Review Article

Older adult transition from hospital to home from caregivers'/older adults' perspective: a scoping review

Transição do idoso do hospital para o domicílio na perspectiva do cuidador/idoso: revisão de escopo

Transición de adultos mayores del hospital al domicilio bajo la perspectiva del cuidador/adulto mayor: revisión de alcance

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Abstract

Objective: To map evidence that discusses transitional care aimed at older adults, from hospital to home, from caregivers'/older adults' perspective.

Methods: This is a scoping review, based on guidance from the Joanna Briggs Institute (JBI). The LILACS, PubMed, Web of Science, Scopus, CINAHL and Embase databases were included in the systematization to search for studies. Independent peer review was performed, selected according to criteria. Then, similarity analysis was performed in Iramuteq.

Results: The sample consisted of 8 studies, published mainly in 2016, predominantly in the United States. It is possible to observe that there was a greater number of difficulties and weaknesses, followed by challenges and, finally, potential in transition.

Conclusion: Older adult transition from hospital to home is a complex and longitudinal process, which involves multiple weaknesses and difficulties for patients and their formal and informal caregivers, as well as there are potentialities and challenges to be explored. The work overload, the effort and dedication required, as well as the relationship with family involvement.

Resumo

Objetivo: Mapear evidências que discutem o cuidado transicional direcionado à pessoa idosa, do contexto hospitalar para o domicílio, na perspectiva do cuidador/idoso.

Métodos: Revisão de escopo, tendo por base a orientação do Instituto Joanna Briggs (JBI). Foram incluídas na sistematização para busca dos estudos as bases LILACS, PubMed, Web of Science, Scopus, CINAHL e Embase. Realizou-se a revisão por pares independente, selecionada de acordo com os critérios. Em seguida, foi realizada análise de similitude no software Iramuteq.

Resultados: A amostra foi composta por 8 estudos, publicados principalmente no ano de 2016, tendo como local predominante os Estados Unidos. É possível observar que houve maior quantitativo de dificuldades e fragilidades, seguido de desafios e, por fim, potencialidades na transição.

Conclusão: A transição da alta hospitalar do idoso para casa é um processo complexo e longitudinal, que envolve múltiplas fragilidades e dificuldades para o paciente e para seus cuidadores formais e informais, assim como existem potencialidades e desafios a serem explorados. Destaca-se a sobrecarga de trabalho, o esforço e a dedicação exigida, bem como a relação com o envolvimento familiar.

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Conflicts of interest: nothing to declare.

Resumen

Objetivo: Mapear evidencias que discuten el cuidado transicional orientado al adulto mayor, del contexto hospitalario al domicilio, bajo la perspectiva del cuidador/adulto mayor.

Métodos: Revisión de alcance, basada en la orientación del Instituto Joanna Briggs (JBI). Se incluyeron las siguientes bases en la sistematización para la búsqueda de los estudios: LILACS, PubMed, Web of Science, Scopus, CINAHL y Embase. Se realizó la revisión por pares independiente, seleccionada de acuerdo con los criterios. Luego se realizó el análisis de similitud en el software Iramuteq.

Resultados: La muestra estuvo compuesta por ocho estudios, publicados principalmente en el año 2016, que tenían como lugar predominante los Estados Unidos. Es posible observar que hubo mayor cuantitativo de dificultades y debilidades, después desafíos y, por último, posibilidades en la transición.

Conclusión: La transición del alta hospitalaria de adultos mayores a su casa es un proceso complejo y longitudinal, que incluye múltiples debilidades y dificultades para el paciente y sus cuidadores formales e informales, así como también existen posibilidades y desafíos que pueden ser estudiados. Se destaca la sobrecarga de trabajo, el esfuerzo y la dedicación exigida, así como la relación con la participación familiar.

Introduction

As an example of integrality in health systems, we have care transition as a crucial part.[1] Transitional care is defined as a group of actions planned at the time when a patient changes their health situation or moves to different levels of care. It involves strategies such as discharge planning, advance care planning, complete communication of information, patient education, promotion of self-management, safety in the use of medications and post-discharge follow-up for outpatient consultations.[2]

The transition period from hospital to home is a challenge, as users find it difficult to manage care in the home environment, which often culminates in hospital readmissions. These entail greater costs to the health system and harm to patients, when they could have been avoided with an effective planning that minimized post-discharge complications.[3,4]

Parallel to this, hospitalization for older adults has repercussions on countless changes that affect their lives forever, whether physically or psychologically. At this point, the importance of stimulating activities, according to their degree of independence, becomes evident.[5] In a study with the objective of describing the experience of older adults and caregivers in the context of the transition from hospital to home, there was a consensus among all participants about the need for independence of care. For this, they felt safer with processes that helped caregivers and involved health professionals, with the transfer of information and discussion of care plan.[6]

A meta-synthesis study conducted in 2017, aiming at improving understanding of user experience and care integration during discharge and transitional care of older adults with multiple chronic diseases, concluded that it is essential to improve questioning and discussion strategies in relation to older adults and the independence of their caregivers in care transitions.[7]

To identify how transitional care occurs in a health system, it is necessary to identify, primarily, the needs found from caregivers'/older adults' perspective, as well as mapping the types of instruments that assess it, in order to stimulate investigations in this field, especially because a reduced number of national studies was identified in another review.[8] For this, we outlined the following guiding questions: what evidence discuss transitional care, from hospital to home, for older adults from caregivers' and older adults' perspective?

Considering the above, the objective of this scoping review was to map evidence that discusses transitional care aimed at older adults, from the hospital context to the home context, from caregivers' and older adults' perspective. Thus, this scoping review is justified, as it is carried out with the purpose of identifying evidence, analyzing knowledge gaps, clarifying the main concepts/definitions on how research is conducted, as well as listing the main characteristics related to the field.[9]

Methods

This is a scoping review of available literature, regarding aspects related to evaluative measures of transitional care for older adults in the hospital-home context from patients' perspective. The

scoping review aims to provide an overview of evidence as well as guide future research.[10]

To this end, the following steps were carried out: identify the research question; establish the inclusion criteria and aligned with the question and the objective; develop the search strategy; identify the relevant studies; select the studies; extract the data; map the data; and summarize the results obtained.[11] All steps were verified according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).[12]

To construct the research question, the conceptual model Population, Concept and Context (PCC) was used. They were defined as follows: P - older adults; C - transitional care from patients' and caregivers' perspective; C - from hospital to home.

There was no time cut, and all languages were included. Duplicate articles, studies that addressed transitional care in contexts other than hospital discharge, studies that did not answer any of the questions and review studies were excluded. Gray literature was not considered for inclusion.

The search strategy consisted of three steps: i) there was an initial search in PubMed and Web of Science using the descriptors found in the Medical Subject Headings (MeSH)– aged, aging, transitional care, patient discharge, continuity of patient care –, then an analysis of keywords contained in articles' title, abstract and descriptors was carried out, identifying the non-controlled descriptors – hospital care and discharge planning; ii) a second search was carried out using all the descriptors identified in the PubMed, Latin American and Caribbean Health Sciences Literature (LILACS), Web of Science, Scopus, CINAHL and Embase databases. As Boolean operators, we used AND and OR.

The following search keys were configured for their respective databases: in PubMed, 532 articles were found with "("aged"[MeSH Terms] OR "aged"[All Fields] OR ("aging"[MeSH Terms] OR "aging"[All Fields] OR "ageing"[All Fields])) AND ("transitional care"[MeSH Terms] OR ("transitional"[All Fields] AND "care"[All Fields]) OR "transitional care"[All Fields]) AND ("patient discharge"[All Fields] OR "hospital care"[All Fields] OR "continuity of patient care"[All Fields] OR "discharge planning"[All Fields])"; in LILACS, we found 6 articles with "((aged OR aging)) AND ("transitional care") AND (("patient discharge" OR "hospital care" OR "continuity of patient care" OR "discharge planning")) AND (db:("LILACS"))"; in Web of Science, we found 56 studies with "TS=(aged OR aging) AND TS=("transitional care") AND TS=("patient discharge" OR "hospital care" OR "continuity of patient care" OR "discharge planning")"; in Scopus, we found 629 articles with "(TITLE-ABS-KEY ((aged OR aging)) AND TITLE-ABS-KEY (("transitional AND care")) AND TITLE-ABS-KEY (("patient discharge" OR "hospital care" OR "continuity of patient care" OR "discharge planning")))"; in CINHAL, we found 414 studies with "(aged or aging) AND transitional care AND (patient discharge OR hospital care OR continuity of patient care OR discharge planning)"; and in Embase, we found 696 articles with "(aged OR aging) AND 'transitional care' AND ('hospital care' OR 'patient care' OR 'hospital discharge')".

To search for additional studies, searches were performed in the references of included articles. The process of retrieving information in the databases, as well as the last search, took place between June and July 2021.

A data extraction form was prepared with the main characteristics and important findings for the research of included articles, containing data such as author(s), year, title, objective(s), country of origin and study design. Two researchers worked independently for the selection of titles, abstract and full text. After assessing the complete versions of selected articles, according to inclusion and exclusion criteria, resulted in the final review sample. In each phase, there was a discussion between the two researchers in order to reach a consensus regarding the disparities. Then, we used Iramuteq for similarity analysis.

Results

From the analysis of the 1,214 identified studies, only 8 (100.0%) were on the theme, corresponding

to the final sample. Study selection was presented in the flowchart (Figure 1).

The sample consisted of eight manuscripts, developed in different regions and countries, with variability of the year of publication, however, there was a predominance of studies with a qualitative character. There were 06 quantitative studies, one of them with a longitudinal design, a quantitative epidemiological one and a mixed method.

As for the country of origin, in addition to the United States, with two works, we found an article for each location indicated below: Brazil, United States, Canada, Norway, Taiwan and Australia. Regarding the year of publication, with the oldest being in 2000, we had in the years 2012, 2015, 2019, 2020 and 2021 and two in 2016. [13-20]

Figure 2 demonstrates similarity analysis from the textual corpus of documents selected in the sample. It is possible to observe that the central nucleus consists of "transition", from which branches emerge with terms related to this transition, such as "process", "need" and "care".

It is also possible to observe that the terms presented at the end arising from the branch of the process concern the changes arising from the discharge of older adults, expressed by "role", "caregivers", "function", "demand", "adjustment". In the branch that emerges from the "need", it is possible to observe content related to the needs and concerns during the care transition, such as "information", "experience", "responsibility", "concern" and "communication". Finally, the "care" branch emerges content related to aspects of family and patient demands after discharge, represented by "family", "involvement", "discharge", "medication", "disease" and "recovery".

Thus, through the content of the documents and similarity analysis, chart 2 was prepared in order to categorize the data into weaknesses and difficulties encountered in the transition process, strengths and challenges. It is possible to observe that a greater number of difficulties and weaknesses was found, followed by challenges and, finally, potentialities in transition.

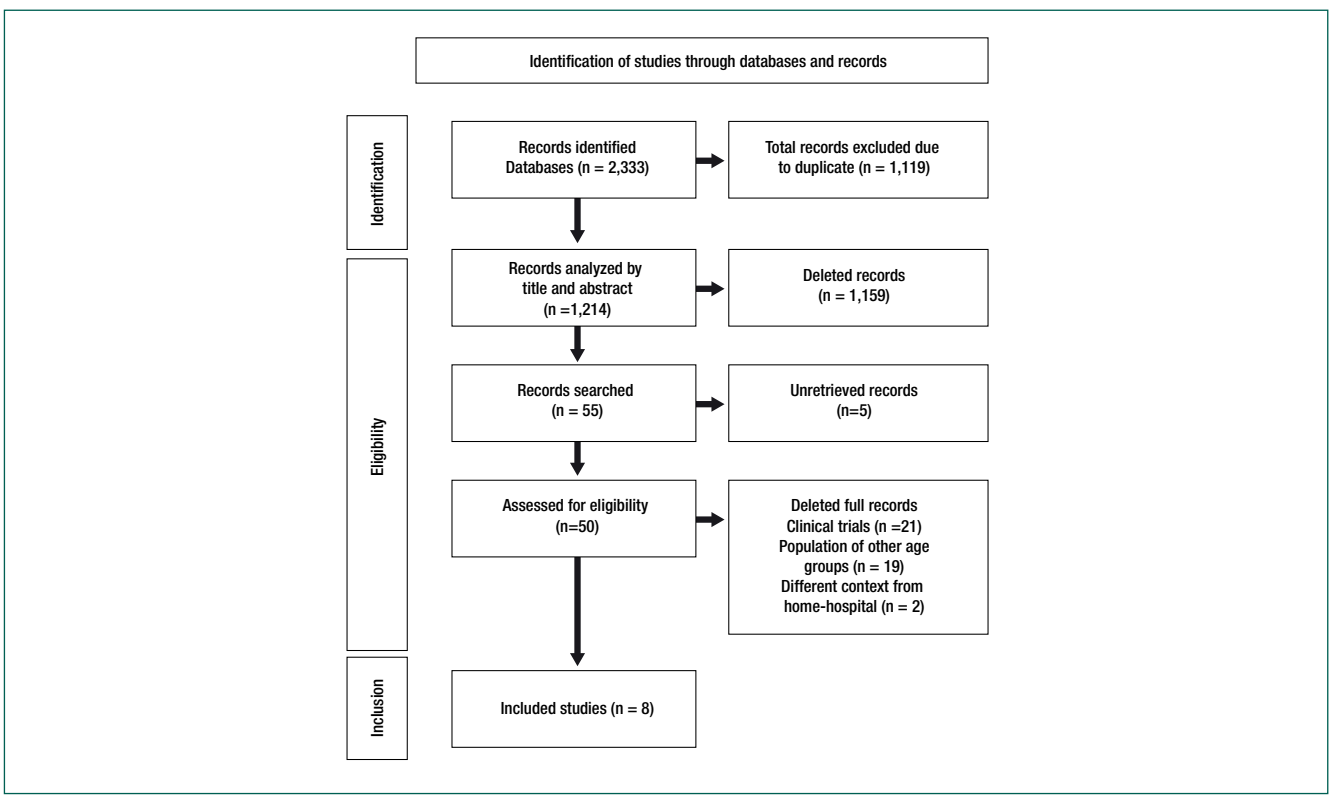

Figure 1. Process of identification and inclusion of studies - preferred report items for systematic diagram of systematic analyses and meta-analyses (PRISMA)

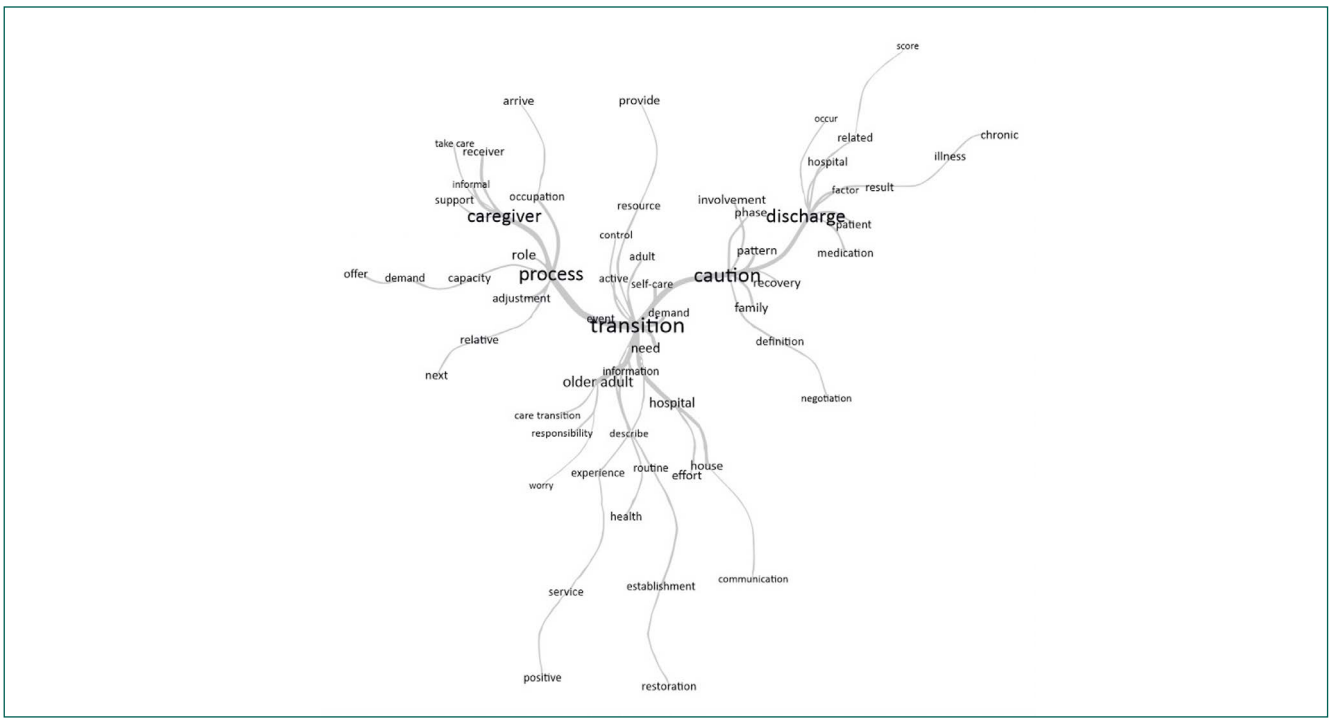

Figure 2. Similarity analysis from the documents included in the sample. João Pessoa, Paraíba, Brazil, 2021

Chart 2. Classification of findings according to weaknesses and difficulties, strengths and challenges in the transition process

Weaknesses and difficulties	Weakness in patient involvement with discharge planning;[13] Follow-up consultation scheduling;[13,14] Assistance for complications after discharge;[13-15] Lack of information and communication with health team;[15,19,20] Caregiver-centered care;[15] Limited resources;[13] Medication management;[13,14,16,20] Insecurity for performing care after discharge;[14,16,20] Inadequate understanding of health conditions;[14] Difficulty in communication between patient and caregivers;[15,20] Caregiver overload/Work demand;[17-20] Patient care overload;[17]
Potentials	Team involvement in discharge;[13] Individualized home care;[13] Resource support;[13] Self-management for discharge;[14] Improvement of patients' physical condition;[17] Desire to keep performing their activities;[17] Family involvement in care;[19,20]
Challenges	Change of caregiver role;[17,20] Lack of self-care training;[17,19] Patient and family involvement in transition management;[13,19,20] Choice of formal caregivers;[15] Investment and effort;[17] Establishment of new routines;[17,20] Changes in eating habits;[17] Communication with health team after discharge; [15,19,20] Emotional support[20]

Discussion

Transitional care is understood to be a set of health activities that must be carried out in a coordinated and continuous way within the health service (transfer between sectors or between institutions) or for residence.[21]

Transitions can be divided into four categories: developmental (related to transition of life stages), organizational (emerges between changes in social environments); situational (occurs as a result of some milestone in an individual's life); and health-illness (refers to the emergence of some health problem that directly affects an individual's style and quality of life, and may apply to situations in which sudden changes in roles occur)[22]

According to the aforementioned theorist, transitions have some characteristics: complexity and multiplicity; they move over time; can cause identity and role changes; individuals may be considered vulnerable, depending on the impact of transition on their lives; and everyday life, context and relationships can be persuaded by the conditions of nature and experiences.[22]

Thus, older adult transition from hospital to home must be seen as a longitudinal phenomenon,[17] which begins with patient admission, goes through the care process in the health service until the planning of discharge and extends until discharge, corroborating the theoretical support mentioned.

For Chick and Meleis,[23] transition consists of "passage or movement from one condition or place to another". This proposed definition takes us to a process that takes time and requires a pass, which

was identified in the maximum tree by the branch "process", plus the terms "role", "caregivers", "function", "demand", "adjustment".

Still in this context of changes and processes, some challenges during care transition were observed among studies, such as changes in habits,[20] caregivers overload/work demand,[17-20] changes of caregiver role,[17,20] limited resources[13] and patient and family involvement in transition management.[13,19,20]

The physiological process that involves human aging is related to complex physiological changes that can lead to the emergence of diseases and comorbidities, making them vulnerable and/or dependent on others for primary care. In the meantime, becoming caregivers for an older adult in the process of transitioning from the hospital environment to the home may require several resignations and changes in their life routine.

When there is an older adult dependent on care in the family environment, the family feels obliged to offer care to this individual, whether for social or affective reasons. Thus, these caregivers begin to experience feelings with conflicting meanings, as it involves the experience of feelings such as love, patience, affection, but also physical and emotional overload.[24] Thus, the overload and the change of roles corroborates the literature.

One of the assumptions of transition theory is that the conclusion of a transition is essentially positive, as it implies that individuals have reached a stage of greater stability than they were previously.[23] This positive perception of transition was also identified in the sample manuscripts through characteristics such as team involvement in discharge,[13] individualized home care,[13] improvement of patients' physical conditions,[18] desire to keep performing their activities and family involvement in care.[19,20]

In the study by Backman,[13] the positive experience was observed during patients' transition between health service sectors, in which the main source of communication between professionals was patients' medical record, which in turn was well filled with information related to their health condition. Nursing team involvement in the transition process was also mentioned as a positive experience in the transfer chain.

Within this premise, nursing care directed to patients and their formal and informal caregivers at the time of discharge can remedy several insecurities and fears regarding the care process. Some of them were identified in the present review as a lack of information and communication with the health team,[15,19,20] medication management,[14,16,20] insecurity for performing care after discharge,[14,16,20] inadequate understanding by patients of health conditions[14] and training support to perform self-care.[17,19]

The construction of adequate discharge planning by the nursing team enhances the quality of care offered to users who are in the process of discharge, should start at the time of patient admission to hospital, as the care to be offered must occur in an integrated and not fragmented way.[25]

Nursing care has mechanisms that enable and guarantee the quality of patient care. Moreover, it improves communication between team, patient and family. In this regard, the elaboration of a discharge plan by nursing should be initiated during hospital admission, given that the nursing process does not occur in a linear way, but interrelated.

In a study developed with 72 nurses from Primary Health Care in Rio Grande do Sul, which aimed to analyze the activities performed by nurses in patient care transition after hospital discharge, the results showed that the actions carried out were aimed at information regarding discharge, medication use and continuity of care. However, patient follow-up after discharge and communication with the reference team were the least reported among professionals.[14] These findings are similar to those found in the review.[15,19,20]

In research developed in Salvador-BA with the objective of understanding how the transitional care of nurses to older adults with artificial pacemakers occurs, the authors concluded that nursing professionals perform the transitional role of an empirical nature, without theoretical foundations, weakening the offer of comprehensive care. The high demand for activities was indicated by professionals as a limitation for offering complete guidelines to older adult patients.[25]

Nursing attributions in the process of changes and transactions include planning care for

discharge, assisting in social rehabilitation (resumption of patients' daily life after hospital discharge), health education, articulation with the care network and patient follow-up after discharge. However, the execution of these actions needs better coordination and articulation with each other, aiming to offer better quality in health care.[26]

Conclusion

Through the study mapping, it is possible to conclude that older adult transition from hospital discharge to home is a complex and longitudinal process, which involves multiple weaknesses and difficulties for patients and their formal and informal caregivers, as well as there are potentials and challenges to be explored. Through similarity analysis, it was possible to identify facets related to the translation process in the branches of the maximum tree, such as the changes that occur after the older adults are discharged from the hospital service to the home, the demands that family members begin to exercise after discharge and the concerns arising from translation. It was also possible to observe that translation consists of a process that involves changes in a patient's life and their caregivers, which can lead to work overload and changes in roles within the environment in which they live, although this transition implies meeting older adults' care needs, which involves effort and training. Finally, transition is related to care, especially for family members, at the time of discharge, including medication administration and management of chronic diseases.

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