas de cirurgia	Sala de Cirurgia
Hoje é a cirurgia	O dia da cirurgia chegou	Chegou o dia da cirurgia
deverá ficar em repouso	deve descansar	deverá repousar
barriga	abdômen	Abdomen
1° dia de pós-operatório	1° dia após a operação	1° dia após a cirurgia
O Paulo não está conseguindo visitar a Laura, mas ele liga todo dia para nós	Paulo não pôde visitá-la, porém telefona todos os dias	Paulo não foi capaz de visitá-la, mas nos liga todos os dias
atualizado a matéria	atualizado todos os temas	atualizei os tópicos
Na enfermaria de Pediatria existem coisas legais: brinquedoteca, parquinho...	No andar da pediatria há coisas boas: brinquedos, playground, videogames...	Na sala de Pediatria tem coisas boas: brinquedos, um parque infantil...
Fui anestesiada com a enfermeira segurando a minha mão	Eu fui anestesiada enquanto a enfermeira segurava a minha mão	Me colocaram anestesia enquanto a enfermeira me deu sua mão.

ing symptoms of shunt malfunction in their children and can contribute to decisions concerning their children's care; however, health professionals did not appear to prioritize this expertise.[20]

The synthesis was performed by a native Spanish speaking nurse, who ensured improved quality at this stage. During the synthesis stage, the translation of terms should not be literal from the original language to another, and it is important to adapt to the particularities of a local language, the cultural context, and the needs of professionals who will use the translated tool.[16] The translation of tools to other languages enables and facilitates exchanges between researchers from different countries and is important for the dissemination of knowledge acquired through academic research. This aspect is significant in the context of scientific research, since the elaboration of cross-cultural studies promotes a more comprehensive understanding concerning health communication in different languages.[21]

Several studies in Spain have been undertaken involving nursing care in relation to patients with hydrocephalus, but with a focus on education for nurses rather than for patients and relatives.[21,22] The Spanish Society of Neurosurgery (http://www.senec.es/) provides educational materials directed to different health conditions, including a folder with questions and answers concerning hydrocephalus and its treatment; however, no specific educational material

Figure 3 Images of ''Laura's diary: hydrocephalus and its treatment''.

was found for children. The Internet and digital educational materials can also provide information for patients and their families. One study reported that 91.7% of caregivers of children with hydrocephalus used the internet generally, 81.9% used the internet to look up information related to hydrocephalus, and 89.8% of the caregivers expressed an interest in being advised by their neurosurgeons concerning which online resources to access.[14]

Healthcare professionals' access to tools that aid health education may reflect positively on the therapeutic procedures applied and in the formation of child care plans as well as helping patients and their relatives to understand the patient's state of health.[11] Health education enables an improvement in the integral development of patients with hydrocephalus, helping them to appreciate their abilities and overcome their limitations. Developing research in the area of health education enables professionals to obtain further information about the needs, priorities, and demands of this population, in addition to providing greater societal recognition of nurse performance and greater excellence in professional performance.[12,23]

Given health education is a vital care strategy of health professionals, this translated booklet may contribute to early identification of the most frequent challenge to managing hydrocephalus, namely, shunt dysfunction.[9] In their qualitative study comprising[25] parents of children with hydrocephalus,[9] highlighted the experiences and decisions the parents made when a shunt malfunction was

suspected. The authors noted three stages, namely: uncertainty, because of the unpredictability and life-threatening nature of an inadequately functioning shunt; developing expertise, because the parents had learned to differentiate between symptoms that suggested an issue with the shunt and other childhood diseases; and a normal life, involving the challenges to strive for and maintain a normal life while aware of the chance that a shunt may function poorly at any moment.[9] Furthermore, the inclusion of the family in child-care plans has been reported to clarify the family caregiver's role, providing more confidence and security in participating in the care provided to children.[9]

Mismanagement of a disease can affect a child's quality of life. One study, conducted in India, aimed to identify the challenges faced by 31 children with hydrocephalus and to evaluate their quality of life. The study indicated that, although the cognitive domain was the most affected, having undergone several surgeries had a more significant effect on their quality of life. The authors emphasized that suitably focused educational interventions and holistic management were essential for improving the quality of life of children undergoing shunt replacement surgery.[24] A quasi-experimental study conducted in Egypt that evaluated the effects of nursing management protocols involving 39 mothers with children with ventriculoperitoneal shunts reported that the mothers' levels of knowledge increased after the implementation of nursing management protocols and that their practices improved ($p < 0.001$).[25] The authors recommended the use of printed and illustrative booklets on the care of children with hydrocephalus rather than simply using color figures to guide practice among mothers, reinforcing the importance of the translated tool here, namely, Laura's diary.[25]

Ultimately, there is limited information available that has been validated for use among this target population and the booklet can facilitate learning content through practice, allowing home access that favors understanding and sharing of information among family and friends.

Conclusion

The booklet ''Laura's diary: knowing hydrocephalus and its treatment'' was translated for use in Spanish as spoken in Spain, comprising three steps: translation, synthesis, and back-translation. Spanish version is freely available at https://drive.google.com/file/d/1z9CORJtm0Stnp_EsjUmbdsSykvYt-Iy7/view.

Appropriate educational material for a target audience can be a useful tool in health education to assist patients with hydrocephalus and their families and can benefit Spanish-speaking populations when made available in effective translations. Communication is essential for health education to help ensure greater participation of patients and families in care plans, and, where language barriers exist, translated tools can facilitate improved communication.

A limitation of this study is the lack of validation and cultural adaptation of the Spanish version of the booklet. This procedure should be performed in future studies, as it is important that children and caregivers validate the booklet and its effectiveness.

Conflict of interest

The authors declare there are no conflicts of interest.

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