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Original article

Health literacy and self-management of patients in care transition

Letramento em saúde e autogerenciamento de pacientes em transição de cuidados

Alfabetización en salud y autogestión de pacientes en transición de cuidados

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Abstract

Objective: To assess the health literacy and willingness to self-manage of patients in transition of care. **Method**: a cross-sectional, analytical study carried out between January and October 2024 with adults scheduled for hospital discharge. The data were collected in a high-complexity hospital, using instruments for sociodemographic characterization, assessment of health literacy *(Health Literacy Scale*), and measurement of willingness to self-manage*(Patient Activation Measure* - 22). The analysis was based on descriptive statistics. **Results**: 39 individuals participated, with an average age of 49.5 years (±17.37), predominantly men, and a high proportion had a complete high school education. The participants also reported the presence of caregivers, comorbidities, and a history of continuous medication use. It was observed that 56.4% had high health literacy, and 84.6% were more likely to engage in self-management. **Conclusion**: The results indicate moderate health literacy and a high willingness to self-manage, which favors safer decisions, better clinical outcomes, and continuity of care at home.

Descriptors: Nursing; Patient Discharge; Transitional Care; Health Literacy; Self Care

Resumo

Objetivo: avaliar o letramento em saúde e a disposição para o autogerenciamento de pacientes em transição de cuidados. **Método:** estudo transversal e analítico, desenvolvido entre janeiro e outubro de 2024, com adultos em programação de alta hospitalar. A coleta ocorreu em hospital de alta complexidade, por meio de instrumentos para caracterização sociodemográfica, avaliação do letramento em saúde (*Health Literacy Scale*) e mensuração da disposição para o autogerenciamento (*Patient Activation Measure* - 22). A análise baseou-se em estatística descritiva. **Resultados:** participaram 39 indivíduos, com idade média de 49,5 anos (±17,37), majoritariamente homens, com ensino médio completo, presença de cuidadores, comorbidades e uso contínuo de medicamentos. Observou-se que 56,4% apresentaram letramento em saúde elevado e 84,6% maior predisposição para o autogerenciamento. **Conclusão:** os resultados evidenciam moderado letramento em saúde e alta disposição para o autogerenciamento, favorecendo decisões mais seguras, melhores resultados clínicos e continuidade do cuidado no domicílio.

Descritores: Enfermagem; Alta do Paciente; Cuidado Transicional; Letramento em Saúde; Autocuidado

Resumen

Objetivo: evaluar la alfabetización en salud y la disposición para el autocontrol de los pacientes en transición de cuidados. **Método**: estudio transversal y analítico, desarrollado entre enero y octubre de 2024, con adultos en proceso de alta hospitalaria. La recopilación de datos se realizó en un hospital de alta complejidad, mediante instrumentos para la caracterización sociodemográfica, la evaluación de la alfabetización en salud (Escala de Alfabetización en Salud) y la medición de la disposición para el autocuidado (Medida de Activación del Paciente - 22). El análisis se basó en estadísticas descriptivas. **Resultados**: participaron 39 individuos, con una edad media de 49,5 años (±17,37), en su mayoría hombres, con estudios secundarios completos, presencia de cuidadores, comorbilidades y uso continuo de medicamentos. Se observó que el 56,4 % presentaba un alto nivel de alfabetización en salud y el 84,6 % una mayor predisposición al autocontrol. **Conclusión**: los resultados evidencian una alfabetización en salud moderada y una alta disposición al autocontrol, lo que favorece decisiones más seguras, mejores resultados clínicos y la continuidad de la atención en el domicilio.
Descriptores: Enfermería; Alta del Paciente; Cuidado de Transición; Alfabetización en Salud; Autocuidado

Introduction

Transition of care refers to an articulated set of actions and strategies aimed at ensuring the safe and effective monitoring of patients between different points in the Healthcare Network, especially at the time of hospital discharge and return to the home environment.[1] This practice involves structured communication between health professionals, adequate discharge planning, and preparing patients and their families for the continuity of treatment, to prevent complications and avoid unnecessary readmissions.[2]

The absence of a well-structured transition of care can lead to numerous problems, including early hospital readmissions, which represent not only a crucial indicator of care discontinuity but also a significant financial and social burden.[3-4] Such readmissions harm the sustainability of the health system and exacerbate the vulnerability of patients and their families, generating feelings of insecurity, emotional stress, and anxiety about the continuity of care, with direct implications for their psychosocial well-being.[5]

Effective continuity of care only occurs when the different levels of health care are connected and act interdependently. This articulation fosters the connection between users and services, provides the necessary support for treatment adherence,

and contributes to enhancing patient autonomy.[3-4] In this sense, care transition interventions are fundamental strategies for minimizing care gaps and ensuring comprehensive healthcare.

In this context, high hospital readmission rates stand out as a relevant indicator of failures in continuity of care, often associated with factors such as ineffective discharge plans, adverse effects of medication, difficulties in accessing Primary Health Care, and low adherence to treatment.[6-7] Among the main tools for mitigating these risks, care transition actions stand out, especially those centered on health education, with a focus on preparing for hospital discharge.[7] These interventions aim to facilitate adaptation to the home, anticipating and preventing post-discharge complications. To be effective, they must consider the needs and learning capacities of the patient and family, which are assessed during hospitalization.[8-9]

This scenario becomes more challenging when it involves patients with complex health needs. The literature defines health complexity as the gap between an individual's health needs and the capacity of health services to meet them in a resolutive way.[10] These individuals often have multiple comorbidities and chronic conditions associated with social and psychological determinants, which makes clinical management more challenging and requires more interventions. In this sense, hospital discharge is a highly vulnerable moment, requiring the patient and their support network to be prepared for the continuity of the therapeutic plan.[10]

To ensure the effectiveness of this process, it is crucial to assess the health literacy (HL) of patients and their families.[11] HL refers to the ability of individuals to access, understand, process, and apply health-related information appropriately, thereby promoting self-care and informed decision-making.[12-13] This competence is influenced by factors such as schooling, income, self-perception of social belonging, and health-related behaviors.[14]

Patients with low HL tend to have difficulties in understanding the diagnosis, reading leaflets and prescriptions, following the therapeutic regimen, and identifying warning signs, increasing the risk of readmissions.[12] Thus, knowing the level of HL of patients allows the implementation of individualized educational strategies, with the potential to improve treatment adherence, reduce readmissions, and promote better

clinical outcomes.[15-16] The multidimensional nature of literacy allows individuals to understand their health condition and actively participate in their care.[15-16]

In addition to HL, the importance of self-management, which involves the knowledge, motivation, and behavioral skills necessary to manage one's own health condition, should be emphasized. Self-management of health is an ongoing process in which the patient takes active responsibility for their health and is a decisive factor in controlling the disease and preventing complications.[17]

Thus, the objective of this study is to assess the health literacy and willingness of patients to self-manage during care transitions.

Method

This was a cross-sectional, analytical study using a non-probabilistic sample, conducted from January to October 2024, at Hospital São Paulo, an institution affiliated with the Federal University of São Paulo (UNIFESP). The quaternary-level hospital serves as a reference in high-complexity care, with 750 beds. It covers an area with more than five million inhabitants and receives patients from other states in the country.[18]

A total of 132 patients were chosen for the study. Of these, 93 were excluded due to inconsistencies in the variables of interest, including those who were unable to answer the questionnaires or understand the instructions provided, and could not be contacted by telephone, or refused to sign the Informed Consent Form. The final sample consisted of 39 adults who were scheduled for discharge from the hospital and required complex care at home. Of the patients included, six dropped out of the sample because they didn't respond to attempts to contact them by telephone or because they requested to withdraw from the study.

Data collection took place through the records of the Care Transition Project (PROTRAC), which provides individualized discharge guidance, at the request of the care team, to patients admitted to the São Paulo Hospital with complex needs (functional limitations, inability to communicate, move around, or care for themselves effectively without help) in home care, as well as telephone follow-up after discharge.

The monitoring carried out by PROTRAC consists of a set of structured interventions within the context of hospital discharge planning, aimed at training

patients and caregivers for continuity of care at home. Inclusion in the program is based on a request from the medical or nursing team, followed by assessment and monitoring by the project team.

The interventions are individualized and multimodal, comprising verbal guidance, the provision of printed educational materials, and practical demonstrations of care, all adapted to the specific needs and conditions of each patient. Post-discharge follow-up includes scheduled telephone contacts on days 2, 7, 15, and 30, lasting an average of ten minutes, aimed at identifying demands, often related to the educational intervention, the list of medications and their adverse effects, and the importance of including the patient in the primary and outpatient care networks.

For data collection, three instruments were used to characterize the participants, assess HL, and measure predisposition to self-care and understanding of their own health conditions.

The variables collected were through a structured questionnaire with the following variables: sociodemographic (age, gender, schooling, whether the patient lives alone, whether they are responsible for their own care, and average income); clinical (presence of comorbidities, use of continuous medication, diagnosis on admission, and the patient's condition at the time of discharge); and discharge (days of hospitalization, guidance provided, whether the patient died after discharge, whether there was readmission, and the outcome of the readmissions).

The second instrument applied was the *Health Literacy Scale*, a validated eight-question survey designed for the Brazilian population, which was used to assess patients' understanding of health information. The answers use a *Likert-type* scale, with a variation of four or five points, and the answer options are: very badly, badly, moderately, well, very well; totally disagree, disagree, agree, totally agree; and, never, rarely, occasionally, often, and always. The total score is calculated by adding up the scores for each item and can range from 0 to 37 points. Thus, the higher the score, the higher the HL, with 0 to 12 points being considered low HL; 12 to 24 points, moderate HL; and above 24 points, high HL. In addition, the mean and standard deviation were calculated for each item.[19]

Finally, the *Patient Activation Measure - 22* (PAM-22) was used to assess patients' predisposition to self-management and understanding of issues related to their own health. The instrument consists of 22 items, and each answer is given a score: totally disagree, 1 point; disagree, 2 points; agree, 3 points; totally agree, 4 points; and not applicable, 0 points. The raw score, obtained by adding up the scores, can vary from 22 to 88 points. The values obtained from the raw score must be converted into an activation score, ranging from 0 to 100 points. The total score can be categorized into four levels: level 1, below 47 points; level 2, from 47 to 55 points; level 3, from 55 to 67; and level 4, equal to or above 67 points. Levels 3 and 4 represent greater activation; the higher the score, the greater the predisposition to care.[16-20]

To minimize possible biases, data collection was conducted by a nurse who had been previously trained in the research instruments and objectives, as well as by nurses with extensive clinical experience dedicated to research and the practice of care transitions. The data was organized in Excel® spreadsheets. For continuous variables, the mean, standard deviation (SD), median, and minimum and maximum values were calculated. For categorical data, absolute and relative frequencies were determined. The comparison between the outcomes (readmission and death within 30 days) and the variables of interest was carried out using the Chi-Square test, using Fisher's Exact test or the Likelihood Ratio when necessary. The significance level adopted was 5% ($p < 0.05$).

This study followed the ethical precepts that comply with Resolutions 466/2012, 510/2016, and 580/2018 of the Ministry of Health, and began after approval by the UNIFESP Research Ethics Committee, under opinion no. 6.669.606 and CAAE no. 76354523.0.0000.5505.

Results

The study included 39 patients, with a mean age of 49.5 years (±17.37), 56.4% (n=22) of whom were male, and 35.9% (n=14) had completed high school. 89.8% (n=35) of the patients lived with their partner, and 51.3% (n=20) had a caregiver, with 48.7% (n=19) having a monthly income of between one and three minimum wages (Table 1).

Table 1 - Sociodemographic characterization of patients in transition care from hospital to home. São Paulo/ SP 2024 (n=39)

Variables	N = 39 (%)
Age	
Mean (± Standard Deviation)	49.5 (±17.37)
Gender	
Female	17 (43.6)
Male	22 (56.4)
Education	
Incomplete fundamental education	9 (23.0)
Completed elementary school	8 (20.5)
Incomplete High school	4 (10.3)
Completed high school	14 (35.9)
Incomplete higher education	1 (2.6)
Completed higher education	2 (5.1)
Postgraduate studies	1 (2.6)
Patient lives alone	
Yes	2 (5.1)
No	35 (89.8)
No information	2 (5.1)
Patients are responsible for their own care.	
Yes	17 (43.6)
No	20 (51.3)
No information	2 (5.1)
Monthly income (minimum wage*)	
Less than 1	6 (16.1)
1 to 3	19 (48.7)
4 to 6	5 (12.2)
No information	9 (23)

* Value of the minimum wage in 2024: R$1,412.00

Regarding clinical variables, 61.5% (n=24) of the patients had comorbidities, and 74.4% (n=29) had a clinical diagnosis on admission. In addition, 76.9% (n=30) of the individuals used continuous use medication (MUC, in Portuguese), with 41% (n=16) using

four or more medications, characterizing polypharmacy. When comparing hospitalization and discharge, 82% (n = 32) of the patients experienced an improved state of health (Table 2).

Table 2 - Clinical profile of patients in transition from hospital to home. São Paulo/SP, 2024 (n=39)

Variables	N = 39 (%)
Comorbidities	
Yes	24 (61.5)
No	15 (38.5)
Number of comorbidities	
From 0 to 1	26 (66.7)
From 2 to 3	9 (23.0)
More than 3	4 (10.3)
MUC *	
Yes	30 (76.9)
No	7 (18.0)
No information	2 (5.1)
Number of MUC*	
From 0 to 1	10 (25.6)
From 2 to 3	11 (28.3)
4 or more	16 (41.0)
No information	2 (5.1)
Admission diagnosis	
Clinical	29 (74.4)
Surgical	10 (25.6)
Patient's condition at the time of discharge	
Improved	32 (82)
Maintained	4 (10.3)
Worsened	3 (7.7)

*MUC: medications for continuous use

The average length of stay was 26.5 days, and after discharge, one patient died. There were five readmissions (two due to urinary tract infection, one due to cognitive impairment and inappetence, one for device removal, and one unspecified), of which four patients were

discharged, and one died. Finally, 15.4% (n = 6) of the patients were disconnected, either because they didn't answer the calls or because they requested the contact to be terminated .

In terms of health literacy, none of the participants had a low level; 43.6% (n = 17) showed moderate literacy, and 56.4% (n = 19) demonstrated high literacy. The results indicate that the patients had an intermediate understanding of the instructions contained in drug leaflets and printed educational materials. They also recognized that they knew where to look for information, both in situations of illness and when adopting health promotion practices. In the social sphere, they reported occasional ability to advise family and friends or to receive advice on health issues. Finally, they were confident in selecting the most appropriate recommendations and discerning the quality of information available on the internet, demonstrating, in general, skills that favor autonomous care management (Table 3).

Table 3 - Survey of responses to the Health Literacy Scale in patients transitioning from hospital to home. São Paulo/SP, 2024 (n=39)

Questionnaire item	Mean (± Standard Deviation)
How much do you understand the instructions on medicine leaflets?	2.58 (±1.99)
How much do you understand about health information in leaflets?	3.25 (±1.66)
When I have questions about illnesses or complaints, do I know where I can find this information?	3.2 (±0.83)
When I want to do something for my health without getting sick, I know where to find this information.	3.23 (±0.85)
How often have you been able to help family members or a friend if they have questions about health problems?	3.1 (±1.63)
When you had questions about health problems and issues, how often were you able to get advice and information from other people (family and friends)?	3.21 (±1.45)
How do you think you know how to choose the advice and recommendations that are best for your health?	3.79 (±1.26)
When it comes to health information on the Internet, I'm able to determine which sources are of high or low quality.	2.71 (±1.14)

Regarding the PAM-22, the average of the answers to the 22 items indicated that patients generally agreed with the questions on the questionnaire (Table 4). The total activation score showed that 7.7% (n=3) of patients are at level 1, another 7.7% (n=3) of

patients are at level 2, 30.8% (n=12) of patients are at level 3, and 53.8% (n=21) of patients are at level 4. As levels 3 and 4 represent greater activation, 84.6% (n = 33) of the patients in this study demonstrated greater activation in self-managing their health.

Table 4 - Analysis of the results of the Patient Activation Measure-22 in patients in hospital transitional care. São Paulo/SP, 2024 (n=39)

Question	Interval obtained	Median	Mean	Standard deviation
At the end of the day, are you the person responsible for looking after your health?	1-4	3.0	2.77	1.25
Is your active participation in your health care the most important thing that influences your health?	1-4	4.0	3.41	0.72
Do you know what each of the drugs you've been prescribed is for?	1-4	4.0	3.15	1.04
Do you feel confident that you can tell your health professional about your concerns, even when they don't ask?	2-4	4.0	3.38	0.81
Are you confident that you know when you need to go to the doctor or health service, or that you can take care of a health problem yourself?	1-4	3.0	3.10	1.02
Do you know what lifestyle changes, such as diet and exercise, are recommended for your health?	2-4	4.0	3.46	0.82
Are you confident that you can follow the health treatments you need to do at home?	2-4	4.0	3.36	0.90
Do you have confidence that you can find reliable information about your health condition and the choices you can make about your health?	1-4	4.0	3.41	0.72
Do you have confidence that you can find reliable information about your health condition and the choices you can make about your health?	1-4	3.0	3.08	1.01
Are you confident that you can follow the recommendations made by your healthcare professional, such as changing your diet or exercising regularly?	2-4	3.0	3.15	0.87
Do you understand your health issues and their underlying causes?	2-4	3.0	3.23	0.84
Do you know what treatments are available for your health problems?	1-4	3.0	3.15	0.74
Have you been able to maintain lifestyle changes, such as eating properly or exercising?	1-4	3.0	2.74	0.91
Do you know how to prevent health problems?	1-4	3.0	2.87	1.15
Do you know about the treatments you can do for your health?	1-4	3.0	2.74	1.09

Have you made lifestyle changes, such as adjusting your diet and exercising, that were recommended for your health?	1-4	3.0	2.74	1.07
Are you confident that you can find solutions when new health problems arise?	2-4	3.0	2.95	0.92
Can you manage your health symptoms at home?	2-4	3.0	3.03	1.11
Are you confident that you can maintain lifestyle changes, such as eating correctly and exercising, even during times of stress (unfavorable situations)?	1-4	3.0	2.64	1.20
Can you deal with your health problems at home?	2-4	3.0	2.95	1.07
Are you confident that you can prevent your health problems from interfering with the things you want to do?	1-4	3.0	2.67	0.96
How difficult is it for you to maintain the lifestyle changes that are recommended for your health daily?	1-4	3.0	2.72	1.17
Gross score	43-84	68	66.72	10.4
Total Activation Score	32-94	70	67.69	15.65

Discussion

The results of this study indicated that the participants had, on average, a moderate level of HL, accompanied by greater activation of self-management of health, as measured by the PAM-22 scale. This combination indicated that individuals could identify the causes of illnesses, understand clinical guidelines, correctly administer medication, and implement lifestyle changes. As a result of this profile, there was a reduced rate of hospital readmission within 30 days of discharge, even among patients with more complex health conditions, reinforcing the relevance of HL and the activation of self-management of health for the effectiveness of the transition from hospital to home.

The detailed analysis of the HL indicated that many participants responded positively to the items assessed, showing functional and interactive skills that are essential for self-management of health. Previous studies have corroborated this relationship, pointing out that higher levels of HL are associated with greater therapeutic adherence and a lower incidence of adverse events.[14-21] In addition, research carried out in Belgium has shown that individuals with low SL use specialized services

more frequently and have worse clinical outcomes,[21] which reinforces the relationship between HL and patient autonomy, especially in the context of continuity of care after hospital discharge, quality of life, and unplanned hospital readmissions. [22-23]

In this study, the majority of participants had completed high school, an aspect that, as shown in the literature, has a positive influence on understanding and applying health information.[12-20] A cross-sectional study carried out in Italy with 452 participants reinforces this association by showing that higher educational levels favor the effective use of knowledge in self-management, promoting continuity of treatment, improved quality of life, and a reduction in unplanned hospitalizations.[24]

It was also observed that the average age of the participants was 49.5 years, an age group considered productive, which may contribute to the favorable HL scores observed. Evidence shows that HL tends to decline with age, due to reduced cognitive capacity and less familiarity with technical vocabulary related to health.[25-26] A study conducted in Europe confirms this trend, indicating that elderly individuals, regardless of gender, have lower levels of HL, which are associated with higher risks of complications and hospital readmissions.[26]

Concerning the PAM-22, participants showed a higher level of activation for self-management, evidenced by their understanding of their own clinical conditions, knowledge about the use of medication, adherence to therapeutic recommendations, and ability to make health decisions. These results indicate not only assimilation of the guidance received but also a willingness to apply it in practice, which is essential for continuity of care after discharge. The literature argues that strategies such as a structured discharge plan, educational guidance, and post-discharge follow-up are associated with greater adherence to treatment, patient engagement, and a reduction in avoidable hospitalizations.[26-27] This evidence reinforces that the level of activation of self-management of health is not just about understanding information, but also about the ability to act in the home environment. This characteristic is decisive for the safe continuity of treatment. By strengthening this dimension, it is possible to increase patient engagement, improve their experience, and reduce their vulnerability after discharge.

However, it is necessary to recognize that structural, socio-economic, and contextual factors intrinsically condition the patient's capacity for action.[28] Placing the sole responsibility on the individual can obscure the need for more responsive health systems, capable of offering adequate support, accessible language, and support networks that encourage the effective exercise of self-care. Thus, strengthening the activation of self-management should be understood as co-responsibility between patients, professionals, and managers, in a person-centered care model committed to equity.[28]

Although this study offers relevant contributions, some limitations should be considered. The cross-sectional design renders it impossible to infer causal relationships between the variables analyzed, and the small sample size, drawn from a single public hospital, restricts the generalizability of the findings. Even so, the results broaden the understanding of SL and activation for self-management in patients with complex health needs, in the context of hospital transition. This area is still in its infancy in Brazil. The assessment of these variables enables nurses, working in multi-professional teams, to develop discharge plans that are tailored to the level of understanding and individual needs, thereby contributing to a reduction in unplanned hospital readmissions, the optimization of healthcare resources, and the strengthening of primary care.

Conclusion

The study indicates moderate HL and a greater willingness to self-management, which can contribute to making decisions that seek better health outcomes and continuity of home care. These findings broaden our understanding of the relationships between sociodemographic profile, clinical conditions, HL, and self-management capacity. By strengthening HL and encouraging self-management, it is possible to promote safe continuity of treatment at home, contributing to a reduction in avoidable hospital readmissions.

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