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Algorithm for transitional care for caregivers of dependent older adults: a validation study

Algoritmo para o cuidado transicional aos cuidadores de idosos dependentes: estudo de validação

Algoritmo para el cuidado de transición de cuidadores de ancianos dependientes: estudio de validación

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ABSTRACT

Objective: To construct and validate an algorithm for transitional care for caregivers of dependent older adults. **Method:** This was a methodological study developed in three phases: a literature review, designing an algorithm, and its validation by a peer panel with twenty-seven experts selected according to pre-defined inclusion criteria. **Results:** The algorithm predicted interventions in transitional care (hospital stay, at discharge, and 30 days at home post-discharge) aimed at the exercise of the caregiver role; needs assessment; training in care management of dependent older adults and management of self-care, and ensuring continuity of care (of older adults and caregivers). **Conclusion:** Agreement between expert raters and a reliability test of 0.92 indicate that the algorithm can be used by professionals to decide the transitional care interventions to be administered to the caregivers of dependent older adults. Future studies should be conducted to perform its clinical validation.
Descriptors: Nursing; Validation Study; Aged; Caregivers; Transitional Care.

RESUMO

Objetivo: Construir e validar um algoritmo para o cuidado transicional aos cuidadores de idosos dependentes. **Método:** Estudo metodológico, desenvolvido em três fases: revisão da literatura, desenho do algoritmo e validação por um painel heterogêneo com vinte e sete peritos selecionados de acordo com critérios de inclusão predefinidos. **Resultados:** O algoritmo prevê intervenções para o cuidado transicional (internamento, momento da alta e até trinta dias após regresso a casa) dirigidas ao exercício do papel, à avaliação das necessidades, à capacitação na gestão dos cuidados ao idoso dependente e na gestão do seu próprio autocuidado e ainda assegurar a continuidade de cuidados (do idoso e do cuidador). **Conclusão:** A concordância obtida entre os peritos e um teste de fidedignidade de 0,92 atestam que o algoritmo pode ser usado pelos profissionais para decidir as intervenções de cuidado transicional aos cuidadores de idosos dependentes. A próxima etapa será a sua validação clínica.
Descritores: Enfermagem; Estudos de Validação; Idosos; Cuidadores; Cuidado Transicional.

RESUMEN

Objetivo: Construir y validar un algoritmo para el cuidado de transición de cuidadores de ancianos dependientes. **Método:** Estudio metodológico desarrollado en tres etapas: revisión de la literatura, diseño del algoritmo y validación por panel heterogéneo de veintisiete peritos seleccionados según los criterios de inclusión preestablecidos. **Resultados:** El algoritmo prevé intervenciones para el cuidado de transición (internación, momento del alta y hasta treinta días luego del regreso al domicilio) orientadas al ejercicio del rol; evaluación de necesidades; capacitación en la gestión de la atención del anciano dependiente y en gestión del propio autocuidado, y garantizar la continuidad de los cuidados (del anciano y del cuidador). **Conclusión:** La concordancia obtenida entre los peritos y una prueba de confiabilidad de 0,92 demuestran que el algoritmo puede ser utilizado por los profesionales para decidir las intervenciones de cuidado de transición de cuidadores de ancianos dependientes. La etapa siguiente será su validación clínica.
Descriptores: Enfermería; Estudio de Validación; Anciano; Cuidadores; Cuidado de Transición.

INTRODUCTION

In recent years there has been population ageing, mostly because of the increase in average life expectancy and improved health care. At the same time, the incidence of chronic and/or disabling diseases also increased[1]. Such diseases result in loss of independence by the older adults, and 55% of them suffer severe functional impairment[2]. For this reason, informal caregiving has gained increasing importance, and the presence of informal caregivers (ICs) is more and more necessary to support the achievement of daily activities and contribute to the maintenance of the quality life of dependent older adults. In order for ICs to best perform their role, they must have prior training, which promotes a safe hospital-community transition.

It is consensus in the field that nurses play an essential role in identifying the needs of ICs and the choice of appropriate interventions, which ensure the continuity of care between the hospital and the community. The goal of this training role is to minimize incapacities and promote knowledge and the acquisition of skills of the patient and IC to adapt to the new health condition[3-6]. However, the criteria for continuity of care are usually determined based on the needs of dependent older adults and not of ICs, who are faced with dependence and incapacity in performing the orientations given by the professionals[5].

The authors of this study consider that to optimize hospital-community continuity of care and to fully satisfy the needs of dependent older adults, it is necessary to recognize and prioritize the needs of ICs. To achieve this objective, it is important to identify such needs and intervene so that ICs feel prepared to care not only for the dependent older adult, but also for themselves. It is worth noting that the stress, depression, and anxiety that result from the provision of daily care to dependent older adults can contribute to the deterioration of the wellbeing of ICs[7], in addition to impacting that of the dependent older adult. Namely, these conditions can cause insufficient functional improvement, unnecessary hospital readmissions, and permanent admissions in long-term older adult care institutions[8]. As such, adequate IC preparation is of utmost importance, not only for the hospital-home transition, but also for the achievement of better health outcomes for the dependent older adult receiving care. This preparation should be provided by healthcare professionals, namely nurses, who should identify existing needs considering sociocultural specificities, difficulties, limitations, and perceptions of each IC. This should serve as the basis for developing care provision and planning and executing out nursing interventions aimed at both the needs of ICs and dependent older adults[9].

OBJECTIVE

To construct and validate an algorithm for transitional care for the caregivers of dependent older adults.

METHODS

Ethical aspects

This study was part of a broader project called Safe Hospital-Community Transition and was approved by the Ethics Committee. The researchers abided by the Helsinki principles for medical research, specifically informed consent, privacy, and confidentiality. The participants were informed that their responses were confidential and anonymous and would only be used within the scope of the study. Furthermore, they were informed that they could withdraw participation at any time and the principles of confidentiality and anonymity of personal information and respect for private life would still be respected.

Study design, location, and period

This was a mixed-method methodological study whose aim was to construct and validate a clinical decision making support algorithm for the transitional care for caregivers of dependent adults. It was carried out between June and November 2019 in Portugal.

The methodology for constructing the algorithm was chosen because clinical decision making support instruments are valuable in the practice of health professionals, especially nurses. They help them assess, decide, and plan care actions and bring available evidence to clinical care[10].

Sample, inclusion criteria

In the first phase, six consultant nurses were selected to advise the design of the algorithm. They were chosen based on the following criteria: nurses who had a Master's degree, who had worked with dependent older adults and their caregivers; and who had professional experience in in-patient hospital services and primary care. The professionals selected by the diversity of experiences in different contexts were familiar with the process of preparing caregivers for the return home and the difficulties that arise in the hospital-home transition and thus were essential to the process of evaluating the instrument.

To validate the algorithm, a panel of heterogeneous experts (nurses, researchers, physicians, social service technicians) was assembled, a practice advocated by some authors to ensure the validity of the results, since multidisciplinarity enables a predictive consensus with greater validity[11-13]. This intentional sample consisted of twenty-seven experts who met the following pre-defined inclusion criteria: more than twenty-five years of professional experience, with research in the area or involved in clinical projects to train caregivers to transition to the role.

The methodological option followed the guidelines of authors who defend that an expert panel allows for consensus and that it is useful when evidence in a given area is limited and the issues at stake are unexplored or difficult to define[13]. Furthermore, other researchers state that obtaining consensus among a group of individuals with experience on a specific topic is a particularly good research method[13].

Study protocol

The investigation was developed in three phases, with complementary studies. The first phase was a literature review to identify the difficulties faced by caregivers. The second included the design of the algorithm with the participation of six consultants to assess the indicators included in the algorithms. In the third

phase, the instrument was submitted to a panel of twenty-seven professionals for their appraisal and feedback.

The literature review allowed the researchers to identify a set of difficulties faced by caregivers in the hospital-community transition, and pointed to the need for transitional care interventions for a group which is often seen as a resource and not as the target of nursing care. The needs of ICs were grouped into five categories: needs in the transition into the role of caregiver; self-care needs; healthcare needs; economic needs; and social and community needs[14-15].

Based on the recommendations found in the literature, the researchers considered that the hospital-community transitional care interventions included three different stages: before leaving the hospital; at discharge; and between the first 48 hours and 30 days after discharge[14-15]. For the present study, dependence was defined as being dependent on someone or something for help and support[16] and caregiver as the one who meets the needs of someone who is dependent[16].

Based on the identification of the interventions that need to be implemented in the hospital-community transition, the researchers developed the first version of the instrument. The algorithm's design was based on the guidelines provided by the Society for Medical Decision Making[10].

Data collection and organization

The two-hour meeting with consulting nurses took place in June 2019 and was moderated by one of the researchers. The six consultants presented their ideas systematically and independently, until the final result was obtained, unanimous among the experts and in line with the objectives of the study. At the end of the meeting, consensus was reached on the final format of the algorithm to be sent to the expert group for evaluation.

The experts were contacted in September 2019. They were informed of the importance that the instrument can have for training, clinical intervention and research; the purpose of their participation, the expected time of response and the methodology. This prior contact helped prevent participant abstention.

The algorithm was sent in October 2019, via e-mail, together with an access link to the Google Drive® form structured in two parts. The first form requested that the experts give their opinion about the inclusion of nursing interventions at each point of the decision, scoring between (-2) not relevant at all, (-1) somewhat relevant (1) relevant and (2) very relevant. The option (0) no opinion was intentionally not included.

In the second part, the experts assessed the instrument according to: a) the comprehensiveness of the nursing interventions included in the graphic representation in terms of the effectiveness of the transitional care for caregivers; b) the clarity of the items; c) the exclusivity of interventions in each point of the decision making process; d) the objectivity of reading; and e) its relevance to decision making. The questions were dichotomous (yes or no).

Data analysis

The content validity index was applied to each of the items (CVII) and to the total algorithm (CVI), and interrater agreement (IRA) was used to assess reliability or interrater agreement. To calculate item and total CVI, the number of judges who assigned a score of 3 or 4 on the Likert scale was divided by the number of experts who assessed the item or the instrument[12-13]. The IRA was obtained by dividing the number of items that obtained an agreement greater than 80% among the panel experts by the total number of items in each dimension[12-13].

A consensus lower than 80% in all indicators[12-13] resulted in a second round of assessment. After the second round, descriptive statistics of the propositions were carried out and the suggestions for item changes/reformulation were analyzed. SPSS version 23 was used for data processing.

RESULTS

The expert panel assembled to validate the algorithm, previously constructed based on the literature and consensus among the six consultants (Figure 1) comprised twenty-seven experts (E), mostly female (88.8%).

The sample was heterogeneous in terms of undergraduate and graduate degrees (twenty-one nurses, three physicians, one psychologist, and one social worker), but all had clinical practice and were involved in projects related with caregivers of dependent older adults. Participant age ranged between 34 and 62 years, with a mean age of 46.97±7.86 years and mean time of professional experience of 26.7±7.67 years.

Charts 1 and 2 present the intervention of caregivers organized in terms of timing (before discharge, at discharge, and 48 hours to 30 days post-discharge)[14-15] and the decision-making flowchart, which was assessed by the expert panel.

To calculate the content validity index (CVII) of the items and of the algorithm, agreement was defined as the experts assessing the intervention as (1) relevant) and (2) very relevant.

The only intervention that did not achieve a consensus greater than 80% was monthly support and follow-up (Figure 2) in cases where the role of caregiver had been achieved. The experts expressed their doubts about the regularity of these support and follow-up visits considering that "the older adult's clinical condition can change, and caregivers do not have the knowledge to identify these changes" (E6) and because "in many cases, the dependence of older adults is severe and it is important to have closer monitoring" (E21).

In a second round conducted with only this item, 88% of the experts agreed that this intervention could be carried out monthly when they were asked to consider actual care needs and human resource management. In this round, only 59.2% of the participants responded (n=16).

The different categories of care represented in the algorithm decision boxes were subject to evaluation as to comprehensiveness, clarity, exclusivity, objectivity, and relevance for decision making. The overall evaluation of the algorithm for each of these criteria is shown in Table 1.

The percentages obtained for the different criteria varied between 85.1% and 100%. The participants were unanimous on the issue of the relevance of the algorithm for decision making about transitional care for caregivers of dependent older adults. The item with the lowest percentage was that of exclusivity (85.1%).

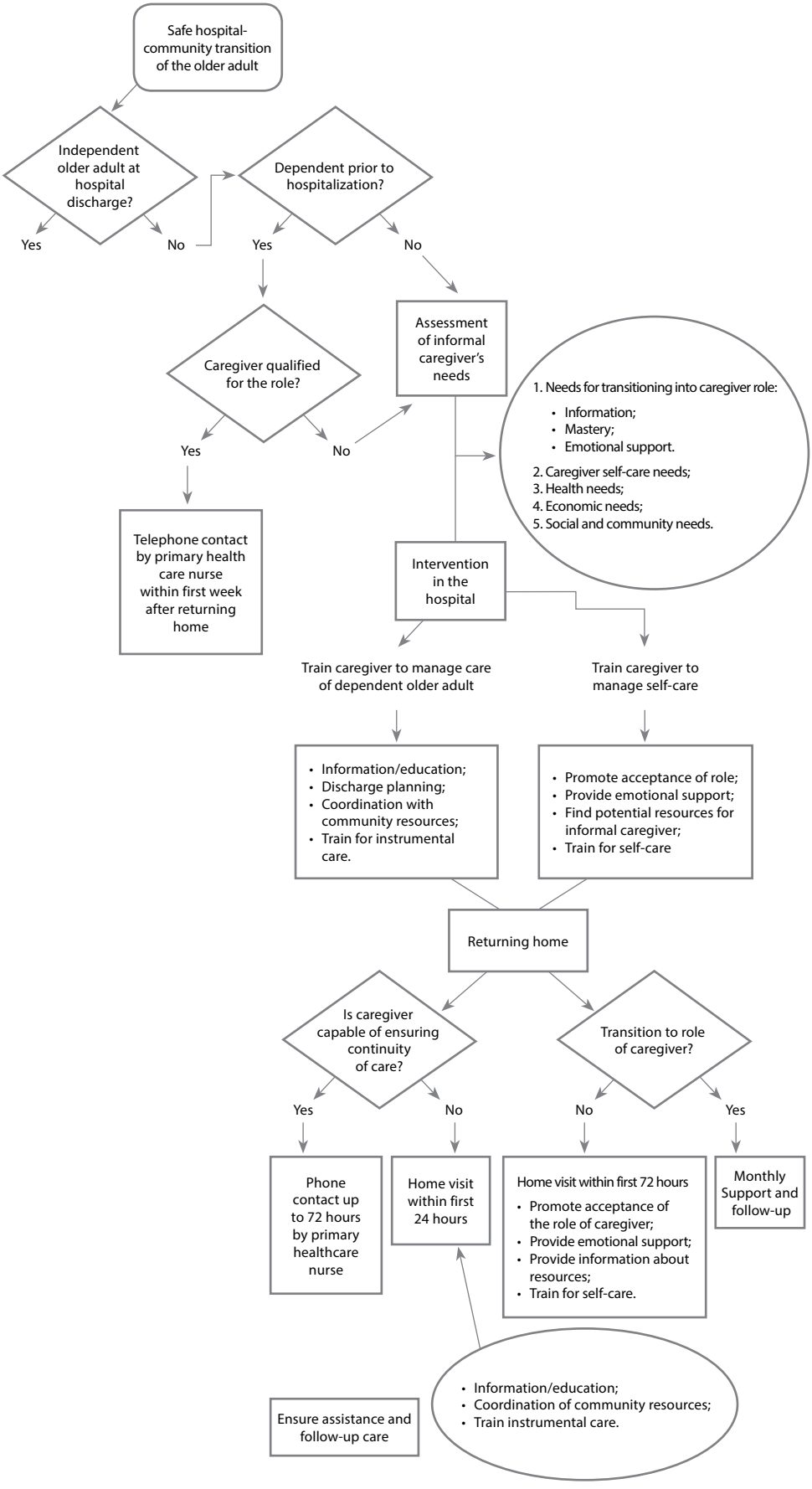

Figure 1 - Algorithm for transitional care for caregivers of dependent older adults Lisbon, Portugal, 2019

DISCUSSION

The complexity of the health-illness processes and the transitions experienced by dependent older adults, combined with shorter average hospital stays and the phenomenon of population aging, poses a challenge to health systems. In many cases, older adults are more dependent on hospitalization, and their clinical condition makes it impossible for them to return to their pre-hospitalization levels of functioning[17], resulting in the need for caregivers who can ensure self-care on coming home.

The instrument presented in this study presented a reliability >0.8, which attests to its potential to support decision making about the transitional care for caregivers of dependent older adults. The loss of participants (40.8%) between the two rounds did not affect the validity and quality of the results, as the panel was composed by experts on the topic and the literature states that the essential feature of the panel is quality, and there is no need for statistical representativity in relation to the quantity of participants in the study[13].

On analyzing the responses of the professionals, the experts suggested the inclusion of more interventions such as education about medication management; hygiene care training; transfers; and positioning and feeding. However, the suggestions were not included because they were already represented in the algorithm by the category "training caregiver to manage care of older adult." Algorithm-construction rules do not allow for an exhaustive explanation of the interventions[10].

Chart 1 - Expert agreement (first round of assessment) about the interventions included in the algorithm for transitional care for caregivers of dependent older adults, Lisbon, Portugal, 2019

Algorithm intervention categories		**CVII***	**IRA †**	**CVI‡**
1. Interventions if caregiver is qualified for the role				
1	Phone contact by primary healthcare nurse first week after returning home	.81	1	
2. Interventions if caregiver is not qualified for the role				
2.1	Needs assessment	1		
2.2	Train caregiver to manage care of dependent older adult	1	1	
2.3	Train caregiver to manage self-care	.96		
3. Interventions when returning home if caregiver is able to ensure continuity of care				
3.1	Phone contact within first 72h by primary healthcare nurse	.81	1	
4. Interventions when returning home if caregiver is unable to ensure continuity of care				
4.1	Home visit within first 24 hours	.85		
4.2	Information/education	1	1	.92
4.3	Coordination with community resources	1		
4.4	Train for instrumental care	1		
5. Interventions if the transition into role of caregiver is successful				
5.1	Monthly support and follow up	.77	0	
6. Interventions if the transition into the role of caregiver is not successful				
6.1	Home visit in first 72 hours	.85		
6.2	Promote acceptance of caregiver role	.92		
6.3	Provide emotional support	1	1	
6.4	Provide information about resources	1		
6.5	Train for self-care	1		

*Note: * Content validity index applied to the interventions; † Interrater agreement applied to the intervention categories; ‡ Content validity index of the algorithm.*

Chart 2 - Expert agreement (first round of assessment) about the interventions if caregiver is not qualified to provide transitional care to dependent older adults, Lisbon, Portugal, 2019

Algorithm intervention categories for interventions if caregiver is not qualified to perform the role		**CVII***	**IRA †**
2.1. Needs assessment			
2.1.1	Transition to the role of caregiver	1	
2.1.2	Self-care	.92	
2.1.3	Health	.81	1
2.1.4	Economic	.81	
2.1.5	Social and Community	.88	
2.2. Train caregiver to manage care of dependent older adult			
2.2.1	Information / education	1	
2.2.2	Discharge planning	1	
2.2.3	Coordination with community resources	1	1
2.2.4	Train for instrumental care	1	
2.3. Train caregiver to manage self-care			
2.3.1	Promote acceptance of caregiver role	.92	
2.3.2	Provide emotional support	.96	
2.3.3	Locate potential resources for the informal caregiver	.81	1
2.3.4	Train for self-care	.92	

*Note: * Content validity index applied to interventions; † Interrater agreement applied to intervention categories.*

Table 1 – Global evaluation of the algorithm as to comprehensiveness, clarity, exclusivity, objectivity, relevance and respect to algorithm formulation rules, Lisbon, Portugal, 2019

Criteria	Comprehensiveness		Clarity of items		Exclusivity		Objectivity in reading		Relevance for decision making	
	n[§]	%[‖]	n[§]	%[‖]	n[§]	%[‖]	n[§]	%[‖]	n[§]	%[‖]
Global Assessment of Algorithm	24	88.8	26	96.2	23	85.1	25	92.5	27	100

Note: [§] n = Number; [‖] % = Percentage.

The present instrument was designed to be administered to all caregivers of dependent older adults. Thus, the first question is whether after the hospital stay, the older adult will be dependent on another person. If the answer is yes, it is important to identify whether the caregiver, according to various criteria, is qualified for the role. The experts in this study considered it important that the primary healthcare team make a phone call to the caregiver within the first week after hospital discharge to check on the hospital-home transition and whether the ICs have any needs/questions, as recommended by other studies[5-6]. If the ICs prove to be unqualified to provide care, their needs must be evaluated and health professionals must act accordingly.

The literature review helped identify the breadth of these needs: transitioning to the role of IC (information, mastering care, and emotional support), the need to acquire new knowledge and skills to respond safely to the dependent older adult's needs[18]; caregiver self-care, with time for leisure, social life and rest, because the constant state of alert negatively influences rest and quality of life[19]; health - caregiving implies ongoing effort at a physical, cognitive, and emotional level and is associated with an increased incidence of diseases[1] and most caregivers are over the age of 65.8 years and about 80% of them take at least one medication chronically[7]; economic - many caregivers have to leave their job[20-21] with a consequent loss of income, which is exacerbated by the financial cost of caregiving[20]); and last, social and community needs, namely those of support services and institutions and of professional teams to help supervise home care[1,22].

After identifying these needs in the literature, the researchers established it was important to begin the interventions with already during the hospital stay. When designing the algorithm, the guidelines of various authors were followed with two objectives: promote adaptation to the new role (transition into informal caregiver) and to acquire knowledge and skills[5-6,18,22-24]. At this point it is important to ensure the following: training to ensure care management of dependent older adults, via information and training, with the goal of providing ICs with theoretical and practical knowledge that will allow them to provide quality care with minimal repercussions for themselves[18]; developing a discharge plan, with training beginning in the initial stages of the hospital stay[6,23]; coordinating with community resources to ensure continuity of care[5,17,24]; and training for instrumental care, such as hygiene, dressing and undressing, feeding, elimination, and mobility[6,17-18].

Already during the hospital stay, priority should be given to training caregivers to manage their own self-care through a set of interventions that facilitate the acceptance of the role[5-6]; provide emotional support to reduce caregiver burden[24], considering the stress associated with the role[9]; identify potential resources, such as family negotiation and searching for resources outside the family[19]; and train for self-care, where nurses must develop strategies that enhance the IC self-care[5-6,25-26] and promote social inclusion[20].

Existing research on this phenomenon is still focused on the biomedical model, which is based on the assumption of ICs as a care resource for dependent older adults and not as the target of care. Studies have indicated that many of these caregivers are older adults themselves, with chronic diseases, and who live with some level of dependence to achieve their activities of daily living[1,6-7]. Therefore, they also experience complex transitions, sometimes simultaneous to the dependent older adult, and have their own specific health needs related to preventing the complications and risks associated to caregiver role.

After the intervention performed at the hospital at discharge, nurses must assess whether the caregiver is capable of ensuring continuity of care and then communicate this information to the primary healthcare team. If the caregiver is deemed qualified, the primary healthcare team will make a phone call within the first 72 hours. In case they are deemed unqualified, a home visit will be made in the first 24 hours to manage the care of the dependent older adult. At discharge, the nursing team must also assess the transition into the IC role. If the transition is achieved, monthly support and follow-up will be provided by the primary healthcare team. If not, a home visit will be made in the first 72 hours to train the IC to manage their self-care.

The results corroborate those of other studies that suggest that when dependent older adults are discharged from hospital, nurses must ensure assistance and follow-up care on returning home. However, this study found that determining the timing of follow-up interventions is not often discussed in the literature, which tends to be centered on the needs of the dependent older adult, and not on those of the caregiver. In fact, this was a concern reported by the experts, namely in situations in which the caregiver has successfully transitioned into the role and in their suggestion that support and follow-up care be provided on a monthly basis. Future studies should explore the relationship between the level of caregiver qualification and the need for support by health teams and for what purposes.

Limitations of the study

Limitations of this study include those inherent to the method and type of sample, with the intentional choice of consultants and experts who participated in both phases. Moreover, even though it was based on a literature review, the validation of the algorithm was also based on the self-perception and clinical

knowledge of the experts, and the responses may have been affected by what may be considered socially desirable. At the same time, sending the document in electronic form increases the likelihood of bias in the responses, due to the possibility of the experts being influenced by other sources.

Contributions to the field

Despite the limitations mentioned above, the flowchart for transitional care for caregivers of dependent older adults can contribute to shifting the paradigm in clinical practice contexts by shifting the focus of ICs as resources of care to targets of planned care. This will achieve a more holistic approach to the IC/dependent older adult dyad. The opinion of the expert panel and researchers was unanimous in considering that the algorithm can contribute to the clinical decision making.

CONCLUSION

This study validated a flowchart to support decision making about transitional care for caregivers of dependent older adults by a panel of experts. Reliability was >0.8, which indicates that the validated algorithm contributes to providing continuity of care in the hospital-community transition and helps to prepare ICs during the hospital stay, providing continuity of care at the time of discharge and 30 days post-discharge through the support, supervision, and guidance deemed necessary for the care provided by the IC to the dependent older adult.

The next step is the clinical validation of the instrument. For this reason, it is important that nurses working in services where dependent older adult patients are hospitalized adopt the algorithm and administer it in clinical practice. The researchers will work in close collaboration with those who use the instrument in order to validate and disseminate the results.

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