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Co-construction of a caregiver-monitoring model
A co-construção de um modelo de acompanhamento aos familiares cuidadores
La coconstrucción de un modelo de apoyo a los familiares cuidadores

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Abstract
Background: The approach to informal caregivers poses new challenges to nursing, supporting the conception of care based on the best available scientific evidence. Care documentation in information systems should create indicators that reflect the nurses' role as facilitators of a healthy transition.
Objective: To redefine the conception of care to the family caregiver though the analysis of records that mirrors the nurses' activity with caregivers.
Methodology: Qualitative study based on the assumptions of participatory action research in health with 16 nurses from primary health care units. Field notes were taken and Bardin's content analysis method was used.
Results: Three categories emerged: work organization, limitations to nursing documentation, and standardization of records. A family caregiver support model was developed in collaboration with the participants.
Conclusion: The assumptions of participatory action research in health facilitated the redefinition of the care model to improve the quality of care and documentation process in nursing information systems.

Keywords: nursing; family caregiver; nursing process; health information systems

Resumo
Enquadramento: A abordagem aos cuidadores informais coloca novos desafios à enfermagem, que deve sustentar a conceção de cuidados na melhor evidência científica. A documentação dos sistemas de informação deve gerar indicadores que espelhem o papel dos enfermeiros como facilitadores de uma transição saudável.
Objetivo: Redefinir a conceção de cuidados ao familiar cuidador a partir da análise dos registos que espelha a atividade dos enfermeiros com os cuidadores.
Metodologia: Estudo com abordagem qualitativa assente na pesquisa ação participativa em saúde, desenvolvido com uma amostra de 16 enfermeiros em atividade de cuidados de saúde primários. Recorreu-se às notas de campo e considerou-se os pressupostos defendidos por Bardin para a análise de conteúdo.
Resultados: Emergiram três categorias, organização do trabalho dos enfermeiros, limitações à documentação em enfermagem e uniformização dos registos. Em conjunto com os participantes desenvolveu-se um modelo de acompanhamento aos familiares cuidadores.
Conclusão: Os pressupostos da pesquisa-ação participativa em saúde facilitaram a redefinição do modelo assistencial conducente a melhoria na qualidade de cuidados e documentação nos sistemas de informação em enfermagem.

Palavras-chave: enfermagem; familiar cuidador; processo de enfermagem; sistemas de informação em saúde

Resumen
Marco contextual: El enfoque hacia los cuidadores informales plantea nuevos retos a la enfermería, que debe apoyar el diseño de cuidados basados en la mejor evidencia científica. La documentación de los sistemas de información debe generar indicadores que reflejen el papel de los enfermeros como facilitadoras de una transición saludable.
Objetivo: Redefinir el concepto de cuidados al familiar cuidador a partir del análisis de los registros que reflejan la actividad de los enfermeros con los cuidadores.
Metodología: Estudio con enfoque cualitativo basado en la investigación-acción participativa en salud, desarrollado con una muestra de 16 enfermeros que trabajan en atención primaria. Se utilizaron notas de campo y se tuvieron en cuenta los supuestos defendidos por Bardin para el análisis de contenido.
Resultados: Surgieron tres categorías, organización del trabajo de los enfermeros, limitaciones a la documentación en enfermería y normalización de los registros. En conjunto con los participantes, se elaboró un modelo de apoyo a los familiares cuidadores.
Conclusión: Las premisas de la investigación-acción participativa en salud facilitaron la redefinición del modelo de atención que condujo a la mejora de la calidad de los cuidados y la documentación en los sistemas de información de enfermería.

Palabras clave: enfermería; cuidador familiar; proceso de enfermería; sistemas de información en salud

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Introduction

Changes in society have affected family dynamics. However, families continue to be a resource for the dependent person (DP; Baptista & Perista, 2018). The family caregiver (FC) is a family member, friend, or neighbor who provides unpaid care to a DP (Baptista & Perista, 2018). Evidence has shown that this role requires knowledge, skills, and competencies (Meleis, 2010; Ploeg et al., 2020) to better support their family member's health-illness transition, which implies abrupt changes in personal, family, and professional life (Cloyes et al., 2020).

The topic under study is pertinent because of the sociodemographic circumstances and the policies that increasingly advocate in-home care.

Nursing faces the challenge to produce evidence supporting the teaching of the discipline in this area, whose transferability to practice will reflect a more meaningful nursing practice. This study aimed to redefine, together with nurses, the concept of care for family caregivers.

Background

Considering the complexity of care and demands of the role of caregiver, it is imperative that health professionals support family caregivers in the transition, adapting nursing interventions to their needs at each stage of the adaptation process (Meleis, 2010). In a study conducted with informal caregivers from the hospitalization phase up to one month after returning home (Shyu, 2000), the needs perceived by the FCs change throughout the transition process. Overall, the adaptation process, designated by the author as *Role Tunning*, has three sequential phases: *Role Engaging*, where the main needs relate to health information; *Role Negotiating*, where the needs relate to mastery in instrumental skills; and *Role Setting*, where the needs relate mostly to emotional support. In order to help individuals to experience healthy transitions, especially FCs who provide care to their dependent family members, nurses should use robust theoretical models to guide the different stages of the nursing process and to obtain relevant information for decision-making. The identification of early transition properties (awareness, involvement, change, and differences) and personal, community and societal conditions that may facilitate or inhibit transition is relevant for implementing nursing therapies that result in positive process and outcome indicators. Role mastery, subjective well-being, well-being of relationships, and adequate symptom management are some of the indicators of healthy transitions (Meleis, 2010).

The nurses' approach to FCs is flawed, which perpetuates their role as invisible in the continuity of care (Cloyes et al., 2020). The nursing therapies implemented by nurses in their interaction with the FC focus mainly on instrumental care, as they aim more at the health-illness transition of the DP and not at the transition to the caregiver role (Ploeg et al., 2020). The interaction with FCs is a crucial process in nursing practice. However, the proper use of records is essential to ensure the continuity and quality of care, translating the health gains that are sensitive to nursing care (Ameel et al., 2020). Nursing records document the autonomous and collaborative activity of these professionals, and self-affirming the nursing profession, distinguishing it from other health professions (Vieira, 2018). The entire documentation process is based on the nurses' scientific method of work, which is characterized by five phases: assessment (diagnostic activity), identification of the diagnosis, action planning, implementation of interventions, and assessment of results (Huitzi-Egilegor et al., 2018). The nursing practice support system with regard to FCs integrates two foci (caregiver role and caregiver stress stress) that support the records of nurses' activity with these clients.

Research questions

What information do nurses record in nursing information systems (NIS) as a result of their interactions with FCs that facilitate continuity of care?

What do nurses consider relevant in the conception of care regarding the foci "caregiver role" and "caregiver stress"? Which strategies do nurses perceive as facilitators of the change process in the implementation of care to the FC?

Methodology

A qualitative, exploratory study was conducted based on the assumptions of participatory action research (PAR) in health. This approach is based on the participation of people from the context where the research project is developed, leading to positive social changes (Banks et al., 2017; Wright et al., 2018). This study corresponds to the phase following the diagnostic stage, which aimed to understand the conception of care used by nurses in primary health care settings regarding FCs.

The convenience sample was composed of nurses ($N = 16$) from two family health units (FHUs) in northern Portugal. One nurse from each FHU was assigned the role of interlocutor to facilitate communication between the team and the researcher. These nurses were selected for being part of the technical board and their privileged and dynamic position in the health teams. A questionnaire was applied to the sample for sociodemographic and professional characterization. The IBM SPSS Statistics software, version 24.0, was used for descriptive statistics. Field notes were also recorded in the meetings and submitted to content analysis according to Bardin (2013). Data collection stopped when data saturation was reached, totaling six meetings from September 2018 to December 2019. A coding strategy was used for data analysis, selecting the letter M and the number corresponding to the meeting.

A favorable opinion was obtained from the National Data Protection Authority (authorization 10744/2016) and the Health Ethics Committee (authorization 105/2016). The objectives of the study were made known to all nurses, who signed the informed consent.

Results

Of the 16 participants, 12 (75.0%) are female, aged between 32-51 years, with a mean of 39.1 ± 5.0 years. They have been exercising their professional activity for a mean of 16.1 ± 5.2 years (9-25 years), of which 11.1 ± 6.0 years (3-23) correspond to activity in PHC units. Half of the sample are specialist nurses in community nursing (3), maternal and obstetric health nursing (3), child health and pediatric nursing (1), and mental health and psychiatric nursing (1).

The field notes from each meeting were analyzed and then triangulated according to Bardin (2013). Then, in the exploration stage, they were coded and categorized. Three categories emerged: Organization of nurses' work; Limitations to Nursing documentation; and Standardization of records.

Nurses' work organization

The nurses' opinions were unanimous throughout the meetings, stating that the documentation on delivery of care to the FC does not illustrate the activities performed: "it doesn't reflect the work . . . we do more than we document" (M1 and M5); "it's impossible, we can't believe it" (M1); "Sadly it's not documented because we do real nursing work" (M1); "we do not record most of what we do" (M3); "there is not much documentation on the caregiver " (M4). All nurses expressed that the results obtained through the records in the diagnostic phase do not reflect the real activity developed with the families: "it's a shame really . . . we are more focused on responding to people's needs at that moment" (M1); "we record the basic procedures" (M1; M5). More information is essential for a more integrative approach.

They recognize that care documentation is an important activity not only to comply with the legal requirements but also to ensure continuity of care and identify the autonomous activity of nurses in the health/disease (DP) and situational (FC) transition processes. They are aware that the undocumented work means that it was not done: "we have no way to quantify it, although we did it" (M5).

The verbal and non-verbal responses to the questions posed by the researchers regarding the NIS mirrored different levels of mastery of the NIS by the participants. In addition to this differentiation in the ability to optimize the potentiality of the NIS used, the answers obtained showed some heterogeneity in the structuring and systematization of the conception of care relating to the foci of caregiver role and caregiver stress. In the first meeting, the nurses identified the absence of a theoretical framework as a complicating factor. This idea was reinforced in later meetings.

> We have some knowledge, but we need an update... this topic has not been integrated into the annual training plans, ... we feel that we need a guideline to help us systematize the process, aiming to standardize its operationalization (M1).

When nurses refer to or corroborate colleagues' opinions about the disparity between what is assessed/identified needs/implemented interventions and the data extracted from the NIS, they identify organizational difficulties, such as lack of time/time management and available resources. Lack of time is the most frequently mentioned difficulty: "lack of time for records" (M3, M4); "we would like to have more time in the consultation so that we can keep the records, or that the scheduled consultations end an hour before the end of work so that we can keep the records" (M3).

They expressed that work overload hinders the interaction with the FC: "we prioritize... the area of emotion management requires more time, and we often have twenty home visits in one shift" (M1). The teams mention that a more comprehensive and integrative approach to the FC is not a common practice due to lack of time and work overload, requiring availability, which they do not have. Work overload, with a high number of scheduled consultations, leads to insufficient time left for record keeping. They mention that they put off record keeping until the end of the shift, due to the excess of nursing consultations, so at the time of the consultation they only record the basic procedures.

The scarcity of resources requires a functional/institutional organization that limits the interaction with the FC/DP. For home visits (HV), nurses share the same transportation (cab), implying constraints when interacting with families. Also, the HV to the family are not always performed by their family nurse: "in home visits, care is provided by the nurses who are on duty for the day. The surveillance nursing consultations are scheduled and performed by the family nurses" (M1); "the home visit may not be performed by their family nurse. A nurse does all the home visits that day. The fact that nurses are not always the same doing the home visits makes the relationship with families more difficult" (M1).

Limitations to nursing documentation

Some participants report the NIS used as a barrier to documentation, considering it to be complex and difficult, either to make the records, stating "lack of simplification of the system" (M1); "the system is not intuitive, and it is not easy to record" (M4), "we spend a lot of the time with the computer when we should be interacting with patients " (M2); "the system is very bureaucratic, not practical and very inappropriate for the PHC context" (M2); or in subsequent consultations: "it takes a long time to reach a particular record" (M1); "the information is scattered throughout the system" (M1); and "a lot of time is lost in the process" (M1); "the process is not simple, we cannot check notes relating to the previous consultation, we have to simulate a printout to see the notes, but it implies interrupting the contact with the person, to sum up, it is a complex and lengthy process, causing constraints during the consultation" (M2).

They mention frequent updates of the system: "the system is very complicated, they are always updating it" (M2); "often what happens are updates not of content, but of the layout of the information, again making it difficult to access the information at the time of consultation and records" (M2).

Standardization of records

The standardization of records was also pointed out as a difficulty. When questioned about the primary FC or if they identified the caregiving family, the nurses mentioned "it is not very common to be the family providing care, what often happens is that the FC is alternated, for example, for periods of time" (M1). To access the records, they mentioned "The FC is identified in the initial assessment", recorded in the DP focus, "or if you open the *family* target, you can identify the caregiver" (M1). When data emerging from the diagnostic activity infer to the diagnosis of compromised caregiver role, the difficulties are not unanimous. Some nurses have difficulties in the continuity of care, mentioning: "When we reach a compromised diagnosis, we cannot specify the area of compromise" (M1); others use free-text notes as a strategy: "the information recorded in free text does not go from one contact to the other, this information is only associated with an intervention, but, alas, the process is very bureaucratic" (M3). Another option is to put the notes on alert. However, while for some it is perceived as a strategy to allow for the continuity of care "when a diagnosis is identified, we manage to record in notes the area of compromise, which is visible to all contacts" (M2), for others, this procedure raises ethical issues "we can put it on alert... but all professionals in the unit have access" (M3).

These observations refer to implications in the continuity of care:

> our records do not allow continuity of care, we cannot easily get to the notes. If we record in general notes, these can be viewed by other professionals, if we make notes associated with the consultation, we have difficulty in reaching the notes again in the following consultations. (M4)

The nurses' opinions differ in the approach to preventive care and its documentation in the NIS, with some considering that this care is adequately recorded: "we can identify foci, but we can only perform diagnostic assessment. If we are going to promote care... provide anticipatory care, it means that some item is not fully achieved, hence the role is compromised" (M4). However, other nurses believe that it is not possible to record preventive care, as the documentation focuses on interventions for existing and already identified situations: "we cannot record interventions when we are facing a positive diagnosis" (M1), "it is not possible in the current system to encourage, praise the person… and it is always necessary to list a negative diagnosis to register this type of interventions ... which we consider wrong" (M2). "Promotion is not valued… We can only do something in the face of disaster" (M2). One of the objectives of the third meeting was to understand the professionals' decision-making when judging the focus of the caregiver role and identify any guidance for decision-making. The nurses explained that "if there is any area of compromise (in the diagnostic activities), we assume that the role is also compromised" (M3).

Regarding the assessment of the caregiver's potential to provide care, a specific parameter allows nurses to record the FC's awareness to provide care. This issue was also addressed with the participants, who mentioned that "there are no defined areas, so each one assesses them as they see fit" (M3), "we have no defined criteria, we assume that there is awareness, since the FC has assumed the caregiver role" (M3).

When questioned about the difference between the caregiver role and providing care, the nurses mentioned that each one performs their assessment as they consider most relevant: "it is very subjective" (M5), which reflects the lack of standardization in the documentation of the caregiver-related foci.

As the meetings progressed, the nurses reinforced the need for the standardization of records and made some suggestions for its feasibility: "we should create a checklist for FC records to guide us in what to assess and define interventions based on possible diagnostic statements" (M1). It is "essential to create a basic procedure to facilitate" (M5) the record-keeping process. "If only there was a mnemonic for these topics" (M5). "Records should be structured so everyone does the same thing" (M5). "It is important to identify the data that everyone would evaluate the same way, create a checklist for everyone to follow" (M5).
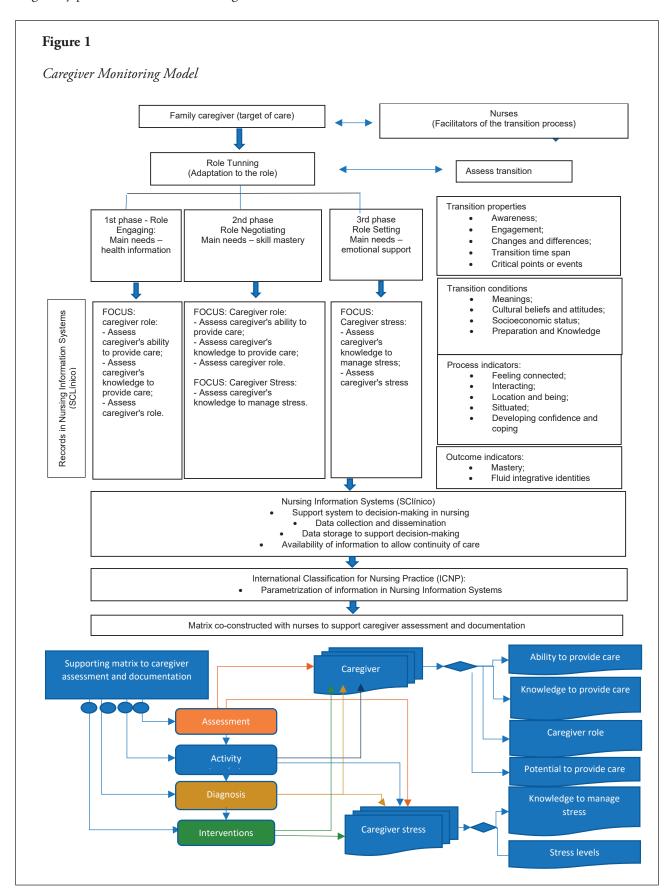
Family caregiver monitoring model

The data obtained from the meetings allowed identifying gaps in the conception of care to FCs and the operationalization of nursing records. From the joint reflection with the participants since the first meeting, reinforced throughout the following meetings, resulted the imperative to construct a Model of Care for FCs (Figure 1), focused on assessing and meeting their needs as caregivers and care targets.

Assumptions for the FC monitoring Model were identified: FCs are considered an indispensable resource in dependent care; FCs are the target of care by nurses in their daily practice; FCs experience a situational transition, concurrent with other transitions; FCs need to acquire knowledge and skills for their role; The caregiver-related underreporting in the NIS is an underexplored area with potential for improvement; Unit nurses report that documentation does not reflect the work developed with FCs and need more information for a more integrative approach; Nurses are aware that if their work in clinical practice is not documented, there is no way it can be quantified; Nurses identify the lack of a theoretical framework to support decision making; Lack of time due to overwork and scarce resources complicates the documentation process and the interaction with the FC; Unit organization does not allow each nurse to always perform the patient's HV; The operating system used is reported as complex and hinders the documentation and consultation of previous records, with constant updates; Lack of standardization in records; Nurses suggested the existence of a document to facilitate the approach to the FC, an easily accessible tool that would help the record-keeping process in this area.

The creation of this model was based on the assumptions identified, with theoretical support from the research developed by Shyu (2000) and Meleis' Theory of Transitions (2010). A guiding matrix was co-constructed within this model, which integrates the caregiver-related parameterization in the SClínico program (foci, diagnostic activities, diagnostic statements, and interventions). In

the case of the more subjective diagnostic activities, the concepts were described, taking into account the most recent evidence. The Matrix, in its embryonic stage, was presented to the interlocutor nurses after the fifth meeting. They presented it to the remaining team members, and the document remained in each unit for a period of approximately 1 month, so that they could appropriate it and make the necessary changes. In the sixth meeting, the proposed changes were discussed and the final version was created and made available in each unit.

Figure 1

Caregiver Monitoring Model

Discussion

The nurses pointed out aspects associated with work organization as complicating factors for the documentation process, such as work overload and scarce resources, considering that the records do not reflect their care activities with FCs. They mention that the information system used (SClínico) limits documentation and subsequent consultation of records, as well as the standardization of records. This study encountered some limitations, such as the use of isolated field notes, indicating that the recording of the meetings could have possibly provided richer data. When faced with the results obtained in the diagnostic phase based on the consultation of the documentation in the NIS, the nurses considered that it did not reflect all the activities performed in their daily practice with FCs of DPs. In their opinion, this disparity is justified by their prioritizing interaction with patients to meet their real needs in loco. These interactions take up more time thatn what is accounted for in the planning of HV, as well as in the consultations performed in the units. This constraint has unfavorable repercussions on the documentation process because nurses only keep records of that they consider minimal for the continuity of care. Vieira (2018) also found in his research that nurses consider that the NIS does not translate either the health gains or the complexity of the care provided. This issue is also mirrored in other international studies (Kebede et al., 2017; Tasew et al., 2019).

One of the limitations identified by nurses in their practice relates is being aware that they do not use a more comprehensive and integrative approach to the FC. This situation is also reported by Cloyes et al. (2020) and corroborated by Ploeg et al. (2020).

Nurses are aware of the impact of underrecording, which does not allow quantifying the activities performed and the results obtained, making it difficult to obtain outcome indicators that mirror the contribution of autonomous nursing interventions in health gains, which is line with Kebede et al. (2017).

Nurses point out that work overload and lack of time allocated for records hinder record keeping, a finding corroborated by literature (Kebede et al., 2017; Samadbeik et al., 2017; Tasew et al., 2019).

The complexity of the NIS in use also poses difficulties to record keeping. Nurses consider it a complex system due to the difficulty in the recording process and data consultation. Other authors also reinforce the nurses' perception of the complexity in optimizing the SClínico program (Gonçalves et al., 2019; Oliveira et al., 2020; Vieira, 2018).

The lack of standardization of records reported by the participants is a relevant limitation, because the use of a common language by nurses is crucial for the construction of formal knowledge (Gonçalves et al., 2019). Also, Oliveira et al. (2020) highlighted the non-standardization of the care documentation process.

Other studies point to the need for nurses' training to improve the documentation process, using a standardized language (Gonçalves et al., 2019; Tasew et al., 2019) and

their participation in the development of NIS (Samadbeik et al., 2017). Also, Kebede et al. (2017) report that a sustained knowledge of nursing care documentation improves familiarity with guidelines and directives for their records, leading to standardization of documentation. The creation of guidelines is a strategy also recommended by other researchers, who point out the use of a multidisciplinary approach for the development of policies and guidelines on the nursing documentation process (Taiye, 2015), providing opportunities for continuous training in this documentation process. Kebede et al. (2017) report that nurses who have had in-service training and nurses with a good knowledge of the documentation process have a higher documentation practice.

In view of these assumptions, training was developed based on the pre-defined conceptual model to improve knowledge in the transition processes, while a matrix was developed together with the nurses to guide the diagnostic activity in each phase of the transition process to identify the main needs. After its conclusion, a trial period was initiated to identify possible improvements.

Conclusion

This study, which focused on the care provided to FCs and the respective nursing documentation in the current NIS, revealed some weaknesses in both care design and documentation.

Nurses consider that the documentation does not reflect their work with FCs; they point out work overload, lack of time for records, and lack of resources as difficulties. They also recognize the lack of standardization of records and different levels of mastery of the operating system (SClínico).

The assumptions of participatory action research in health enabled the construction of a model to support family caregivers, which aims to guide the design of care and the documentation process in the approach to the FC of the DP. The study contributed to raising nurses' awareness of the discrepancy between the model in use and the guidelines issued based on scientific evidence. The nursing teams started a path of change to a better systematization of the diagnostic activity, particularly in the assessment of the FC and the transition properties, as well as the implementation of nursing therapies concerning the caregiver as a patient and the standardization of records. Future research should include a higher level of representativeness of the FHUs in the northern region of Portugal and use a study design that does not compromise external validity in order to extrapolate the results.

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