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RESEARCH

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Health literacy of informal caregivers of patients undergoing neurosurgery[a]

Letramento em saúde de cuidadores informais de pacientes submetidos à neurocirurgia

Alfabetización en salud de cuidadores informales de pacientes sometidos a neurocirugía

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ABSTRACT

Objective: identify the level of Health Literacy (HL) of informal caregivers and their knowledge about the surgical treatment and postoperative period of patients undergoing neurosurgery. **Method:** QUAL+quan study conducted in 2023 in a public hospital in São Paulo. Participants included informal caregivers of neurosurgical patients aged 18 years or older. Data collection employed a sociodemographic questionnaire, the European Health Literacy Survey Questionnaire short-short form (HLS-EU-Q6) to measure HL, and the Ask Me Three® tool. **Results:** among the 71 caregivers, 71.8% were women, with a mean age of 47 ± 13 years, and 61.9% exhibited likely problematic HL. Three categories and eight subcategories emerged from the guiding questions. From the caregivers' experience, three categories and eight subcategories emerged. Caregivers identify and understand the patients' care needs in the postoperative period. However, they have doubts about the care to be provided at home and consider themselves important for the patient's recovery. **Final considerations and practice implications to practice:** assessing the caregivers' HL level can contribute to the transition from hospital care to home care. Furthermore, the Ask Me Three® tool can help nurses identify the need for guidance and implement educational actions that promote caregivers' HL.

Keywords: Caregivers; Health Literacy; Neurosurgery; Postoperative Care; Perioperative Nursing; Health Education.

RESUMO

Objetivo: identificar o nível do Letramento em Saúde (LS) de cuidadores informais e seu conhecimento sobre o tratamento cirúrgico e o período pós-operatório de pacientes submetidos à neurocirurgia. **Método:** estudo QUAL+quan realizado em 2023, em um hospital público paulista. Participaram do estudo cuidadores informais de pacientes neurocirúrgicos com 18 anos ou mais. Utilizaram-se os questionários, sociodemográfico, o *European Health Literacy Survey Questionnaire short-short form* (HLS-EU-Q6) para medir LS e o *Ask Me Three*® para guiar as perguntas norteadoras. **Resultados:** dos 71 cuidadores, 71,8% eram mulheres, com média de idade de 47 ± 13 anos, e 61,9% apresentaram LS provavelmente problemático. Da vivência dos cuidadores, emergiram três categorias e oito subcategorias. Os cuidadores identificaram as necessidades de cuidado dos pacientes no pós-operatório e as compreenderam. Contudo, apresentaram dúvidas sobre o cuidado a ser realizado no domicílio e se consideraram importantes para a recuperação do paciente. **Considerações finais e implicações para a prática:** a avaliação do nível do LS dos cuidadores pode contribuir para a transição do cuidado hospitalar para o domicílio. Ademais, a ferramenta *Ask Me Three*® pode contribuir para que os enfermeiros identifiquem as necessidades de orientações e realizem as ações educativas que possam promover a LS dos cuidadores.

Palavras-chave: Cuidadores; Cuidados Pós-Operatórios; Enfermagem Perioperatória; Letramento em Saúde; Neurocirurgia; Educação em Saúde.

RESUMEN

Objetivo: identificar el nivel de alfabetización en salud (AS) de los cuidadores informales y su conocimiento sobre el tratamiento quirúrgico y el período postoperatorio de pacientes sometidos a neurocirugía. **Método:** estudio CUAL+cuan realizado en 2023, en un hospital público en São Paulo. Participaron cuidadores informales de pacientes neuroquirúrgicos mayores de 18 años. Se utilizó un cuestionario sociodemográfico, el *European Health Literacy Survey Questionnaire short-short form* (HLS-EU-Q6) para medir AS y la herramienta *Ask Me Three*® para orientar las preguntas guía. **Resultados:** entre 71 cuidadores, el 71,8% eran mujeres, con una edad media de 47 ± 13 años, y el 61,9% presentó una AS probablemente problemática. Surgieron tres categorías y ocho subcategorías de las preguntas orientadoras. De la experiencia de los cuidadores emergieron tres categorías y ocho subcategorías. Los cuidadores identifican y comprenden las necesidades de cuidado de los pacientes en el postoperatorio. Sin embargo, presentan dudas sobre el cuidado a realizar en el domicilio y se consideran importantes para la recuperación del paciente. **Consideraciones finales e implicaciones para la práctica:** la evaluación del nivel de AS de los cuidadores puede contribuir a la transición del cuidado hospitalario al domicilio. Además, la herramienta *Ask Me Three*® puede ayudar a los enfermeros a identificar las necesidades de orientación y realizar acciones educativas que puedan promover la AS de los cuidadores.

Palabras clave: Alfabetización en Salud; Cuidadores; Cuidados Posoperatorios; Enfermería Perioperatoria; Neurocirurgia; Educación en Salud.

INTRODUCTION

Health literacy (HL) is defined by the Health Promotion Glossary of Terms (World Health Organization - WHO) as a set of knowledge and skills acquired throughout life through daily activities and social interactions. This knowledge is influenced by organizational factors and the availability of resources, enabling people to obtain, understand, evaluate, and use health information and services to promote their own well-being and that of those around them.[1] Additionally, the most recent definition of the term was presented by the Health People 2030 initiative in the United States, which described HL as the degree to which individuals have the ability to find, understand, and use information and services to make health-related decisions and actions for themselves and others.[2]

HL is an important determinant of health outcomes,[3] but it is poorly understood in the perioperative setting and in determining surgical outcomes.[4] A systematic review that evaluated HL in the surgical context, including 51 studies and 22,139 patients, revealed that the prevalence of low HL affects more than one-third of patients (34%), mainly in the subspecialty of abdominal transplantation and breast surgery.[3] A multicenter study conducted in 11 countries, including 1,365 adult patients undergoing heart transplantation, using the Subjective Health Literacy Screener (SHL) instrument, found that 33.1% of patients had low HL.[5]

Low HL levels have been associated with poor adherence to preoperative and discharge instructions, longer hospital stays, higher readmission rates, and higher healthcare costs.[6] They are also associated with a higher risk of emergency care, a higher number of hospitalizations, poor adherence to medication regimens, and higher mortality rates. [3,7] A systematic review and meta-analysis, which analyzed 18,895 patients from 40 studies using 19 different instruments, identified that approximately 31.7% of surgical patients have low HL. Limited HL was associated with unfavorable outcomes, such as lower adherence to pre- and postoperative care and difficulties in decision-making. The authors highlighted the need for systematic interventions to improve communication between professionals and patients, promoting safety and quality of surgical care.[8]

It should be noted that none of the studies analyzed above were conducted in Brazil, highlighting the magnitude of the problem, which may become more relevant in the neurosurgical context. A scoping review highlighted that these patients' recall and understanding after receiving guidance are often limited, with perspectives that differ from those reported by neurosurgeons.[7]

In view of this, it is pertinent to develop a care plan aimed at neurosurgical patients that includes the transition from hospital to home care with the aim of minimizing postoperative complications and hospital readmissions.[9,10] In this sense, the level of HL of patients and their caregivers can guide the health information needs to be made available to each family. The prevalence of low HL in informal caregivers of neurosurgical patients was described in a Brazilian study, in which 61.8% had problematic HL.[9]

From the patients' perspective, the qualitative approach conducted in Brazil, including patients in the late postoperative period of coronary artery bypass grafting, revealed that unsatisfactory HL hinders the understanding and implementation of disease care. The participants' statements highlighted gaps in the planning and guidance provided by health professionals, transferring responsibility for the implementation of therapy in the home environment to family members.[11] Given this, informal caregivers are fundamental in post-operative patient care.[12] By acting in a dyadic manner, they assist in performing tasks and monitoring rehabilitation, promoting treatment adherence.[13] Adequate postoperative care, based on preventive measures and a multifaceted approach, is essential to mitigate risks and ensure effective recovery.[14]

In corroborating this scenario, the model proposed by Nutbeam[15] stands out, which considers three different levels of HL: functional, which involves understanding health information acquired throughout life; interactive, which allows the active application of this information in health decisions and to access health services; and critical, in which individuals are able to analyze the social determinants of health and promote individual and collective changes.

Thus, given the relevance of the topic and from the perspective of the model proposed by Nutbeam,[15] understanding the HL of caregivers becomes essential for the transition from hospital care to home care, justifying the conduct of this research. The objective was to identify the HL level of informal caregivers and their knowledge about surgical treatment and the postoperative period of patients undergoing neurosurgery.

METHOD

This is a QUAL+quan study.[16] In the quantitative approach, a descriptive analysis was performed. The qualitative stage had as its theoretical reference the assumptions of HL according to Nutbeam's model[15] and as its methodology Bardin's Content Analysis.[17] The study sample was non-probabilistic of the intentional type, using theoretical saturation.[18] The study followed the recommendations for conducting qualitative research from the Consolidated Guidelines for Reporting Qualitative Research (COREQ).[19]

The research was conducted in an adult neurological inpatient unit in a public hospital, a reference for 68 municipalities in the interior of São Paulo, Brazil. This inpatient unit had 17 beds during the data collection period, which took place from March 7 to December 15, 2023.

Informal caregivers of patients undergoing neurological surgery participated in the study. An informal caregiver was defined as an individual who did not receive remuneration for providing postoperative care to the patient and who considered themselves primarily responsible for this activity.

Participants were identified through visits to the inpatient unit, based on the following inclusion criteria: informal caregivers of patients undergoing neurological surgeries, aged 18 years or older, with some level of dependency, and were in the process of being discharged from the hospital or had already been discharged.

Data collection was conducted by one of the researchers trained to do so. None of the study participants had prior knowledge of the researcher. They were informed about his academic background, his interest in the subject, and the objectives of the research.

The invitation to participate in the research was made by the researchers through direct communication, during which potential participants were informed about the objectives of the study and invited to participate in the research on a voluntary basis. Data collection was carried out on the day scheduled for hospital discharge or, in cases where the patient had already been discharged while waiting to be taken home.

Participants were then invited to go to the ward waiting room to ensure privacy during data collection. In cases where they chose to remain with the patient, the interview was conducted in the patient's room, in their presence. First, sociodemographic data and HL data were collected through interviews. Subsequently, the guiding questions were posed and recorded using a smartphone, lasting an average of one to two minutes.

Data collection was terminated due to theoretical saturation, i.e., the inclusion of new research participants was suspended when the data obtained began to show repetition and redundancy, ceasing to contribute significantly to the study.[18] The themes were identified after data collection.

The data collection instruments consisted of:

Sociodemographic questionnaire

Caregivers: Sex (male and female), age (years), race/ethnicity (white, brown, black), marital status (married, single, living with partner, separated or divorced, widowed), years of study (years), profession (health care, related field, other), employment status (working, unemployed, retired), health insurance/health plan (public only, public and private), living in the same residence as the caregiver (yes or no), and family relationship (child, spouse, sibling, mother/father, friend, other).

Patients: Sex (male and female), age (years), previous neurological surgery (yes or no), type of surgery (elective, urgent, and emergency), medical diagnosis category (tumor, hydrodynamics, trauma, vascular, infection, and others), and length of postoperative hospitalization (days). The classification of variables was developed by the authors. This questionnaire was administered as an interview.

European Health Literacy Survey Questionnaire short-short form (HLS-EU-Q6): In Brazil, it was validated by Mialhe et al.,[20] and its internal consistency was assessed using Cronbach's alpha coefficient and McDonald's omega, obtaining a coefficient of 0.87. Its factor loadings ranged from 0.64 to 0.84. The HLS-EU-Q6 questionnaire consists of six questions from the HLS-EU-Q47. The response categories are coded between one and four, where 1 = very difficult, 2 = difficult, 3 = easy, and 4 = very easy. Higher scores indicate better HL levels. The final HLS-EU-Q6 score classifies individuals according to three HL levels: Probably Inadequate (≤ 2), Probably Problematic (> 2 and < 3), and Probably Sufficient (≥ 3). This instrument was administered as an interview.

Ask Me Three®: was developed by the Institute for Healthcare Improvement and the National Patient Safety Foundation. It is an educational tool designed by HL experts to involve patients/caregivers in their own care by increasing communication and helping them better understand treatment and care.[21] The guiding questions for the qualitative stage were conducted following the tool, in reverse, based on Six Means:[22]

"1. What is the patient's main problem?", "2. What should I do?" and "3. Why is it important for you to do this?"

Quantitative data were analyzed using descriptive statistics. Categorical variables were presented in absolute and relative frequencies, while continuous variables, such as age, caregiver time, and postoperative hospitalization time, were expressed as mean and standard deviation.

To guide the qualitative analysis of the data, we used the Content Analysis proposed by Bardin,[17] which is divided into three stages: pre-analysis, in which a floating reading of the obtained data is performed; exploration of the material, a phase in which relevant points of each question are highlighted and then grouped and organized into thematic categories; and finally, the interpretation of results phase, in which the empirical data are analyzed according to the revealed thematic categories. The qualitative data were supported by NVivo software.

Each interview was transcribed, preserving the accuracy of the statements. Two of the authors coded the data, which was then reviewed by a third researcher. No interviews were repeated, and no field notes were taken at that time. After transcription, the interviews were not returned to the participants.

The theoretical framework used was that proposed by Nutbeam,[16] who classified HL into three levels: functional, communicative/interactive, and critical. In the development of the study, these dimensions guided the interpretation of the results. Functional HL was assessed based on the participants' ability to understand information related to reading and writing, such as medication labels and medical prescriptions. Communicative/interactive HL was analyzed considering the individuals' abilities to apply the knowledge acquired to actively participate in their daily lives and social context. Critical HL was examined based on the participants' ability to interpret and critically evaluate health information, aiming at social transformations and improvements in quality of life. This structure allowed for a comprehensive and well-founded analysis of the HL level of the studied population.

The research followed Resolutions No. 466/2012 and No. 510/2016 and was approved by the Ethics and Research Committee (REC), opinion No. 6,911,464. The identities of the study participants were preserved and they were identified by the letter "C" followed by a number, respecting the order in which the interviews were conducted. Next, each caregiver was assigned an HL score according to the HLS-EU-Q6. All participants agreed to participate in the study by signing the Free and Informed Consent Term (FICT).

RESULTS

First, we present the characteristics of the study participants, highlighting that among the 71 caregivers, 51 (71.8%) are women, with a mean age of 47 years. Most are white (56, 78.8%) and married (36, 50.7%), with 39 (54.9%) being employed, as shown in Table 1.

Regarding the caregivers' HL level, according to the HLS-EU-Q6, 4 (5.6%) had probably inadequate HL, 44 (61.9%) were classified as having probably problematic HL, and 23 (32.3%) had probably sufficient HL.

The profile of the patients followed by the participants revealed that 41 (57.7%) were women, with a mean age of 56 years. Most of the procedures performed were elective surgery 36 (50.8%), and the most prevalent medical diagnosis was tumor 28 (39.5%), as shown in Table 2.

Subsequently, after coding and analyzing the data, categories emerged for each Ask Me Three® question, as shown in Figure 1 below.

Three categories were identified: "Identifying postoperative care needs," "Understanding and presenting questions about the care to be provided," and "Considering the importance of the caregiver and care in patient recovery."

The first category, "Identifying postoperative care needs," addresses the guiding question: "What is the patient's main problem?" In the context of neurosurgical patients, this has to do with three related aspects: identifying care needs related to the medical diagnosis; identifying care needs related to the reason for hospitalization; and identifying care needs related to the patient's signs and symptoms.

Regarding identifying care needs related to medical diagnosis, this refers to the perceptions of caregivers who identified the main problem of the patient in the postoperative period of neurosurgery as the diagnosis of the disease, that is, they relate the patient's current condition to the disease that led to the surgical intervention. It was observed that caregivers tend to focus on the disease that led to the surgery, possibly leaving specific postoperative issues in the background, which already signals an aspect of HL (understanding of the clinical condition), as shown in the following transcripts:

> *He had a tumor in his head.* (C3) HL 3.6
>
> *Normal pressure hydrocephalus.* (C9) HL 2.8
>
> *The main problem was cancer, a tumor in the brain.* (C15) HL 2.5
>
> *A cerebral aneurysm was discovered in the central part of the brain.* (C50) HL 2.6
>
> *[...] she had a lump and needed surgery [...] she had the tests and the surgery, but unfortunately it became infected.* (C57) HL 2.8

Table 1. Sociodemographic characteristics of informal caregivers. Botucatu (SP), Brazil. 2023. (n=71).

Variables	n	%
Sex		
Female	51	71.8
Age + SD (years)	47.2 ± 13.0	
Years of schooling		
2-7	14	19.7
8-13	31	43.6
14-20	26	36.6
Color		
White	56	78.8
Brown	13	18.3
Black	2	2.8
Marital Status		
Married	36	50.7
Single	18	25.3
Living with partner	7	9.8
Separated or divorced	6	8.4
Widowed	4	5.6
Health-related or related profession		
No	60	84.5
Employment status		
Working	39	54.9
Unemployed	21	29.5
Retired	11	15.4
Health services used		
Public only	48	67.6
Public and private	23	32.4
Resides with the patient		
No	38	53,3
Family relationship		
Child	31	43.6
Spouse	18	25.3
Sibling	10	14.0
Mother/Father	6	8.5
Friend	3	4.3
Others	3	4.3
Average time as caregiver (months)	7.8 ± 16.8	

Table 2. Sociodemographic and clinical characteristics of patients. Botucatu (SP), Brazil. 2023. (n=71).

Variables	n	%
Sex		
Female	41	57.7
Age + SD (years)	56.3 ± 15.8	
Previous neurological surgery		
No	56	78.8
Type of surgery		
Elective	36	50.8
Urgent	20	28.1
Emergency	15	21.1
Medical diagnosis category		
Tumor	28	39.5
Trauma	15	21.1
Hydrodynamics	14	19.7
Vascular	9	12.6
Infection and others	5	7.1
Postoperative hospitalization time (days)	10.7 ± 10.8	

> *Stroke, which left her debilitated, because of it she became incapacitated.* (C69) HL 2.1

As for the care needs related to the reason for hospitalization, the discourses seemed more related to the main problem, which is identified as the event that led to the patient's current condition. In their statements, caregivers identified the problem in a cause-and-effect manner, i.e., the event led to the diagnosis that was reflected in the intervention. These individuals, whom caregivers related the main problem to the event, had a history of falls and head impacts that led to neurological repercussions and the need for surgical intervention, as evidenced in the following transcripts:

> *She hit her head.* (C13) HL 2.8
>
> *The main problem is the accident. He fell, hit his head, and had to have a drain put in. He came to the neuro ICU, underwent surgery, and is now undergoing treatment to see if he improves [...]* (C33) HL 2.8
>
> *My father had to have surgery on his head because of an accident [...]* (C47) HL 3.0
>
> *[...] she stumbled, fell, and hit her head.* (C51) HL 2.6
>
> *She fell and hit her head, forming a clot.* (C53) HL 2.6
>
> *It's because he fell [...] and hit his head.* (C58) HL 2.3

Lastly, regarding the third aspect, identifying care needs related to the patient's signs and symptoms, caregivers ended up identifying the patient's main problem with their current needs. That is, they realized that their attention should be focused on postoperative care, as indicated in the following transcripts:

> *Her main problem is her current condition.* (C8) HL 2.6
>
> *I believe the problem regarding the surgery is cognitive. And, at the moment, her diet is very limited, as is her breathing [...]* (C12) HL 2.5
>
> *From now on, it's post-operative recovery.* (C22) HL 3.6
>
> *Now it's his neurological condition, his movements, his speech, everything. He can't eat or change his clothes.* (C68) HL 2.6

Regarding the second category: "Understanding and raising questions about the care to be provided," the second question was observed: "What should I do?" In this context focused on the caregiver's responsibility, three related aspects were highlighted: performing activities of daily living; monitoring and considering the care provided by health professionals; and identifying gaps in care.

Performing the patient's daily activities is one of the most common responses in caregivers' statements, whether assisting with feeding, performing physiological needs, or domestic tasks. It is understandable that much of the care provided by these caregivers stems from the importance they attach to the explanations and guidance given by professionals, often medical professionals, but generally healthcare professionals. It is in line with this understanding on the part of caregivers that they will show confidence in what they are going to do, as indicated in the transcripts below:

> *But I know a little, with the tube, with suctioning the tracheostomy, being careful on the stairs, and turning her from one side of the bed to the other.* (C16) HL 2.3
>
> *Whatever is possible. I help with bathing, feeding, and changing. I do basic care.* (C35) HL 2.8
>
> *Everything the doctor says: medication, correct treatment, feeding, hygiene, talking to her a lot, doing physical movements, and stretching to help her recovery.* (C41) HL 2.5
>
> *So, now [...] it's about being very careful with the tube, with his hygiene, and with the medication.* (C47) HL 3.0

With regard to monitoring, considering the care provided by health professionals, it is clear from the following statements that caregivers ended up transferring most of their responsibilities to health professionals. However, many are waiting for guidance from professionals to determine what they should do in relation to the patient's current condition. In short, these caregivers do not completely transfer their responsibilities to the healthcare team and services, but end up identifying these points as the

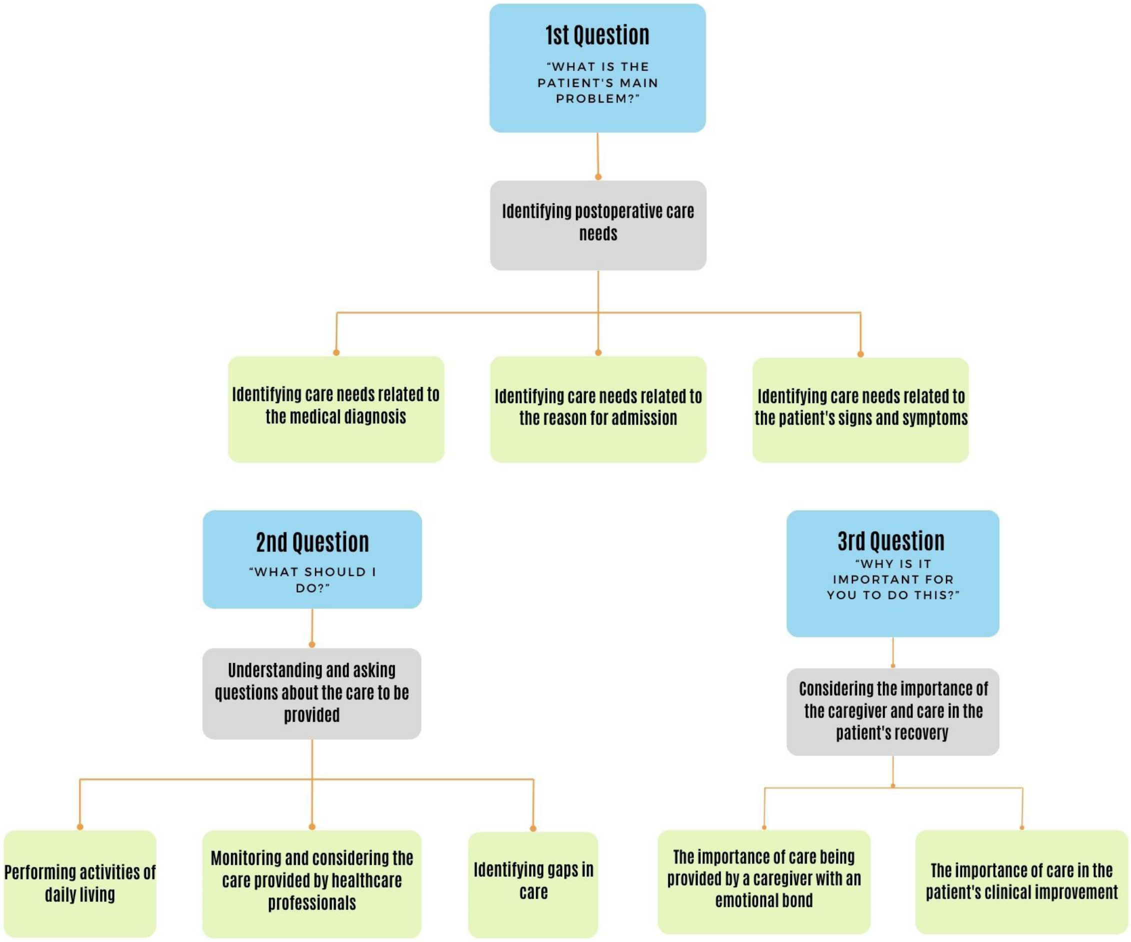

Figure 1. Categories and subcategories listed from Ask Me Three ®.

main ones in the actions that should be taken, as shown in the following transcripts:

> *Follow-up with doctors and physical therapy. I take him to all the doctors he has appointments with.* (C4) HL 2.1
>
> *Now we only know with the help of the hospital staff, right? Because we have never dealt with this situation before.* (C7) HL 2.3
>
> *The first thing is to see a doctor and get medical advice before doing anything.* (C18) HL 3.1
>
> *I will have to give full support and seek guidance from doctors*. (C33) HL 2.8
>
> *So, here the hospital provides everything you need, I'm not helping with anything.* (C58) HL 2.3

Finally, identifying gaps in care, some caregivers reported that they did not know what to do at home, suggesting that some aspects of postoperative care were unclear, which could compromise home care. However, they were willing to learn and use this missing knowledge, as transcribed below:

> *Not yet.* (C11) HL 2.6
>
> *After surgery? Not yet.* (C14) HL 2.3
>
> *I don't know. I don't know at the moment.* (C31) HL 2.0

Finally, the third category, "Considering the importance of the caregiver and care in the patient's recovery," reflected the last question: "Why is it important for you to do this?" In this context, it brought up two related aspects: the importance of care being provided by a caregiver with an emotional bond and the importance of care in the patient's clinical improvement.

Regarding the importance of care being provided by a caregiver with an emotional bond when affirming the importance of providing care, many caregivers refer to the fact that the care is for a member of their family, whether by blood or marriage. When observing the statements, one can see what is most significant for these caregivers, that is, the relationship they have with the individual, which highlights the importance of their care. In addition to family relationships, this importance due to the emotional bond also fits into other contexts, such as friendship, as presented below:

> *Because she is my wife and I cannot abandon her at a time like this.* (C7) HL 2.3
>
> *Firstly, because he is my brother and someone has to look after him, has to take care of him.* (C12) HL 2.5
>
> *It's important. Rewarding. I'm her husband. It's an honor for me, and I take care of her with love.* (C46) HL 2.5
>
> *Because we have a bond, we're cousins. She's family, and we're going to help her.* (C49) HL 2.6
>
> *Yes, very important, because our friendship transcends feelings*. (C50) HL 2.6

The importance related to clinical improvement arose from statements that expressed the desire to provide care focused on the significant results that such care would bring to individuals. These caregivers associate the importance of their care with an improvement in the patient's current condition, highlighting how their attention and care can positively influence both the patient's physical health and emotional balance. This perception indicates an understanding that home care has a direct impact on the patient's health outcomes, which is a positive sign of involvement and understanding of the importance of the therapeutic process, as indicated in the following transcripts:

> *So that she can recover faster, live a healthy life, and get back to her activities.* (C41) HL 2.5
>
> *So that he remains healthy and continues to recover from his stroke.* (C48) HL 3.3
>
> *So that he can recover faster.* (C53) HL 2.6
>
> *For his recovery and well-being.* (C60) HL 4.0

DISCUSSION

The highlight of this study is the identification of the HL level of caregivers of patients undergoing neurosurgery, revealing that 67.5% (n = 48) had problematic or inadequate HL. This condition can compromise the understanding of health information provided by health professionals, resulting in losses both in the quality of care provided to the patient and in the adequate use of health support services, which are essential in the postoperative period. Complementing these findings, and considering the perspectives of caregivers, it is observed that critical HL,[15] in which active interaction between the person and their environment is expected, was not identified. Thus, the role of nurses is essential in the transition of care, acting as a facilitator for caregivers to better understand the patient's health conditions and make decisions in postoperative care.

The low level of HL among caregivers identified in this study was higher than the prevalence found in a systematic review and meta-analysis that analyzed 51 studies covering 22,139 surgical patients. Among the 40 quantitative studies, the estimated prevalence of limited HL was 31.7% (95% CI 24.7–39.2%). A possible explanation for this difference is the fact that 70% of the studies were conducted in the United States of America,[8] while none included populations from Latin America and the Caribbean or neurosurgical patients, which could better represent the profile of the participants studied.

In the context of pediatric surgery, although caregivers did not report information overload, they pointed out a lack of guidance on postoperative recovery.[23] A cross-sectional study conducted in Iran, including 259 dyads, revealed that there was no correlation between caregivers' HL and patient adherence to treatment. However, there was an association between being an older caregiver and greater patient adherence, while more time spent on daily care correlated with lower treatment adherence.[24]

Low HL was also identified in non-surgical contexts. In a study conducted in Turkey with 140 informal caregivers of home care patients, HL was significantly associated with education, employment status, and perceived income, with education being the only predictor in the regression. [25] Such socioeconomic factors limited effective performance at home, and the authors recommended that educational interventions targeting caregivers may be effective in strengthening their ability to understand and apply health information in the home setting.[25]

Although this study did not evaluate the impact of HL on postoperative patient outcomes, the importance of analyzing these data is recognized. English et al.[6] showed that low HL is a determining factor for worse surgical outcomes, being associated with higher complication rates, prolonged hospital stays, and high costs. The identification of vulnerable groups, such as the elderly, individuals with low levels of education, and black populations, reinforces the need for targeted interventions. Considering that HL is a modifiable variable, multi-level strategies, such as more accessible communication, the use of visual educational materials, and improvements in the navigability of services, are fundamental to reducing disparities and improving surgical care.[6] In addition, to achieve better HL levels, public health systems must invest in ways of learning and teaching about health to improve service delivery and outcomes.[26]

Identifying the HL level of patients and caregivers provides an opportunity to improve care indicators and health service management. In a study involving 1,239 participants, Wright et al.[27] reported that patients with limited HL had, on average, one additional day of hospitalization after gastric, colorectal, hepatic, or pancreatic surgery.[27] Other findings indicated that reduced HL levels are related to an increased occurrence of minor complications after radical cystectomy,[28] as well as a higher risk of readmission after elective surgeries in a veteran population.[29] Furthermore, insufficient HL was associated with an increased chance of postoperative complications in colorectal surgeries, especially surgical site infections. On the other hand, the authors did not observe a higher frequency of readmissions or an increase in hospital stays among patients with limited HL.[30] One hypothesis for these results would be the implementation of enhanced recovery protocols in the institution, which have already demonstrated efficacy in reducing inequalities in length of stay[31] and readmission rates.[32] Such protocols, by valuing the standardization of educational guidelines, may represent initial strategies for HL care, although the findings still indicate the need for advances in this area.[30]

Complementing the quantitative data, qualitative analysis, guided by Nutbeam's model,15 allowed us to identify manifestations of HL levels among caregivers. Functional HL was observed in reports in which participants demonstrated an understanding of basic guidelines and performed care activities such as hygiene and feeding. Communicative/interactive HL emerged as caregivers reported applying the guidelines received from professionals in everyday situations, albeit with some dependence on validation by the health team. However, the statements indicated that caregivers did not seem to develop critical HL, which can negatively impact decision-making and the quality of home care.

Reinforcing this perspective, the category "Identifying postoperative care needs" indicated that caregivers recognize the patient's postoperative needs, mainly focusing on the medical diagnosis and the event that led to hospitalization, while reporting less attention to specific postoperative care demands. In addition, many caregivers reported insecurity regarding home care and valued the care provided based on emotional bonds and the expectation of contributing to the patient's recovery. These findings corroborate qualitative research in the context of cardiac surgery, which showed that caregivers' knowledge is linked to the medical diagnosis and causes of the patient's main problem.[33] The authors considered that this understanding helps to contextualize the disease in the life history of patients and family members and allows caregivers to reframe experiences of illness based on expectations of recovery or worsening.[33]

Through the category: "Understanding and presenting questions about the care to be provided," the importance of nurses in implementing educational strategies that promote HL among families and contribute to functional recovery in the postoperative period is recognized.[34] Some researchers have pointed out that neurosurgery patients and caregivers need more information about their responsibilities,[7,35] and have questions about the postoperative period due to ineffective HL methods, such as complex educational materials and low-quality videos.[7]

In a scoping review including 12 studies on the HL of adult caregivers and its relationship with health outcomes, it was highlighted that, in addition to identifying the level of HL, it is necessary to carry out targeted interventions to improve the HL of caregivers, aiming to improve outcomes for both caregivers and patients receiving care.[36] Strategies such as multimodal audiovisual interventions, e-books, three-dimensional models, and virtual reality are possibilities for improving HL.[7]

Although the beneficial aspects of care are less explored in research, the reports of the interviewees indicated that the act of caring plays a fundamental role in the patient's recovery and is significant for the caregiver. The subjective experience of caregivers, which shapes the importance of caregiving, is marked by a range of emotions ranging from satisfaction and pride to frustration and exhaustion,[37] and influences both their well-being and the effectiveness of the care provided.[38] Recognizing these dimensions is essential for developing interventions that offer support, such as mental health services and support groups, helping them to cope with stress, overcome physical, emotional, and social barriers, and ensure a better quality of life for themselves and those they care for.[39]

Finally, when conducting guiding questions based on the Ask Me Three® tool, it is considered that it can contribute to increasing patients' HL levels, facilitating the preparation of families in the transition from hospital care to home care. The use of Ask Me Three® signaled the important role that the tool can play in care, in addition to being a quick-to-apply tool. Through the informal caregivers' questions about the patients' health conditions, a window of opportunity opens for providing guidance that can increase these caregivers' HL levels. It should be noted that this tool was designed as a powerful vehicle for patient empowerment, by making them an active part of their health-disease process and understanding their diagnosis and treatment.[21-22] Reverse use, with professionals questioning patients, has proven effective in the educational process, broadening understanding of the medical condition and therapeutic plan, as well as improving satisfaction with communication between patients and health professionals.[22] In a review conducted to identify best practices for improving patient engagement by increasing HL levels, of the five tools evaluated, Ask Me Three® stood out for increasing interaction between the professional and the patient, reducing patient anxiety, and increasing their understanding of their condition.[21] However, its application in research in Brazil has not been identified and should be further studied.

The limitations of this study include the sample size, which may not represent all informal caregivers, and the narrow focus on neurosurgical patients, compromising generalizability. The subjectivity of the responses may have been influenced by emotional or cognitive factors, and the absence of feedback from participants may have impacted the reliability of the results. In addition, the brevity of the interviews limited the depth of the reports, and the qualitative structure restricted the exploration of other dimensions of HL, making it difficult to follow up on spontaneous statements by participants. Also, Ask Me Three® may not cover all variations of HL. It is recommended that multicenter studies be conducted that include caregivers at different stages of the perioperative period, as well as the investigation of specific instruments for assessing caregivers' HL.

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

Most caregivers (44, 61.9%) presented HL which was likely problematic. Caregivers showed understanding of the patients' disease or condition designation, in addition to being able to organize the events that led patients to their current circumstances. They also showed engagement in seeking information from the healthcare team and making essential decisions for postoperative care, identifying its importance in the clinical recovery of patients. However, from the analysis of the participants' statements, it can be inferred that the caregivers did not present critical HL.

These results reinforce the importance of considering HL as an essential component in hospital discharge planning and continuity of care, especially in complex scenarios such as neurosurgery. Furthermore, the fundamental role of informal caregivers in continuity of care. In this sense, we suggest using the Ask Me Three® tool, adapting it to the specific circumstances of caregivers, and integrating it effectively into health education and communication processes.

The category: "Understanding and asking questions about the care to be provided" signals the need for new accessible educational technologies that can contribute to the HL of caregivers and patients. Future research can evaluate specific educational programs aimed at the surgical context, assessing their impact on understanding health guidelines, qualifying the transition of care to the home, and reducing post-discharge complications. Thus, the importance of further exploring the topic in different contexts is reinforced, encouraging new approaches that broaden the applicability of the findings and contribute to improving patient care and safety.

The findings of this study pointed to the need to incorporate HL assessment as a formal step in the hospital discharge process, allowing early identification of limitations that may compromise the continuity and safety of home care. In this context, it is important to structure accessible educational interventions, using clear, objective language that is compatible with the caregivers' level of education, with an emphasis on verbal communication and the use of visual aids when necessary.

In addition, it is essential that health professionals are properly trained in HL practices, both in initial training and through continuing education actions, with a focus on caregiver- and patient-centered communication. It is also recommended to strengthen post-discharge planning and follow-up, with special attention to the first days of care transition, using strategies such as telenursing to clarify doubts and prevent complications. Finally, it is important to recognize and value the emotional bond as a therapeutic resource that enhances adherence to care and promotes patient recovery.

In the field of education, this study reinforces the importance of including HL in the training curriculum of healthcare professionals to enable them to use tools such as Ask Me Three® to improve communication between professionals and patients and/or caregivers. In healthcare, it highlights the fundamental role of adapting communication approaches to each reality, that is, to the specific needs of caregivers, promoting empowerment so that, consequently, patients' postoperative outcomes are more favorable.

Finally, promoting strategies that favor HL is fundamental to achieving the goals of Sustainable Development Goal (SDG) 3 "Good Health and Well-Being,"[40] which aims to ensure healthy lives and promote well-being for all, including informal caregivers.

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DATA AVAILABILITY RESEARCH

Data will be available upon request to authors.

CONFLICT OF INTEREST

No conflict of interest.

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