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EDITORIAL

Self-Management of Health Status: Challenges Ahead

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The capacity for self-care is recognized by the World Health Organization (WHO) as the basis of healthcare. Self-care is interconnected with the physical, psychological, emotional, and spiritual dimensions, and also with self-knowledge and well-being. Self-care is closely linked to personal balance throughout the life cycle and is at the heart of people's lives. Acknowledging this, WHO considers interventions to promote self-care as within the scope of health promotion interventions, since they have the potential to increase choice and provide more opportunities for individuals to make informed decisions about their health and healthcare. Those interventions must be accessible and affordable by indviduals.[1]

Self-care interventions can be sorted into three levels: Self-knowledge (self-help, self-education, self-regulation, self-efficacy, self-determination); Self-assessment (self-selection, self-screening, self-diagnosis, self-collection, self-monitoring); and Self-management (self-medication, self-treatment, self-examination, self-injection, self-administration, self-use),[1] which is recognized as the one having the greatest potential for personal well-being.

Self-management of health in chronic disease encompasses 3 dimensions. The first concerns the Person, considering that the person must actively participate and take responsibility in the care process and have a positive way of facing adversity. The second concerns the Person's Relationship with the Care Environment, recognizing that people must be informed about their condition and treatment, must be able to express their needs, priorities, and values, in an environment of partnership and openness to social support, and its self-management process must be individualized. Finally, the third-dimension states Self-Management as an Activity, considering that it is a lifelong task that requires personal skills (namely, decision-making and problem-solving) and covers both management of health and emotions.[2] As chronic disease conditions are related to lifestyles, many times the first step towards change is often the most difficult, as it includes awareness of the problem, mobilization of internal resources and decision-making that “may need” the support of a health provider. This is where Nursing care can be decisive, as self-care interventions or self-management training, when provided in a safe and supportive environment, offer an opportunity to increase people's active participation in their own health, increase functionality and improve quality of life.[3,4]

Behavior change is one of the most difficult decisions and actions to begin and maintain, which is why research into self-care and empowerment for self-management of health still on the international research agenda.[5] Now is the time for action and empowerment, and the world's population expects to rely on all health providers, half of which are 28 million nurses worldwide. These professionals need to be able to deal with the unpredictability of the person “with whom” they are caring of, have the ability to accept their choices, even when they include health-risk behaviors, and to accept that the power lies with each person. Person-centered care is not real if the person is not truly involved in planning and making decisions or whenever their wishes and expectations, even if harmful, are not respected. A lot is asked to these professionals these days, but the potential of their workforce is also threatened by multiple factors: the shortage of health professionals pointed out by different international organizations; the attempt to generalize and downgrade the training of nurses in several countries around the world as a way of reducing costs, depriving people of being cared by differentiated nurses; the decrease of health training in higher education; and the disinvestment in national health systems, benefiting private services that do not invest on health promotion strategies, including self-care interventions.

Research in this area can make a decisive contribution to both people and health professionals, empowering them to enable and respect rights and choices, but it needs to integrate both lived experiences into the development of evidence-based and person-centered interventions.

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This Journal's contribution is minor, but Self-Management of Health was the most published topic on this issue nr. 27.

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Barriers influencing nurses' attitudes towards palliative care in the neonatal intensive care unit: a scoping review

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Abstract

Objectives
To identify the barriers that influence nurses' attitudes towards palliative care in the neonatal intensive care unit.

Background
Neonatal nurses play a crucial role in caring for the newborn suffering from a complex chronic illness or who is at the end of life and needs palliative care. In the neonatal intensive care unit, the implementation of palliative care is inconsistent due to the existence of barriers that influence nurses' attitudes when faced with the need to make decisions related to newborns' end-of-life or the suspension of curative treatments.

Methods
Following the methodology designated by the Joanna Briggs Institute and the PRISMA-ScR as a complementary checklist, this scoping review was conducted in three phases and 10 databases were searched for relevant primary research studies, systematic reviews and meta-analyses, in English, Portuguese, French, and Spanish from 2016 to 2021. The data obtained through the extraction process were gathered in a table, and included the study characteristics, the population involved, the key findings related to the barriers influencing the nurses' attitudes towards the provision of palliative care in the neonatal unit and the instruments used to assess those attitudes.

Results
Sixteen studies met the inclusion criteria. The main barriers identified by the studies are related to the absence of training in palliative care, difficulty in communication with parents and between health professionals, and the absence of policies related to the provision of neonatal palliative care. The semi-structured interview has been the most common and widely used instrument for qualitative studies. Questionnaires were selected for quantitative studies, with the NiPCAS being the most commonly used in the NICU.

Conclusion
The barriers influencing nurses' attitudes towards the implementation of neonatal palliative care are identified by the scientific literature, however care remains inconsistent. The definition of training strategies and organizational policies can reduce the impact of barriers faced by neonatal nurses in the provision of palliative care.

Keywords
Attitudes; Barriers; Intensive Care Unit; Neonatal; Nurse; Palliative Care.

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Background

The survival of premature newborns at the limit of viability and other newborn with very serious pathology is due to the evolution of technical and scientific knowledge in the field of Neonatology. However, if survival rates are higher, the potential for well-being and a healthy life decreases due to morbidity, disability and complex chronic diseases (CCD) leading to unpredictable levels of health difficult to manage, which may influence the newborn development in the short, medium and long term.[1]

Palliative care (PC) needs in the neonatal population are mainly important in situations of pre or postnatal diagnosis of life-limiting and/or life-threatening conditions (e.g. bilateral renal agenesis, anencephaly, trisomy 13 and 18…), when there is a high risk of morbidity or death (e.g., severe bilateral hydronephrosis, hypoplastic left heart syndrome, neurological disease…), when newborns are at the threshold of viability (22-23 weeks' gestational age), postnatal situations with high risk of sequelae and compromised quality of life (e.g., severe hypoxic-ischemic encephalopathy, severe peri-intraventricular haemorrhage), or postnatal situations causing great suffering and no possibility of cure (e.g., severe necrotizing enterocolitis) or no cure.[2] Thus, in the context of neonatal intensive care, it is necessary for health professionals, specifically nurses, to develop skills in palliative care (PC) in order to support the newborn and his/her family[3,4] by providing holistic, active, and total family-centred care from diagnosis, throughout the newborn life, at death, and beyond. Neonatal palliative care (NPC) encompasses physical, emotional, developmental, social and spiritual elements, and focuses on enhancing the newborn quality of life and supporting the whole family, including management of distressing symptoms, end-of-life care and bereavement support.[5]

The decision to initiate PC to the newborn should involve the multidisciplinary team and consider the relevant facts related to the newborn clinical situation, the opinion of caregivers, including parents, and, if necessary, the opinion of an PC expert team and the Ethics Committee.[6]

The literature and practice show that the implementation of NPC is inconsistent[7–9], often due to the emotional distress and ethical dilemmas that nurses experience when faced with the need to make decisions related to the newborn end-of-life or the suspension of curative treatments.[4,10] The assessment of neonatal nurses' attitudes toward the implementation of NPC has been carried out through instruments that enabled researchers to identify barriers to the provision of NPC.[3,11,12] Some of those barriers include human resources with inadequate ratios and lack of training in PC, an unfavourable physical environment, technological imperatives, difficulty in communication between team members and with parents, and unrealistic parental expectations.

The use of instruments highlights the impact that nurses' attitudes may have on the provision of palliative care for newborns, and enable the implementation of policies that help health professionals make consistent and holistic decisions in a constant search for improved quality of care.

A preliminary search conducted in the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports, Cochrane Library, MEDLINE and CINAHL, did not identify a scoping review on this topic. Scoping reviews aim to map the main concepts that underpin an area of research and the main sources and types of evidence available.[13,14] Therefore, this approach was considered a useful way to map and examine the scientific evidence on the barriers influencing nurses' attitudes towards PC in NICU.

Aim

The aim of this scoping review is to identify and map the literature about the barriers that influence nurses' attitudes towards palliative care in neonatology.

This scoping review will focus specifically on the following questions:

What are the barriers that influence nurses' attitudes towards palliative care in neonatology?

What instruments have been used to assess nurses' attitudes toward palliative care in neonatology?

Methods

The scoping review strategy followed the recommendations of the Joanna Briggs Institute (JBI) methodology, namely, identification of research objective/s and question/s, developing the inclusion criteria, searching for the evidence, evidence selection, evidence extraction, analysis of the evidence, presentation of the results, summarizing and reporting results.[14,15] The Covidence® software and the Preferred Reporting Items for Systematic Reviews extension for Scoping Reviews (PRISMA-ScR) reporting guideline and checklist[16] were used to support data management. Assessment of methodological limitations or risk of bias of the evidence included within this scoping review was not performed because it is not generally recommended in scoping reviews.[14] This study is registered in the Open Science Framework: osf.io/phcm7

Search Strategy

The search considered studies written in Portuguese, English, French and Spanish, published between 2016 and 2021. All scientific articles addressing the study objective of a quantitative, qualitative or mixed nature, and those unpublished (grey literature) were included.

In a first stage the search was limited to four databases, namely CINAHL Complete, MEDLINE Complete, COCHRANE Database of Systematic Reviews (via EBSCOhost), and Joanna Briggs Institute EBP Database via OVID, whereby analysing the words contained in the title and abstract of the studies, the indexing terms (MeSH 2020 descriptors and keywords) were identified. The second stage was carried out in the databases referred to in the first stage, as well as Academic Search Complete (via EBSCOhost), b-on, BioMed Central, Science Direct for Elsevier publications, PubMed, Scopus, and Biblioteca Virtual da

Saúde. In a third stage, the references of the identified documents were analysed in order to identify some additional bibliography. The literature search included the following combination of MeSH headings and Keywords searching: ((“barriers”) AND (“nurse” OR “nurses” OR “nursing”) AND ((MM “palliative care”) OR (“end of life”)) AND ((MM “neonatal intensive care unit”) OR (“NICU”))). The CINAHL Headings descriptors used were ((“barriers”) AND (MH”nurses+”) AND ((MM “palliative care”) OR (“end of life”)) AND ((MM”intensive care units, Neonatal”) OR (“NICU”))).

Eligibility

The eligibility criteria are described in table 1.

After the identification of the relevant studies, they were imported into the Covidence® software. Duplicates were removed using this software and, after applying the inclusion and exclusion criteria, the studies were screened, first by analysing the title and abstract, and, in a second phase, by reading the full text. The process of study selection and data extraction was independently performed by two reviewers and with a third reviewer who intervened whenever a conflict arose in the selection of studies.

Table 1 – Eligibility Criteria

Eligibility criteria	
Inclusion Criteria	**Exclusion Criteria**
All studies in which the participants are nurses who provide care in the NICU.	All studies whose focus of interest is not on neonatal nurses. All studies whose participants include healthcare professionals other than neonatal nurses.
All studies whose phenomenon of interest is related to the barriers, challenges or any impediments influencing nurses' attitudes towards PC in the NICU. Studies exploring attitudes, perceptions, and experiences of neonatal nurses in relation to NPC.	
All studies developed at the NICU, regardless of their level of differentiation or complexity.	All studies whose context of care is not the NICU, such as in the Paediatric Intensive Care Unit or Hospices
Studies in English, Portuguese, French, and Spanish from 2016 to 2021.	

Data extraction and synthesis

Following the JBI methodological guidance for scoping reviews on the data extraction instrument[15], at the protocol stage the authors developed a charting table to register the information of the records, specifically the authors, country where the study was developed, year, title, aims, methodology and topics that would provide answers to PCC. Once the data extraction table was completed, the main key findings were extracted in a synthesis table (Table 2). This table contains the participants, the context, and the barriers identified as those influencing nurses' attitudes toward palliative care in the NICU and the instruments used by the authors to assess these attitudes. The data extraction was performed by one reviewer, and a second one verified the extracted data. Where there was a conflict, a third reviewer intervened to ensure that the data extraction remained consistent with the objective and questions outlined. A word cloud was generated in order to extract the most relevant topics from the studies, and a narrative analysis was performed.

Table 2 - Synthesis table with key fidings of the studies included in the review (n=16)

1st Author Studies	Participants Context	Barriers			Instruments
		Parents	Nurses	Health Institution	
Razeq, N. 2019/Jordan Quantitative	Nurses (n=289) NICU	Difficulty in interpreting Parents' attitudes	Insufficient time to make decisions; difficulty in establishing a prognosis	Lack of policies; conflicts between NICU policies and those of each professional	Parents' information and ethical decision making in neonatal intensive care units: staff attitudes and opinions
Forouzi, M. 2017/Iran Quantitative	Nurses (n=57) NICU	----------	Inappropriate nurse/newborn ratio; absence of PC training	Inadequate environment; absence of protocols	Neonatal Palliative Care Attitude Scale (NiPCAS)
Beckstrand, R. 2019/USA Mixed	Nurses (n=121) NICU	Difficulty in communication with parents	Conflicts with parents; Inconsistency in medical staff decisions; therapeutic futility	Inadequate environment; lack of privacy	National Survey of NICU Nurses' Perceptions of End-of-Life Care

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Chin, S. 2020/USA Mixed	Nurses (n=200) NICU	Non-inclusion of Parents in decisions; requirement for continuation of treatment	No understanding of the goals of neonatal PC; stigma; staff use life support technology beyond what is comfortable	Lack of support for neonatal PC by society; protocols; the physical environment of the NICU; lack of privacy	NIPCAS Questionnaire with open questions
Cerratti, F. 2020/Italy Quantitative	Nurses (n=347) NICU	Suboptimal communication between parents and healthcare professionals; families are not aware of neonatal palliative care options	Inability to share personal views; clinicians felt out of tune with parents' requests to prolong infants' lives; unsatisfactory previous experience in providing care in a palliative setting	Physical environment not appropriate; shortage of resources; for palliative care; lack of formal end-of-life policies and neonatal palliative care in-service education for staff	NIPCAS
Kilcullen, M. 2017/Australia Qualitative	Nurses (n=8) NICU	Family is far away from the hospital; no use of technology to communicate	Lack of experience in PC; emotional distress; difficulty in changing the model of care from curative to palliative	Lack of privacy; lack of recommendations, procedures and policies, absence of evaluation	Semi structured, individual interviews
Kim, S. 2019/ South Korea Qualitative	Nurses (n=20) NICU	Communication with parents; demands for the continuation of treatment; parental expectations	Lack of experience in PC; difficulty in supporting parents; conflicts about deciding between comfort care and curative care; therapeutic futility	Inadequate environment, lack of privacy; restriction of visits; performance of administrative functions	Semi structured, individual interviews
Oliveira, FC. 2018/Brazil Qualitative	Nurses (n=9)	------------------------	Emotional distress; identification with families; lack of skills to provide PC; lack of education/formation; emotional disengagement, repression of feelings and thoughts, avoidance	Limited institutional support for PC; inconsistencies in hospital policies; lack of standardized PC and protocols	Semi structured, individual interviews
Gibson, K. 2018/Australia Review of the Literature	Nurses	Decisions made by parents to continue treatment; irrational expectations relating to the long-term outcomes of infants	Moral distress; sense of powerlessness; prolonged emotional involvement with families; avoidance; lack of knowledge, experience, and competence; lack of palliative care education	Inadequate environment; NICU guidelines on palliative care poorly reflect the values and ideals of staff or the community	
Kachlová, M. 2021/Czech Republic Quantitative	Nurses (n=109) UCIN	Parental demands to continue curative treatment	Lack of training in PC; lack of emotional support	Inadequate ratio of human resources; Inadequate environment; Lack of support for training	NiPCAS
Sadeghi, N. 2021/Iran Qualitative	Nurses (n=12) UCIN	Parents do not accept death of the infant; parents' presence	Inadequate ratio of nurses; emotional stress; medical indication for continue treatment	Inadequate environment	Semi-structured in-depth interviews
Salmani, N. 2018/Iran Review of the Literature	UCIN	Requirement for continuation of treatment; culture and religion	Health professionals' negative attitude toward death; religion; lack of training in PC; ethical dilemmas	Absence of training courses; Inadequate environment; low nurses/infant ratio	
Kim, S. 2017/South Korea Qualitative	Nurses (n=20) UCIN	Denying the infant's medical situation; discourage the creation of memories by grandparents	Emotional stress; beliefs and cultures; inadequate ratios; work overload	Absence of protocols and recommendations; inadequate environment; absence of team of specialists' in PC	Semi-structured interviews
Silva, I. 207/Brazil Qualitative	Nurses (n=8) UCIN	Parents not aware of palliative options	Lack of PC training; lack of dialogue between medical and nursing teams; impossibility of expressing opinions in end-of-life decisions	NICU organization; routines; dealing with the rules established by institutions	Semi-structured interviews
Silva, E. 2017/Portugal Qualitative	Nurses (n=15) UCIN	Conflicts with parents and between the couple; difficulty in decision-making	Lack of communication; inability to provide support; therapeutic boundaries; lack of consensus	Inadequate environment; lack of privacy; absence of protocols	Semi-structured interviews

Carvalhais, M. 2019/Portugal Qualitative	Nurses (n=15) UCIN	Difficulty in decision-making; parents' suffering	Lack of PC training and PC education	Absence of protocols, recommendations; diminished psychological support	Semi-structured interviews

Results

Search Results

According to figure 1 (PRISMA 2020 flowchart of the study selection process), the search conducted in 10 databases identified 483 records. Of these, 75 records were removed by Covidence® for duplication. The screening of the title and abstract of the remaining 408 records was performed and 370 were excluded for not meeting the inclusion criteria, leaving 38 reports for eligibility. After reading the full text, 22 reports were excluded for not meeting the inclusion criteria, namely the context, the population, and not making reference to the study design. Therefore, 16 studies were included in this scoping review.

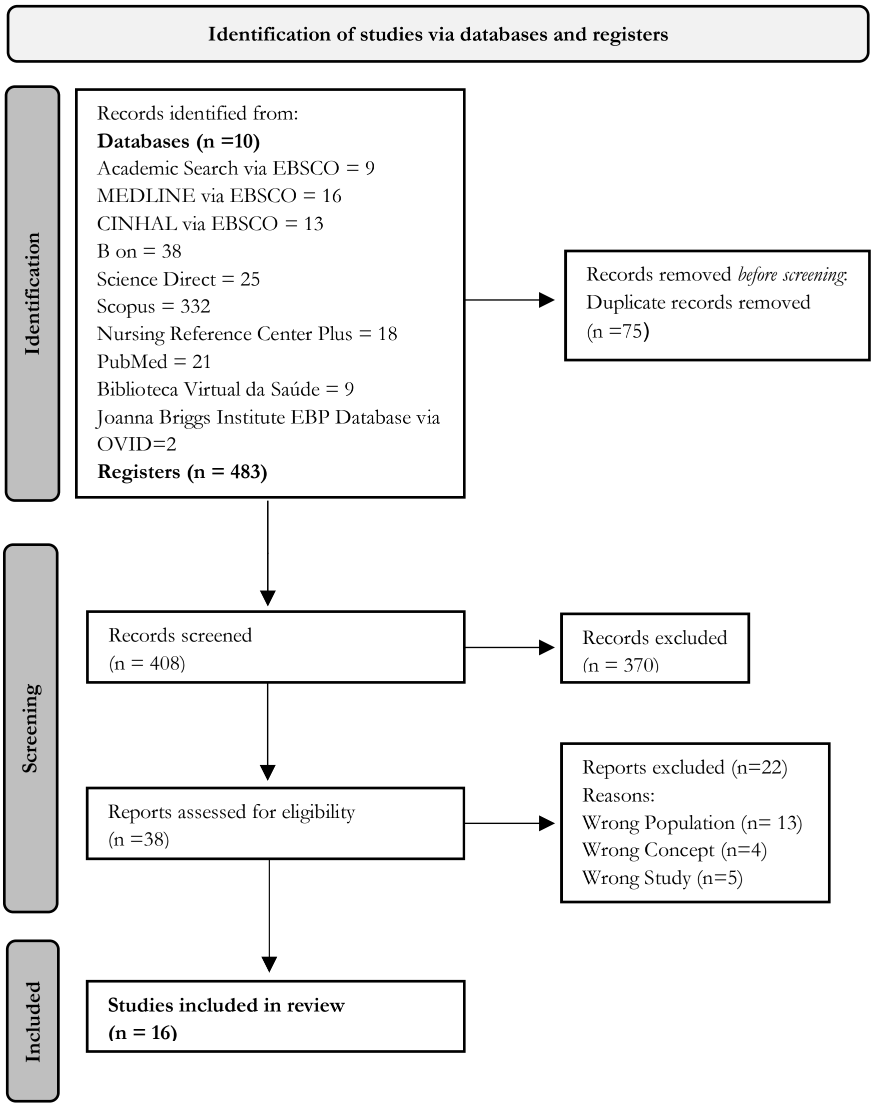

Figure 1 - PRISMA 2020 flowchart of the study selection process

Characteristics of the studies included

In relation to the year of publication, there was a continuum from 2016 to 2021. The year 2018 included 5 studies, 2017 and 2019 included 3 studies respectively, 2020 and 2021 with 2 studies respectively, and 2016 with only 1 study. The studies were conducted in European countries (n=4), North America (n=2), Middle East (n=4), South America (n=2), Asia (n=2) and Oceania (n=2). The 16 studies analysed adopted as methodological strategy the qualitative approach (n=8) and the quantitative approach (n=4). Academic dissertations with a mixed approach (n=2) and Literature Reviews (n=2) were also identified. All studies elected the NICU as context, and nurses as participants (n=16). The main research objectives focused on exploring the experiences [9,17–19], perceptions, and[3,20–22] attitudes[23–26] of nurses towards the implementation of neonatal palliative care and the challenges[24,27] or barriers that exist.

Thematic analysis

Using the NVivo® software, a thematic analysis of the 16 studies was carried out and four themes (figure 2) emerged reflecting the barriers influencing nurses' attitudes towards palliative care in the neonatal intensive care unit, namely, (1) the nurses' experience in providing palliative care to newborn and their families; (2) the nurse's communication with the multidisciplinary team and parents; (3) the unfavourable conditions in which palliative care is provided, (4) the institutional and organizational support through the existence of protocols, guidelines, policies, and expert teams in palliative. A word frequency counts of the 16 studies included in the review was carried out, and a word cloud was generated (Figure 3). The most frequent topic was "experience" (0.54%), followed by "environment" (0.29%), "experiences" (0.28%), "healthcare" (0.24%), "guidelines" (0.18%) and "perceptions" (0.17%). These words reflect some barriers that may influence nurses' attitudes towards palliative care in the NICU.

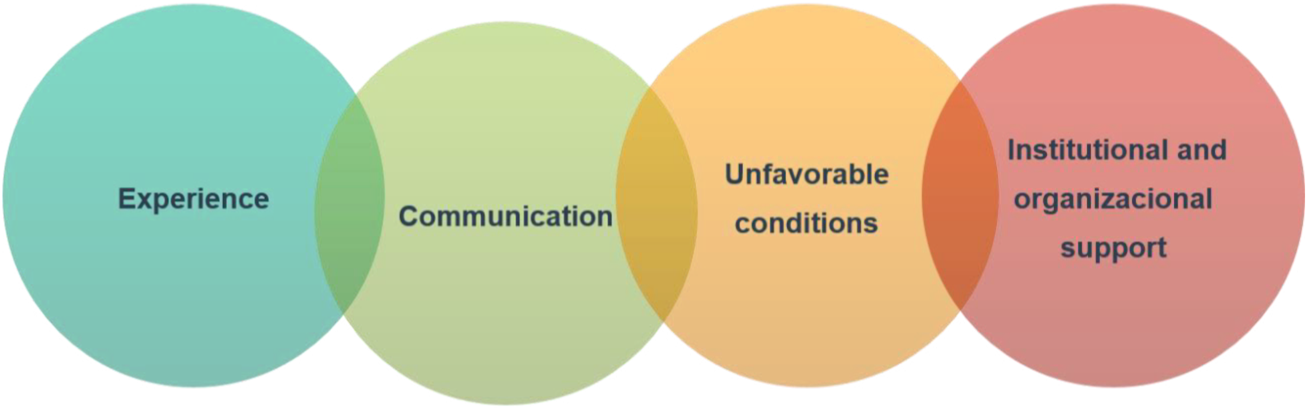

Figure 2 - Thematic analysis of the studies included in the scoping review (n=16)

Figure 3 - Word cloud analysis of studies included in the scoping review (n=16)

Instruments that enable the assessment of nurses' attitudes towards palliative care in the NICU

Regarding the second question, "*What instruments have been used to assess nurses' attitudes toward palliative care in neonatology?",* from the analysis of the 16 studies included in the review, eight (n=8) used the interview to identify the barriers that influence nurses' attitudes toward NPC.[3,7,17,19,21,22,29,30] Six studies used scales and questionnaires, namely *parents' information and ethical decision-making in neonatal intensive care units: staff attitudes and opinions*[24] (n=1), the *National Survey of NICU Nurses' Perceptions of End-of-Life Care*[7] (n=1) and the *Neonatal Palliative Care Attitude Scale - NiPCAS*[12,20,25,31] (n=4). *The Parents' information and ethical decision-making in neonatal intensive care units: staff attitudes and opinions* is a questionnaire dating from 1997 and was used as an instrument for the European study EURONIC.[32] It was constructed to record data on the organization and NICU policies, to survey the opinions and attitudes of health professionals regarding the transmission of information to parents, and the ethical decision-making process in the NICU in relation to the social, cultural, legal and ethical backgrounds of different countries. The *National Survey of NICU Nurses' Perceptions of End-of-Life Care*, used in a mixed study, is a questionnaire aimed to identify nurses' perceptions of end-of-life care. It was based on four similar questionnaires applied to nurses in adult intensive care units, emergency departments, oncology units and paediatric intensive care units. The *Neonatal Palliative Care Attitude Scale - NiPCAS*[11] was developed to examine neonatal nurses' attitudes towards palliative care, attitudes which may constitute barriers or facilitators to PC in the NICU. It is a five-point scale (1 to 5) ranging from strongly disagree to strongly agree. It assesses three dimensions, namely organization, resources, and clinicians. This scale has been used in several studies, translated and validated for other countries[12,25,31,33,34] and the results obtained are very similar, i.e., the barriers identified are related to the lack of training in PC, lack of communication with parents, lack of institutional support, the existence of an environment not conducive to the practice of PC and the imperatives related to technology.

Discussion

In the vast majority of studies, the barriers influencing nurses' attitudes towards palliative care in the NICU relate to lack of experience in providing NPC, lack of training, lack of skills/competencies in communicating with parents and among health professionals, difficulty in dealing with one's own emotions and difficulty in decision-making.

Not having experience in providing palliative care to the newborn, or having had bad experiences, may increase emotional stress and promote situations of avoidance and difficulty in communicating with the family.[9,26,28]

Nurses' little experience in PC combined with lack of knowledge about the philosophy, principles, and practices of PC, is one of the barriers that influence their attitudes towards the implementation of palliative and support measures for the newborn and their family.[3,9,19,30,31,35,36] Therefore, nursing schools curricula[37], health services and institutions[27] should promote PC training at different levels and create a culture that promotes and supports the philosophy of PC[3,9,38], and nurses' professional and personal development.

As a very demanding and specific area, NPC requires theoretical education, technical preparation and training in order to ensure quality care that is culturally sensitive and meets the needs of the newborn and the family. There are recommendations[39] for nurses' training in the area of PC at basic, intermediate and specialized level. The purpose of this training is to understand the concept of PC, assess and manage the symptoms, pain, and discomfort experienced by newborn, children and young people, acquire communication skills with these age groups and their families, and understand suffering, the dying process, death, and grief. Obtaining knowledge on symptom control, namely pain control, is essential to ensure the comfort of the newborn and the reduction of parental stress. PC training provides tools and skills that allow demystifying the use of certain medications for pain relief in newborns, namely the use of opioids. The health team learns to recognize the signs and symptoms of pain and discomfort, objectively assesses the level of pain and justifies the use of opioid, analgesic and sedative drugs, promoting the quality of life of the newborn and his/her family and, finally, the reduction of the emotional distress of the health professionals caring for the triad.

Another key issue in training and acquisition of PC skills is communication of bad news, including those related to end-of-life. Nurses consider it a challenge and a complex intervention to give bad news to parents[40], a procedure causing emotional distress, but essential for decision-making centred on the needs of the parents and the newborn. Communication is the foundation stone of PC and family-centred care (FCC), and may be a barrier that influences the attitudes of nurses towards PC at the NICU since there may be conflicts between parents and the health team[22], and within the health team itself.[31,36–38] Language, culture, and religion of the parents (but also of the health professionals) may be an obstacle[27,36], hindering the transmission of information on the newborn clinical condition, diagnosis, and decision-making regarding curative versus palliative care options.[31] Parents may not understand and accept the decision to initiate PC, demanding that active treatment and life support be continued[22,27,36,38,41], presenting to the healthcare team ethical dilemmas and emotional distress that may hinder the change from curative to palliative care. According to the FCC philosophy, the information parents receive should be consistent, honest, and realistic[7], and parents should be incorporated into the definition of the anticipatory care plan[4,30,34], allowing them to adapt to difficult situations, as parental stress levels may decrease if the health team consistently adheres to FFC practice, reducing inconsistencies in the implementation of interventions and fostering the use of the "same language" by the health team.

Another theme described as a barrier influencing nurses' attitudes towards NPC is the unfavourable conditions in

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which palliative care is provided.[3,7,27,31,34–36,41] An unsuitable environment that does not allow for privacy[3,7,23,25] is perceived by nurses as a barrier to the provision of palliative care. his/her family. The vast majority of NICUs are characterized by being a large, open space, where newborn, parents and health care team coexist, thus reducing the parents' privacy and comfort. The possibility of caring for newborn with PC in a room separate from the NICU would allow parents to enjoy the support of other relatives and also to release their emotions and feelings regarding the process of suffering that they are experiencing. However, this option would require structural and physical changes to the NICU itself and an increase in the nurse ratio, which may not be possible due to organizational issues.[27,38] The shortage of nurses promotes a reduction in the nurse/newborn ratio, which makes it difficult for nurses to be available to accompany and be with parents, to respond to parental wishes and provide all the comfort care they need.[12,18,27]

Institutional and organizational culture and support may be a barrier that influences nurses' attitudes towards the implementation of NPCs.

The absence or lack of recommendations, protocols, standards, and policies favours the ad hoc implementation of NPC[42,43] because decision-making, tasks to be developed, and responsibilities in the different phases of the process depend on the attitude of each member of the healthcare team towards NPC[3,9,17,41,44], promoting inconsistency of care and increased stress for parents and health team. The lack of guidelines, protocols or organizational policies[9,21,22,24,26] may promote situations where decision-making is not based on the needs of the newborn and his family.

The existence of recommendations, standards, and policies together with the possibility of consulting a team of experts in PC can reduce barriers and favour decision-making. Also, the hospital institutions should create an Intra-Hospital Paediatric Palliative Care Support Team, scaled to local characteristics and needs, which can provide direct care and guide in the execution of the individual care plan for children and young people in a situation of complex chronic illness and their families, whenever their intervention is requested.

One barrier associated with the implementation of NPC is related to the use of the word *end-of-life* and the effect it has on care provision. The word end-of-life[7,17,19,30,35,44], relates PC with dying and death. This relationship between PC and death promotes ethical dilemmas and moral distress in nurses[27], since they experience feelings of personal failure[37] in the face of death and parents' expectations and demands[27,34,38,41], adopting interventions related to therapeutic futility, therapeutic distress and the difficulty in changing the model of curative care to palliative care.[7,19,30,34,41] However, the focus of NPC is not entirely on end-of-life and death, but rather on life and the possible transition of the newborn home. This way of being enables newborn and families to live their lives to the fullest while coping with complex medical conditions[45], promoting parenting and parental roles, positive experiences and memories for the whole family for as long as life lasts.

Regarding the identified instruments, the interview is one of the techniques used in qualitative research and gather information about participants' experience and views. Knowing that providing NPC in neonatal unit can place an emotional burden on nurses, the interview is a suitable tool to explore the complex problems nurses experience in their practice and to understand how and why their attitudes impact the provision of palliative care.

With regard to quantitative studies, in this scoping review only one instrument was identified to assess nurses' attitudes towards palliative care in the NICU – NiPCAS.[11] The barriers to the provision of NPC, namely attitudinal, educational, environmental and institutional barriers, identified through the interview in studies with a qualitative approach are similar to the barriers identified by studies that used a quantitative approach using questionnaires or scales.

Limitations

In this scoping review only neonatal nurses were considered as participants and other health professionals were excluded, which may have offered a different perspective on the barriers influencing nurses' attitudes towards palliative care in neonatology. The content of some instruments, such as the interviews, was not available, so the analysis of the studies may have been incomplete.

Conclusion

This scoping review included 16 studies whose focus was on identifying the barriers influencing nurses' attitudes towards palliative care in the neonatal intensive care unit and the instruments that enable the assessment of nurses' attitudes towards palliative care in the NICU. Our findings reinforce the need for neonatal nurses to respond not only to technological demands, but also to the newborn and parent's personalized demands and to those posed to themselves as people. Neonatal nurses face a number of barriers that may influence their attitudes towards neonatal palliative care. The lack of experience and training in palliative care and the deficit of communication between the healthcare team and the one established with parents were considered to be the major barriers to the provision of neonatal palliative care. Thus, we may say that it is urgent and important to develop and boost training programmes related to palliative care, namely those directed to the area of neonatology, define policies and protocols that specify the tasks and responsibilities that each professional develops in the different phases of the care process, to reduce the moral distress and ethical dilemmas faced by nurses, decrease parental stress, and allow for interventions focused on the newborn and the family. Different instruments are used to assess nurses' attitudes towards neonatal palliative care, however, only one of these instruments is dedicated to the area of Neonatology. Further research with other health professionals is important to adjust interventions and promote the improvement of neonatal palliative care.

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Experiences of having lived with Broca's aphasia: a scoping review

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Abstract

Introduction

Broca's aphasia, a non-fluent aphasia, is a frustrating condition with extensive psychological, familial, and social impact. The reports of people who have already recovered or can express themselves are essential to increasing knowledge about the experience of living with Broca's aphasia. A-FROM is a framework designed to organize thinking about the impact of living with aphasia and includes four key domains: *Communication and language environment*; *Language and related impairments*; *Personal identity*, *attitudes and feelings*, and *Participation in life situations*. Nursing intervention is central to optimizing recovery and positively influencing the experience of successfully living with this clinical condition.

Objective

To map scientific evidence about the experience of people who lived through a period of Broca's aphasia.

Methods

A Scoping Review was performed following the Joanna Briggs Institute methodology. The review was based on the research question, "*How does the person report the experience of having lived through a period of Broca's aphasia?*", formulated according to the PCC strategy. The search was carried out in *MEDLINE®*, *CINAHL®*, *Psychology and Behavioral Sciences Collection*, and *Scopus* electronic databases in November 2022. Articles were selected based on the eligibility criteria. The review followed the PRISMA-ScR EQUATOR checklist.

Results

Seventeen articles published between 1961 and 2022 were included. Data obtained were grouped according to the key domains of the A-FROM tool. Information related to *Personal identity, attitudes and feelings*, and *Participation in life situations* were the most cited, followed by *Language and related impairments* and *Communication and language environment*.

Conclusion

It was identified that health professionals, therapeutic interventions, spirituality, hope, context, interactions, and psychosocial factors influence the experience of Broca's aphasia. It is essential to continue investigating how people report the experience of having lived through a period of Broca's aphasia to improve the quality of care and people's quality of life.

Keywords

Aphasia, Broca; Communication; Language Disorders; Life Change Events; Nursing; Review Literature as Topic.

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Introduction

Aphasia, an acquired language disorder, can affect a person's ability to understand or formulate language[1]. Stroke is the most common cause[2]. Broca's aphasia is an expressive aphasia, a non-fluent aphasia, and currently, it is accepted that two main variants exist[3]. In one true Broca's aphasia, extensive damage involves the Broca's area, the surrounding frontal fields, the underlying white matter and basal ganglia[4]. In Broca's aphasia, a drastic loss of speech fluency occurs[4]. The ability to name and repeat is disturbed but listening comprehension is usually normal for colloquial language[3]. One of the most substantial changes is a loss of the ability to introduce some rules into the form of speech. The logic of sequencing the constituent elements may be correct and yet there are no linking particles or verb conjugations[3]. These changes create a communication impairment and impact the quality of life and well-being[5]. Broca's aphasia is a frustrating condition with extensive psychological, familial, and social impact, where the person is often aware of their communication difficulties[2,5]. Because of each person's individuality, context, and injury etiology, Broca's aphasia is a unique and idiosyncratic experience[6].

Living with aphasia: a framework for Outcome Measurement (A-FROM) is a structure designed to understand, guide, and organize thinking related to the impact of living with aphasia[7]. It was adapted from the World Health Organization International Classification of Functioning, Disability, and Health (ICF) and incorporated concepts from other models, such as the Canadian Disability Creation Process model[8]. It is a broad, non-prescriptive approach to outcome measurement that considers the impact of aphasia in important areas of life for the people with aphasia and their families. It is designed to help healthcare professionals and researchers think about the aphasia results, addressing several factors that affect the success of living with aphasia[7].

The A-FROM structure encompasses four key domains, which are dynamic, overlap, and interact with each other: *Communication and language environment* (any element outside the person who facilitates or acts as a barrier to communication, including individual/social attitudes, partner attributes or physical factors); *Language and related impairments*; *Personal identity, attitudes and feelings*, and *Participation in life situations* (involvement in relationships, functions, and daily activities)[9].

Because of impaired communication, people with aphasia often face barriers in accessing health information[10]. Their capacity to transmit symptoms, question, request care, and express feelings, needs, wills, and decisions concerning their healthcare is compromised[10]. In nursing, understanding and being understood while communicating is crucial to quality of care and to meet the patient's care needs[11]. Nursing interventions are central to promoting effective and therapeutic communication, optimizing recovery, and positively influencing the experience of successfully living with this clinical condition[12].

People experiencing Broca's aphasia cannot communicate changes at that moment. Due to this, reports of people who have recovered from aphasia or can express themselves are vital to understanding Broca's aphasia experience[13]. Narrating the "internal world" is a vital source of information for understanding the experience of living without language[13]. Experience is what happens to us, what touches us, and when it reaches us, it shapes and transforms us[14]. In this context, knowledge of experience is about the meaning of what happened[14], how the person interprets, understands and explains this experience, which presupposes an individual reflection[15]. Illness experiences are full of meanings[16], which can only be understood through the meaning attributed by those who experienced them. Understanding the individual experience of the person who went through a period of Broca's aphasia from a retrospective perspective and not from an immediate lived experience, increases the comprehension of the phenomenon and reveals subjective truths. The experience is always subjective, individual and unique, including Broca's aphasia experience.

In a preliminary search, it wasn't found any literature review about the experience of having lived through a period of Broca's aphasia from the perspective of people who have experienced this clinical condition. Thus, the high prevalence of strokes, as the main cause of aphasia[2] and the impact of this language disorder on the person's life justified the need to develop this Scoping Review. Besides mapping and reporting the existing evidence, this review will clarify key concepts and identify gaps in the knowledge regarding the experience of having lived with Broca's aphasia[17]. It's crucial to decrease the gap between the people's perspective who have experienced this phenomenon and the external perspectives on aphasia[18].

Aims

The main aim of this Scoping Review is to map the available scientific evidence about the experience of adults who lived a Broca's aphasia period according to their perspective, regardless of etiology. More specifically, the purpose of this review is to identify what people report about their Broca's aphasia experience, the impact and changes, the feelings and needs that emerged, factors that influenced the experience, which supports and resources they had and which they would have like to have had, always from the individual's perspective.

Exploring the experiences of people with aphasia can improve the quality of care[19]. Thus, the understanding gained in this review and the transferring this knowledge into practice can improve the health care provided to individuals with Broca's aphasia, including the quality of nursing care, by implementing more efficient nursing interventions addressing this population's needs. This knowledge can also be important for people with other language disorders and may contribute to improving health outcomes.

Methods

A Scoping Review was developed following the Joanna Briggs Institute methodology as a guide for transparent

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research that allows understanding and replicating the entire path[20]. The review was based on the research question: "*How is reported by the person the experience of having lived a Broca's aphasia period?*". It was formulated according to the PCC strategy: P=Population (adults who experienced Broca's aphasia); C=Concept (report of Broca's aphasia experience); C=Context (ambulatory and hospital). This study adheres to the PRISMA-ScR EQUATOR checklist (Supplementary File 1).

Eligibility criteria

Study inclusion criteria:

- Population: adults aged 19 years or over (according to the adult's definition of World Health Organization[21]) with no maximum age limit, who have lived a Broca's aphasia period (or expressive aphasia or a non-fluent aphasia), or that are still in recovery but are able to express themselves.
- Concept: Broca's aphasia experience from the participants' perspective regardless of Broca's aphasia etiology. What people report (e.g., direct quote, interview data) about Broca's aphasia experience, the impact, changes, feelings, specific needs, strategies and resources used, factors that influenced the experience, and which supports and resources they would like to have had.
- Context: ambulatory and hospital context.
- Primary studies, theoretical articles, literature reviews, and reports of experiences in English, Spanish and Portuguese, regardless of the year of publication, published in periodical journals, with access to the full text.

Study exclusion criteria:

- Population: children; participants who are diagnosed only with other types of aphasia; participants who have chronic aphasia (chronic aphasia was defined as coexisting at least one year after the injury that caused it[22]); participants who cannot express themselves; participants who have impaired communication resulting from sensory loss, dementia, delirium, or coma; participants who are diagnosed only with motor speech disorders resulting from muscle weakness or incoordination.
- Concept: experiences only from the perspective of caregivers, couples, friends, and healthcare professionals.

Sources of information and search strategy

The research was carried out in November 2022. A strategy that encompasses three stages was adopted[20]. The first step included a search in the MEDLINE® (Medical Literature Analysis and Retrieval System Online Complete) and CINAHL® (Cumulative Index to Nursing and Allied Health Literature Complete) databases, using terms in natural language. Subsequently, the titles and abstracts' words were analyzed, as well as the indexed words used to describe the article, which allowed us to identify relevant search terms for this Scoping Review. In the second stage, a search was performed in the MEDLINE®; CINAHL®; Psychology and Behavioral Sciences Collection (via EBSCO) and in the Scopus database using search terms in natural language and DeCS and MeSH indexing terms in all fields of the articles without selecting a specific field, applying boolean operators "OR" and "AND", as explained in Table 1. The third phase of the research comprised the analysis of the references lists of the articles selected for this review to find important complementary studies to answer the research question.

CINAHL	MEDLINE	PSYCHOLOGY AND BEHAVIORAL SCIENCES COLLECTION	SCOPUS
(Narrati* **OR** (MH "Narratives") **OR** (MH "Narrative Medicine") **OR** (MH "Life Histories") **OR** (MH "Reports")) **AND** ((Experience* **OR** (MH "Life Experiences") **OR** (MH "Life Change Events") **OR** (MH "Psychosocial Aspects of Illness") **OR** Psychosocial adjustment) **AND** (Aphasi* OR (MH "Aphasia, Broca") OR (MH "Speech Disorders") OR Communicat* Disorders OR Communicat* Difficulties))	(Narrati* **OR** (MH "Narration") **OR** (MH "Narrative Medicine") **OR** Life Histories **OR** Report*) **AND** ((Experience* **OR** Life Experience* **OR** (MH "Life Change Events") **OR** Psychosocial Aspects of Illness **OR** Psychosocial adjustment) **AND** (Aphasi* **OR** (MH "Aphasia, Broca") **OR** (MH "Speech Disorders") **OR** Communicat* Disorders **OR** Communicat* Difficulties))	(Narrati* **OR** Life Histories **OR** Report*) **AND** ((Experience* **OR** Life experience* **OR** Life Change Events **OR** Psychosocial Aspects of Illness **OR** Psychosocial adjustment) **AND** (Aphasi* **OR** Broca Aphasia **OR** Speech Disorders **OR** Communicat* Disorders **OR** Communicat* Difficulties))	(Narrati* **OR** Life Histories **OR** Report*) **AND** ((Experience* **OR** Life experience* **OR** Life Change Events **OR** Psychosocial Aspects of Illness **OR** Psychosocial adjustment) **AND** (Aphasi* **OR** Broca Aphasia **OR** Speech Disorders **OR** Communicat* Disorders **OR** Communicat* Difficulties))

Table 1 – Search terms used in databases

Selection of sources of evidence

Following the search in databases, the articles identified were uploaded into the electronic tool Rayyan® to organize the results and remove duplicates. The selection of the studies was carried out according to the inclusion and exclusion eligibility criteria. It started with reading the titles and abstracts, followed by reading the full text of the studies identified for eligibility. Studies that did not meet the inclusion criteria were excluded. Two reviewers performed the selection of sources of evidence. The consensus of the independent reviewers resolved discrepancies in the inclusion or exclusion of articles.

Data collection and synthesis of results

To extract relevant information from the studies included in the review, an instrument (table) was built in Microsoft Excel®, based on Joanna Briggs Institute guidelines[20]. This table includes information about the author(s), year of publication, country, aims, participants, methodology, aphasia etiology, concept (Broca's aphasia experience), and context.

Results

Selection of sources of evidence

A total of 1012 articles were obtained from the search in CINAHL®, MEDLINE®, Psychology and Behavioral Sciences Collection, and Scopus databases.
After removing duplicates, 961 articles were obtained. The selection of the studies was carried out according to the inclusion and exclusion criteria. After reading the title and abstract, 905 articles were excluded because they weren't related to the theme and didn't meet the inclusion criteria. 56 articles were sought for retrieval, but 2 could not be retrieved. 54 articles were assessed for eligibility. After analysis, 44 articles were excluded: 15 because the participants were people with chronic aphasia; 23 for not addressing the aphasia experience according to the participant's perspective; 2 because the focus was not the phenomenon under study, and 4 because they only address other types of aphasia. Of these articles, 10 were included in the review. From the analysis of the included studies' references 7 more articles were added, totaling 17 papers at the end. The PRISMA 2020 flow chart[20] (Figure 1) shows the study selection process.

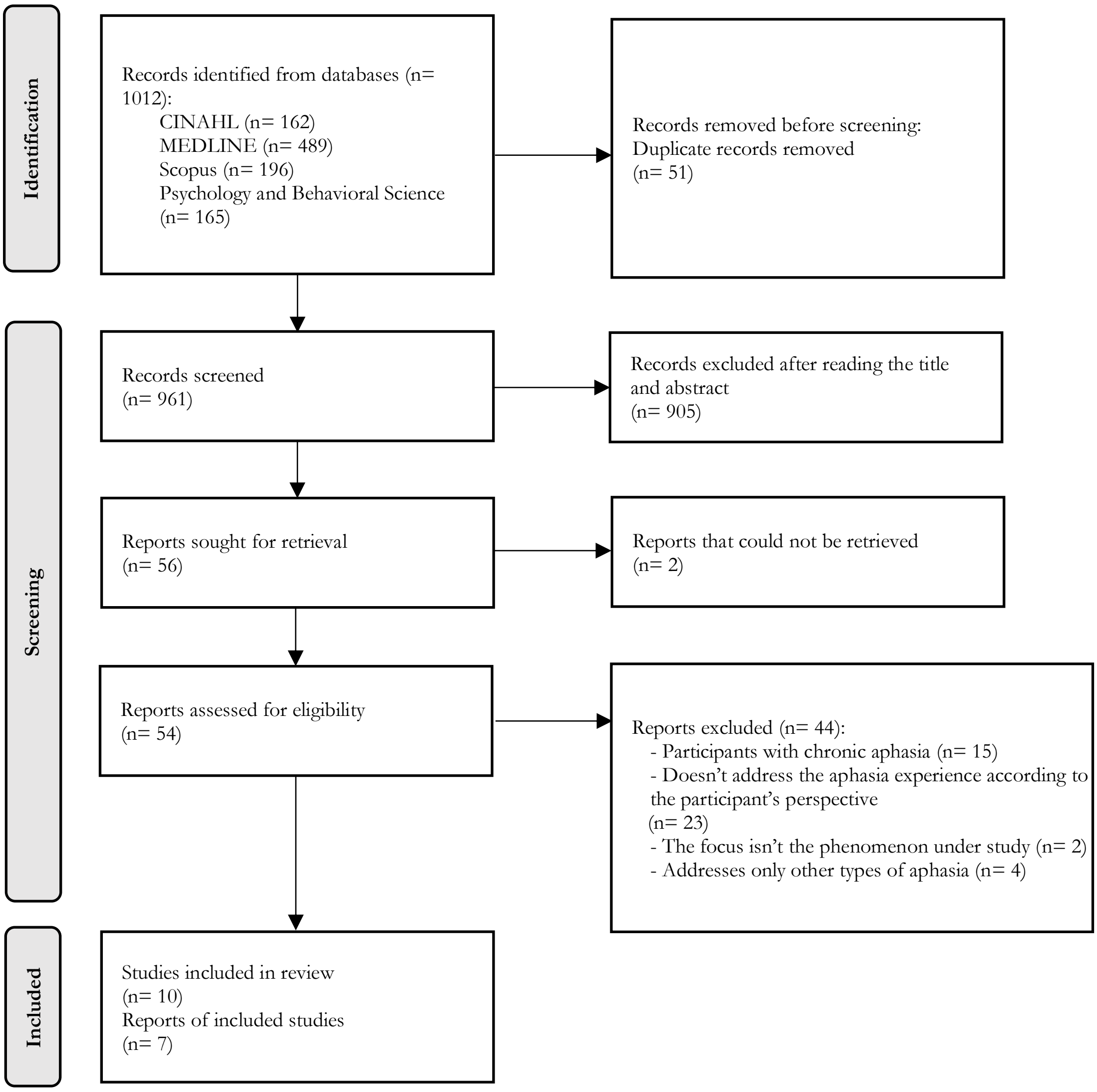

Figure 1 - PRISMA 2020 flow chart[15]

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Characteristics of included studies

Seventeen articles published between 1961 and 2022 were identified. Seven studies were developed in Australia[23,24,29,30,31,37,38], five in United States of America[26,32,33,34,35], two in United Kingdom[27,36], one in Netherlands[28], one in New Zealand[25], and one in Argentina[13]. The methodology used in the selected articles varied from primary qualitative studies[23,24,25,26,27,28,30,31,33,34,36,37,38], experience reports[29,32], and theoretical articles that contain a first-person experience report[13,35]. The aphasia etiology in the analyzed articles was, in its great majority, the stroke.

It is essential to state the difficulty in finding studies only with people diagnosed with Broca's aphasia. The justification probably is because, in most situations, the biggest problem occurs in expression, but often this is not unique, rigorous, specific and doesn't occur in isolation. In the search carried out, it wasn't found any article exclusively about the experience of Broca's aphasia with participants that only experienced Broca's aphasia and without other associated language disorders. One article reports the experience of Broca's aphasia and speech apraxia[35]. Still, all the selected articles for this review include participants diagnosed with Broca's aphasia, or expressive aphasia or non-fluent aphasia.

Only one study explicitly and specifically reports the impact of writing impairment in Broca's aphasia experience[36]. All the other articles included in this review address mainly or only language disorders regarding oral communication.

Synthesis of results

The analysis of the selected studies allowed us to answer the research question. The results extracted from this Scoping Review varied between the impact of Broca's aphasia, which affects a person's different dimensions, inhibitory factors, and facilitating factors of living successfully with this clinical condition. The following Table 2 enables visualizing the results extracted from the analyzed articles and framing them with the review's question and objectives.

Table 2 – Results extraction

Author(s)/ year/ country	Aims	Methodology	Population	Concept: Broca's aphasia experience	Context
S1 - Ardila A and Rubio-Bruno S[13] **2017** **Argentina**	To analyze how people with aphasia experience the world and what they report about the experience of living without language	Theoretical article (contains a first-person experience report)	Adults with aphasia, including adults with Broca's aphasia	- People with aphasia live in an idiosyncratic cognitive world. The internal cognitive world is altered due to the lack of language. Cognitive strategies need to be reorganized ("*I had to reinvent the world around me because this universe was only in words*"); (verbal) intelligence is compromised; - In aphasia, only external stimuli are available. A particular dimension of the world is lost (language) and only the visual-perceptual information remains ("*And suddenly the words disappeared*"); - Nonverbal skills are sometimes affected in aphasia; - "*It was no longer important to discover the beauty since it cannot be expressed in words*".	Not specified
S2 - Armstrong E et al.[23] **2012** **Australia**	To present stories of living with aphasia	Qualitative	Two people with expressive aphasia who can already express themselves, and one person who had aphasia (not specified) but recovered quickly	- During hospitalization, it was important to meet people for not to feel isolated or the only one with a problem; - Frustration due to difficulties and failures, and with some therapeutic activities (difficulty or not being able to perform simple tasks); - Emphasis on using humor to help; - Importance of independence to direct their own communication recovery; - Reading the newspaper every day to help to recover language; - Talking with animals at home to practice speaking; - Feeling that could help himself more effectively than speech therapists; - It was important to feel connected to family and friends and talk to them.	Ambulatory

S3 - Baker C et al.[24] **2020** **Australia**	To describe, from the perspective of people with aphasia, the experience of mood changes, depression, and current practice; to describe preferences within a stepped psychological care approach	Qualitative	Ten adults with aphasia, including adults with expressive aphasia	- All participants experienced mood changes but didn't experience gradual psychological care in rehabilitation; - The onset is traumatic, with negative changes in mood and depression, with negative emotional, social, and behavioural consequences (social evasion, persistent low mood, sadness, and withdrawal from rehabilitation); - People try to overcome communication and mood difficulties with limited psychological support and rehabilitation services (low mood and depression are rarely addressed, and people aren't always supported to be independent or make decisions on rehabilitation with an impact on mood); - Positivity, supporting communication, and access to individualized therapeutic interventions would be essential through gradual psychological care to improve rehabilitation results.	Ambulatory and hospital context
S4 - Bright F et al.[25] **2013** **New Zealand**	To explore how hope was experienced by people with aphasia and identify factors that influence it	Qualitative: interpretative description	Five people with aphasia: one with Broca's aphasia, three with anomic aphasia, and one with conduction aphasia	- Hope is fluid, changes frequently and in a short period, and is important; - It seems to be related to how people get involved in rehabilitation and can be influenced; - Factors that influence hope: family, friends, health professionals (either supporting or reducing) and other patients; uncertainty about the future; see hope with a double face (positive and negative aspect) and a sense of disruption (in identity and/or involvement in meaningful activities).	Ambulatory
S5 - Carcello K and Susan M[26] **2020** **United States of America**	To gain a greater understanding of the therapeutic use of blogs for stroke survivors with aphasia, from a psycho-socio-emotional perspective	Inductive qualitative content analysis	Five stroke survivors with aphasia: two with Broca's aphasia and three with an unknown type of aphasia	Participants used blogs to explore what living with aphasia was like: - Difficulty in communicating, writing, and interacting with others by expressing their emotional responses and personal experiences; - Loss of words: "*I'm constantly trying to find the word I need.*"; the devastation of aphasia and emotional impact: "*the speech I used to rely on for a living was gone …It hurts having to search for words.*" - Process of writing: "*sometimes I can't remember the word I want. Sometimes I leave out several words. My spelling is awful. But the thing that pains me most is the grammar … this writing thing is hard*"; - Aphasia affects self-expression and often-times self-concept and identity: "*Before, I could talk intelligently and think straight. After this, I'm virtually mute (…).*"	Not specified
S6 - Clancy L et al.[27] **2018** **United Kingdom**	To explore the experience of stroke survivors with aphasia, caregivers and healthcare professionals	Qualitative	Six stroke survivors with aphasia (including adults with expressive aphasia), ten caregivers and six health professionals	- Aphasia has an emotional impact; - "Interactions" and "context" can help or hinder the process of making sense, the emotional burden and the involvement in rehabilitation; - Three broad themes were identified: "*being in a foreign country*", "*finding a voice*", and "*being just a number*".	Ambulatory and hospital context
S7 - Dalemans RJ et al.[28] **2010** **Netherlands**	To explore how people with aphasia, perceive their participation in society and investigate the factors that influence it, focusing on individual experiences and perspectives	Qualitative	Thirteen adults with aphasia (including adults with expressive aphasia) and twelve caregivers	- The involvement and feeling of belonging in social activities (the quality of the activities is more important than the quantity); - People with aphasia feel isolated, but want to feel involved; - Feeling of being a burden to others, wanting to function normally; - Inability to work often, wishing to contribute in other ways; - Feeling stigmatized, wishing to be respected; - Factors that influence involvement in social participation: • Personal factors: motivation, physical and psychological condition, and communication skills; • Social factors: the role of the central caregiver and the characteristics of the communication partner (s), namely will, skills and knowledge; • Environmental factors: home peace and familiarity.	Ambulatory
S8 - Green C and Waks L[29] **2008** **Australia**	Share the language recovery (expression ability) of a person with aphasia	Experience report	Adult with expressive aphasia who has greatly recovered	- "*I had no words to express myself*"; "*In the hospital, they do not deal well with aphasia or language problems. If a person cannot communicate, the whole system collapses*"; "*I had to rebuild my life*"; "*Progress has been very slow*"; "*I found that even the simplest things were difficult*"; "*Contacting with a person who went through a similar situation in rehab gave me a glimpse of hope*"; - When he got home, he didn't want to go in and felt like he didn't belong there anymore, like a stranger in his own home. Although he was loved, life changed;	Ambulatory

				- "*Four months later, I only had a handful of words*"; "*I felt that I had lost the most important thing in my life. I didn't see the future*"; "*I wish I wasn't alive*"; Nine months after the stroke he had to resign his position; "*I was recovering the language over time, but I couldn't see it*"; "*I felt that the language was stuck*"; "*I learned to enjoy life again*"; "*Recovery is extremely difficult and people feel that they lost something and lament*; "*We lost our dreams, hope, and planned future*"; "*We lost our confidence*".	
S9 - Grohn B et al.[30] **2012** **Australia**	To describe the experience of the first three months post-stroke; to identify factors that facilitate the success of living with aphasia	Qualitative: a prospective longitudinal study	Fifteen people with aphasia, including adults with expressive aphasia	- Factors that facilitate the success of living with aphasia: • Be involved in recovery, be independent, feel to be in control of life and have a purpose in life; • Carry out activities to improve communication: reading, sudoku, Scrabble, writing a shopping list, using the computer and the phone, homework prescribed by therapists; • Social support and involvement of family and friends (including using communication strategies) to help restore confidence and feel competent; • Meet people in the hospital and group therapy (source of support, courage, and motivation); • Importance of rehabilitation, speech therapy, and health professionals (important in the recovery of language, for social interactions, source of information, motivation, courage, and confidence); • Adaptation (using strategies to improve communication); • Have a positive outlook (optimism, hope, determination, and gratitude); - Inability to participate in activities that define the role and previous identity leads to anguish about the future and has and impacts identity/self.	Ambulatory and hospital context
S10 - Grohn B et al.[31] **2014** **Australia**	To describe the insider's perspective of what is important to living successfully with aphasia and the changes in the first year	Qualitative: longitudinal prospective study	Fifteen people with aphasia, including adults with expressive aphasia	- The perception of communication improvements; - Moving forward actively through positive actions and involvement in meaningful activities; - Social support, family, and friends; - Maintaining positivity about the future.	Ambulatory
S11 - Hall WA[32] **1961** **United States of America**	Not mentioned	Experience report	An adult who has experienced expressive aphasia	- Inability to communicate feelings; - Not accepting the inability to speak; - Feelings of pity and pity of the family and others; - Feeling of self-rejection and worthlessness received with comforting words instead of rejection; - Visits invaded the private world; - Anxiety; - Speaking and writing were incompatible with simultaneous thought processes; - The speech was inappropriate for competition and success in the job market; - Importance of speech therapy and psychotherapy in speech rehabilitation.	Hospital context
S12 - Holland AL et al.[33] **2010** **United States of America**	To provide ideas on topics/content for treatment that are meaningful to people with aphasia	Qualitative	Thirty-three adults with aphasia (twenty-nine with non-fluent aphasia)	- Talk about their life experiences, reconnect with families and focus on communicating on the following topics: • Life's history; • Prayers, testimonies, speeches, and palestras; • External interests; • Making plans; • Talking to family and other people and talking about work; • Search or provide information (about strangers, about the family; asking and answering questions); • Making an order at a restaurant; • Telephone.	Not specified

S13 - Laures-Gore JS et al.[34] **2018** **United States of America**	To explore the spiritual experience of adults with aphasia, to understand the role of spirituality in recovery	Qualitative	Thirteen adults with aphasia, including adults with expressive aphasia	- Spirituality can contribute to the recovery, understanding, and acceptance of life changes (coping strategy): as a greater power in controlling events and as an auxiliary; - Other people are essential for aphasia recovery (social relationships imbued with spiritual meaning), which offer a better quality of life, the opportunity to practice language, and motivation for communication, that are important in the search for meaning; - Other forms of spiritual coping can amplify negative reactions to stress and cause people to engage in inappropriate behavior.	Not specified
S14 - Simmons-Mackie N and Kagan A[35] **2007** **United States of America**	To describe aphasia using the World Health Organization ICF; address the impact of contextual factors on the aphasia experience and participation in life activities	Theoretical article (contains a first-person experience report)	An adult reporting their experience of Broca's aphasia and apraxia of speech	- Experience of severe activity limitations and participation restrictions; - Protection of the family, removing responsibilities, and avoiding activities create barriers to participation in life situations. - Feelings of incompetence and dependence (levels of confidence, optimism, and personal identity are influenced by the social environment and performance. When confidence and self-esteem decrease, personal barriers to participation are created). - Therapy focused on (1) improving expressive speech and language, (2) obtaining the necessary communicative skills to perform household chores (3) learning compensatory strategies to engage in interactions, (4) returning to activities (5) reducing barriers to participation (training of the partners to help eliminate attitudinal barriers and group therapy to develop conversational skills and confidence).	Not specified
S15 - Thiel L and Conroy P[36] **2022** **United Kingdom**	To explore the experiences of people with aphasia living with language-related writing difficulties and the impact on their lives	Qualitative	Eight people with post-stroke aphasia and writing difficulties (including adults with Broca's aphasia)	- Participation in society, self-esteem and confidence was impacted by writing difficulties.	Ambulatory
S16 - Worrall L et al.[37] **2011** **Australia**	Understand what people with aphasia want from services; to describe the goals of people with aphasia; code objectives according to the ICF	Qualitative: Descriptive	Fifty adults with post-stroke aphasia, including adults with expressive aphasia	- Desire to return to the previous life, communicate basic needs and opinions (feelings of frustration, hopelessness, isolation, and depression); - Aphasia was a higher priority than physical disabilities; - The need for communication rehabilitation to be connected to real life and to foster trust; - Desire for information about aphasia (impaired communication made it difficult to obtain adequate information), available services, prognosis, therapy and rehabilitation stages (having information allowed to take control and participate in decisions about therapy and rehabilitation); - Wanting more speech therapy, greater autonomy, dignity and respect; - Importance of involvement in social, leisure, and work activities, as well as the recovery of physical health; - Wanting to help others; - The goals are mostly linked to Activities and Participation, Environmental Factors, Body Functions, and Structures, and Personal Factors.	Ambulatory
S17 - Worrall LE et al.[38] **2017** **Australia**	To determine factors that contribute to living well with aphasia in the first twelve months after a stroke	Qualitative: prospective longitudinal cohort study	Fifty-eight adults with aphasia, including adults with expressive aphasia	- Higher family income, greater social network size, being female, and having milder aphasia were positively associated; - Graduate or postgraduate educational levels, low mood, and poor physical functioning were negatively associated with participation; - Psychosocial aspects were the most significant predictors; - Professionals can help spouses communicate effectively with the person with aphasia, help to return to work by ensuring that the person with aphasia is safe and well cared for, and ensure that they have access to information.	Ambulatory and hospital context

Legend: S – Study

These results were grouped according to the A-FROM structure dimensions[9] and are presented in Table 3, for easier data visualization and interpretation. In the *Communication and language environment* field, all elements external to the person that positively and negatively affect communication and language were included, such as other people's services and attitudes. The *Language and related impairments* domain include changes in the language and communication process and facilitating and inhibiting factors that influence the recovery. The *Personal identity, attitudes and feelings* dimension comprises information related to how the patients see themselves, how they see aphasia

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and face the future, feelings, and attitudes, as well as facilitating and inhibiting factors. The *Participation in life situations* area includes data about relationships, roles, responsibilities, participation in activities, and facilitating and inhibiting conditions[9]. Data associated with personal identity, attitudes, and feelings, and participation in life situations, were most often mentioned in this literature review, followed by the language and related impairments and the communication and language environment, respectively.

Table 3 – Results presentation (adapted from A-FROM)[7]

BROCA'S APHASIA EXPERIENCE	
COMMUNICATION AND LANGUAGE ENVIRONMENT	**Facilitating factors -** Support and communication strategies; individualized therapeutic interventions; interactions and context; family and caregivers; speech therapy and health professionals; "*Finding a voice*" (the voice of a loved one); social support[S3;S6;S9].
	Inhibitory factors - Limited rehabilitation services; hospital environment (noisy, fast-paced, constantly changing, not conducive to effective communication; inconsistent use of communication strategies); interactions and the context; difficulty in the hospital to deal with people with aphasia[S3;S6;S8].
LANGUAGE AND RELATED IMPAIRMENTS	**Experience -** Difficulty or inability in communicating through words (including expressing feelings and personal experiences); difficulty in writing; the internal cognitive world is altered; non-verbal skills can be affected; only external stimuli and visual-perceptual information remained, which acquire particular importance; (verbal) intelligence is compromised; "*Had the language stuck*"; need to use strategies to improve communication; speech and hand were incompatible with simultaneous thought processes; blocks or hinders access to information and services[S1;S5;S8;S9;S11;S16].
	Facilitating factors - Read the newspaper every day; talk to the animals; independence to direct recovery; Feeling of being able to help yourself; positivity; individualized therapeutic interventions; hope; communication strategies; reading, sudoku, Scrabble, writing a shopping list, using the computer, phone, homework prescribed by therapists; rehabilitation, speech therapy, and health professionals; spirituality[S2;S3;S4;S9;S11;S13].
	Inhibitory factors - Recovery is extremely difficult and progress is very slow[S8].
PERSONAL IDENTITY, ATTITUDES AND FEELINGS	**Experience -** Devastation and emotional impact; need to reinvent the world around and rebuild life, which has completely changed; changes in the world emotional interpretation; feeling of frustration due to difficulties, failures and with some of the therapeutic activities; negative mood changes and depression, with negative emotional, social and behavioral consequences (social evasion, low mood, persistent sadness and withdrawal from rehabilitation); feeling of "*Being in a foreign country*" (uncertainty, unknown, confusion) and the shock of being sick; sensation of disruption; experience of a biographical rupture with the need to make sense of this new reality; feeling that it is just a number, without being seen as a unique individual and feeling of isolation; feeling of being a burden to others; often feel stigmatized, but wish to be respected; feeling like a stranger in your own home (feeling of not belonging); feeling of having lost the most important thing and regret it; inability to envision a future; feeling of not wanting to be alive; loss of dreams, hope, the planned future and confidence; feelings of anguish about the future; impact on identity/self; not accepting the inability to speak; feelings of pity and pity from others, self-rejection and feeling of uselessness; anxiety; feelings of incompetence and dependence; decrease of confidence, optimism and self-esteem; feelings of frustration, hopelessness, isolation; desire to return to the previous life and communicate their needs and opinions[S1;S2;S3;S5;S6;S7;S8;S9;S11;S14;S15;S16].
	Facilitating factors - Use of humor; meeting people in the hospital, in group therapy and the relationship established with the therapists (source of support, courage, and motivation); family and friends; access to individualized therapeutic interventions through gradual psychological care; having a positive vision (optimism, hope, determination, and gratitude); hope; interactions and the context; caregivers; feeling of being heard by the team; recovery; "*Finding a voice*" (your own voice); contact with a person who has gone through a similar situation; feeling loved; perception of improvements in communication, involvement in significant activities; maintaining positivity about the future; speech therapy and psychotherapy; spirituality; higher family income, self-assessment of successfully living with aphasia and having lighter aphasia[S2;S3;S4;S6;S8;S9;S10;S11;S13;S17].
	Inhibitory factors - Some therapeutic activities (difficulty or inability to perform simple tasks); psychological support and limited rehabilitation services (low mood and depression are rarely addressed in rehabilitation); interactions and context; procedures are done for people instead of being done with people; the focus of health professionals were on their physical condition, contributing to the lack of attention to psychological needs and social objectives; be infantilized and depersonalized; visits that invade the private world[S2;S3;S6;S11].
PARTICIPATION IN LIFE SITUATIONS	**Experience -** Dependence on others; frequent inability to work; the wish to contribute to the community in other ways; need to give up employment; severe activity limitations, difficulty in performing tasks, needing more time to perform activities; participation restrictions; inability to compete and succeed in the job market; impact on society participation[S5;S6;S7;S8;S9;S11;S14;S15].
	Facilitating factors - Having a positive vision (optimism, hope, determination and gratitude); recovery; independence; interactions and context; "*Find a voice*"; degree of involvement, commitment and sense of belonging in social activities (the quality of activities is more important than the quantity), leisure and work; motivation, physical and psychological condition and communication skills; caregiver and the characteristics of the communication partner (s) (will, skills and knowledge); home peace and familiarity; feeling of being in charge or in control of life and having a purpose in life; talk about life experiences, reconnect with the family and focus on communicating on topics that are meaningful to them; speech therapy and compensatory communication strategies; reducing barriers to participation (partner training and counseling and group therapy); information about aphasia, available services, prognosis and rehabilitation stages; dignity and respect; higher family income, greater social network, being female and having mild aphasia[S2;S3;S6;S7;S9;S10;S12;S14;S16;S17].
	Inhibitory factors - People are not always supported to be independent or make decisions; interactions and context; physical functioning and fatigue; protection of the family, removing responsibilities; internal personal barriers (fear of failure, feelings of incompetence and dependence, low confidence, low self-esteem, and negativism); undergraduate or graduate schooling levels, depressed mood[S3;S6;S9;S14;S17].

Legend: S – Study

S1 - Ardila A and Rubio-Bruno S, 2017[13]; S2 - Armstrong E et al., 2012[23]; S3 - Baker C et al., 2020[24]; S4 - Bright F et al., 2013[25] ; S5 - Carcello K and Susan M, 2020[26];
S6 - Clancy L et al., 2018[27]; S7 - Dalemans RJ et al., 2010[28]; S8 - Green C and Waks L, 2008[29]; S9 - Grohn B et al., 2012[30]; S10 - Grohn B et al., 2014[31];
S11 – Hall WA, 1961[32]; S12 - Holland AL et al., 2010[33]; S13 - Laures-Gore JS et al., 2018[34]; S14 - Simmons-Mackie N and Kagan A, 2007[35];
S15 - Thiel L and Conroy P, 2022[36]; S16 - Worrall L et al., 2011[37]; S17 - Worrall LE et al., 2017[38]

Personal identity, attitudes and feelings
The need to reinvent the world and rebuild life has emerged, as well as the negative impact of aphasia on[S1;S2;S3;S5;S6;S7;S8;S9;S11;S14;S15;S16]:
- Emotional level: frustration, depression, feeling of isolation and stigmatization, of "Being in a foreign country", of being a burden to others, not accepting the inability to speak and not wanting to be alive, decreased confidence and self-esteem, anguish, feelings of self-rejection and worthlessness, anxiety, feelings of incompetence, decreased optimism and hopelessness;
- Social and behavioural level: social evasion and disconnection from rehabilitation;
- Identity: feeling of disruption and experience of a biographical rupture with the need to make sense of their new reality.

The facilitating factors that influence this dimension encompass[S2;S3;S4;S6;S8;S9;S10;S11;S13;S17]:
- Internal conditions: use of humour, hope, language recovery, optimism, determination and gratitude, spirituality, and having mild aphasia;
- External conditions: interactions and context, family, friends, and caregivers, contact with a person who has gone through a similar situation, speech therapy and psychotherapy.

The inhibiting factors that emerged include therapeutic interventions: disability or difficulty in performing some therapeutic activities, limited psychological support and rehabilitation services, the procedures being done for people and not with people, health professionals focus on physical condition, which contributes to the lack of attention to psychological needs and depersonalization[S2;S3;S6;S11].

Participation in life situations
Information related to this dimension was the second most mentioned. The negative impact was evident in roles (dependence on others), responsibilities, and activities (inability to work, with the need to give up employment, difficulty in performing tasks, and participation restrictions)[S5;S6;S7;S8;S9;S11;S14;S15]. One study specifically addresses the impact of writing difficulties on social participation[S15].
In this domain, facilitating factors include[S2;S3;S6;S7;S9;S10;S12;S14;S16;S17]:
Internal conditions: recovery, a feeling of control, independence, involvement, commitment and sense of belonging in social activities, motivation, physical and psychological condition, having a purpose in life, learning compensatory communication strategies, being female and having milder aphasia;
External conditions: the context, interactions, caregiver, speech therapy, clinical condition, recovery information, greater family income, and greater social network.
The inhibiting factors comprehend[S3;S6;S9;S14;S17]:
Internal barriers: fear of failure, feelings of incompetence and dependence, low confidence, low self-esteem and optimism, graduate or postgraduate educational levels, low mood, and physical malfunction;
External elements: interactions and context, people weren't always supported to be independent or to make decisions and family protection.

Language and related impairments
It was the third most mentioned dimension. In this context, were identified: difficulty or inability to communicate through words, mostly orally but also in writing; difficulty in expressing feelings and personal experiences; changes in the internal cognitive world; non-verbal skills affected sometimes; (verbal) intelligence was compromised, and speech and hand were incompatible with simultaneous thought processes[S1,S5,S8,S11]. This makes accessing adequate information and services complex, and the need to use other strategies to improve communication[S1,S8,S9S11,S16]. Only one study explicitly addresses writing difficulties and refers to their impact on social participation, self-esteem and confidence[S15].
As facilitating factors for aphasia recovery, the performing activities emerged (talking with the animals, reading, sudoku, scrabble, writing a shopping list, using the computer and the phone, and the homework prescribed by the therapists); the internal forces (hope, spirituality, feeling of being able to help oneself), and the external aids (rehabilitation, speech therapy, and health professionals)[S2;S3;S4;S9;S11;S13]. As negative aspects, recovery is complicated, and progress is plodding[S8].

Communication and language environment
Finally, data within the scope of this domain was the least mentioned. As positive factors emerged: communication support and access to individualized therapeutic interventions; interactions and context; the family and caregivers; "find a voice" through the voice of a loved one; feeling heard by the team; social support; use of communication strategies and the role of speech therapy and health professionals[S3;S6;S9].
Factors that have a negative influence were identified, namely: limited rehabilitation services; the hospital environment (noisy, fast-paced, constantly changing, not

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conducive to effective communication and the inconsistent use of communication strategies); the interactions and context, and the inability at the hospital to deal with the person with aphasia[S3;S6;S9].

Discussion

Summary of evidence

The results of this Scoping Review are aligned with the impact of aphasia on the fundamental needs described by Thompson (2014)[1]. Corresponding to *personal identity, attitudes and feelings*, Thompson (2014)[1] defends that aphasia impacts identity; affection (by the difficulty in expressing emotions and affection), and people feel perceived as a physical presence rather than a person. Regarding *Participation in life situations,* Thompson (2014)[1] states that aphasia impacts freedom (it is a threat to autonomy, and people have difficulty in expressing choices and claiming rights), participation (with feelings of isolation) and subsistence (by the inability to communicate verbally). Related *Language and related impairments*, aphasia affects protection (because of the difficulty in asking for support and the inability to alert)[1].

Broca's aphasia has a tremendous negative effect, and the psychosocial impact of this clinical condition was clear. It was also clear that therapeutic interventions[S3], context and interactions[S6], health professionals[S9,S11,S17], hope[S4], spirituality[S13], and psychosocial factors influence the experience of Broca's aphasia.

According to Thompson and McKeever (2014)[39], aphasia has a negative impact on relationships by denying access to support networks, which leads to isolation. Aphasia also results in a 'loss of self', intensified by inadequate healthcare communication strategies[39].

Concerning the influence of therapeutic interventions and health professionals, a study developed to explore the factors influencing the satisfaction and dissatisfaction of people with aphasia regarding their health care identified seven areas of care[19]. Two of these areas are Manner and Methods of Service Delivery (related to the individual behaviour of health professionals, health professionals' approach to health care, a health professional's personality, the level of inclusion of the person with aphasia, understanding shown to the person, the level of involvement in decision-making, goal-setting and therapy activities) and Information, Communication and Knowledge[19].

About hope, a study carried out concluded that hope could be important for people with aphasia, and the authors identified it being experienced in two ways: *Simply "having" hope* (broad feeling, but passive, which seems to be the main form of hope) and *Actively hoping* (an active and future-oriented form of hope)[S4]. In that same study, hope seems related to how people get involved in rehabilitation and how it can influence it. The factors that influence hope were identified as: family; friends; health professionals (either supporting or reducing) and other patients; uncertainty about the future; seeing hope with a double face (positive and negative aspect) and a sense of disruption (in identity and/or involvement in meaningful activities)[S4]. These factors are influenced by past experiences, present reality, and perceived future[S4]. In line with this, a study developed more recently concluded that social support, a sense of progress, and engagement in meaningful activities and interactions seem essential in supporting people (re)develop hopes for their future[40].

On the sphere of spirituality, according to a study[S13], it could be seen in two ways: as a higher power that is important for the understanding of oneself, for recovery, communication improvement, being in control of events, and directing recovery, which does not involve much personal activity; and/or as a relationship with a higher power as a source of help and strength, with more frequent religious and spiritual practices (seeking the Sacred for comfort, support and to understand the aphasia meaning). Other people can also be essential for aphasia recovery (social relationships imbued with spiritual meaning), which offer a better quality of life, an opportunity to practice language, motivation for communication and are essential in search of meaning[S13]. Still, other forms of spiritual coping can be associated with severe existential suffering in this context. They can amplify adverse reactions to stress and cause people to engage in inappropriate behaviours[S13].

Regarding interactions and context[S6], it can help or hinder making sense of the experience, the emotional burden, and how the patient gets involved in rehabilitation. In a study carried out, three broad themes were identified: "*being in a foreign country*", "*finding a voice*", and "*being just a number*"[S6]. "*Being in a foreign country*" includes uncertainty and confusion regarding the condition, the hospital, dependence on others, and the shock of being ill aggravated by the ward environment (noisy, fast-paced, constantly changing, not conducive to effective communication and the inconsistent use of communication strategies); "*Finding a voice*" was fundamental to make sense of what happened and for adaptation[S6]. Feeling like "*Just being a number*" instead of being seen as a unique individual is related to the perspective that the focus of health professionals is the physical condition, contributing to the lack of attention to psychological needs and social goals, with the perception that the team focuses in the technical procedures of rehabilitation and not in the person[S6].

Limitations of the study

The search was conducted in only four databases and only articles written in English, Portuguese and Spanish were included, which may have limited access to other articles with relevant contributions to this review. Another limitation is that it was not possible to access two full-text articles. It is important to point out that not including theses, dissertations and "grey" literature in this review may have contributed to not getting important scientific evidence, which can also represent a limitation.

Conclusion

This review aimed to map the available scientific evidence on the experience of people who have gone through a Broca's aphasia period. The Scoping Review enabled us to answer the research question and deepen the understanding of the phenomenon under study. More precisely, it allowed recognizing the negative impact and changes resulting from Broca's aphasia, the feelings associated, the specific needs, factors that influenced the experience, what support and resources people would like to have had, from the perspective of those who experienced this clinical condition. In this study, data related to *Personal identity, attitudes, feelings*, and *Participation in life situations* were the most often mentioned in the literature, followed by the *Language and related impairments* and the *Communication and language environment*, respectively, regarding Broca's aphasia experience.

The importance of health professionals, therapeutic interventions, spirituality, hope, context, interactions, and psychosocial factors became clear in caring for patients with Broca's aphasia.

The knowledge gained in this Scoping Review allows health professionals to better understand the needs of people with Broca's aphasia and to implement appropriate improvements to health care and service delivery[19]. This includes improvements in nursing care, which will promote well-being, enhancing safety, reducing harm, and improving satisfaction with the care provided.

This review shows that it is essential to continue investigating how people report the experience of having lived a period of Broca's aphasia to comprehend better the experience and the needs of this population and continually improve the assistance of people with this clinical condition. Considering the difficulty in this review in finding studies only with people diagnosed with Broca's aphasia, as a suggestion for future research, it would be pertinent to investigate how people report the experience of having lived a period of Broca's aphasia, focusing only on participants who have fully recovered from this specific type of aphasia. Besides that, it would be pertinent to investigate the current practice regarding teaching about the experience of Broca's aphasia in health-related professions, including nursing. It would also be helpful to study the impact of what is already known about the experience of this clinical condition in the management of health care in contexts that provide care to people with Broca's aphasia.

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Nurses adverse events report adding safety to pediatric nursing

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Abstract

Introduction
Adverse Events remain a current challenge in healthcare, being defined as incidents that resulted in unnecessary harm to the patient. The choice of the pediatric population the object of this study is based on certain characteristics making it the most susceptible to Adverse Events. Reporting them is a key action of the strategy to reduce its occurrence, while Nurses remain essential elements to the process. The ultimate goal is Patient Safety, the reduction of the risk of unnecessary healthcare-related harm to an acceptable minimum.

Objective
Describe Nurses' Adherence to Adverse Events Reporting and the Factors associated with it in a Pediatric setting.

Methods
A Cross-sectional Observational Study is presented, based on a survey conducted in the Pediatrics Department of a hospital. The study included 88 categorical variables, related to respondents' perception of Adverse Events, Errors, Incidents and Patient Safety. Univariable, bivariable, and correlation analysis were used.

Results
A total of 69% of nurses did not report any Adverse Event in 2019. The events more frequently reported were those with the most serious consequences for the patients (54%) and those related to organizational dysfunctions of the institution (74-90%). Factors which facilitate the occurrence of Adverse Events include the lack of human resources (19%), communication failures and overtime (17%), and the main barrier to Reporting is forgetting to do so when there is a greater workload (63%).

Conclusion
A low percentage of reporting related to nurses' adherence to adverse events was found in this investigation. This highlighted the need to invest in the institution's Safety Culture by enhancing healthcare professionals' awareness of the importance of their role in improving Patient Safety. Integrating notification into the daily practice of professionals, using continuous awareness enhancement, strengthening multidisciplinary teams, investing in communication and down grading workload is essential and can facilitate improvement.

Keywords
Patient Safety; Risk Management; Quality Improvement; Adverse Event; Medical Error; Pediatric Nursing.

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Introduction

Adverse Events (AE), defined as incidents that resulted in unnecessary harm to the patient,[1] remain a serious Public Health problem.[2] They occur in hospital, primary health care and long-term care settings.[3] Regardless of context, they affect patients and their family, have direct consequences in professional, organizational, economic, and social levels, leading to a lack of trust in health providers and organizations where they occur.[3-4]

Errors or AE in healthcare aren't new, going back more than 150 years, when the first records were collected by Florence Nightingale in the Crimean War.[5] Several figures intervened and promoted Quality Improvement and Patient Safety, as highlighted by Ernest Codman, Avedis Donabedian and the Institute of Medicine.[5-10] A journey with a single purpose: harmless, timely, and undelayed care, based on evidence and guidelines, for all patients, responding to their individual and specific needs.[11]

However, it is unequivocal that the scientific-technological evolution, which allows advances in medicine, generates situations leading to Errors and AE. Thus, it becomes necessary to implement strategies to avoid and minimize these situations.

Reporting potentially dangerous situations for the patient, Near Misses, Errors and AE is a strong strategy in ensuring Patient Safety.[12-13] Reporting generates awareness of an event with a negative impact on the patient, causing certain harmful consequences, of the factors leading to this event, and of the strategies that can be identified and adopted to avoid it.[14] With the collected data, it is possible to build databases for future analysis by the Risk Management Team, but also share the information with the multidisciplinary team and the rest of the Institution. With this information it is possible to identify factors leading to certain events and develop specific practices to prevent them, and other similar situations.[12-13] Thus, it contributes to build a Safety Culture in the institution, based on trust and shared experiences, without fear of punishment, bearing in mind Patient Safety guidelines during their stay.[10,15-16]

Although health professionals are progressively more aware of the need to Report, it still falls below expectations.[17-18] Several reasons have been given to justify this low adherence, including fear of blame, of administrative and legal sanctions, resistance to bureaucracy, the perception that reports have no impact on the quality of care, the lack of organizational support, late or inadequate feedback, and the lack of knowledge about the Adverse Events Reporting System (AERS).[17,19-21]

In addition, the lack of human resources in health, both physicians and nurses, may result in work hours and providers function overload, leading to the reorganization of health care practices. Professionals focus their attention on patients and the rapid resolution of potentially dangerous situations or Errors that may have occurred, leaving bureaucratic issues in the background, such as AE Reporting. We emphasize that this behavior does not favor Patient Safety or Quality of Care in the long term because it does not allow an anticipation of dangerous situations, nor the context in which Errors occur, preventing it from being repeated in the future.

On the other hand, adherence to reporting seems to depend on the severity level of the Event, the type of Incident and the professional.[20] There is a consensus that healthcare professionals more frequently report the most serious events which include death (tragic harm), disability (moderate harm) and severe harm caused to the patient, when compared to non-harmful events or risk situations.[22-24] Nurses are identified as essential to reporting, not only because they are on the front line of care, but also because they spend more time with patients. Scientific evidence shows that nurses are three times more likely to report when compared to physicians.[20]

It is unanimously recognized that the pediatric population is more susceptible to AE.[25] In addition to the health condition, due to its intrinsic characteristics, it is subjected to complex health care, in different contexts, with multiple players, during which it is possible to identify opportunities for communication failures between the team, that may, in the end, result in potentially dangerous situations for patients.[26]

Some of the Errors, described in the literature, that characterize this population include: Medication and total parenteral feeding errors; Respiratory care, resuscitation, and ventilation errors; Invasive procedure errors and Healthcare-Associated Infections; Patient identification errors; Diagnostic errors;[10] Breast milk errors;[27-28] and Healthcare-associated Infections.[29] Medication errors are the most prevalent and reported in the different care settings.[10,15,30-32]

In association with AE Report, several measures have been taken to prevent the occurrence of Errors in this population, which deserve attention: the adaptation of clinical guidelines, use of the double-check method,[33] trigger tools,[9] barcode systems,[30-31] among others.

In this sense it was elaborated a study which objective was to describe Nurses' Adherence to Adverse Events Reporting and the Factors associated with it in a Pediatric setting. The results confirm the interest in deepening the problem and consequences of AE, the need to continue to invest in Reporting, and the essential role of Nurses in the process.

Materials and Methods

The study was observational, cross-sectional, and quantitative in nature, with the objective of determining nurses' adherence to Adverse Event Reporting and the factors associated with it, in the Pediatric Department of a general hospital in Lisbon.

The subjects of this study were Nurses, Specialist Nurses and Nurse Managers working in the department's services, in a total of 192 nurses. The recruitment of participants was performed through convenience sampling, consisting of all nurses who were working in the period between November 2019 and January 2020. A total of 102 nurses agreed to participate by completing the survey.

Data were collected through a survey, after permission was granted by the author, Paula Bruno (2010), published in "Registo de Incidentes e Eventos Adversos: Implicações Jurídicas da Implementação em Portugal". The survey includes 13 closed questions, distributed into two groups: Characterization of the sample (questions 1, 2, 3, 4 and 5) and Respondents' perceptions of AE, Error, Incident Reporting and Patient Safety (questions 6, 7, 8, 9, 10, 11, 12, and 13). Slight changes were made to the original survey, to adapt it to the subjects of the study, without altering its characteristics. The survey was chosen because it assessed the reporting of adverse events by health professionals, intended in this study. The survey was given to the Head Nurses, who were responsible for delivering them individually to each nurse under them. They were later collected by the researcher in a sealed, unmarked envelope to protect participants' privacy and confidentiality.

Data was analyzed using the Statistical Package for the Social Science (SPSS), version 26, with approximately 88 categorical variables. Univariable analysis, presenting frequency distribution tables (%), bivariable analysis using the Chi-square test for comparison of proportions and analysis of correlations of ordinal variables using Spearman's Correlation Coefficient were performed. Fisher's Exact Test was used in place of the Chi-square Test for low expected frequencies, while the 5% significance level was used in hypothesis testing.

The research work was confidential, with guaranteed anonymity of the data throughout the process. Participation in the study was voluntary (without any penalty) and anonymous. A cover sheet was attached to each survey corresponding to the informed consent. To ensure the anonymity and confidentiality of the information, the consent form was separated from the rest of the survey and placed in a separate envelope. The identity of participants was not known to the researcher or to any third party, and the data remained confidential during and after the study. The research process began with requests for permission to conduct the study, which included the following formal written requests: to the author of the survey, to the Director of the Pediatrics Department, to the Nurse Director and to the Ethics Committee of the hospital. Consent was obtained from all the above.

Results

This chapter presents the results obtained based on the questionnaires applied, representing the Nurses' perception on the questions asked.[34]

Table 1 - Characteristics of the Pediatric Nurses in the sample.

Variable under review	Variable Category	Count: Absolute frequency	Percentage: Relative frequency	(n=)
Sex	Female	96	94,1	(n=102)
	Male	6	5,9	
Age Group	21 a 30 years	33	32,4	(n=102)
	31 a 40 years	30	29,4	
	41 a 50 years	17	16,7	
	51 a 60 years	18	17,6	
	>60 years	4	3,9	
Years of Work	<1 year	17	16,7	(n=102)
	1 a 10 years	25	24,5	
	10 a 20 years	27	26,5	
	20 a 30 years	23	22,5	
	30 a 40 years	10	9,8	
Function/Title	Nurse	73	71,6	(n=102)
	Nurse Specialist	27	26,5	
	Nurse Manager	2	2,0	
Unit Typology	Ambulatory	19	16,7	,(n=102)
	Emergency and Intensive Care	64	62,7	
	Pediatrics	19	18,6	

As showed in table 1, the sample was mostly composed of female nurses (94.1%), aged between 21 and 30 years (32.4%). Most professionals work at the institution for 1 to 30 years (73%), and the category of 10 to 20 years is the most prevalent, reaching 26.5% of the sample. The most prevalent position is that of nurse (71.6%). Approximately 62.7% of the sample worked in the Emergency and Intensive Care services, followed by the Pediatric Ward, with 18.6%, and Ambulatory Care, with 16.7%.

When asked about the AERS, about 98% of the sample reported knowing that the hospital has one of these systems, but only 59.8% agreed with it. About 93.1% of the sample knew that the hospital under study participates in Accreditation Programs, namely the Pediatrics Department.

In 98% of nurses who are aware of the existence of an AERS, 69% answered not having reported any AE in the last year and 31% have reported at least one AE. The most frequently reported AEs are those with more serious consequences to the patient, such as tragic harm (58%) and moderate harm (33%). AEs with no danger to the patient and Near Misses are rarely reported. The service with the highest number of AEs reported was Emergency and Intensive Care (38%), followed by Medical Pediatrics (21%) and Ambulatory Care (18%).

Evaluating the report according to the severity of the AE and the nurses' characteristics (gender, age group and position in the institution), we found that there seems to be no statistically significant association between the frequency of Reporting of the different events and the nurses' characteristics.

With regard to the type of AEs, we found that AEs related to organizational dysfunctions of the institution occurred more frequently: malfunction or defect of medical materials/devices (89%), lack of material/clothing/equipment (82.4%), lack of clinical material and equipment (77.5%), computer system malfunctions (74.5%) and conflicts with the patient/family (73.5%). Product or drug prescription errors (71.6%), product or drug administration errors (64.7%), incorrectly filled or illegible prescriptions (65.7%), and healthcare-associated infections (52.9%) stand out as frequent occurrences. One of the questions allowed us to analyze the sample's perception regarding the AEs that occur and those that are recorded. According to the nurses' perception, we found that the AEs that occur more frequently are those with a higher percentage of notification.

According to the nurses' perception, the most important factor contributing to the occurrence of AEs was the lack of human resources (19%), followed by communication failures and work overload (both with 17%). The main barrier to Reporting was forgetting to do so when there was a heavy workload (63%).

Discussion

Healthcare professionals recognize the importance of the AE report for Patient Safety and Quality of Care Improvement,[17] as well as the need for a local and national system for AE reporting.[24] Despite 98% of the nurses knowing that the hospital has an AERS, only 59,8% agreed with it, which is in line with values found in other studies.[24,35] This value raises some questions, namely nurses' understanding of the system and its adequate use, which AEs to report, how to report and also the development of the feedback process.

About 69% of the nurses refer that they did not report any AE in the previous year, showing a low adherence rate. However, it seems to us that there has been an increase in awareness for AE Notification, since in 2011 non-adherence was 80%[18] at national level. More recent data from the National Patient Safety Agency[36] shows an increase in AE reporting between 2013 and 2015. The observed improvement, a small step in the long path ahead, should safeguard the need for professionals' training, elaboration of strategies and institutional norms that allow the growth of a Safety Culture.

The level of AE severity presents itself as a major factor for Adherence to Reporting. The study data indicate that AEs causing tragic harm (death) (58%) and moderate harm (disability) (33%) were more frequently reported, when compared to non-harmful events or risk situations, which aligns with previous studies.[20,22-24]

The privilege of reporting serious events instead of all situations leads to a lack of data on the real number of AEs that occurred, restricting the prevention of potentially dangerous situations for the patient in future care. The need to report all types of AEs, even those that had no impact on the patient, is imperative for the learning process to be as useful as possible and the implemented interventions to address the identified difficulties.[12-13,37]

The types of AE that occurred more frequently were related to organizational dysfunctions of the institution, corresponding to the results found by Bruno[24] and Martins.[35] However, at the international level, the most frequent AEs in Pediatrics are those related to medication.[10,15,30,32,38] In this study, they present high percentages of occurrence, with product or drug prescription errors, product or drug administration errors and incorrectly filled or illegible prescriptions standing out. On the other hand, according to the nurses' perception, the AEs that occur more frequently are those with the highest percentage of recording.

The difference in AE Reporting percentages detected between the different services may derive from the fact that the sample was mostly composed of nurses from the Emergency and Intensive Care unit (62.7%) and/or because this is one of the services with a higher propensity for the occurrence of AEs.[31]

Nurses pointed out the lack of human resources followed by communication failures and the overload of working hours as facilitating factors for the occurrence of AEs, and these results coincide with the literature findings. This is a recurring situation in the health area, where the lack of human resources remains a reality,[39] leading to an increase in the working hours and the functional overload of health providers.[16,40]

Communication is essential to ensure Patient Safety and Quality of Care and deserves special attention. The Portuguese General Health Direction[41] calls for an effective communication between health professionals, stating that communication failures, with 70% of the main causes of AEs, occur during the transition of care. Patients and family members can be key allies of health professionals to ensure effective and safe communication, since they are the ones who know the clinical situation best and are able to detect miscommunication at shift transitions.[10]

According to the perception of the nurses, the main reason for missing the communication with AERS is being forgetfulness when there is a heavy workload. Working conditions lead to the need to reorganize the health care provided by focusing on patients and on the quick resolution of unexpected or unplanned situations, leaving issues such as AE Reporting in the background. We believe that this behavior, even if it seems the most appropriate at the moment, will not favor Patient Safety and Quality of Care in the long term.

In these contexts, it becomes essential to integrate AE, Error, Near Misses and potentially dangerous situations for the patient report into the daily practice of professionals. The steps to be taken include continuous awareness-raising, strengthening multidisciplinary teams, improving communication and lightening the workload, and at the same time, greater dissemination and accessibility to the system.

At the national level, we advocate greater specificity and detail in the development of Health Policies with a view to promote the Report of AEs in a transversal way, as a framework and path to be followed. In terms of Risk Management, the Report of Incidents, Adverse Events and also Near Misses should be encouraged by all professionals, with a view to resolving the potentially dangerous situations identified and preventing future AEs,[12-13] both for patients and for the health professionals themselves.

At last, it's crucial to value and invest in the qualification of professionals in Risk Management and Patient Safety, in the elaboration of Guideline Standards, as well as the establishment of teams with experience in AE cause analysis and in the preventive identification of possible failures in the system.

To reduce errors in the pediatric setting is recommended the use of pre-made solutions, therapeutic formulas for the pediatric population, barcode system when administering medication or identifying patients, development of protocols.[30-31] Peer review, clinical quality improvement and education, staff training through simulation of clinical situations, and the incorporation of a drug library in the infusion pumps, with a safe dose range that alarms when the programmed dose does not fall within this range, are also advocated.[9] The use of computerized electronic prescribing and therapeutic dispensing systems demonstrated a significant decrease in medication-related errors. The use of trigger tools also seems to have a positive positive impact in preventing AEs by increasing the detection of errors in pediatrics.[9]

This research aimed to describe the adherence to adverse event reporting in pediatrics, based on the nurses' perception of such reporting. A future study, with more refined specifications, may help to clarify some of the issues raised and allow corrective measures to facilitate the AERS improvement.

Conclusion

The growing evolution and demand for the provision of safe care, with minimal risk to the patient and appropriate to their characteristics and needs, has become the motto of health care worldwide. However, and despite the strategies to reduce the risk and negative consequences for the patient, the occurrence of AEs remains a reality.

Reporting of all potentially dangerous situations or situations that have led to negative consequences, particularly for the patient, should be instituted to avoid the normalization and acceptance of errors as routine, as if they were a mandatory consequence of the professionals' practice or performance.

Nurses, as part of the frontline of health care delivery, with a closer contact with the patient and family, can become more aware and experienced in the recognition of situations potentially conducive to the occurrence of Errors and AEs, as well as in their identification, becoming more accountable.

If, on the one hand, the results obtained point to the need to promote the institution's Safety Culture, making health professionals aware of the importance of their role, as individuals and as a multidisciplinary team, to improve Patient Safety, on the other hand, we believe that nurses, as part of the front line of care, are also frequently subjected to AEs, which should also be reported.

We believe that the involvement of health professionals in reporting programs adherence will be greater and stronger if the dissemination, the access to the platform, and the awareness of its use is implemented. As well as the recognition of the real benefits for the patient, the knowledge of the results and corrective measures activated, and even the evolution and interactivity in the operation of the system are improved. If this is understood as transversal to health, in an integrative vision of the duties and rights concerning the professionals themselves, they will be more aware and motivated to individual and group participation.

One limitation of the study was the time gap between data collection and dissemination, because it is the result of a Master's Thesis. Even so, it's considered important to summarize and share this work due to the clear implications for nursing practice, for patients' benefit, and for the quality and safety of health care improvement.

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Interventions for self-management in adolescents with Type 1 Diabetes: a scoping review protocol

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Abstract

Introduction

Adolescent development involves building autonomy and progressive independence from parental supervision. Challenges that are more complex when they have a diagnosis of type 1 diabetes and have to take responsibility for managing their condition. At this age, it is crucial to implement interventions to promote self-management skills in adolescents with type 1 diabetes.

Objective

The aim of this scoping review is to identify and map interventions that promote self-management skills in adolescents with type 1 diabetes.

Methods

The methodology will follow the Joanna Briggs Institute recommendations for scoping reviews. Studies published in English, Portuguese and Spanish between 2009-2021 will be considered, with no geographical or cultural limitations. The process of data analysis, extraction, and synthesis will be performed by two independent reviewers, based on the inclusion criteria. The results of the study selection will be presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for scoping reviews. This protocol is registered at Open Science Framework https://osf.io/z6wbj.

Results

Mapping the interventions for adolescents with type 1 diabetes, may constitute a tool for the design of a structured intervention to promote self-management behaviour in adolescents with type 1 diabetes and contribute to the dissemination of available evidence on the topic.

Conclusion

The results from this review are expected to gather relevant information that will serve as a basis for the development of a nursing intervention for adolescents with diabetes.

Keywords

Adolescent; Diabetes Mellitus, Type 1; Program Evaluation; Self-Management.

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Introduction

Worldwide, more than 1.1 million children and adolescents are living with diabetes, and the incidence of Type 1 Diabetes Mellitus (T1D) has been increasing, particularly at ages below 15, with a higher prevalence in Europe than in other regions.[1]

Adolescents are in a crucial phase for building their autonomy, becoming progressively independent from their parents and assuming more and more responsibility in decision-making.[2] During this phase, education and training is essential for promoting T1D self-management.[3] Once there is no cure, treating T1D implies fostering healthy growth to minimize the impact of this disease.[3] The ultimate goal for adolescents with T1D is to assume increased self-care responsibility for managing diabetes.[4]

T1D is a chronic disease caused by an autoimmune reaction in which the immune system destroys the pancreas beta cells, preventing insulin production.[5] The treatment of diabetes is demanding and complex requiring continuous control carried out through the management of the following triad: diet, physical exercise, and tuning of insulin doses.[6] Regarding diet, counting carbohydrates is a complex and challenging task (complex carbohydrates and simple carbohydrates, e.g., glucose, fructose, lactose, sucrose, and maltose). This task becomes even more complex with the management of insulin and diet during physical exercise/sports.[6,7] Thus, managing T1D entails deep thought on behaviors and decision-making, which is a significant responsibility for adolescents and their families.[8]

Self-management focuses on self-regulation of chronic disease and management of risk factors, and includes goal-setting, self-monitoring, decision-making, self-care planning and participation, self-assessment, and management of physical, emotional, and cognitive responses associated with behavior change.[9] Promoting self-management is associated with encouraging self-efficacy, knowledge, functionality, and social interactions, improving mental health, providing effective management of symptoms, a better quality of life, and lowering the need for emergency services.[10,11]An adequate self-management of the disease also drives better health care and resource management[12], preventing or delaying secondary conditions such as micro and macrovascular complications.[13,14] Self-management of a chronic condition is the individual ability to manage the symptoms and treatment, physical repercussions, psychosocial and emotional dimensions, and changes in the lifestyle, which are inherent to chronic illness.[15] Kate Lorig[16] highlighted three self-management tasks (medical management, role management and emotional management) and several self-management skills (problem-solving, decision-making, resource utilization, the formation of a patient-provider partnership, action planning, and self-tailoring).

To manage T1D is essential to have well-planned and organized strategies and well-defined objectives.[9] Management of diabetes involves knowledge about the pathophysiologic of diabetes and acute and chronic complications of the disease: hypo and hyperglycaemia, insulin administration, measurement of blood glucose, and health maintenance (diet, and physical exercise).[17]

Self-management support is the process of educating and supporting people with a chronic condition, helping them and their families understand their central role in managing their disease.[18] It includes a commitment to patient-centered care. Implementing programs with specific strategies could be helpful. Structured programs for T1D should integrate topics within education, the definition of goals and objectives, social inclusion, and self-efficiency associated with glycaemic control measures.[10] These programs comprise psychoeducational principles, training of daily routines, continuous support in promoting self-management, parental engagement and participation, and the use of new cognitive-behavioral techniques and new technologies as motivators for adolescents is recommended.[11]

It is up to the health teams within a multidisciplinary network, particularly nurses, to facilitate and encourage the self-management of diabetes in adolescents, therefore contributing to a healthier and more capable population in managing their disease.[11] The team's intervention focuses on the individual, their family, the group, and the community; their intervention can occur in many contexts: work-based during regular appointments, home-based, community-based, school-based, or informal scenarios such as summer camps.[19]

A preliminary search of MEDLINE (PubMed), CINAHL (EBSCO), the Cochrane Database of Systematic Reviews and JBI Evidence Synthesis, PROSPERO, and Open Science Framework (OSF) was conducted, and no current or underway systematic reviews or scoping reviews (published or in progress) on the topic were identified.

More precisely, this scoping review seeks to answer the following questions:

a) What are the characteristics of the interventions that promote self-management in adolescents with Type 1 Diabetes?

b) Who are the professionals responsible for implementing the interventions?

c) What are the indicators of change in self-management skills after the intervention?

This scoping review aims to map interventions that promote self-management skills in adolescents with type 1 diabetes.

Methods

This scoping review follows the Joanna Briggs Institute (JBI) guidelines for scoping reviews.[20,21] This review protocol was registered in the Open Science Framework (OSF) (https://osf.io/z6wbj /accessed on 11 November 2022).

Eligibility criteria

Participants

This scoping review will consider studies focused on interventions to adolescents aged 10 to 19 years old with T1D and/or their parents/family, that have participated in an intervention focused on self-management of diabetes, developed, or implemented by any health professionals.

Concept

The concept considered in this review will include studies that analyse programs and interventions to promote self-management in adolescents with T1D: medical management, role management, and emotional management. Programs or interventions that do not show results will be excluded.

Context

This scoping review will consider all interventions implemented and evaluated to promote self-management in adolescents carried out in any context. The context may include interventions via virtual or attendance in a health care setting (hospital or ambulatory), diabetic camps, or at a person's home.

Types of Sources

This scoping review aims to identify and map any interventions developed to promote self-management in adolescents with T1D. For this purpose, the authors will consider experimental and quasi-experimental study designs, including randomized controlled trials, non-randomized controlled trials, before and after studies. Qualitative studies focusing on qualitative data will be included, but are not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description, action research. In addition, systematic reviews that meet the inclusion criteria will also be considered.

Search strategy

The search strategy will aim to locate both published and unpublished studies. This review will use a three-step search strategy. An initial limited search of MEDLINE (via Pubmed) and CINAHL (via EBSCO) to identify articles on the topic. We used the text words contained in the titles and abstracts of relevant papers and the index terms "AND" or "OR" to describe the articles were used to develop a complete search strategy. The search strategy, including all identified keywords and index terms, will be adapted for each database and information source (Table 1). Afterwards, we will screen the reference list of all included articles for additional studies. Studies published in English, Portuguese and Spanish between 2009-2021 will be considered.

The databases to be searched will include CINAHL Plus with Full Text, PubMed, Cochrane Central Register of Controlled Trials, LILACS, Scopus, Library, Information Science & Technology Abstracts, PsycINFO, JBI Connect, and the Cochrane Database of Systematic Reviews. Will also include sources of unpublished studies and grey literature from the RCAAP – Repositório Científico de Acesso Aberto de Portugal.

Table 1 – Search Strategy conduced in March 2021

CINAHL complete Cochrane Central Register of Controlled Trials; Nursing & Allied Health Collection; Library, Information Science & Technology Abstracts (via EBSCO)		Results Retrieved
S6	TI (adolescen* OR teen* OR youth* OR young*) AND TI (diabetes OR "diabetes mellitus, type 1" OR T1DM OR "diabetes mellitus type 1" OR "DM1" OR "type 1 diabetes") AND TI (manage* OR "self management" OR "self care" OR "self-efficacy" OR "health and life quality" OR " quality of life" OR "glycaemic control" OR "glycemic control" OR Glycosylated hemoglobin* OR hemoglobin A*) AND AB (intervention* OR program* OR strateg* OR project* OR action* OR function* OR care* OR preparation OR education OR instruction* OR train*). Filters: Boleano, English, Portuguese and Spanish, from 2009-2021	485
S5	TI (adolescen* OR teen* OR youth* OR young*) AND TI (diabetes OR "diabetes mellitus, type 1" OR T1DM OR "diabetes mellitus type 1" OR "DM1" OR "type 1 diabetes") AND TI (manage* OR "self management" OR "self care" OR "self-efficacy" OR "health and life quality" OR " quality of life" OR "glycaemic control" OR "glycemic control" OR Glycosylated hemoglobin* OR hemoglobin A*) AND AB (intervention* OR program* OR strateg* OR project* OR action* OR function* OR care* OR preparation OR education OR instruction* OR train*). Filters: Boleano, from 2009-2021	974
S4	TI (adolescen* OR teen* OR youth* OR young*) AND TI (diabetes OR "diabetes mellitus, type 1" OR T1DM OR "diabetes mellitus type 1" OR "DM1" OR "type 1 diabetes") AND TI (manage* OR "self management" OR "self care" OR "self-efficacy" OR "health and life quality" OR " quality of life" OR "glycaemic control" OR "glycemic control" OR Glycosylated hemoglobin* OR hemoglobin A*) AND AB (intervention* OR program* OR strateg* OR project* OR action* OR function* OR care* OR preparation OR education OR instruction* OR train*)	1,280
S3	TI (adolescen* OR teen* OR youth* OR young*) AND TI (diabetes OR "diabetes mellitus, type 1" OR T1DM OR "diabetes mellitus type 1" OR "DM1" OR "type 1 diabetes") AND TI (manage* OR "self management" OR "self care" OR "self-efficacy" OR "health and life quality" OR " quality of life" OR "glycaemic control" OR "glycemic control" OR Glycosylated hemoglobin* OR hemoglobin A*)	2,245
S2	TI (adolescen* OR teen* OR youth* OR young*) AND TI (diabetes OR "diabetes mellitus, type 1" OR T1DM OR "diabetes mellitus type 1" OR "DM1" OR "type 1 diabetes")	15,567
S1	TI adolescen* OR teen* OR youth* OR young*	640,993
Pubmed		
	adolescent [MeSH Terms] AND diabetes mellitus, type 1 [MeSH Terms] AND ("self-management" [MeSH Terms] OR self-care [MeSH Terms] OR quality of life [MeSH Terms] OR "glycated hemoglobin a" [MeSH Terms]) AND (Program Evaluation [MeSH Terms] OR "health promotion" [MeSH Terms]). Filters: English, from 2009-2021	59
Medline complete (via EBSCO)		
	adolescent [MeSH Terms] AND diabetes mellitus, type 1 [MeSH Terms] AND ("self-management" [MeSH Terms] OR self-care [MeSH Terms] OR quality of life [MeSH Terms] OR "glycated hemoglobin a" [MeSH Terms]) AND (Program Evaluation [MeSH Terms] OR "health promotion" [MeSH Terms]). Filters: English, from 2009-2021	27

Study/Source of Evidence selection

Following the search, all identified records will be removed as duplicates using the Mendeley. Two independent reviewers will be screening titles and abstracts for assessment against the inclusion criteria for the review. Potentially relevant studies will be retrieved in total. Two independent reviewers will assess the full-text citations against the inclusion criteria. The scoping review will report, in the full text, the reasons for the exclusion of sources of evidence in full text that do not meet the inclusion criteria. Any disagreements between the reviewers will be discussed with a third reviewer. The search results and the study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram.[20]

Data Extraction

Quantitative and qualitative data will be extracted from articles included in the review by two independent reviewers using a data extraction tool developed by the reviewers as indicated by the methodology for scoping reviews proposed by JBI.[22]The data extracted will include specific details about the participants, concept, context, study methods, and critical findings relevant to the review questions. A draft extraction form is provided (Table 2). The draft data extraction tool will be modified and revised as necessary while extracting data from each included evidence source. We will detail all modifications in the scoping review. Will resolve any disagreements between the reviewers through discussion or with an additional reviewer/s. If appropriate, we will contact the authors of papers to request missing or additional data, where required.

Table 2 - Data Extraction Instrument

Main Field	Extraction Categories	Category Description
Study ID	Reference number; Authors; Year; Title; Journal; Issue no; Vol no.	
	Type of reference	1. Primary research 2. Systematic review
Inclusion/ Exclusion criteria	P – Adolescents with T1D C - Programs and/or interventions to promote self-management in adolescents with T1D. Excludes programs do not should results. C - Interventions via virtual or attendance in health care setting (hospital or ambulatory), diabetic camps or at person's home.	1. Yes 2. No
Characteristics of population	Who are the participants involved in the intervention?	1. Adolescents 2. Adolescents and parents/ family
	Who are the healthcare professionals in the healthcare practice/intervention?	1. Physicians 2. Nurses 3. Psychologists 4. Physiotherapists 5. Nutritionists 6. Multidisciplinary 7. Other, please specify
Characteristics of interventions	How is the intervention designed?	1. Educational 2. Psychosocial 3. Supportive 4. Communicational 5. Other, please specify
	General characteristics of interventions	1. Contents 2. In group 3. Individually 4. Duration of the sessions
Characteristics of context	What is the setting of intervention delivery?	6. Health care setting (Hospital or ambulatory) 7. Person's home 8. Virtual 9. Other, please specify
Outcomes	What are the indicators of change in self-management skills after the intervention?	1. Self-management (Acute and chronic complications of the disease:

hypo and hyperglycemia, insulin administration, measurement of blood glucose, health maintenance: diet, and physical exercise)

2. Self-efficacy
3. Knowledge
4. Quality of life
5. Self-care
6. Glycated Hemoglobin

Results

Data analysis and presentation

The results will be summarized and presented in a tabular form. A draft results table has been developed to address each question (table 3). A narrative summary accompanies the tabular results and describes how these are related to the review's objective and questions. We will present what is known, the literature gaps in the field, and the potential implications for health care and research.

Table 3 - Tabular Summary for Results Presentation

Review questions	Study 1	Study 2	Study 3	...
a) What are the characteristics of the interventions that promote self-management in adolescents with T1D? b) Who are the professionals responsible for implementing the interventions? c) What are the indicators of change in self-management skills after the intervention?				

Discussion

Mapping of the available interventions implemented for adolescents with T1D may constitute a tool to design of a structured intervention to promote self-management behaviour in adolescents with T1D and contribute to the dissemination of available evidence on the topic. This scoping review will only consider English, Portuguese, and Spanish studies, which can be registered as potential study limitation. In order to minimize the effects of this limitation, if we find an article relevant to the topic, in another language, we undertake to use tools so that can be integrated in this review.

Conclusions

The literature points to the development of interventions in different contexts for adolescents with T1D focused on self-management and empowerment to promote autonomy to promote better quality of life and reduce complications. The scoping review, which will result from this protocol is expected to gather relevant information that will serve as a basis for the development of a nursing intervention for adolescents with T1D.

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Fear of falling in the elderly in a hospital setting: scoping review protocol

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Abstract

Introduction

The expected changes in an aging process contribute to the increased risk of falling and influence the person's own assessment of their risk of falling. In addition to physical injuries, falls can have psychological consequences, such as fear of falling. This concept was defined as a continuous concern of an individual, when standing or walking, with the occurrence of falls, compromising the performance of daily activities. In this sense, the fear of falling is a sensitive human response to nursing care. As health professionals, nurses should consider evaluating the fear of falling and understand how this phenomenon manifests itself in the elderly.

Objective

Mapping the available scientific evidence related to the fear of falling in the elderly in a hospital environment.

Inclusion criteria

Quantitative, qualitative, or mixed studies will be considered, as well as systematic reviews and grey literature. The review will include studies on the fear of falling in elderly people who are in hospitals.

Methods

Scoping review protocol according to the Joanna Briggs Institute method. Three-phase research strategy that will aim to locate published and unpublished studies in Portuguese, English and Spanish. Temporal, geographic, or cultural limits will not be considered in the research. The search strategy will be adapted to each database/repository in order to identify relevant studies. The selection of studies will begin by analysing the title and abstract. The full text of the selected studies will be analysed by two independent reviewers who will extract data using a specific instrument.
The protocol was registered on the Open Science Framework platform (DOI - https://doi.org/10.17605/OSF.IO/B5V6K).

Keywords

Fear of Falling; Elderly; Hospital; Review.

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Introduction

According to the World Health Organization [1], by 2030, it is estimated that the number of people over 60 years of age will increase by 34%, from 1 billion in 2019 to 1.4 billion. By 2050, this population will have doubled to 2.1 billion worldwide.

In Portugal, demographic aging continues to increase significantly. According to the 2021 Census[2], the population aging index, an indicator that compares the population aged 65 or over with the population aged 0 to 14, is 182, which means that there are 182 elderly people for every 100 young people.

With advancing age, it is expected that there will be changes typical of the aging process. At the biological level, a variety of molecular and cellular damage occurs, leading to a gradual loss in physiological reserves and a functional decline in the person's intrinsic capacity.[3] Muscle weakness, compromised balance, difficulties in locomotion and worsening of cognition are some of the changes that occur in aging, and these contribute to the increased risk of falls in elderly people.[4, 5]

A fall can be defined as an unintentional event that results in the change of position of the individual to a lower postural level in relation to his/her initial position.[6] The International Council of Nurses (ICN) [7] in addition to considering that a fall is an "event or episode", adds that falling is "a descent from a body from a higher level to a lower level due to imbalance, fainting or inability to support weight and stay upright".

In the elderly, falls are frequent events with possible serious consequences for the individual and with a significant economic impact on health institutions. Globally, the prevalence of falls in elderly people is 26.5%[8], with one third of this population falling at least once a year[6], which contributes to falls being considered the second leading cause of injuries in the elderly.[9]

There are several risk factors that contribute to the occurrence of falls, *and it is consensual to use the classification of intrinsic and extrinsic factors.

Intrinsic factors are conditions that are related to the client, such as age, comorbidity, history of previous falls, gait, visual and auditory impairment, musculoskeletal changes, and cognitive impairment.[10]

The extrinsic factors are related to the environment where the client is inserted. At the hospital level, we highlight acute illness, delirium, postoperative period, medication, change of environment, support equipment, bed rest and immobility, use of inappropriate footwear, lighting of spaces, lack of knowledge about fall prevention, failure to communicate between the client and the health professional.[6, 10] In this way, it is noticeable that the hospital environment is a context where elderly people can present an extremely high risk of falling.

With regard to the consequences of falls, in addition to physical injuries, such as fractures and traumatic brain injuries, it is important to analyse the psychological consequences, which are harmful for the elderly in the long term and contribute to a decrease in quality of life. Loss of confidence and fear of falling are two examples of psychological consequences and can result in compromised activity levels, leading to reduced physical function and social interactions.[11]

The ICN [7] defines fear as a "negative emotion: feeling threatened, endangered or upset due to known or unknown causes, sometimes accompanied by a physiological response of the fight-or-flight type".

The fear of falling has been recognized by the scientific community, since the 1980s, as a health problem in the elderly. This concept was called ptophobia, in 1982, and is understood as the phobic reaction to keep standing and walking, even when there is no neurological or orthopaedic alteration.[12]

Subsequently, the fear of falling was defined as a continuous concern of an individual, when standing or walking, with the occurrence of falls, compromising the performance of daily activities.[13]

Currently, fear of falling can be considered a protective or pathological condition. On the one hand, fear as a protective factor will lead the elderly to avoid risky behaviour and seek to promote safety, either through measures that prevent falls or through gait adaptations that increase stability. On the other hand, the pathological fear of falling can lead to a decline in quality of life and increase the risk of falls by reducing the activities necessary to maintain self-esteem, confidence, strength, and balance.[5, 14]

The fear of falling can cause a loss of confidence in the ability to perform everyday tasks, leading the elderly to restrict their daily activities[15], social isolation, decline in physical capacity and loss of independence[16], which can result in changes in mental health, namely the emergence of depressive and anxious states.[17–19] Other psychological aspects, such as self-efficacy related to falls and self-perception of health status, are associated with fear of falling.[16]

The fear of falling proves to be a risk factor for falls in elderly people, whether or not they have a history of previous falls.[20] People who are afraid of falling tend not to be confident in their ability to prevent or avoid falls, which increases the risk of falling and requires psychotherapeutic and physical rehabilitation intervention.[21]

The estimated prevalence of elderly people with fear of falling is around 36%, which is more evident in people who have fallen in the last three months.[22] In a hospital environment, the fear of falling in elderly people who are hospitalized varies between 36 and 83% .[17, 23]

It is also known that in hospitalized elderly people, the fear of falling may have a greater influence on functional recovery than the presence of pain or emotional changes. Fear of falling also reduces the participation of individuals in exercises during the rehabilitation process, as they have functional limitations and reluctance to move.[17, 24]

The International Classification of Nursing Diagnoses by NANDA International, Inc. (NANDA-I) [25] presents the diagnosis "Risk of falls in adults" which is defined as the "adult susceptibility to experience an event that results in inadvertent displacement to the ground, floor or other lower level that may compromise health".[25(p468)] Still in this diagnosis it is possible to verify that the fear of falling appears in the risk factors, namely in the "psychoneurological factors".[25]

In this sense, it is noticeable that the fear of falling is a sensitive human response to nursing care. As health professionals, nurses should consider evaluating the fear of falling and understand how this phenomenon manifests itself in the elderly.

Considering this issue, a preliminary scoping review was carried out in the following databases/sources: Open Science Framework (OSF), Medical Literature Analysis and Retrieval System Online (MEDLINE) (via PubMed) and Cumulative Index to Nursing and Allied Health Literature (CINAHL) (via EBSCO). A scoping review[18] was found that mapped the evidence about fear of falling in elderly people living in the community. In addition, the review concentrated on the results of articles published between 2015 and 2020 and the search was carried out only in a database.

In this way, this review differs from the scoping review mentioned above in that it intends to address the fear of falling of elderly people who are hospitalized. Knowledge on this topic lacks completeness and a scoping review will facilitate the necessary mapping of this knowledge.

In addition to a scoping review allowing to map the available evidence about a phenomenon, it also allows the identification of the main characteristics or factors related to a concept, including those that are related to methodological research.[26]

The objective of this scoping review is to map the available scientific evidence regarding the fear of falling in the elderly in a hospital setting.

Review Question

Following the recommendations of the Joanna Briggs Institute (JBI) [27] for the preparation of a scoping review, the review question is designed using the PCC mnemonic for scoping review, where P stands for "participants", C for "concept" and C for "context".

For this review, it was defined as Participants – people aged 65 or over, Concept – fear of falling and Context – hospital environment, which leads us to the following review question:

What is the published evidence on the fear of falling in the elderly in a hospital environment?

From the defined review question, this scoping review may also answer the following questions:

- What is the published evidence on the related/etiological factors inherent to the fear of falling in the elderly?
- What is the published evidence on the clinical indicators/defining characteristics of fear of falling in the elderly?
- What are the instruments that assess the fear of falling in the elderly in a hospital environment?

Inclusion Criteria

Based on the PCC mnemonic, we defined the inclusion criteria regarding participants, concept, and context

Participants

Regarding Participants, the review will consider all studies that include elderly people as participants. Gender, ethnicity, or other personal characteristics will not be considered. An elderly person is understood to be one who is 65 years of age or older.[28]

Concept

As for the Concept, the review will consider studies that explore the fear of falling. Fear of falling is understood as a continuous concern of an individual, when standing or walking, with the occurrence of falls, compromising the performance of daily activities.[13]

Context

Regarding the Context, the review will consider all studies carried out in a hospital context, regardless of the type of establishment, whether public or private, general, or specialized, urban, or rural, teaching or not, and certified or not.

Types of sources

This scoping review will include studies with quantitative, qualitative, or mixed methods designs.

Quantitative studies include any experimental study (including randomized controlled trials, non-randomized controlled trials, or other quasi-experimental studies, including before and after studies) and observational studies (descriptive studies, cohort studies, cross-sectional studies, case studies, and follow-up studies, series of cases). Qualitative studies include studies with qualitative data analysis, but are not limited to phenomenological studies, grounded theory, ethnography, qualitative description, and action research.

Systematic reviews that meet the inclusion criteria will also be considered, depending on the research question. Finally, the grey literature, namely theses and dissertations, will also be included in the research.

Methods

The scoping review will be conducted in accordance with the methodology proposed by the JBI for scoping review.[27] This scoping review protocol is registered on the OSF platform (DOI - https://doi.org/10.17605/OSF.IO/B5V6K).

Search strategy

The search strategy will aim to locate published and unpublished studies in Portuguese, English and Spanish. Temporal, geographic, or cultural limits will not be considered in the research.

JBI [27, 29] recommends a three-phase research process that should be used in developing a comprehensive research strategy:

The first phase involved conducting a limited initial search of the MEDLINE (via PubMed) and CINAHL (via EBSCO) databases to find articles on the phenomenon of interest, using the search terms: “fear of falling”; “aged”; "hospital*". In relevant articles, the words contained in the titles and abstracts were analysed, as well as the indexing terms used to describe the articles, in order to develop a complete search strategy for CINAHL complete (via EBSCO), Web of Science Core Collection, MEDLINE (via PubMed), Scopus.

Search strategies will be adapted and individualized for each database of published studies, as each uses its own controlled vocabulary. Chart 1 presents a research strategy proposal in one of the databases.

Chart 1 – Search strategy used in the database - MEDLINE (via PubMed)

Data base	Research Strategy	Results
MEDLINE (via PubMed)	#1: "fear of falling"[All Fields]	2,279
	#2: "aged"[MeSH Terms] OR "aged"[Title/Abstract]	3,898,782
	#3: "elder*"[Title/Abstract]	302,509
	#4: “older”[Title/Abstract]	535,444
	#5: "senior*"[Title/Abstract]	49,998
	#6: "older adult*"[Title/Abstract]	113,680
	#7: "older people"[Title/Abstract]	38,820
	#8: "geriatric*"[Title/Abstract]	75,485
	#9: "older person*"[Title/Abstract]	13,565
	#10: #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9	4,221,852
	#11: "hospital setting"[Title/Abstract]	13,929
	#12: "inpatient*"[MeSH Terms] OR "inpatient*"[Title/Abstract]	157,237
	#13: “hospital*"[MeSH Terms] OR "hospital*"[Title/Abstract]	1,991,749
	#14: "ward*"[Title/Abstract]	71,416
	#15: #11 OR #12 OR #13 OR #14	2,066,169
	#16: #1 AND #10 AND #15	262
	#17: #16 AND (English[Filter] OR Portuguese[Filter] OR Spanish[Filter])	**246**

Sources of unpublished studies, namely grey literature, include OpenGrey, RCAAP (Portuguese Open Access Scientific Repository) and Coordination for the Improvement of Higher Education Personnel Theses Bank (CAPES) (Brazil). The search in this grey literature was carried out with the term “fear of falling”.

The second phase involves performing database-specific searches on each of the bibliographic databases and information sources selected and reported in the protocol.

The third phase involves the inclusion of any relevant additional studies in the reference lists of all studies selected for the review.

Selection of studies

All identified bibliographic references will be grouped and managed in the Rayyan Intelligent Systematic Review software, (Cambridge/United States of America, Doha/Qatar), and duplicates will be removed.

After the search, the selection of relevant results will begin with the analysis of titles and abstracts by two independent reviewers, based on the inclusion criteria for the review previously described.

Subsequently, the full text of the selected studies will be evaluated in detail based on the inclusion criteria by two independent reviewers. After analysing the full text, studies that do not meet the inclusion criteria will be excluded. The reasons for excluding these studies will be described in one of the appendices of the scoping review.

Any disagreements that arise between the reviewers will be resolved through discussion and consensus or by resorting to a third reviewer.

The evaluation of the methodological quality of the included studies will not be carried out because it is a scoping review.[29]

The research process will be exposed in full in narrative form and presented in schematic form through a flow diagram known as Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), using the extension for scoping reviews called Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).[30] This diagram demonstrates, in detail, how the search was carried out, the selection of results used in accordance with the inclusion criteria and the elimination of duplicates.[27]

Data extraction

Data extraction from the included articles will be carried out by two independent reviewers, with the support of a third reviewer to resolve any divergence.

An instrument will be used that considers specific details about the population, concept, context, and research methods relevant to the issue and stated objective of this scoping review, as indicated by the methodology developed by the JBI (Chart 2).

Chart 2 – Data extraction instrument

Scoping Review details	
Review title:	Fear of falling in the elderly in a hospital setting: *a scoping review*
Purpose of the review:	Mapping the available scientific evidence related to the fear of falling in the elderly in a hospital environment.
Review question:	What is the published evidence on the fear of falling in the elderly in a hospital environment?
Inclusion criteria	
Participants	Studies that include elderly people aged 65 or over as participants.
Concept	Studies that explore the fear of falling.
Context	Studies carried out in a hospital environment, specifically hospitals, regardless of the type of establishment, whether public or private, general, or specialized, urban, or rural, teaching or not, and certified or not.
Font types	Quantitative, qualitative, or mixed studies. Systematic reviews and grey literature.
Details and Characteristics of the Studies	
Article title	
Magazine (volume, edition, pages)	
Publication year	
Author(s)	
Country	
Context	
Participants	
Methodology used for data collection and analysis	
Results found	
Fear of falling in the elderly person in a hospital environment	
Related/etiological factors inherent to the fear of falling in the elderly	
Clinical indicators/Defining characteristics of fear of falling in the elderly	
Instruments that assess the fear of falling in the elderly in a hospital context	
Research Recommendations/Suggestions	
Relevant bibliographical references	

In order for researchers to become familiar with the data extraction instrument, a pilot test will be carried out with the first five articles. If necessary, the data extraction instrument may undergo relevant changes, according to the conclusions of the pilot test and the emerging needs of the analysis of eligible articles.

Data Analysis and Presentation

The organization and synthesis of the collected information will be carried out using tables and charts that facilitate the reader's interpretation. In this way, the collected data will be presented in schematic form through a table and accompanied by descriptive summary tables of the articles included in the *scoping review*. The conclusions of the selected studies will be described through a narrative summary.

Subsequently, the results found will be categorized according to their similarity, in line with the objective and review questions that were proposed in this protocol.
In short, the presentation of the data will allow identifying, characterizing, and synthesizing the knowledge about the fear of falling in the elderly in a hospital setting.

Authors' contributions

RO: Study conception and design; Data collection; Data analysis and interpretation; Manuscript writing.
OR: Analysis and interpretation of data; Drafting of the manuscript.
JC: Critical revision of the manuscript.
DC: Critical revision of the manuscript.

Conflicts of interests

No conflict of interest declared by the authors.

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Nursing care in the prevention of skin tears in the elderly: integrative review of the literature

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Abstract

Introduction
Skin tears are considered injuries of traumatic etiology that can result from a variety of mechanical forces, such as shear or friction forces, blunt trauma, falls, improper handling, injury caused by equipment or removal of adherent dressings.
These are acute wounds that have a high probability of becoming complex chronic wounds. They cause pain, increase healthcare costs, reduce quality of life and are a source of stress for the person. They lengthen hospital stay and increase the risk of morbidities. Skin Tears are a growing problem, making it crucial to invest in this topic in order to promote their prevention and proper treatment.

Objective
To identify nursing care and strategies to prevent skin tears in the elderly.

Methods
A bibliographic survey of publications was carried out in the EBSCOhost search engine, which incorporates the CINAHL Complete, MEDLINE Complete and Cochrane Database of Systematic Reviews databases and in the PubMed database, carried out in June 2022. 26 records were returned, five meeting the inclusion criteria. The included studies (n=5) were carried out between 2012 and 2022.

Results
In the sample of articles, it was possible to identify the benefits of twice-daily application of topical products, moisturizing creams and emollients, and the relevance of oral administration for 8 weeks of an oral nutritional supplement in the hydration of the stratum corneum and in the elasticity of the skin, as well as the importance of primary prevention and the promotion of health education in elderly skin care.

Conclusion
Preventive care to avoid skin tears in the elderly focuses on the daily topical application of moisturizing creams and emollients, nutrition (administration of oral nutritional supplements with 10g of collagen peptides) and adequate hydration; to prevent cutaneous traumas by providing a safe environment with adequate devices, and through the promotion of health education.

Keywords
Skin Tears; Prevention; Effectivity; Elderly; Health Care; Nursing Care.

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Introduction

Ageing is characterized by natural, dynamic and progressive decline in which morphological, physiological, biochemical and psychological modifications occur, thus increasing the vulnerability of the elderly and causing a greater occurrence of pathological processes.

With advancing age, according to Papaléo,[6] the skin tends to become thinner and more flaccid. There is a decrease in the thickness of the epidermis-dermis, in the size of the keratinocytes, in cell proliferation in the stratum basale and in structural and architectural alterations of the elastic fibers that make the collagen system vulnerable to mechanical forces. There is also a strong compromise of the collagen metabolism, and consequently, the skin becomes less elastic and thinner.

For Oriá *et al.,*[7] the barrier function of the skin is also affected. There is a decrease in the hydration of the stratum corneum, a compromise of the sebaceous and sweat glands and a decrease in the vascular bed along with the fragility of the blood vessels. According to LeBlanc *et al.,* [8] these physiological changes that occur with ageing lead to an increase in the occurrence of skin tears and, consequently, to the compromise of the human body's homeostasis.

Skin tears are considered injuries of traumatic etiology that can result from a variety of mechanical forces, such as shear or friction forces, blunt trauma, falls, improper handling, injury caused by equipment or removal of adherent dressings. These may occur in any anatomical region, but are more frequent in the extremities, particularly in the upper limbs, where they occur 70 to 80% in the hands and forearms.[5,9,10]

Skin tears are a problem with some prevalence in the elderly and with a negative impact both on their quality of life and on the increase in costs for the person and the health system. It is therefore essential to address this subject and analyze the scientific evidence, in national and international studies, about nursing care in prevention for the elderly.

Considering the different professional contexts of the reviewers, it was consensual that skin tears are increasingly prevalent and transversal to distinct services, raising the need to deepen the knowledge and improve the quality of the nursing care provided, in order to prevent possible complications.

The starting question for this study was: "What are the nursing care practices in the prevention of skin tears in the elderly?", where the general objective is to assess the state of the art regarding the prevention of skin tears in the elderly. As a specific objective we aim to identify nursing care practices and strategies in the prevention of skin tears in the elderly. This integrative review is divided into four parts: the methodology, where a description of the research elaboration method and a presentation of the flowchart of the article selection process are carried out; the sample results organized by the name of the article, year, objective, sample, type of study, methodology and the main conclusions; the discussion of the main results of the review and the limitations of the study; the conclusion, which includes the general interpretation of the results, their relevance for clinical practice, implications for future research and the strengths and limitations of the review.

Methods

According to Soares *et al.*[11] a integrative literature review is developed with the purpose of gathering and synthesizing results from studies carried out using different methodologies to deepen the knowledge on the chosen subject.

Based on the starting question: "What are the nursing care practices in the prevention of skin tears in the elderly?", a search was conducted in the EBSCOhost search engine integrating the CINAHL Complete, MEDLINE Complete and Cochrane Database of Systematic Reviews databases and in PubMed, to identify the articles on the subject, using natural language words and terms indexed by the PEO elements described, applying the Boolean operators "OR" and "AND" and the use of truncations (see Table 1).

Table 1- OR and AND combination across the key concepts identified for the research strategy

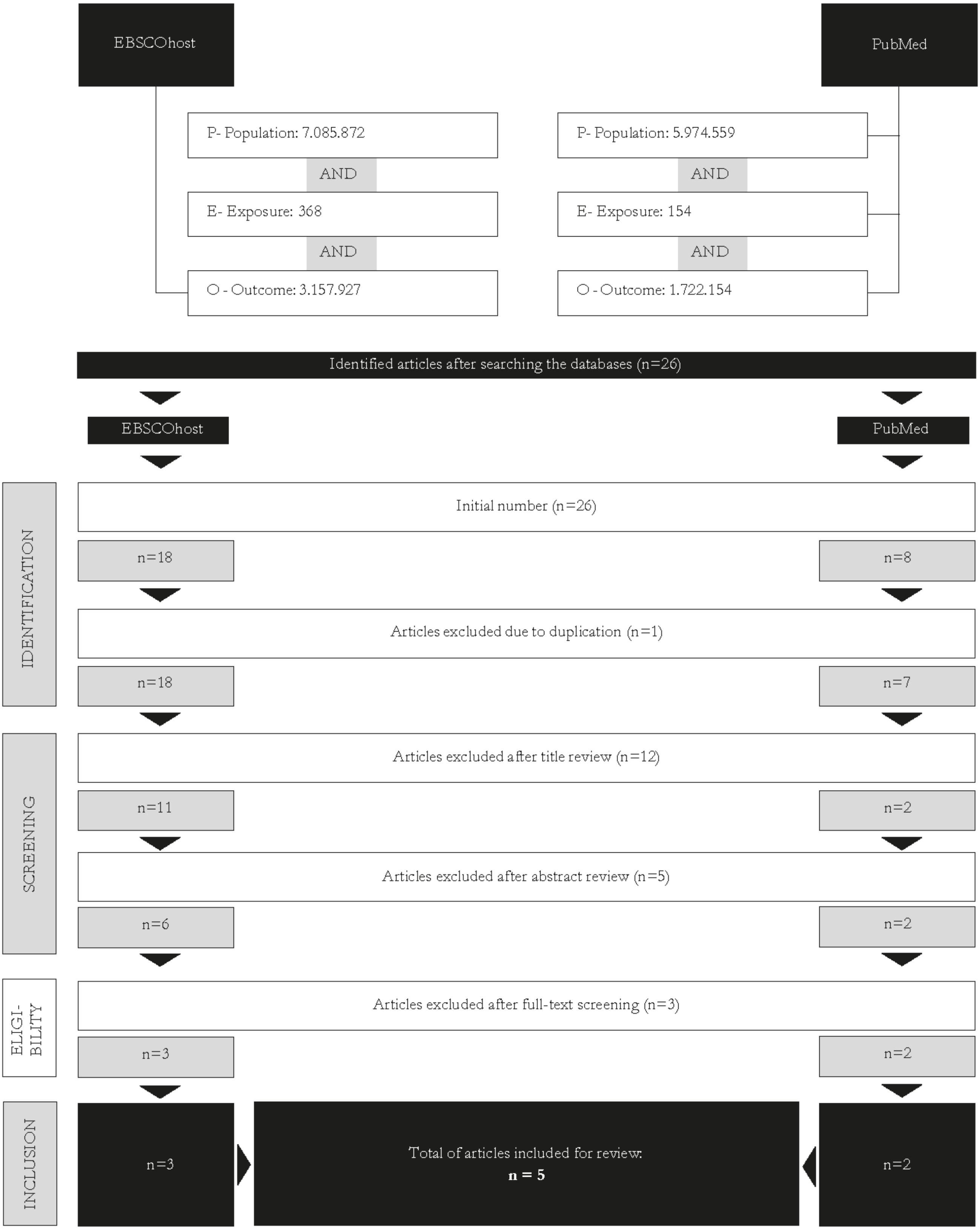
P - Population	AND	**E - Exposure**	AND	**O - Outcomes**
Elderly over 65 years old		Skin Tears Prevention		Nursing Care
Elderly OR "old man" OR "aged" OR "frail elderly" OR "Old people" OR "65 over" OR "older people"		Prevent* OR Effectiv* AND 'Skin tears" OR "skin laceration"		"nursing care" OR 'nursing strategies" OR "nursing tasks" OR nursing procedures" OR 'nursing guidelines" OR "nursing involvement" OR "nursing activities" OR "Nurses's Role" OR 'Nursing" OR "nursing interventions" OR "nursing instructions" OR 'nursing recommendations" OR "Health care"

All articles addressing the research question were considered, in full text available for free online in the databases used, published between 2012 and 2022, written in Portuguese, English and Spanish, as these were the languages mastered by the reviewers.

The age range was defined as the research inclusion criterion: the elderly (over 65 years old) and without social context, that is, people in an outpatient basis or admitted to hospitals, day centers, convalescent units or other health institutions were included.

From this search conducted in the aforementioned databases in June 2022, the sum of twenty-six articles was obtained, among which one was duplicate, twelve were excluded by reading the title, five rejected by reading the abstract and three eliminated by reading the full text. The final result was the inclusion of five articles for review, after their full reading, as explained in figure 1.

Figure 1 - Flowchart of the article selection process after applying the inclusion criteria.



The search steps on the retrieved articles were carried out independently by the three reviewers, to assess compliance with the eligibility criteria for the present review. After this first selection, the full texts (of potentially relevant evidence) were extracted and assessed thoroughly in order to detect any deviations from the inclusion criteria.

For an article to progress to the full reading stage, it was necessary for at least two of the three reviewers to consider it eligible.

Results

The sample results are presented in the table below, organized by article name, year, objective, sample, type of study, methodology and the main conclusions regarding the final articles that were included in this integrative review.

Table 2 – Results of the final articles included in the integrative review

Article name	Objective	Sample	Type of Study	Methodology	Main conclusions
The effectiveness of a twice-daily skin-moisturizing regimen for reducing the incidence of skin tears; Carville K, *et al*, 2014 [4]	To assess the effectiveness of a standardized twice-daily hydration regimen in preventing skin tears in hospitalized patients in health facilities.	980 hospitalized patients in 14 Western Australian health facilities	Cluster randomized controlled clinical trial	Elderly care facilities were divided into 7 pairs, defined by number of beds and provision of high or low clinical care. One healthcare unit from each matched pair was randomized to the intervention group and the other to the control group. In the intervention group, the elderly received a twice-daily application of a standardized pH-neutral, perfume-free moisturizer on the extremities of the body, applied in a gentle, downwards direction. The elderly in the control healthcare units did not receive any standardized skin hydration regimen. *SPSS, version 19* application software was used to analyze the data collected over the course of 6 months.	Applying moisturizer twice-daily, reduced the incidence of skin tears in almost 50% of the users living in the health facilities. The highest percentage of skin tears on the extremities of the lower limbs was observed in the facilities with low clinical care. The most dependent elderly showed skin tears at arm level. The main contributing factor to skin tears in both groups was age-related skin fragility.

Skin tear prevention in elderly patients using twice-daily moisturizer; Finch K, *et al*, 2018 [12]	To test the efficacy of a twice-daily application of moisturizer to the extremities of hospitalized elderly patients over a 12-month period (January to December 2013).	Included 762 eligible patients in the intervention group and 415 users in the historical control group (over 65 years old)	Prospective intervention study	The prospective intervention study was conducted and compared with the results of historical controls (study conducted from July to December 2011, involving 415 patients, with a duration of 6 months). Patients were admitted to a Brisbane private hospital (45 beds in the rehabilitation ward and 30 in the *acute/subacute ward*). The following exclusion criteria were applied: patients who did not sign the consent form; those who had a day admission to the rehabilitation ward; those deemed unsuitable by medical officer; and those who could not apply the cream due to medical conditions. Inclusion criteria: patient's age; gender; inpatient ward; pressure ulcer risk assessment (using the *Waterlow Scale*); patient's risk of falls; cognitive status; skin characteristics such as dry or discolored skin; number of skin lesions; day and time of skin tear occurrence; anatomical location of skin lesions; the STAR *Skin Tear* Classification; factors that may have contributed to a skin lesion (assessed by a team member after discussion with the patient) and the location of the ward where the skin lesion happened. Patients in the intervention group were subject to a twice-daily application of a pH-neutral, non-perfumed moisturizer on their arms and legs, while users in the control group were not subject to any cream application. Monthly incidence rates of skin lesions were calculated as number of skin lesions/days of occupied beds and the statistics were carried out with IBM SPSS for Windows, Version 2.3.	Applying a pH-neutral, non-perfumed moisturizing cream on a twice-daily basis reduced skin tears by almost 50%. This frequency helps maintain skin hydration and supports and repairs the skin's barrier function, regardless of the healthcare facility. It produces evidence to support the benefits of applying twice-daily moisturizing cream to the extremities of hospitalized elderly patients when the goal is to reduce the incidence of skin tears. This relatively low-cost intervention has the potential to reduce healthcare costs and improve healthcare outcomes.

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Effect of an Oral Nutrition Supplement Containing Collagen Peptides on Stratum Corneum Hydration and Skin Elasticity in Hospitalized Older Adults: A Multicenter Open-label Randomized Controlled Study; Nomoto T, Iizaka S., 2020 [13]	To investigate the effect of the oral administration of a nutritional supplement containing collagen peptides on stratum corneum hydration.	39 inpatients 65 years or older	Open-label randomized controlled study	A multicenter, open-label, randomized controlled study was conducted to examine the effect of 8-week oral administration of an oral nutrition supplement, containing 10g of collagen peptides on stratum corneum hydration and skin elasticity in 39 elderly inpatients in convalescent rehabilitation wards. Comparison with residents in the control group. IBM *Statistical Package for the Social Sciences (SPSS)* version 19 was used to analyze the data.	Oral nutritional supplements containing collagen peptides can reduce skin vulnerability in the elderly and thus helping to prevent problems such as skin tears After 8 weeks, stratum corneum hydration and skin elasticity were significantly higher in the intervention group that consumed oral nutritional supplements than in the control group that did not. This indicates that oral nutritional supplements containing collagen peptides can reduce the vulnerability of the skin of the elderly, helping to prevent problems such as skin tears. The mechanisms of such improvements are unknown, but the intake of collagen peptides contained in oral nutritional supplements may stimulate the growth of skin fibroblasts and the synthesis of hyaluronic acid.

Skin Tear in the Elderly; Spin M, e *et al* ; 2021 [14]	To identify, in the scientific literature, the knowledge produced about skin tears in the elderly.	Eight articles were selected, grouped into qualitative and quantitative categories, and categorized into themes, according to the similarity of the conclusions of the analyzed studies.	Integrative literature review	Research was carried out on the platforms/databases *National Library of Medicine, Biomedical Answers Virtual Health Library*, with descriptors and the Boolean operators *"and"* and *"or"* between the years 2014 and 2019, using the following inclusion criteria: full articles made available free of charge and in full in Portuguese, English and/or Spanish. The research question was defined based on the PICO strategy.	Patients who presented malnutrition, hydration and low levels of serum albumin, were more prone to the appearance of skin tears. Activities performed during daily care can halve the incidence of skin tears, (the use of topical skin products such as hypoallergenic moisturizers based on lactic acid or urea twice-daily). For bathing, the use of soaps can affect the physiological characteristics of the skin and make it prone to the appearance of tears. The use of alkaline, antibacterial, or perfumed soaps can alter the skin's microbiome, so it is recommended to replace them with pH-neutral soaps, to use lukewarm water and to reduce the duration and frequency of the bath (bathing every two days is recommended). For the prevention of skin tears in the elderly emerged the following pillars of care: • maintaining organic and tissue homeostasis with a focus on proper nutrition and hydration; • avoiding trauma to fragile skin, providing a safe environment with suitable devices; • systematization of health care and education for elderly skin care. • prevention mechanisms that encompass primary prevention through a unique care plan and healthcare education activities, focused on risk factors and vulnerabilities, minimizing damage and complications.

Preventing skin tears among older adults in the community; Palmer SJ, 2021 [15]	Preventing skin tears among the elderly in the community - guidance from 2018 from Wounds UK and Wounds International.	Not applicable	Expert opinion	Not applicable	The prevention of skin tears should focus on the risk factors for the person with skin tears. Emollient therapy promotes general skin health and twice-daily application reduces the incidence of skin tears by 50%. The bath should be carried out with emollient and pH-balanced products when necessary. Frequency of bathing should be minimized. The water temperature should not be too hot, so as not to damage the epidermis, and care should be taken to dry the patient's skin (not rub), with the use of soft cloths and towels that are not abrasive on the skin. The skin tear prevention regimen should also involve holistic elements that consider the patient's general health, adequate nutrition and hydration, and polypharmacy. Educating the patient about preventive measures and general skin health can be beneficial, so that they can monitor their own skin for changes. Patients can also be encouraged to be aware of potential risks and attentive to their environment, therefore avoiding self-injury to fragile skin. A self-care checklist can be provided to patients who are able to comprehend and use it, so that they can monitor their own skin health and wellbeing. The risk of trauma can be mitigated with a few considerations: avoid friction and shearing, and perform good manual handling techniques, resorting to equipment when necessary. Equipment with sharp and moving surfaces can be padded to provide a safe environment, as well as proper and unobstructed lighting. Education and awareness are vital, both for the patient and for the health professional, to minimize the risk of skin tears.

Discussion

The discussion of results aims to provide the most relevant, current and credible information obtained by reading the entire sample, in order to answer our starting question: “What are the nursing care practices in the prevention of skin tears in the elderly?”

The sample consists of articles from different types of studies, namely: prospective intervention; cluster-randomized controlled clinical trial; multicenter, open-label and randomized controlled study; integrative literature review; and expert opinion article.

Of the final studies: two assessed the benefits of applying topical products, moisturizing and emollient creams; another about the effect of oral administration of a nutritional supplement for 8 weeks on stratum corneum hydration and skin elasticity; the integrative review identified in scientific literature the knowledge produced on the prevention of skin tears in the elderly; and finally, an expert opinion article addressed the prevention of skin tears among the elderly in the community.

Studies that have evaluated the benefits of using topical preparations show that the incidence of skin tears in the elderly has decreased dramatically, regardless of the place of hospitalization.[4,12] It is important to emphasize that the studies applied the topical preparations to the upper and lower limbs, since skin tears are more likely to occur at these anatomical sites.

The study by Finch *et al.*[12] showed that applying moisturizer twice-daily in a sample of 762 users reduced skin tears by almost 50%, highlighting the benefits associated with applying it regardless of the healthcare setting.

Carville *et al.*[4] found that in a sample of 980 elderly people in 14 residential facilities in Western Australia, over a six-month period, a gentle, downwards application on the upper and lower limbs twice-daily of a standardized, pH-neutral, perfume-free moisturizer reduced the incidence of skin tears by almost 50% in the elderly. The highest percentage of skin tears on the extremities of the lower limbs was observed in the facilities with low clinical care. The most dependent elderly showed a higher percentage of skin tears at arm level.

The use of topical skin products, such as hypoallergenic moisturizers based on lactic acid or urea, twice-daily can halve the incidence of skin lesions, and the use of alkaline, antibacterial or perfumed soaps can alter skin's microbiome, so it is recommended to replace them with pH-neutral soaps, to use of lukewarm water and to reduce the duration and frequency of the bath, (bathing every two days is recommended), advocated by Spin *et al.*.[14]

This conclusion is also reached in Palmer's[15] article, stating that emollient therapy promotes general skin health and twice-daily application reduces the incidence of skin tears by 50%. The frequency of bathing should be minimized and only performed when necessary, with the use of pH balanced emollient products. The water temperature should not be too hot, so as not to damage the epidermis, and care should be taken to dry the skin of the patient (not rub), with the use of soft cloths and towels that are not abrasive on the skin.

According to Palmer,[15] the prevention of skin tears should involve holistic elements that consider the patient's general health, proper nutrition and hydration.

Advising the patient about skin tears and preventive measures can be beneficial so that patients are able to monitor changes in their own skin and avoid self-injury to fragile skin.

The risk of potential trauma can be mitigated with a few considerations: avoiding friction and shearing, good manual handling techniques resorting to devices such as hoists and transfers; equipment and furniture should be padded; and ensuring a safe environment (for example, with proper and unobstructed lighting).

Nomoto & Iizaka's[13] study, concludes that administering oral nutritional supplements containing collagen peptides for 8 weeks can reduce skin vulnerability among the elderly and thus prevent skin tears. The mechanisms of such improvements are unknown, but the intake of collagen peptides contained in oral nutritional supplements may stimulate the growth of skin fibroblasts and the synthesis of hyaluronic acid.

Spin *et al.*,[14] state that patients who present malnutrition, dehydration, and low levels of serum albumin are more prone to the appearance of lesions, as the body mass index contributes to the premature ageing of the skin.

Therefore, and according to Spin *et al.*,[14] for the prevention of skin tears in the elderly emerged four pillars of care:

- maintaining organic and tissue homeostasis with a focus on proper nutrition and hydration;
- avoiding trauma to aging skin, providing a safe environment with suitable devices;
- systematization of health care and education for elderly skin care.

prevention mechanisms that encompass a unique care plan and healthcare education activities, focused on risk factors and vulnerabilities, minimizing damage and complications.

Education and awareness are vital, both for the patient and for the health professional, to minimize the risk of skin tears.

Conclusion

The development of this integrative literature review allowed us to obtain some answers to the initially proposed PEO question.

From the analysis of the articles, which were part of the sample, we conclude that there is a relationship between the topical application of skin care products, such as moisturizing creams and emollients, and the reduction in the prevalence of developing skin tears, by about 50%.

Though the study had a small sample size, it showed that administering oral nutritional supplements with 10g collagen peptides can reduce skin vulnerability among the elderly and thus prevent skin tears.

Primary prevention and the promotion of healthcare education for elderly skin care play a critical role in preventing skin tears in this age group. The holistic view towards the person with skin tears, promotion of skin care, hygiene care management, a safe environment and a balanced diet are pivotal to the prevention of skin tears in the elderly regardless of whether they are in a home or institutional setting.

After the systematic literature review, the scarcity of studies to support nursing care in the prevention of skin tears in the elderly was evident.

Considering that skin tears are painful, affect the quality of life of the person with the injury and the caregivers, can be a source of infection and cause burdens for the person/family and the health system, further studies on this issue are essential in the future.

This study, for the health professionals who carried it out, was enriching in the sense that knowledge was obtained about the benefits applying of skin care products, such as moisturizing and emollient creams (mainly by following a twice-daily application), serving as a basis for the development of technical guidance in their respective health facilities.

As nurses, we have the responsibility to educate families and caregivers, as well as health operational technicians, on the prevention of skin tears. This study will serve as a basis for the development of future in-service training on the subject, targeting health professionals from the multidisciplinary team and/or informal caregivers.

With low-cost, easy to apply care, we can reduce the incidence of skin tears by about 50%, increase the quality of life of individuals, and reduce the burden of this type of tissue damage on the health system and patients/families.

Authors' contributions

ACCT: Elaboration of the article, from data collection, analysis and interpretation of data, writing of the work and revision of the article.

LMSCO: Elaboration of the article, from data collection, analysis and interpretation of data, writing of the work and revision of the article.

MIRVB: Elaboration of the article, from data collection, analysis and interpretation of data, writing of the work and revision of the article.

Conflicts of interests
No conflict of interest declared by the authors.

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Empowerment of hypertensive individuals and families in disease management: a community nursing intervention

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Introduction
Hypertension is a chronic disease with high national prevalence, being the main risk factor for cardiovascular brain disease. Thus, training for disease management is essential for disease control and eviction of complications. By determining the level of knowledge of the person and family about hypertension, it was possible to structure the intervention aimed at promoting autonomy for conscious decision-making, adopting healthy lifestyles and active participation in their health project.

Objective
Empower hypertensive people aged 45-65 years and family, enrolled in a Family Healthcare Unit in the intervention area of the Health Centre's Cluster Almada/Seixal.

Methods
The analytical cross-sectional observational study was based on the methodology of Health Planning, underpinned by the theoretical framework of Dorothea Orem's Nursing Self-Care Model. A questionnaire was designed and applied to conduct the Situation Diagnosis for the sociodemographic characterization of the sample and to identify the behaviors for disease management. The sample was composed using the purposive sampling technique. A favorable opinion was previously obtained from the Ethics Committee for Health of the Regional Health Administration of Lisbon and Tejo Valley (ARSLVT) under reference - 5043/CES/INV2022.

Results
The situation diagnosis revealed a deficit of knowledge about the disease and its management, as well as a deficit of self-care, which compromises the quality of life of the participants. With the prioritization of the problems, health education was selected as a strategy. After the community intervention, 70% of the participants assess and record daily BP values; 100% of them correctly identify risk behaviors for worsening hypertension; 63% of the participants practice regular physical activity; 87% of the participants report having reduced the daily intake of salt; and, 100% of family members identified two areas in which their family member needs more support, being the most frequent, encouragement for physical activity and restriction/substitution of salt in food.

Conclusion
This project was an important contribution to the empowerment of the hypertensive person and family to manage the disease, since after its completion there was an increase in knowledge of the participants, as well as behavioral changes associated with healthy lifestyles.

Keywords
Empowerment; Health management; Treatment Adherence and Compliance; Hypertension; Nurse.

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Introduction

Arterial Hypertension (HT) affects one billion people worldwide, accounting for 7.6 million premature deaths worldwide. It is the most prevalent risk factor for cardiovascular disease (CVD), causing approximately 14% of all deaths worldwide, and 143 million disability-associated life years [Disability Adjusted Life Years (DALYs)].[1,2] In Portugal, according to data from the Instituto Nacional de Saúde Doutor Ricardo Jorge (INSA)[3], resulting from the National Survey with Physical Examination (INSEF)[3], the national prevalence of hypertension is 36%. It constitutes a public health problem, given its high prevalence in the adult population, low levels of therapeutic adherence and often late diagnosis[4]. It is a chronic non-transmissible disease, which consists of the sustained elevation of systolic blood pressure values equal to or greater than 140mmhg and diastolic pressure values equal to or greater than 90mmhg.[5,6] Its installation is progressive, which is why, initially, its signs and symptoms are not perceptible, however its continuous increase over time generates lesions in the vessels, weakening them, which may later give rise to aneurysms, cerebrovascular accident (CVA), heart failure (HF), acute myocardial infarction (AMI), renal failure, among others[1]. Its symptoms are nonspecific and easily associated with other causes, leading to late diagnosis[4]. It is classified into three levels of severity: (1) Grade 1 - mild arterial hypertension (140-159/ 90-99 mmHg); (2) Grade 2 - moderate arterial hypertension (160-179/100-119 mmHg); and (3) Grade 3 - severe arterial hypertension (180/110 mmHg), according to the etiology it is classified as: essential, primary or idiopathic hypertension, the most frequent (unknown cause); and secondary hypertension, less frequent, derives from an associated pathology (potentially treatable or not), such as, for example, kidney disease, obstructive sleep apnea syndrome; obesity; among others[4,5,6]. Hypertension is a multifactorial condition, according to the Portuguese Society of Hypertension (SPH)[7] the risk factors for its development are, essentially, uncontrollable genetic factors, related to ethnicity, age, history familiar; behavioural factors, linked to unhealthy lifestyles, subject to modification; and socioeconomic factors such as education level, low family income and poor housing conditions. As for potentially modifiable risk factors, the World Health Organization (WHO)[1] identified overweight and/or obesity, smoking, sedentary lifestyle, excessive consumption of alcoholic beverages, excessive intake of foods high in fat and salt. In Portugal, about two thirds of hypertensive people do not know that they are, and of those who are diagnosed, only 11% have their hypertension controlled[3].

Amorim et al.[8] suggest that the management of hypertension should mostly be the responsibility of primary health care, thus in this sense, urging the need to identify effective strategies for managing the disease, preventing situations of disability, and reducing the quality of care. life, which lead to a high expression in the consumption of health services, medications, and hospitalization episodes[1]. The current rules of the Directorate-General for Health (DGH)[9] dictate that "the person with HT must have the opportunity to make informed decisions about their treatment"(p.14) and that for this the treatment should "be culturally appropriate and accessible"[9](p.4), as well as allowing "family members to be involved in decisions about patient care and indicated treatment".[9(p.5)] Since it is fundamental to involve the person and family in the therapeutic process, we are guided by the assumption that the better informed they are about the disease, therapy, and healthy lifestyles, the greater the autonomy in managing the disease, achieving better results of health[4]. Aligning the aforementioned assumptions with the National Health Plan (NHP) 2021-2030 "the complexity of health problems and their determinants, and their dynamics of interpenetration and dependence require us to move (...) to multidimensional approaches",[10(p.36)] they choose "Education for (Self)Management of chronic illness" as one of the intervention strategies aimed at health determinants.[10(p.182)]

In the field of chronic disease (CD) management, the differentiated intervention of the Specialist Nurse in Community Nursing (SNCN) aims at the systematic and cohesive training of the person and family for the management of chronic disease.[11] In order to promote a practice based on the most current scientific evidence, as Ferreira et al. [12] points out, it is essential to promote adherence to the therapeutic regimen, especially with regard to physical activity and dietary care, and the CEE must act on these determinants to increase the effectiveness of HT disease management. Thus, and according to the studies consulted, regarding the most effective nursing interventions for training hypertensive patients and their families, the potential of Health Education (HE) in groups or individually stands out, with a focus on changing behaviours in everyday life, monitoring, promoting health literacy, person-centred care, and family involvement.

Objective

Train hypertensive people between the ages of 45 and 65 and their families to manage the disease, enrolled in a Family Health Unit (FHU) in the intervention area of the Grouping of Health Centres (ACeS) Almada/Seixal.

Method

An analytical cross-sectional observational study was carried out,[13] developed according to the Health Planning methodology (Tavares, 1990)[14], based on Orem's Self-Care Model (2001)[15], aiming at predetermining a set of actions to achieve the expected results.[16,17] Planning, in health, "is a continuous process of forecasting resources and necessary services, to achieve certain objectives according to the established order of priorities, allowing to choose the optimal solution(s) in several alternatives; these choices take into account current or foreseeable future constraints".[14(p.29)] It consists, then, of a continuous dynamic process, with several stages that provide for methodological rigor. The community intervention was developed in the area of influence of ACeS A-S. The population of this geographical area has great cultural diversity, low level of education and the highest unemployment and morbidity rate in ACeS A-S. [17] With an illiteracy rate of 5.21%, it is the highest in the country. It has an unemployment rate of 19%. [17(p.13)] According to PLS A-S17 regarding the priority population groups, "(...) the analysis of the health status of the population showed the high risk of premature death of the population residing in the municipality of Almada, namely associated with ischemic heart disease(...)".[17(p.13)] As diseases of the circulatory system are the most frequent cause of proportional morbidity and mortality in all ages and genders within the area of influence of ACeS. The project population is all individuals enrolled in the FHU, the target population being defined as users enrolled in the USF with a diagnosis of uncomplicated hypertension in the age group between 45 and 65 years old, enrolled in the FHU, which translates into in a total of 113 people. The following inclusion criteria were defined: population diagnosed with uncomplicated hypertension (coded with the ICPC-2 code K86 in the MedicineOne computer system); in the aforementioned age group; and, who voluntarily agreed to participate in the study. The sample was constituted using the technique of convenience or intentional sampling, composed of people with the aforementioned diagnosis and age group, who had a surveillance consultation with the family doctor and/or nursing consultation in the period between June 8th and 30th. 2022, and of these, those who made themselves available and gave their informed consent to participate in the collection of information. Integrated by thirty participants. A questionnaire was constructed and applied, which is structured in three parts: 1st part - sociodemographic characterization; 2nd part - clinical situation and lifestyle and 3rd part - The Medication Adherence Reasons Scale (MARS)[18]. The scale consists of seven questions structured in order to be able to synthesize the habits and beliefs of adherence to treatment medicinal product, was created by Morisky, Green and Levine (1986) translated, adapted and validated for the Portuguese population and culture, by Delgado and Lima[18], who were requested and obtained authorization for its application. To ensure an ethically sound intervention, authorization was requested to carry out the project from the USF Coordinator and Mr. Director of ACeS Almada/Seixal, having been granted. Obtained a favourable opinion (5043/CES/2022) from the Health Ethics Committee (HEC) of the Regional Health Administration of Lisbon and Tagus Valley (ARSLVT). After the favourable opinion of HEC ARSLVT, the participants were informed about the methodology, purpose and objectives of the project, and the questionnaires were applied to all participants in the sample, ensuring that they completed and signed the informed consent. Ensuring that they understand the risks and benefits of their participation, their rights, including the right not to participate or to withdraw from participation at any time without prejudice. A duplicate informed consent form was given to each participant. The questionnaires were self-completed, with the exception of situations in which the participants needed help to complete them, due to illiteracy and/or vision changes, being replaced in this task by one of the project's researchers. However, aiming to minimize data bias, the questionnaires were completed at the beginning of the nursing consultation, and those that were completed with assistance, the questions were read as written in the questionnaire. The collected data was coded, ensuring anonymity and confidentiality.

The empirical material, resulting from the application of the data collection instrument, was treated using descriptive statistics analysis, through the SPSS software – Statistical Package for the Social Sciences (28.0.0.0 version).

Results

Participants have a mean age of 56.27 (SD=6.38) years, 47% of participants are male. With regard to the constitution of the household in the sample, 34% of respondents live in a nuclear dyad type family after the children leave, 23% in a nuclear family with spouse and children, 13% are single parents and 30% refer to living alone, the reason being most frequently, the death of a spouse. It was asked if there is any other element in the household with HT, 47% answered yes, referring to being the spouse, 60% of the participants are professionally active, in different professional areas. Regarding the monitoring of Arterial Pressure (AP) values, 66% of the respondents only evaluated it in a biannual consultation at the FHU. Regarding the practice of physical exercise, 87% of the participants reveal high levels of physical inactivity and sedentary lifestyle. They were asked if they had changed their lifestyle habits after the diagnosis of HT, 73% reported not having changed, and the 27% who answered affirmatively, were asked which habits had changed, and these responded to the reduction of salt in their diet, not specifying what is the amount of salt ingested previously, nor the current reduction, the questionnaire does not allow us to quantify the number of grams ingested per day.

Regarding the control measures they use in their daily lives, 80% of the participants mention only complying with the prescribed medication without associating with other control measures. As for salt restriction in their daily diet, 53% reported not restricting it. Regarding family support for the implementation of measures to control their HT, 70% reported not having support from their household. Most participants do not consider changing lifestyle habits as a benefit in controlling hypertension. The MAT[18] scale was also applied to identify medication adherence behaviour, since 80% reported only complying with the medication as a measure of hypertension management. Based on the authors' recommendation, 39% of the participants do not meet all the criteria for adherence to treatment. The answers to the questions that make up the scale were analysed separately, and the weaknesses in the adherence criteria were listed, namely: forgetting to take, delay in taking the time, treatment abandonment due to improvements and abandonment due to the end of the

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medication. On average, study participants were overweight, with an average weight of 75.46 kg, in relation to personal history, 60.0% of non-insulin dependent Diabetes Mellitus and 80% of participants suffer from dyslipidaemia.

After surveying the problems and consequent needs, nursing diagnoses were prepared according to the International Classification for Nursing Practice (ICNP)[19]: (1) health surveillance [on HT] compromised; (2) knowledge about compromised physical exercise regime; (3) knowledge about the committed dietary regimen; (4) knowledge about the process of changing committed behaviours; (5) knowledge [about HT] compromised; (6) compromised family knowledge about the disease; (7) compromised adherence to the therapeutic regimen; (8) compromised self-care; (9) compromised family capacity to manage the regime; (10) risk of impaired cardiovascular function. Thus, defining the starting point from which the benefit of the intervention will be evaluated[14]. The prioritization of real health needs was carried out with the support of experts, according to the Hanlon Method. The method was applied in an adapted way to the sample, considering the criteria set out by Tavares[14]: (1) Amplitude/Magnitude of the Problem; (2) Gravity; (3) Effectiveness of the Solution and (4) Feasibility of the Project classified with the acronym PEARL (P- Relevance, Economic Feasibility, Community Acceptance, Resources and Legality). According to the results obtained, the objective and the time limit of the project, we intervened in the problems that obtained the highest score, namely, compromised health surveillance; family knowledge about the compromised disease; compromised self-care; knowledge [about HT] compromised; knowledge about the process of changing committed behaviours; knowledge about committed exercise regime; and knowledge about the committed dietary regimen. We continued with the setting of objectives, formulating the general objective - To train hypertensive people and their families enrolled in the FHU to manage the disease, from October 2022 to January 2023 and the specific objectives for the target population in the same time period: (1) train hypertensive people and their families on the importance of health surveillance; (2) train the hypertensive person and family to manage the exercise regimen; (3) train the hypertensive person and family to manage the dietary regimen; (4) enable the hypertensive person and family to identify risk factors; (5) train the person and family on the health gains of changing behaviours in the control of hypertension; and, (6) involve the family in the process of managing the illness of the hypertensive family member. With regard to the selection of strategies, it was essential to rethink the CD management concept. According to WHO[20], the costs attributable to CD for health systems worldwide are equivalent to 60%-80% of total expenses, revealing the burden and problems of financial sustainability for health systems. In Portugal, according to INSA[3] data, around 43.9% of the Portuguese population suffers from CD. Facts that highlight the importance of implementing strategies that promote CD management, as a guarantee of clear gains in health with positive repercussions in terms of health costs and quality of life[20]. By definition, the concept of CD management consists of a system coordinated interventions aimed at the individual, group or population, through the implementation of strategies and/or creation of programs that integrate the most recent norms and guidelines, for the promotion of autonomy for the self-care of the person with CD[21].

Considering that the community intervention developed corresponds to the level of secondary prevention, aiming to empower the person and family to make autonomous decisions, increasing their motivation to change behaviours and promote the ability to manage the disease, we combine a set of strategies health promotion, such as health education, involvement of the person and family and follow-up. In this process, possible barriers to existing learning were taken care of and thus implemented strategies to facilitate learning and to motivate and encourage the participation of individuals and families. The activities carried out allowed the achievement of the defined objectives, and aimed to provide adequate follow-up to the participants, creating an environment that promotes the acceptance of CD, motivating them to acquire knowledge, change behaviours and manage the disease. As methods we used group discussion, analogies, lecture, demonstration and practice, questions, and answers.

The group sessions were an opportunity to encourage participants to identify strategies, share experiences and identify.

We also individually monitored the person and family in the context of nursing consultations and home visits of participants who revealed some degree of dependence according to the Barthel scale assessed in Sclinic®, using Figueiredo's family assessment model[22], more specifically in the functional domain (caregiver role). The activities included a walk, ludic-pedagogical games, video exhibition, AP self-assessment training, and the transmitted information was compiled and distributed in the form of informative leaflets.

In order to evaluate the objectives, activities and indicators of the community intervention, the knowledge obtained by the participants regarding the addressed themes was considered, in line with the defined objectives and result indicators. By weighting: the responses of the participants after the end of the individual educational process in an HT nursing consultation; answers to the questionnaires applied after the end of the HE sessions; and finally, after the end of all activities, a final questionnaire was applied consisting of some questions extracted from the data collection instrument and questions that intend to measure the acquisition of knowledge and the possible change of behaviours for the management of the disease. Its analysis and comparison with values obtained in the DS phase allows inferring that all objectives were achieved as shown in Table 1. As for the changes obtained with the intervention, we analysed using descriptive statistics, the data obtained with the final questionnaire, which was presented in tables 2, 3, 4, 5 and 6.

Chart 1 – Evaluation of the result indicator, referring to the defined operational objectives

Objective: 30% of participants evaluate and record their blood pressure values	
Result Indicator	**Value obtained**
% of participants who regularly assess and record blood pressure values	**70%**
Objective: 70% of participants and their families who were present at the activities identified risk behaviours	
Result Indicator	**Value obtained**
% of participants who identified risk behaviours after EC.	**100%**
Objective: 50% of the participants who were present at the activities identified the importance of practicing 30 minutes of physical activity in a row, daily or at least three days a week	
Result Indicator	**Value obtained**
% of participants who consider it important to perform regular physical activity	**100%**
Objective: 50% of the participants who attended the activities would restrict salt intake in their daily diet	
Result Indicator	**Value obtained**
% of participants restricting salt intake	**87%**
Objective: 70% of the participants who attended the activities could identify options for replacing salt in their daily diet.	
Result Indicator	**Value obtained**
% of participants who correctly identify options for replacing salt in their diet, through the 2nd HE assessment questionnaire “control your heart, reduce salt in your diet”	**100%**

Data referring to changes in behaviour were also analysed, which we present in a table, contrasting the initial data and those obtained with the intervention.

Chart 2 – Comparison of the variable frequency of assessment and recording of AP in the 1st and 2nd moments

How often do you measure and record your Arterial Blood Pressure?	1st Moment (July 2022) Diagnosis of situation f=30		2nd Moment (January 2023) Final evaluation f= 30	
	f	**%**	***f***	**%**
Always	0	0%	**21**	**70%**
Often	0	0%	**9**	**30%**

Chart 3 – Comparison of the variable HT control measures in the 1st and 2nd moment.

What kind of measures are taken to control HT	1st Moment (July 2022) Diagnosis of situation f=30		2nd Moment (January 2023) Final evaluation f= 30	
	f	**%**	***f***	**%**
Just medication	24	80%	**0**	**0%**
Decreased fat intake	1	3%	**7**	**23%**
Medication and reducing salt intake	5	17%	**23**	**77%**

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Chart 4 – Comparison of the physical activity practice variable in the 1st and 2nd moments

Practice physical activity	1st Moment (July 2022) Diagnosis of situation f=30		2nd Moment (January 2023) Final evaluation f= 30	
	f	**%**	***f***	**%**
Yes	4	13%	**19**	**63%**
No	26	87%	**11**	**37%**

Chart 5 – Comparison of the dietary salt restriction variable in the 1st and 2nd moments

Salt restriction in food	1st Moment (July 2022) Diagnosis of situation f=30		2nd Moment (January 2023) Final evaluation f= 30	
	f	**%**	***f***	**%**
Yes	14	47%	**26**	**87%**
No	16	53%	**4**	**13%**

Chart 6 – Comparison of the family support variable in the 1st and 2nd moments

Family support to follow HT control recommendations	1st Moment (July2022) Diagnosis of situation f=30		2nd Moment (Janeiro 2023) Final evaluation *f*= 30	
	f	**%**	***f***	**%**
Yes	9	30%	**24**	**80%**
No	21	70%	**6**	**20%**

After analysis and evaluation, all the objectives were reached, as well as the pre-established values, regarding the process and activity indicators. The results reflect the acquisition of knowledge by the participants, as well as the acquisition of skills that promote behaviour change, adopting healthier lifestyles.

Discussion

The increase in CD worldwide is a multifactorial phenomenon, however it is essentially related to the lifestyles and consumption patterns of today's society. Approximately half of people with CD develop comorbidities associated with the difficulty in managing the disease[1,23]. This fact points to the importance of adopting health promotion strategies in an approach that promotes disease management.

Hypertension is a CD with a high national prevalence[3,25], associated with non-adherence to the therapeutic regimen.[1,25,26] Inappropriate behaviours and lifestyles are generators of comorbidities that lead to loss of quality of life and high economic impact, social and family life, as well as the increase in premature deaths[27,28,30]. Thus, the central importance of the SNCN in the process of empowering the person and family to develop skills that facilitate decision-making and the implementation of self-care behaviours emerges, as stated by Silva et al.[29].

In the community intervention developed, the main needs identified in the SD stage corroborate what has been verified in other studies developed in Portugal[30,31,32,33], where the need to promote nursing interventions for guidance, knowledge acquisition, skills development, and instrumentation in self-care. Thus, according to the defined objectives, HE was used as a strategy, aiming at training for the management of the disease of the hypertensive person and family. As mentioned by Oliveira et al.,[35] in their study, HE as a strategy to promote adherence to healthy lifestyles for the control and management of hypertension is the most effective strategy with regard to changes in lifestyles, having found a significant change regarding salt intake, physical activity, and blood pressure control. The same is reaffirmed by Gama et al.[36] in the bibliographic review, where HE is highlighted as the most effective intervention for increasing levels of knowledge, adherence to recommendations and healthy lifestyles of hypertensive people.

Thus, in relation to the sample, the gender variable deserves special attention, because although there are no significant differences in prevalence between genders within the sample, there are different self-care behaviours, with female participants being more participatory in the activities carried out, a fact that we relate to the different perception of their health condition, greater demand for health services, as well as greater compliance with the recommendations of health professionals, as verified in the study developed by Motter et al.[37]

As for the level of education, most of the participants have low levels of education, as in the study by Ribeiro[32], corroborating the data expressed in the INSEF[3], where a higher prevalence of hypertension is verified in individuals with a lower level of education. Regarding the SD phase, poor monitoring of Arterial Pressure (AP) values was verified, most participants only evaluated the tension in the context of a consultation at the FHU or occasionally at the pharmacy when associated symptomatology (dizziness, headache, or tinnitus), revealing little knowledge about the disease, as well as skills for monitoring and evaluating AP at home. Recent studies highlight the importance of monitoring AP in disease management.[27,30,36] A high rate of sedentary lifestyle and physical inactivity, with 87% of participants not practicing regular physical activity, a value higher than the values described in the Report on the point of the global situation of physical activity[33], 27.5% of adults do not comply with the levels of physical activity recommended by the WHO[34]. With regard to salt restriction in their daily diet, 53% refer not to restrict it, a value that coincides with national studies, as in the priority program for healthy eating.[39,41,25]

With regard to changing lifestyle habits after the diagnosis of hypertension, most participants did not make any changes, a fact similar to the results of recent studies, where participants prior to the intervention had not autonomously, following the diagnosis, changed lifestyle habits[35 ,40], which we relate to the lack of knowledge about the disease, its course and management. With regard to the control measures they use in their daily lives to manage high blood pressure, at the time of the SD, most participants were only complying with the medication prescribed by the doctor, not adhering to the non-pharmacological measures for controlling high blood pressure[25], data that coincide with the study by Ferreira et al.[13]; Pereira[38]; Dantas et al.[44], where the rate of adherence to control measures varies between 16.9% and 49.8%.

Regarding family support for the implementation of measures to control their hypertension, 70% of participants deny having family support for controlling hypertension, revealing the family's non-involvement in the disease management process. Thus, once again highlighting the need to promote adherence to the therapeutic regimen, increasing the quality of care provided to the person and the family, and thus, consequently, health gains[32,44,46,46].

The results obtained after the intervention reveal the success in achieving the defined objectives, corroborating the scientific evidence consulted, which highlights the HE as a fundamental resource in the therapeutic intervention of nurses, to increase knowledge and change behaviors.[36,38,42,43,44,45]

The implementation of the educational process, in the context of a nursing consultation, HE group sessions and home visits revealed a high potential in the acquisition of knowledge and consequent motivation for changing behaviors[30]. It was possible to promote the strengthening of the bond between the professional of health, the person, and the family, encouraging the development of educational processes aimed at the person and the specificities of each family, which, as a social support for the hypertensive person, are crucial for the implementation and maintenance of healthy habits.[29,30,43,45]

In the FHU where the community intervention took place, an HT nursing consultation (CEHTA) has not been implemented, so a guide to good practices for the CEHTA was developed and applied in a nursing consultation, which includes the most recent protocols and guidelines for management. HT, which made it possible to guide the intervention in a way adapted to the person and family, guiding the educational process in each consultation to the needs felt, avoiding redundant teaching,[29,35,43] stimulating adherence to the recommendations for the management of HT, through the counselling and monitoring.[22,30,42]

Therefore, we believe that the activities carried out, the distribution of informative material, the on-site training of AP self-assessment, the supply of instruments (label decoder) that facilitate the interpretation of the amount of salt in each food at the time of its purchase and the ludic games, allowed establishing a positive correlation between the educational process developed, adherence to recommendations regarding lifestyle and the reduction of risk factors related to the disease, as an example of this we have the increase of participants who evaluate and record blood pressure values frequently, who decreased daily salt intake and increased regular physical activity.

In short, the SNCN, through specific skills[48], promotes the process of empowering the person and family to manage the disease, increasing their involvement in the health project, fostering an attitude that promotes autonomy for informed decision-making. The HE strategy contributed to improving the health conditions of the group, increasing health literacy, involvement and identification, strengthening the therapeutic relationship, improving the quality of care.[36,45,49]

The results obtained allow us to state that the planning of the appropriate intervention for the population, the HT nursing consultation, home counselling and partnerships that reinforced the transmission of information about the dietary regimen, physical activity, health surveillance, self-care and family involvement, promoted greater adherence to the therapeutic regimen, as well as increased the change in the behavioural pattern.

During the course of the community intervention, some limitations were identified, delaying its initiation and development, given the delay in responding to the various requests necessary to ensure ethical procedures. In an initial phase, there were several requests for authorizations and opinions that could not be requested simultaneously, the request for an opinion was first submitted to the TIN of ACES A-S and only after the response with a positive opinion, was it possible to submit it to the CES of ARSLVT), the which conditioned the beginning of the application of the data collection instrument. After the opinions, participants were called who, given their age group, are professionally active, which made it difficult for them to be available to attend the FHU, leading to a sample of thirty participants in a universe of one hundred and thirteen. However, it was possible and extremely important to survey the real needs of the population, as well as its contribution to the proper development of community intervention.

Conclusions

The increase in life expectancy, combined with changes in the lifestyles of the population, generates an increase in CD.[39] The high prevalence of hypertension at national level leads to high costs, at economic, social, and individual levels[40], which makes it urgent to intervene. Hypertension must be approached considering the most effective nursing interventions, through evidence-based practice, considering the evolutionary course of the disease, in order to obtain health gains. For this reason, the intervention of the SNCN[48] is fundamental, which in its daily practice resorts to partnerships with other professionals, as well as with the person and family, promoting their active participation in the whole process.

The person with CD and their family need systematic monitoring given the specificity of their needs[29,42,45,46] through an integrated approach, considering the changes they manage to make, the necessary adaptations, internal resources, support networks and life situation.

The community intervention developed, supported by the Health Planning methodology and the theoretical framework of Orem[15], contributed to the training of hypertensive people and their families to manage the disease in a FHU of ACeS A-S, constituting a contribution to practice by highlighting the benefit of the SNCN intervention in the process of training hypertensive people to manage CD, leading to an approach centred on the person and family with a focus on avoiding complications, maintaining quality of life and involving the family. It highlights the contribution of the SNCN's intervention in improving the population's health through interventions based on Health Promotion and Education. It reveals that HE strategies within the scope of CD management mobilized by nurses enhance autonomous and informed decision-making by hypertensive people in their daily lives with adequate family support. It also consists of a contribution to training in the sense that it encourages the development of educational competence integrated into the curricula of the nursing course, with the mobilization of individual resources in clinical practice. Considering that, for this purpose, training should begin in the degree course, deepening in specialization courses, with the transmission of theoretical assumptions and research results, which allow the development of specific skills in interpersonal relationships and knowledge, guiding conduct, and dissemination of relevant information to the target audience.

Finally, it constitutes the same as a contribution to research, as scientific evidence, on the benefit of interventions in the context of nursing consultation, HE sessions and home visits, in the process of training the person and family for the management of CD.

With the end of the community nursing intervention, most of the project participants increased their knowledge regarding the course of the disease, measures to control and monitor HT and a healthy lifestyle adapted to their condition, revealing behavioural changes in their daily lives.

Regarding the theoretical framework, it was decided to use the support-education system, recommended in Orem's Self-Care Deficit Theory[1], which proved to be adequate and essential for the acquisition of knowledge and training of the person and family for conscious and informed decision-making the management of the disease. This system presupposes the association of effective help techniques with support, provision, guidance, and teaching, where the person's requirements are related to decision-making, behaviour control, acquisition of knowledge and strategies, through learning behaviours, becoming a self-care agent. As for the person's and family's help needs, they were related to decision-making, behaviour control and the acquisition of knowledge and development of competences, where training for the management of the disease of the intervenients was stimulated. Since, Orem[15] sees self-care as a skill that can be trained and thus improve the health status of the person, group, or community.

With the implementation of the community intervention, it was possible to promote the training of the participants, the HE sessions were a fundamental strategy to promote the self-care of the person and family, favouring the identification of peers, sharing of knowledge, experiences, and the acquisition of knowledge. The evaluation, as a stage of the methodology, indicated the success of the intervention through process, activity, and result indicators, allowing the identification of effective health gains. There was an increase in knowledge and changes in self-care behaviours, however, there is a discrepancy between knowledge and its consistent operationalization in everyday life, which we intend to reduce with the implementation of the HT nursing consultation, promoting the effectiveness of teaching moments, commitment to the process of change, ability to self-care and health literacy. Such as, home visitation, which, as we have seen, was a very successful strategy, as an assistance tool, based on the care plan for training related to disease management, enabling the educational process, on-site training and family interaction, the family is the first social unit where the individual is inserted and has a key role in maintaining and encouraging the management of chronic illness. The promotion of healthy behaviours and lifestyles cannot be decontextualized from the socioeconomic and political environment where the person and family are inserted, thus highlighting the importance of the intervention of the SNCN[47], given the proximity to the community, it identifies health problems, having a role primordial in the support and monitoring of the community, through its specific interventions that lead to the improvement of the provision of care, with the implementation of projects that respond to the identified needs.

Thus, ensuring the continuity of this project, the results obtained were presented to the FHU multidisciplinary team, the pedagogical material developed was given to the nursing team, enabling the continuity of its application. During the project, the nursing consultation, based on the best practices guide that compiles all the national norms and policies regarding the management of the disease and the training processes at home, revealed an added value for the results obtained, all the material that allows implementation and operationalization, allowing, in addition to continuity, improvement with the introduction of new strategies and interventions, which allow monitoring, counselling, and teaching. And as for the home visit, the in loco training of the hypertensive person and family, focusing attention on family interaction.

Despite the evidence that proves the management of hypertension through effective non-pharmacological and/or pharmacological measures, the control rates of this disease remain low[41], constituting one of the greatest global challenges, highlighting the relevance of the study developed, since, the health education process, the established partnerships and the involvement of the multidisciplinary team made it possible to increase the knowledge of both the professionals where it was possible to validate the relevance of the implemented strategies and activities, and the participants in terms of health literacy and skills development for disease management.

That said, we reinforce the need to continue research in this area, with the implementation of intervention projects in the community, promoting the training of the person and family for the management of chronic illness, identifying the strategies that promote training for the management of chronic illness and of measures capable of increasing it by reducing the costs for the person, family, and society. In future studies, we deem it pertinent to reach more participants, especially those less frequenting health services.

Authors' contributions

SF: Study conception and design; Data collection; Data analysis and interpretation; Statistical analysis; Manuscript writing.

MB: Data analysis and interpretation; Critical revision of the manuscript.

ES: Conception and design of the study; Data analysis and interpretation; Statistical analysis; Critical revision of the manuscript.

Conflicts of interests

No conflict of interest declared by the authors.

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Self-care capacity of Portuguese elderly people living at home

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Abstract

Introduction
This article presents an analysis of the Self-Care Capacity of elderly people living at home, identifying variables that interfere with it. Aging is a stage of life in which health needs undergo continuous changes resulting from disease situations and the aging process, therefore, the implementation of adequate and effective support for the ability to take care of oneself will contribute to the promotion of health and well-being.

Objective
To identify variables that interfere with the Self-Care Capacity of elderly people living at home.

Method
This is a non-experimental, cross-sectional, quantitative descriptive and correlational study, involving 400 participants who met the inclusion criteria. Assessment of self-care capacity using the *Exercise of Self-Care Agency – ESCA*.

Results
Based on the multivariate analysis of variance, the existence of statistically significant differences was identified in some domains of Self-Care Capacity according to age, education and self-perception of the elderly person's health status. Overall, positive correlations were found between age and the domain Initiative and responsibility (3.6%) and between education and the domain Knowledge and information seeking (5.2%) and negative correlations between age and the domain Knowledge and information seeking (3.7%). We also found that elderly people who perceived themselves as unable to take care of themselves showed lower scores in the Knowledge and information seeking domain than those who perceived themselves as able to take care of themselves, both when self-perceived as healthy or as having a pathology (difference in mean scores of -.38 and -.53, respectively, $p<.05$).

Conclusion
In view of these data, and given that ageing is a stage of multiple challenges in self-care, we suggest that nurses should consider multiple strategies for elderly people to access, understand, interpret and integrate the content of the information that allows them to take care of themselves.

Keywords
Self-care; Nursing Care; Aging; Elderly People.

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Introduction

In the 21st century, the trend towards population ageing is notorious, with longevity being one of humanity's greatest achievements.[1] The United Nations[2] identifies the elderly as the age group with the highest growth in the last 72 years, representing 13.9% of the global population. The same Body estimates that the world population aged 60 years or more should double by 2050 and more than triple by 2100, rising from 962 million in 2017 to 3.1 billion in 2100. In Portugal, the aging index in 2020 would be 167%, with the percentage of people over 65 being the fourth highest in the European Union.[3]

At this stage of life, health needs undergo continuous changes due to the aging process and/or pathology situations, interfering or potentially interfering with the ability of elderly people to take care of themselves, in their capacity for self-care, a potentiality that is an integral part of the human being.

According to Orem's Theory,[4] self-care is associated with the performance or practice of activities that individuals perform for their own benefit to maintain life, health and well-being, the potential to engage in actions aimed at caring for themselves, in a close relationship with the person's autonomy. As the author mentions, in self-care, the focus is placed on the human power activated and evidenced by the person when it searches, judges, make decisions and produce *self-care operations*.[4] The way in which each person performs self-care activities leads to different levels of self-care ability/deficit and, consequently, the ability to develop health-promoting behaviours and healthy ageing.

Thus, this is an issue which has already been studied in different contexts, with several studies showing statistically significant associations between self-care ability, health promotion behaviours and well-being in the elderly.[5,6,7,8] The relevance of the dimension of self-care in a health context is also highlighted by the increasing number of studies providing instruments to assess the self-care ability of elderly people,[9,10] allowing to objectify their needs associated with the diversity of events that occur throughout the course of life, and not only as a direct result of chronological age,[11] and contribute to the development of interventions that respond to the individuality of the person's life.

In this line of thought, the most recent world report on ageing and health presents a social approach to address this issue,[11] highlighting that advanced age does not imply dependence and that, although most elderly people coexist with multiple comorbidities, the diversity of their capacities and needs is not random.

Similarly, Orem's Nursing Self-Care Deficit Theory[4] identifies basic conditioning factors that influence self-care and transcend age (gender, developmental stage, standard of living, environmental factors, resource availability and adequacy). However, the available scientific evidence identifies a small number of studies reporting the influence of variables such as gender[5,12] and education.[5]

Thus, the interest in analysing the elderly person's ability to take care of themselves, contributing to the maintenance of their health, and identifying how the socio-demographic variables interfere with the ability for self-care emerges.

Considering this perspective, in line with the proposal to recommend a focus on population ageing that enhances the transformation of health systems in order to replace curative models by preventive ones, focusing on the needs of elderly people,[11] it is essential to identify the variables that interfere with elderly people's self-care skills in order to implement adequate and effective support for the development of these skills.

Objective

To identify variables that interfere with the Self-Care Capacity of elderly people living at home.

Method

This is a non-experimental, cross-sectional, quantitative descriptive and correlational study, with a favourable opinion from the Ethics Committee of the Regional Health Administration of Lisbon and Tagus Valley (Proc.086/CES/INV/2018), developed ensuring the ethical and legal dimensions underlying studies of this nature. Sample composed of 400 elderly people residing in home care settings, recruited in day care centres (6 settings) and nursing consultations (6 Personalised Health Care Units and 8 Family Health Units), through a convenience sampling. Data were collected in paper format and the researcher was present throughout the process to ensure compliance with the sampling criteria, namely the cognitive ability to understand the questions, informed consent and clarification of language included in the questionnaire and/or reading it, in participants who could not read or had decreased visual acuity. To determine the self-perception of health status, the elderly person could answer considering three levels: a) Unable to take care of itself, needs help from others; b) Able to take care of itself despite the pathology and c) Healthy, able to take care of itself.

The assessment of the self-care ability was performed through the application of Kearney and Fleischer's[13] *Exercise of Self-Care Agency* – ESCA, revised by Riesch and Hauck[14] and translated, culturally adapted and validated for the Portuguese population by the authors of this article, during which a reliability study was conducted through the analysis of internal consistency using *Cronbach's Alpha coefficient* and construct validity through exploratory factor analysis in a sample of 625 elderly people living at home. The resulting instrument is composed of 29 items (6 less than the original scale), distributed by 4 domains conceptually congruent with the original authors and with psychometric characteristics suitable for use in clinical or research contexts (global scale α= .871; subscales: Self-concept α= .705, Initiative and Responsibility α= .843, Knowledge and information seeking α= .755 and Passivity α= .646).

Data analysis was performed using the IBM SPSS *Statistics Base*, version 27.0. Descriptive statistics (measures of central tendency and measures of dispersion) were used to characterise the sample. For the multivariate analysis of variance, the assumptions of independence of observations and homogeneity of variance/covariance were duly checked. We used *Pillai's Trace* due to its robustness to modest violations of normality and *Wilks' Lambda* whenever homogeneity was verified, which is in line with Marôco's recommendations.[15]

Results

As regards the sample's characteristics, the sample was mostly composed of elderly females (68.5%), aged between 65 and 97 years old (*M* = 75.52 years old; *SD* = 7.16). Regarding education, the majority had primary education (61.3%), followed by those who had attended or concluded Secondary Education (27.3%). With less representation, those who had higher education (7.2%) and those who never attended school (4.3%). Most elderly people reported being able to perform their usual self-care activities despite the pathology (55%), 33.5% reported perceiving themselves as healthy and only 11.5% reported a self-perception of inability to perform usual self-care activities, requiring the help of others.

As results of this study, it was found that gender does not interfere with Self-Care Capacity, since the data from the multivariate analysis of variance revealed no statistically significant differences [Wilks´ *Lambda* = .988, F (4, 395) = 1.23, p = .297, η_p^2 = .012, (1-β) = .386]. Univariate tests also failed to identify any statistically significant differences.

With regard to age, *Pearson's correlation coefficient* analysis identified a positive correlation of low magnitude with the dimension Initiative and responsibility (r = .191, $p<$ .01), and a negative correlation, also of low magnitude, between age and Knowledge and information seeking (r = .193, $p<$ .01) (see Table 1). It was also identified that the greater the age of the elderly person, the greater the Initiative and Responsibility and the lower the Knowledge and search for information.

Table 1 - Pearson's correlation coefficients between participants' age and the ESCA measures

	Age of participants Pearson correlation coefficient (r)
ESCA (global scale)	.036
Initiative and responsibility	.191**
Self-concept	-.005
Knowledge and information seeking	-.193**
Passivity (inverted)	.031

**p* < .05 ***p* < .01

With regard to the influence of the level of education, the multivariate analysis of variance showed an influence of the level of education on self-care ability, since a statistically significant overall effect was observed [*Pillai Trace*= .150, *F*(12, 1185)= 5.18, $p<$ .001, η_p^2= .050, (1-β)> .999].This effect is due to the existence of differences at the level of the dimensions Knowledge and information seeking (magnitude corresponding η_p^2= 5.2%), Self-concept (η_p^2= 2.6%) and Initiative and responsibility (η_p^2= 2.0%)(see Table 2).

Table 2 - Mean scores and standard according to the deviations of the ESCA participants' education level: Univariate tests (F), magnitude of experimental effect (r;p2) and power of investigation (1-β)

	Education level												
	Did not attend school (*n*= 17)		Primary education (*n*= 245)		Secondary Education (*n*= 109)		Higher education (*n*= 29)		Total (*N*= 400)				
	M	*DP*	*M*	*DP*	*M*	*DP*	*M*	*DP*	*M*	*DP*	*F* (3, 396)	η_p^2	1-β
ESCA (global)	3.14	.56	3.20	.45	3.20	.50	3.12	.40	3.19	.46			
Initiative and responsibility	3.50	.56	3.36	.56	3.25	.59	3.13	.51	3.32	.57	2.76*	.020	.666
Self-concept	3.49	.65	3.63	.37	3.56	.42	3.41	.40	3.59	.40	3.46*	.026	.774
Knowledge and information seeking	2.33	1.23	2.84	.89	3.14	.69	3.21	.49	2.93	.86	7.20**	.052	.983
Passivity (inverted)	2.58	.93	2.50	.81	2.58	.98	2.52	.71	2.52	.86	.25	.002	.098

* $p < .05$ **$p < .01$

The *Games-Howell tests* indicated statistically significant differences in Self-concept, exclusively in the mean scores between elderly people with Primary Education and those with Higher Education (mean score difference of .22, $p<.05$). In terms of Knowledge and information seeking, statistically significant differences were found between elderly people who did not attend school or have Primary Education and those with Higher Education (difference in mean scores of .88 and .36, respectively, $p<.05$), as well as between participants with Primary and Secondary Education (difference of -.30, $p<.01$). In addition to these aspects, we found that elderly people who did not attend school had low levels of Knowledge and information seeking (M=2.33; SD=1.23). We also identified a progressive increase in the values obtained with increasing education level (primary education M= 2.84; SD=.89; secondary education M=3.14; SD=0.69 and higher education M=3.21; SD=0.49) (see Table 2).

Regarding the influence of Self-perception of health status on Self-Care Capacity, the results of the multivariate analysis revealed a statistically significant overall effect, with a magnitude for the multivariate test in the order of 6.5% [*Pillai trace* = .130, $F(8, 790)= 6.84$, $p< .001$, $\eta_p^2= .065$, (1-β)>.999].

The *Games-Howell tests* allowed identifying higher scores at the Self-concept level in healthy elderly people, compared to those who perceived themselves as unable to take care of themselves (mean score difference of .25, $p<.05$). Elderly people who perceived themselves as able to take care of themselves despite their pathology also showed higher scores compared to those who perceived themselves as unable to take care of themselves, needing support from others (mean score difference of .31, $p<.01$). With regard to the Knowledge and information search factor, elderly people whose self-perception is of inability to care for themselves, showed lower scores than those who perceive themselves as able to care for themselves despite the pathology and those who perceive themselves as healthy (difference in mean scores of -.38 and -.53, respectively, p<.05).

In the Passivity (inverted) dimension, elderly people self-perceived as healthy indicated greater activity compared to those who perceived themselves as unable to take care of themselves and to those who said they perceived themselves as able to take care of themselves despite pathology (difference in mean scores of .56 and .23, respectively, p< .05) (see table 3).

Table 3 - Mean scores and standard deviations of the ESCA as a function of the variable Self-perception of health status: univariate tests (F), magnitude of the experimental effect (η_p^2) and power of the investigation (1-β)

	Self-perception of health status										
	Unable to look after themselves, need help from others (*n* = 46)		Ability to take care of oneself despite the pathology (*n* = 220)		Healthy, able to care for itself (*n* = 134)		*Total* (*N* = 400)				
	M	*DP*	*M*	*DP*	*M*	*DP*	*M*	*DP*	*F* (2, 397)	η_p^2	1-β
ESCA (global)	2.95	.44	3.21	.44	3.25	.49	3.19	.46			
Initiative and responsibility	3.22	.59	3.35	.55	3.32	.60	3.32	.57	1.02	.005	.228
Self-concept	3.34	.53	3.65	.34	3.58	.42	3.59	.40	11.63***	.055	.994
Knowledge and information seeking	2.54	.88	2.92	.86	3.07	.80	2.93	.86	6.78**	.033	.918
Passivity (inverted)	2.16	.70	2.49	.85	2.71	.87	2.52	.86	8.00**	.039	.955

* $p < .05$ **$p < .01$

Discussion

When identifying variables that interfere with the Self-Care Capacity of elderly people living at home, we found no statistically significant gender differences, which is in line with the results identified in Turkish elderly people[5] and Chinese elderly people.[12]

In relation to age, Initiative and responsibility tends to increase with age, whereas the opposite is true for Knowledge and information search. These results may be related to the intentionality assigned by the elderly person to search for information, since, according to Orem,[4,16] concern for oneself, motivation and hierarchy of values are key aspects to engage in self-care actions. On the other hand, since perception, memory and learning skills are considered to be essential for self-care actions,[16] the biological losses which become progressive with age may be the basis for lower levels in the Knowledge and information search domain at older ages.

We also identify an influence of the education level in the domains Self-concept, Initiative and Responsibility, as well as in the Knowledge and Information-seeking domain. Overall, we found that a progressive increase in education level is associated with an increase in the level of Knowledge and information seeking. These results are in line with the findings of other studies which reveal: a low level of education accompanies an insufficient knowledge about the pathology and treatment[12,17] and a lower capacity to engage in self-care actions.[5]

Although it is important to mobilize the dimension of skills development throughout life, in reality, elderly people with low education may have greater difficulty in accessing information related to their health and health care, as well as, less ability to understand and manage information that allows them to make decisions related to their health. Although a vast amount of information may be available to the public from different formats and sources of information, many people may have difficulty interpreting and applying it, which may contribute to greater complexity when putting good health practices in place, despite the information made available.[18] Another factor that may be associated to this problem is the low degree of health literacy of the elderly population in Portugal, which may condition the ability to obtain and apply relevant health information[19,20,24] or the management of pathology situations.[20,21,24]

When this situation is associated with the self-perception of inability to care for oneself, lower levels of self-concept are found, which may be related to the impact of dependence on the person's identity. Some authors state that certain pathology situations in which the person loses control over its own routines cause profound changes in self-concept.[22,23]

In view of these results, which are relevant for understanding care planning strategies and are aligned with the guidelines of the Orem Mode,[14,16] as well as the reasoning structure proposed by the author, we suggest the development of interventions that allow for a follow-up leading to the integration of information in the person's self-care, by mobilizing the guidance inherent to the support and education system for self-care proposed by the author.[3,16]

Conclusions

As nurses, we should consider multiple strategies so that people are able to access, understand, interpret and integrate the content of the information that allows them to take care of themselves, given that, in elderly people, with lower levels of education and with the perception of being unable to take care of themselves, lower scores were found in the Knowledge and information search domain.

In situations of disability, the promotion of self-concept also emerges as one of the relevant dimensions for self-care capacity. So this should be a dimension to be included in care planning.

Considering that this study only includes elderly people living at home, further studies including hospitalisation settings of different types are suggested. An analysis of other variables based on the basic conditioning factors set out by Dorothea Orem[4] in her Nursing Self-Care Deficit Theory would contribute to a broader understanding of the issue.

Authors' contributions

FC: Study conception and design; Data collection; Data analysis and interpretation; Statistical analysis; Manuscript writing.

MRP: Collaboration in statistical analysis; Writing of the manuscript.

MV: Conception and design of the study; Data analysis and interpretation.

Conflicts of interest

The Authors declares that there is no conflict of interest'.

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Social skills of primary care nurses and the communicative action of Jürgen Habermas

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Abstract

Objective
Promote a reflection on social skills in the work of primary care nurses from the perspective of Habermas' communicative action.

Method
This is a reflection article that proposes a discussion about social skills in the work of primary care nurses, based on Habermas' theory of communicative action.

Development
Social skills refer to the behaviors in the individual's repertoire to deal with the demands and social situations that occur in everyday life. In the work process, the nurse, being the team manager, must develop their potential to expand the skills relevant to the management of care, especially in terms of effective communication.

Conclusion
The research concluded that the theory of communicative action of Jurgen Habermas contributes to the managerial practice of nurses and supports a positive social performance since, by submitting their attitudes to a communicative action, nurses will be in search of greater interaction with their team, patients, family and other professionals who constitute the care networks.

Keywords:
Primary Care; Communication; Nursing; Philosophy in Nursing; Interpersonal Relations.

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Introduction

Primary Health Care (PHC) is the set of individual, family, and collective health actions that include promotion, prevention, protection, diagnosis, treatment, rehabilitation, harm reduction, palliative care, and health surveillance, conducted through integrated care practices and qualified management, developed by a multidisciplinary team for the population in a defined territory, over which the teams assume health responsibility.[1,2]

The PHC actions are based on four pillars: first contact care, continuity of care, comprehensive care, and coordination of care. It is necessary to carry out management compatible with the needs of the population to achieve these objectives, following the principles and guidelines of the Unified Health System (SUS), and have trained professionals to lead the teams.[1,2]

In this perspective, nurses represent the principal actor in health actions, as they have assumed leadership positions in current scenarios that can define the quality of care provided. The work of nurses in Brazilian PHC has been configured as a tool for changes in health care practices in the SUS, providing a new care model that is not centered on biologicism but on the integrality of care, intervention against risk factors, disease prevention, and promotion of health and quality of life.[1,2]

Authors affirm that the work of nurses in PHC is based on two dimensions: a) production of care and management of the therapeutic process, and b) management activities of the health service and the nursing team. Thus, the nurse, as manager of the nursing team, in addition to articulating the activities of several other professionals in the health team, must develop the potential to expand the skills relevant to the management of the work process, especially in effective communication, interpersonal relationships, and development of a positive climate for the exercise of leadership.[3]

Thus, in this scenario, the nurse's performance involves several dimensions of clinical practice, such as care, assistance, teaching, research, and management, incorporating health promotion and disease prevention actions. It is necessary to be a professional who constantly seeks to develop their social and interpersonal skills to achieve the objectives of this type of care.[3]

Social skills (SS) encompass classes of behaviors valued in a given culture, with a high probability of positive results for the individual, his group, and community that can contribute to socially competent performance in interpersonal tasks. Such skills are divided into self-monitoring, communication, civility, coping: rights and citizenship, empathy, SS of work and SS of expression of positive feeling.[4, 5]

This repertoire of behaviors can be born with the person, be acquired throughout their life, through training programs, or by experience. In this way, it is possible that a socially incompetent person can competently perform a particular task.[6]

Considering that interpersonal relationships and SS need vigorous and non-reductionist treatment, and considering the nurse's work process, recognized as a social practice that promotes the construction of complex group relationships, this study will use Habermas' theory of communicative action for the development of this reflection.[7, 8]

Thus, the objective is to promote reflection on social skills in the work of primary care nurses from the perspective of Habermas' communicative action. Such review is significant since it will contribute to the (re)construction of efficient communicative practices and, thus, can make this space of action more effective in caring for people, families, and communities.

Method

This is a reflection article that proposes a discussion about social skills in the work of primary care nurses, based on Habermas' theory of communicative action,[8] considering that the work of nurses is recognized as a social practice that promotes the construction of group relationships of a complex and non-reductionist nature.

Development

Jürgen Habermas' Theory of Communication Action

Jürgen Habermas, a German philosopher and sociologist born in 1929, is one of the most important philosophers and sociologists of the twentieth century and is considered one of the last representatives of the Frankfurt School of social theory and philosophy. His whole his work highlights three fundamental ideas: the first lies in the construction of a theory of communicative action; the second supports the existence of a public sphere in which citizens, free from political domination, could expose ideas and discuss them; the third idea defends that the natural sciences follow an objective logic.[9]

Habermas argues that societies are complex and deficient in social integration. Consequently, they constitute potential spaces of conflict, hinder studies on moral values, and harm the freedom of individuals. Considering the aforementioned, "human beings, in general, are often searching for their own interests, mirrored through calculations of advantages and arbitrary decisions. One acts on the other and not with the other, i.e., a rational action directed to merely strategic ends."[10 (p177)]

The theory of communicative action seeks a communicative concept of reason and a society in which the community actively participates in both individual and collective decisions, consciously and responsibly. This theory understands the individual as a participatory being who, before acting, evaluates the possible consequences, considering the rules, norms, values, and laws. Therefore, he should not act mechanically.[10-11]

The present theory concerns two types of actions: instrumental action and communicative action. The societies that have places where instrumental action is prevalent are identified by the philosopher as a systemic world, and those in which the prevalence is of communicative action are named as lifeworld.[12]

The systemic world would be that in which instrumental and reparative rationality predominates. Therefore, the critique of instrumental reason is related to an expansion of the concept of rationality. Thus, Habermas develops the concept of communicative rationality, which is fundamental to the world of work or communicative reason, where the main objective is the search for one's own interests.[9]

The lifeworld would be the private sphere of family and friendships and the public sphere is where the subjects can understand the other spheres of the social system through the communicative process and communicative action, which in turn brings better decisions for individuals. The world of communicative action is the lived world or the lifeworld.[10]

Chart 1 represents aspects that underlie the mutual understanding and the interface between the lifeworld and acting based on norms, i.e., the systemic world.[13]

Chart 1 - Theoretical pillars of the Theory of Communicative Action, Londrina/PR, Brazil, 2021

THEORETICAL PILLARS	Guidelines for mutual understanding *versus* guidance for success
	Mutual understanding as a mechanism for coordinating actions
	Action situation and speech situation
	The background of the lifeworld
	Process of mutual understanding between the world and the lifeworld
	References to the world and validity claims
	World perspective

Source: Adapted from Habermas (1989)

Therefore, communication must be intelligible, considering the universe of the receiver when elaborating a speech since the main objective of communication is understanding. The emphasis given by Habermas is the paradigm that dialogical reason is the result of the process of intersubjective learning because the subjects, historically situated, through speech, establish an interpersonal relationship in which one can try to understand that the contemporary world is governed by communicative reason.[13]

Interfaces between social skills in the performance of nurses in primary care and communicative action

The activities of nurses in PHC promote actions between the health system and people through the production of care, the management of the nursing team, and management staff. "Care management is related to the private activities of the nurse concerning planning, executing, coordinating, supervising and evaluating nursing care, considering the ethical-legal point of view".[14(p1)]

Nurses, in daily practice, by exercising a leadership position, need to provide their team with moments of integration that favor the thinking, reflection, feeling, and action of all those involved in activities related to patient care and community. Given this, this professional must be skilled in communication and relationship processes, as they are inherent to their managerial performance. To this end, he must have an accurate repertoire of social skills.[15]

In this scenario, the nurses' daily practice permeates the mechanistic and reductionist aspects. Therefore, an appropriate communication process is essential, considering the diversity of actions under their responsibility, besides articulating the activities between their team and other professionals, health sectors, and care networks as a whole, with the common intention of serving the community. Thus, it is necessary to implement effective communication in the daily work of nursing, especially by nurses as leaders of this team.[15,16]

According to Habermas, it is essential to provoke constant and renewing learning "since consensus exists until the moment of dissent," when something or situations can be renegotiated. He explains that "consensus does not occur when the lifeworld is very different" because, in situations where cultures are quite different, there may not be the motivation of one or both parties to investigate, to search for understanding through communication. Therefore, communication is not restricted to what is said or written since it turns into action, and this is how individuals interact with each other "in an argumentative back and forth". [15,16]

The ideas mentioned above permeate the universe of SS since skill classes encompass behaviors related to the individual's repertoire for a positive performance in society. Therefore, SS are interdependent in the social daily life of man, and communication is a skill that passes between all others and is strictly intertwined with communicative action. When an action requires the mutual understanding and cooperation of peers for a common goal, there must be an understanding of the individual contexts and positioning of the recipient in front of the speech act.[16]

Through language, nurses can reduce weaknesses and enhance common strengths in the relationships between the health team members. The understanding of the relevance and the capacity of communicative action make the individualities, which form the heterogeneity of the team and the particularities of their entities, stop being pieces that harm communication and become contributions of the consensus built by the participation of all.[17]

It is fundamental to have self-monitoring as a principle to put into practice the behavior repertoire of the SS and obtain a positive social performance for the individual to be considered socially skilled and, for this, self-knowledge is indispensable. Thus, according to Habermas, it is essential to believe that people who behave irrationally are mistaken in their self-knowledge, and people who manage to have a reflective attitude about their subjectivity, through self-reflection, can achieve their dreams and goals through their own experience.[16-18]

However, it is essential to transcend the communicative process characteristic of the lifeworld to enter the process of reflective and critical rationality. In the managerial language of the universe of attributions of socially skilled nurses, it is crucial to use reflective rationality for an ideal scenario reading and solution of critical issues in the care process. It is necessary, through the argumentative procedure, that the group seeks consensus based on principles that seek to ensure its validity. Thus, truth does not come from isolated reflection but is exercised through dialogue guided by rules established by the group members in an ideal dialogical situation. The excellent speech situation consists in avoiding coercion and providing conditions for all participants in the speech to exercise speech acts. For Habermas, the criterion of truth does not consist in the correspondence of the statement with the facts but in the discursive consensus. [16-18]

Some weaknesses found in the communication process can affect the communicative action of nurses and their team, such as inadequate data records, extremely fast information dissemination speed (fake or not), generating complications of various proportions and making it difficult to control the communicative process.[19]

Thus, it is necessary for nurses, as team managers, to ascertain whether strategic action is only guiding their actions, so as not to face a lack of understanding. Thus, to subsidize their actions, they must search for elements of the social sciences and become aware of the importance of communication in the process of care and management, so that it can transform nurse-client, nurse-team and team-client relationships. When nurses act according to their social skills and based on communicative action, they can provide understanding and great social transformations.[15, 18]

Effective communication is essential for teamwork. It is necessary to establish effective communication between all those involved, that is, managers, workers, patients, and families to provide quality and more humane health care.[17]

Thus, it is essential to focus more on the communicative action of the nurse's work process to allow a better performance and interpersonal relationship, with the autonomy of its agents and mutual construction of usual goals among the health team as a whole. In this way, the members of the process recognize themselves as actors of a social world amid cultural divergences, knowledge, and subjectivities to provide an effective relationship.[17]

Finally, the study emphasizes that, in the Habermasian theory, a communicative action is an act that aims at mutual understanding through help between those involved, corresponding to an effective strategy for other actions, and it develops from an annular process in which the actor is the initiator and product of the process.[20]

Conclusion

Jurgen Habermas' Theory of Communicative Action contributes to the nurse's managerial practice and supports a positive social performance since, by submitting their attitudes to a communicative action, the nurse will be in search of closer interaction with their team, patients/clients, family and other professionals who constitute the care networks. Health professionals, in general, need to be committed to developing their social and communication skills in order to promote more humanization and reduce mechanistic acts.

Whereas Habermas suggests that interaction is indispensable for social organization, everyone must understand that the objective will always be the search for consensus without duress. Nurses' actions with their team aim to promote the health and well-being of all, including internal and external clients. Communicative action should be a concern of all professionals.

Furthermore, the conceptions about communicative action, in the habermasian view, can be implemented by managers and nursing staff in their daily work, as they stimulate the involvement of all, considering the particularities of each one to build the whole, overcoming adversity and maximizing the capabilities.

Finally, this reflection contributed so that nursing, especially nurses who act as health service managers, can be instigated to seek means capable of transforming strategic and instrumental actions into a communicative action.

A limitation of the study was that few studies use Habermas' philosophy of communicative action for a better basis of effective communication in nursing. The article identified the need for new studies that address this theme in greater depth, which is one of the basic pillars of nursing care.

Authors' contributions

ALMB: Conceção e desenho do estudo; Recolha de dados; Análise e interpretação dos dados; Redação do manuscrito; Revisão crítica do manuscrito.

SSM: Conceção e desenho do estudo; Análise e interpretação dos dados; Redação do manuscrito; Revisão crítica do manuscrito.

TSMM: Conceção e desenho do estudo; Análise e interpretação dos dados; Redação do manuscrito; Revisão crítica do manuscrito.

MCFLH: Conceção e desenho do estudo; Recolha de dados; Análise e interpretação dos dados; Redação do manuscrito; Revisão crítica do manuscrito.

Conflicts of interests

No conflict of interest declared by the authors.

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Advanced Nursing: remembering the past, appreciating the present and perspecting the future

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Abstract

Introduction

This article arises from the analysis of care practice as a Nurse, in a sense of continuous improvement. Thus, by understanding the professional history, the paradigms of the profession and the positioning of Nursing in terms of society in today's world, it is possible to envision possible paths for the profession.

Objective

This article aims to reflect on the historical evolution of Nursing in Portugal and to envision the future of Portuguese Nursing in the light of international influences.

Development

The historical perspective and the implications in Nursing care practice, Person/Client-Centred Care and the individualisation of the intervention and, finally, Advanced Nursing and Advanced Practice Nursing were addressed. Analysing the historical perspective of Nursing over the centuries, from its abnegated period, through the romantic era, medicine and the technicist phase, we understand some current practices and doubts regarding the perspective of the future. The development of knowledge and practice in Nursing should go through the recognition and advancement of the core competencies of the discipline.

Conclusion

An approximation between scientific production and care practice is essential for the development of Nursing. Facilitating this process is the development of the Nursing specialties as a master's degree course, promoting not only different practices, but also the critical look and thinking of professionals. In this process, the existence of other sciences – health, social and human sciences, among others – that will promote the development of the Nursing body should not be relegated to second place, but it is also crucial to disseminate scientific production in Nursing, in order to give visibility to the science and practice of the discipline.

Keywords

Nursing; History of Nursing; Person-centered Nursing; Advanced Practice Nursing.

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Introduction

Care has existed since life came into existence: it is necessary to 'care' for life so that it can remain. [1 (p.117)] Nursing cannot be detached in its focus or in its history from people. Looking back at the past, one can state that Nursing and its development as an art and science is intricately entwined with the care of Women. Women have always played the role of carers within the family, promoting the harmonious development of children, ensuring the hygiene and maintenance of the home/household, helping in the collection and preparation of food, to name but a few. These responsibilities embedded in the role of the Woman-Mother are still present to this day, despite the significant social changes that family and its representation are currently undergoing. Historically, Women have had a less active social role until the twentieth century – the century of wars. Despite this social erasure, Women have not ceased to be a cornerstone of society over the centuries, not only for their critical role in the family – the structural and fundamental unit of society – but also for their involvement in social, solidarity and merciful causes. [2,3]

Furthermore, the historical relationship between Nursing and religion cannot be denied. In the case of Portugal, Christianity, with its altruistic and fraternal basis, is associated with caring for others. Looking at the works of mercy spread by the Catholic Church, the seven corporal works of mercy (to feed the hungry, to give drink to the thirsty, to clothe the naked, to shelter the homeless, to visit the sick, to visit the imprisoned and to bury the dead) and the seven spiritual works of mercy (to instruct the ignorant, to counsel the doubtful, to admonish the sinners, to bear wrongs patiently, to forgive offences, to comfort the afflicted, to pray for the living and the dead) are highlighted. [4] From the description of the works of mercy, it can be stated that the fundamental values or principles of Nursing are embedded in these religious principles. This intimate relationship between Nursing and Religion was further strengthened during the Middle Ages due to epidemics, war and famine, which worsened social and health conditions. In this regard, religion emerged as a safe haven for medieval society, providing the necessary healthcare through the intervention of religious orders. [5]

Despite this role of religion in society, the expression of this care in most cases was done by Women, involved in the action of the religious orders of the time. Hence, one can see the triad Nursing – Women – Religion, whose pinnacle is assumed in Florence Nightingale – the mother of modern Nursing. In the nineteenth century, during the Crimean war, the lack of assistance conditions to the military led Nightingale to reformulate and restructure the existing conditions – hygiene and cleanliness, food, ventilation, lighting, organization and separation of circuits and spaces, among other things. This laboratory served as a catapult to her contribution in modern healthcare. [5–7]

This reflection arises following the analysis of everyday practice as a Nurse, in a sense of continuous improvement. Thus, by understanding the professional history, the paradigms of the profession and the positioning of Nursing in terms of society in today's world, it is possible to envision possible paths for the profession. This article aims to reflect on the historical evolution of Nursing in Portugal and to envision the future of Portuguese Nursing in the light of international influences. For its development, the abridged historical path will be discussed: from Nightingale to the biomedical model and the Nursing models – implications for Nursing care practice; Person/Client-Centred Care and the individualisation of the intervention; and Advanced Nursing and Advanced Practice Nursing.

Formatted for holistic care since the beginning of training, creating a distance from the biomedical model, focused on signs and symptoms, professional practice was guided by the individualisation of care. In this regard and in that of competencies development, it became evident to rethink professional practices to advance the Nursing care provided in the transition phase from generalist nurse to nurse specialist.

Abridged Historical Path: From Nightingale to the Nursing Models – Implications for Nursing Care Practice

The World Health Organization (WHO) defines health as "not merely the absence of illness but a state of complete physical, mental and social well-being"[8]. This mid twentieth century definition of health attempts to encompass more than the physical realm of health, i.e., the absence of illness, originating in classical, mechanistic physics. This dualistic view between health and illness can be at the root of the biomedical model, focused on signs and symptoms - objective, measurable aspects - and on the healing process. [9]

The biomedical model guided Nursing training because of the intimate professional and formative relationships between the Doctor and the Nurse. According to this model, Nursing care focuses on routines or tasks that meet the physical needs of the patient. Following this line of thought, the image of Nursing emerged as being subordinate to Medicine, with the aim of curing or controlling the illness, while the doctor was the main person responsible for health care. [9]

Returning to the influence of religion – Christianity – in Nursing, the biomedical model came to add the values of romanticism and pragmatism to Nursing. Embedded since its genesis in asceticism, Nursing has always had a focus on donations and total dedication to others. With scientific evolution and the consolidation of the biomedical model, subjugation to the doctor and the technicality of the profession also became predominant in Nursing. With these underlying conceptions, it can be stated that Nursing

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lies between the care for the body, influenced by Medicine, and the care for the spirit or soul, the result of religious weight. [9]

With Nightingale's revolution, Nursing added Science to its Art[1]. The development of Nursing's own body of knowledge can be said to have been initiated by Nightingale's work.[10] In the multidisciplinary context of health, the influence that the various disciplines have amongst each other cannot be ignored. In constant development, Nursing's own body of knowledge, a requirement for the definition of the profession and discipline, undergoes mutations that develop Nursing practice[10,11] For Florence Nightingale, Nursing focuses on caring for the person, rather than on the Nursing process, the therapeutic relationship, or the Nurse. In this way, Nursing *shapes itself* to meet the needs of each person. The Nurse and the person being cared for are influenced by environmental factors that should be addressed in order to modify them so as to provide better care to the person according to their needs. It was with Nightingale's work that training in Nursing was developed, because according to her perspective Nurses should have specific training and instruction for their work, allowing for the improvement of the care provided. [10,11]

During the twentieth century, several conceptual models of Nursing were developed. Pepin et al.[10] classify Nursing theory into five schools of thought:

- School of Needs: focused on situations of dependence, Nursing supplements or complements the person to meet fundamental needs, promoting independence (Roper, Henderson);
- School of Interaction: focused on the interpersonal and therapeutic process between the Nurse, the person and the context, in order to facilitate the processes of transition and to maximise health functionality (Peplau, King);
- School of Results: focused on the adaptation of the person to the environment (internal or external), promoting appropriate adaptive responses (Roy, Neuman);
- School of the Unitary Human Being: focused on the well-being of the person, maximising individual health potential in every moment and place (Newman, Rogers);
- School of Caring: focused on the phenomenological process of sharing between the Nurse and the person being cared for (Leinninger, Watson).

Theoretical models in Nursing serve as a lens to look at and understand the reality of Nursing care. In its conception, there are four metaparadigm concepts that are the basis for the theoretical model – Nursing, Person, Health and Environment. Resulting from the influence of the current paradigms, the various schools of thought in Nursing gave body to the Science produced. [10]

In the current Nursing care provided, it may be stated that the holistic paradigm and holistic Nursing are guiding the professional reality. Thus, *Nursing encompasses the care of individuals, families, groups and communities, ill or healthy and in all environments. [...] It includes health promotion, illness prevention and care for ill people, people with disabilities and people in the process of dying. Protection, promotion of a safe environment, research, participation in the formulation of health policies and in the management of patients and health systems and education are also important roles of Nursing.* [12] In this regard, the person is much more than a source of signs and symptoms, they have a prior history and experience (culture, religion, spirituality, relationships, among others) that influence the way of being and interacting with others (in this case with the Nurse). It is during this interaction that the Nurse reinforces the existence and singularity of the person in the illness process. [13,14]

Person/Client-Centred Care and the Individualisation of the Intervention

The Person-Centred Nursing Model reflects the ideals of humanistic care, in which there is a moral component and Nursing practice is based on a therapeutic intentionality, which translates into relationships built upon effective interpersonal relationships. [15] According to the model, Nursing is an approach to the practice established through the formation and promotion of therapeutic relationships, based on respect for people; the individual right to self-determination; and mutual respect and understanding, through cultures of empowerment that promote humanistic development[15]. According to McCormack & McCance [15], Person-Centred Nursing is focused on 3 major aspects:

- Nurses' competencies (professional competencies, personal competencies, commitment to work and personal traits);
- Organisational aspects (time, combination of competencies and the role of the nurse);
- Client attributes.

In addition to the focus on technical competence, it is extremely important to develop humanistic and holistic care practices to embrace all forms of knowledge and action

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[1] For Hesbeen (43), *to care is an art, a therapeutic art, (...) that will enable you to help someone in their unique situation* p.37).

to promote choice and partnership in care decision-making. [15]

The middle-range theory of Person-Centred Nursing is characterised by four fundamental aspects[15,16]:

- Pre-Requirements: these focus on the attributes of the nurse and include being professionally competent; having developed interpersonal skills, self-knowledge; being committed to the job; being able to demonstrate clarity of beliefs and values, and knowing oneself;
- Care Environment: focuses on the context in which care is delivered and includes an appropriate mix of skills; systems that facilitate shared decision-making; effective relationships between staff members; a responsible sharing of power; physical environment; supportive organisational systems; potential for innovation and risk-taking;
- Person-Centred Processes: focus on delivering care through activities that operationalise person-centred Nursing and include working with the client's beliefs and values; sharing decision-making; authentic engagement; empathetic presence; holistic care delivery;
- Expected Outcomes: include a positive experience with the care provided; involvement in care/care giving; feeling of well-being; the existence of a healthy culture.

Person-Centred Care develops from the communication between the person and the professional. Therefore, nurses' interventions should focus on listening to people's narratives about their experience of falling ill, the personal meaning they attach to the illness and the social restrictions caused by suffering and symptoms. By understanding these experiences, nurses can strengthen the person's involvement in care decision-making. [17]

When effective communication is established, interest is shown in listening and the professional is available to understand the person's perspective, this leads to greater trust in the person, a caring environment is created in which there is greater sharing of their feelings and greater engagement in the decision-making process. [17]

The person-centred model emphasises the meaningful interaction between the nurse and the person. In this aspect, McCormack & McCance[15], when describing the person-centred processes, describe the *Engagement*[2] as a mirror of the quality of the nurse-person relationship. According to the ability to jointly solve problems and/or work together, the authors describe three levels: full engagement, partial disengagement, and complete disengagement.

In the 2017 review, McCormack & McCance[16] rename the process to *Engagement Authentically*[3]. In its description, Engagement Authentically is considered as the Nurse's connection with the patient/person and family (or significant others), determined by the person's knowledge, clarity of beliefs and values, self-knowledge and professional experience. This interaction between nurse and person is unique, both for the individuals that comprise it and for the moment in which it is established. Despite this change, the authors maintain the levels of engagement described previously.

By analysing the care practice, the presence of the biomedical model is observed in the Nursing records. Although the theoretical Nursing model adapted by the institution is that of Roper, Logan and Tierney about Activities of Daily Living, the Nursing records produced in most situations give response/visibility to the tasks performed, to symptomatic control, to continuous improvement programmes and/or to the needs or obligations of the directive/management component. In terms of organisation and structure, the records are based on the satisfaction of needs/activities of daily living. However, the record on functionality is noted.

It is considered that the Nursing records document the care provided, making it visible. Despite their importance, they are sidelined in more complex or work overload situations. [18–20]

Indeed, the above is in line with what is described by Kärkkäinen et al. [21] Records often seem to reflect the tasks performed by nurses, rather than personalised care. In addition, there is reference to the way records are made, which is recommended by the institutions, and which may hinder the production of records focused on individualised care. Hence, the content of Nursing records does not meet comprehensive and person-centred criteria.

Furthermore, Kärkkäinen et al.[21] consider that the visibility of individualised care in Nursing records should take into account the experience, needs and wishes of the people being cared for and that care plans should be drawn up with the person/patient and family. Although this cooperation between nurse/person should exist, the documentation of care should not be to exclude the technical knowledge of the professional, the technology, the practice of care or the ethical principles.

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[2] Free translation of the term Engagement described by McCormack & McCance[15]).

3 Free translation of the term Engagement Authentically described by McCormack & McCance[16]).

Advanced Nursing and Advanced Practice Nursing in the Portuguese reality

Nursing in Portugal underwent a great development in the last century. This explosion occurred not only in its effective care practice, associated with the evolution of medical knowledge and the demands of the people cared for regarding the care provided, but also in its training, through the integration of Nursing as a higher education course (baccalaureate and later undergraduate degree) and the development of master's and doctoral degrees in Nursing Science. [22]

With the evolution in care practice, there was a need to regulate the profession - the Regulamento do Exercício Profissional dos Enfermeiros (Regulation for the Professional Exercise of Nurses) was developed and the Ordem dos Enfermeiros (Portuguese Order of Nurses) was created. In the Regulamento do Exercício Profissional dos Enfermeiros[23], the nurse develops two types of interventions: on the one hand, autonomous interventions, initiated by the nurse's prescription and, on the other hand, interdependent interventions, initiated by the prescription of another health professional.

In some countries, due to difficulties in medical assistance, the technical competencies of some nurses were developed, making them legally qualified for diagnosis, therapeutic prescription and prescription of complementary diagnostic tests and their interpretation. This increase in nurses' medical competencies led to the creation of the *Nurse Practitioner*[4]. [22,24,25]

According to the International Council of Nurses (ICN), Nurse Practitioners *"are generalist nurses who, after additional education (master's degree for entry level), are autonomous clinicians"*. [26] In the national reality, this advance in Nursing practice may be compared to the development of interdependent competencies of nurses. Gardner et al.[27] and Silva[22] also compared the Nurse Practitioner in their conception as a hybrid model between doctor and nurse, based on the biomedical model.

In light of this advancement in Nursing practice, it became urgent to define the path to where it was intended to develop the body, practice and science of Nursing. The Canadian Nurses Association defined Advanced Practice nurses as:

An umbrella term for registered Nurses and Nurse Practitioners who integrate graduate nursing educational preparation with in-depth, specialized clinical nursing knowledge and expertise in complex decision-making to meet the health needs of individuals, families, groups, communities and populations. [28]

These advanced practice nurses have the following competencies: comprehensive/extended in the provision of direct care; health systems optimisation; education/training; research; leadership; and consultation and collaboration. [28]

More recently, the ICN has defined Advanced Practice Nursing as:

Enhanced and expanded healthcare services and interventions provided by nurses who, in an advanced capacity, influence clinical outcomes and provide direct healthcare services to individuals, families and communities[26].

In the same document, the ICN defines the *Clinical Nurse Specialist*[5] as a professional with advanced knowledge in Nursing, beyond the knowledge developed in generalist or specialty training, in making complex decisions in a specific context, promoting quality and positively impacting the health services. [26] This professional designation arises in response to the development of the context of specialised care practice, requiring further education beyond the Nursing Speciality. Comparing with the Portuguese reality, the acquisition of a Nursing Specialty by a Master's degree – reference level for the attribution of the title of *Clinical Nurse Specialist*[26] – may be considered a path towards the development, or rather, the advancement of the Portuguese Nursing practice.

In this line of thought and in the national reality, Silva[22] described Advanced Nursing as a development of competencies in the area of caring and decision-making. Thus, the development of masters and doctoral degrees in Nursing has deepened the knowledge of human responses to the care provided, but also developed nurses' competencies for the effective delivery of care. [29] Within the scope of nurse specialists, the Portuguese Order of Nurses defined four domains of common competencies: Professional, ethical and legal responsibility; Continuous quality improvement; Care management; and Development of professional learning. [30]

With regard to the development of Nursing competencies, Benner[31] conceptualised it in five levels or phases, whereby the phases of Proficient and Expert may be framed with the competencies of nurse specialists. In her description, the proficient nurse apprehends and understands care situations as part of a life process, making decisions based on the holistic model and learning and modelling practice/decision-making with experience. Regarding the

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[4] The decision was made to keep the original/international designation, as there is no equivalent in Portuguese practice.

[5] The decision was made to keep the original/international designation, as there is no equivalent in Portuguese practice.

expert nurse, they support their action based on intuition, thus having a high performance. [31]

Comparing with the Strong Model of Advanced Practice, [27,32] it can be stated that the common competencies of the nurse specialist meet the five areas of advanced practice, with the provision of specialty care[6] corresponding to Integral Direct Care[7] and the underlying processes of advanced practice.

Conclusion

The principles of quality and safety in health are underlying Lei de Bases de Saúde[33] (Basic Healthcare Law). Nursing, as a health science, seeks to answer to Quality and Safety in health. [25]

The WHO understands Quality in Health as a high degree of professional excellence, with minimum risks, positive health outcomes for patients and efficient use of available resources. [34] Additionally, quality in health is considered as a relationship between professionals and patients/populations that aims at the best desirable health outcomes according to current knowledge. [35]

On the other hand, health Safety is more than "the prevention of harm to patients". [35] For Mitchell[36], *patient safety* means the absence of preventable injuries and the reduction of the risk of unnecessary harm associated with healthcare to an acceptable minimum, based on current knowledge, available resources and the context where the care was provided, compared to the risk of non-treatment or other treatments. This way, quality and safety in health appear interconnected. This way, quality and safety in health appear interconnected.

In the sense of professional excellence and in the development of its body of knowledge as a science, it is essential for Nursing[8] to focus on the increase of competencies for person-centred performance – the primary target of Nursing care. [22] Looking at the historical evolution of Nursing and the current paradigm, it makes sense to understand the middle-range theory of Person-Centred Care. In the specific context of Rehabilitation, the person-centred approach becomes a practice of excellence: to approach the person in a holistic way, in order to solve their daily difficulties, considering them as an expert in their living experience; and emphasising the participation and empowerment, respecting the person beyond the impairment or ilness. [37]

In the reality of care giving, the main obstacles to person-centred care are in line with those described by Moore et al.[38], namely traditional practices and structures, time constraints and the documentation and organisation of the institution. Furthermore, the lack of documentation supporting person-centred care and the low visibility of the actual care provided in the records emphasise the difficulties in implementing this type of care.

The multidisciplinary intervention in health, not only of several medical specialties, but also of several health professionals, turns health care into a sea of interventions, in which the person may sink. Therefore, by applying the holistic paradigm to its practice, Nursing may be considered a safe foundation, or rather a safe haven, from which, alongside the person, strategies, processes, among others, are developed to improve their health and reduce the impact of their illness situation on their life path. [39]

Despite the needs felt in other countries to include medical competencies in nurses[40], in Portugal the average number of nurses is below the OECD[41] average. In this sense, it may be stated that, given the difficulty in providing Nursing care to the population, the acquisition of extraprofessional skills will not make sense. However, the literature highlights that nurses with added competencies – Nurse Practitioners – add value to the vision and provision of Nursing care to the population. [24,27]

In summary, analysing the historical perspective of Nursing over the centuries, from its abnegated period, through the romantic era[9], medicine and the technicist phase, we understand some current practices and doubts regarding the perspective of the future. [9] Thus, the development of knowledge and practice in Nursing should go through the recognition and advancement of the core competencies of the discipline. [22] An approximation between scientific production – from the academic domain - and care practice – from the community and hospital domain - is fundamental for the development of Nursing. Facilitating this process is the development of the Nursing specialty as a master's degree course, promoting not only different practices, but also the critical look and thinking of professionals.[29] In this process, the existence of other sciences – health, social and human sciences, among others – that will promote the development of the Nursing body should not be relegated to second place, but it is also crucial to disseminate scientific production in Nursing, in order to give visibility to the science and practice of the discipline. [22,40,42]

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[6] In accordance with the various Regulations of the Specific Competencies of Nurse Specialists.

[7] Free translation of *Direct comprehensive care* used in Mick & Ackerman's model[32].

[8] Nursing, that is, nurses in the delivery of care, teachers in Nursing Schools and Nursing researchers.

[9] Term used by Pearson & Vaughan[9]

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Authors' contributions

JS: Drafting the manuscript; Critical revision of the manuscript.

Conflict of interests

The author declares no conflict of interest.

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Internet as a source of information and health literacy in pregnancy: a scoping review

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Introduction

The social reconfigurations of the last few decades have changed the role of women in society, moving them away from the extended family and reducing their time to build supportive relationships, essential factors of informal support during the transition to parenthood. This new reality led to the emergence of alternative informal sources of support, namely the internet, currently constituting one of the main sources of health information for pregnant women. However, it is not enough to have access to online information to know how to apply in health decisions, it is also necessary to evaluate, understand and interpret it, that is, it is necessary to have health literacy.

Objective

Map the existing literature on the relationship between the internet as a source of information and the level of health literacy of pregnant women.

Methods

Population: pregnant women; concept: health literacy; context: internet. Primary and secondary sources of qualitative and quantitative research were considered, as well as unpublished literature, as master's dissertations.
Research in three stages according to the JBI methodology, using the databases Medline, CINHAL, Web of Science, Google Scholar and Open Access Scientific Repository of Portugal. Considered articles published since 2015, in Portuguese, English, Spanish and French. Data extraction and analysis performed in a table elaborated according to the JBI methodology, 2020.

Results

13 articles were included. Pregnant women with a higher level of health literacy conduct more online health research, resorting more to formal sources and discussing the information accessed with health professionals. Pregnant women with a lower level of health literacy have more difficulties in understanding, evaluating and applying the information accessed online, resorting more to sources such as blogs and social networks.

Conclusion

The level of health literacy of pregnant women has a decisive influence on the use of the internet as a source of health information, being positively related to greater frequency of use, recurrence to formal sources and discussion of the information accessed with health professionals. In contrast, a lower level of health literacy is associated with greater difficulty in evaluating and understanding the information accessed, requiring support from health professionals. The level of health literacy of pregnant women should be considered for a personalized recommendation of valid and reliable online information.

Keywords

Pregnant Women; Internet; Health Literacy.

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Introduction

The transition to parenthood is a developmental transition caused by a major life event [1] that begins before or during pregnancy, leading the woman to start preparing herself essentially through the search for information and self-care. [2] There are several factors that contribute and influence the development of skills for the role of mother, namely social support, which is an essential source of information, understanding and emotional support. [3] However, society has undergone reconfigurations over the last few decades, with family networks being more distanced and women playing increasingly significant roles in the labor market, limiting the time available for the development of meaningful relationships. [3] This reality has led to around ¾ of pregnant women globally resorting to alternative sources of information and support, as the internet. [4]

The internet, defined by The Oxford English Dictionary [5] as a global and interconnected computer network that provides a variety of information and means of communication, is a privileged mean of obtaining health information, especially for people of reproductive age [6], becoming preferred over sources of information based in interpersonal relationships, [7] such as the relationship between health professionals and clients.

During the transition to parenthood, the main resources of pregnant women are health professionals, family, friends and, increasingly, the internet, [8] an information resource that is growing exponentially, offering information in a fast, accessible, personalized and anonymous way. [3] However, the accessibility and availability of online information raises questions related to its reliability and credibility, and even with the suitability of the information for the person searching for it. [7] Despite the existence of abundant health information online, the one which is based on scientific evidence, it is not easily accessible to the general public. [9]

However, to make informed health decisions on a daily basis, it is not enough to have the ability to access information, it is also necessary to have Health Literacy, that is, the knowledge, motivation and skills to access, understand, evaluate and apply health information in different everyday situations. [10] Health literacy is a tool to empower people, which must be built and improved throughout the life cycle, [11] helping them to manage their health, enabling them to use information correctly and thus obtain gains on a personal and social level, being a means for social and human development. [9] It involves psychological factors, such as personal motivation and the perception of self-efficacy, social and environmental factors, which influence decision-making and health behaviors, promoting greater ability to deal with illness, more effective use of health services and better understanding and control of life situations. [12]

The higher the level of health literacy, the greater the prevalence of information-seeking behaviors in all available means, namely the internet. [6] On the other hand, a low level of health literacy is associated with less competence in assessing the quality of health information that is accessed, and it is in people with a lower level of health literacy that there is a lower incidence of preventive behaviors and a high rate of use of health services. [9]

Regarding the search for online information, people with a lower level of health literacy tend to be distracted by extra elements of a website (such as links), to choose the first answer to their question, not confirming its veracity. They also have difficulty in identifying the differences between high and low quality information and tend to give up the search if do not quickly find the answer to what they are looking for, disregarding information with complex and technical words that are not part of their lexicon. [13]

Therefore, the role played by health professionals is crucial, as seeing their traditional relationship being remodeled by new technologies, [14] they should promote the health literacy of those they care for, understanding which new sources of health information are used, mediating its use and taking advantage of the potential of new communication and information technologies, such as the internet, to expand people's access to reliable health information. [10]

Midwives have as one of their specific competences the care of women inserted in the family and community during the prenatal period, [15] promoting their health and well-being and individualizing care according to their specificities, as their level of health literacy. [16] Considering the internet as a privileged source of information for pregnant women, midwives should be familiar with the most used online resources related to pregnancy, as well as direct women to reliable sites, [16] enabling them to conscious and informed decision-making throughout pregnancy.

Considering the growing use of the internet as a source of health information by pregnant women, as well as the existing asymmetries in the search for online information between people with a higher and lower level of health literacy, the objective of this Scoping review is to identify in the existing literature the relationship between the level of health literacy of pregnant women and the use of the internet as a source of health information. To this end, the following initial question was defined: What is the relationship between the level of health literacy of pregnant women and the use of the internet as a source of health information?

Methods

A review protocol was created, registered on the platform OSF Registries (https://osf.io/k8hea).

The following keywords were defined: pregnant women; internet; health literacy.

A preliminary search was carried out in May 9, 2022 in the systematic reviews database of the Joanna Briggs Institute (JBI) and the Cochrane Database of Systematic Reviews, and to date, no scoping reviews have been found on this topic.

Inclusion criteria

The inclusion criteria were defined according to the methodology of the JBI. [17] The types of participants were pregnant women, the concept of interest, health literacy and context, the internet as a source of information.

As sources of information, research studies of primary and secondary sources of qualitative and quantitative research were used, as well as unpublished literature, as master's dissertations. The inclusion and exclusion criteria are systematized in chart 1.

Chart 1 - Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Design of the study	Research studies of primary and secondary sources of qualitative, quantitative and mixed-methods research were used, as well as unpublished literature, as master's dissertations Articles published in English, Portuguese, French and Spanish Articles published since 2015	Articles published in different languages. Articles published before 2015
Population	Articles with pregnant women as population	Articles with postpartum woman or mothers of small children as population Articles with health professionals who care for pregnant women who use the internet as a source of information
Concept	Articles with the concept of health literacy	Articles about only one of the topics in study and not both simultaneously
Context	Articles about the search of health information online	

Search Strategy

The research process aimed to identify published and unpublished primary and secondary research and it took place between 9 and 14 June 2022. For unpublished research, Google Scholar and the Open Access Scientific Repository of Portugal were used, where the terms pregnancy, internet and health literacy were searched, aggregated with the boolean operator AND.

The research strategy was carried out in three stages, as recommended in the JBI[17] methodology.

In the first stage, an initial search was carried out in the two most relevant databases for the subject under study, MEDLINE and CINAHL, through the EBSCOhost platform. In this research, the terms pregnancy, internet and health literacy were used, some articles were identified, and the words included in the titles and abstracts, as well as the indexing terms, were subsequently analysed. In the second stage, an organized search was carried out in three separate databases, MEDLINE, CINHAL and Web of Science, using the set of keywords in natural language and identified indexed terms. Each concept was researched as the main one, as it was only intended to identify articles in which they appeared as the main concept under study.

For each database, the terms indexed for the selected keywords were identified and, when the existence of terms with truncation was verified, they were aggregated according to its relevance. The identified natural and indexed terms are shown in chart 2.

Chart 2 - Systematization of keywords in Medline and CINHAL databases

	Natural term	Indexed term Medline	Truncation terms	Indexed term CINHAL	Truncation terms
Population	Pregnant	Pregnant women		Expectant mother	
Concept	Health Literacy	Health Literacy		Health Literacy	
Context	Internet	Internet	Web archives as topic Internet based intervention Internet of things Internet access Social media	Internet	Social media World Wide Web Email Gopher Internet access Internet connections Internet protocols Internet based intervention

After identifying all relevant natural, indexed and truncation terms for each keyword, they were aggregated using the boolean operator OR. In the end, among all the keywords already aggregated, their association was performed with the Boolean operator AND. Database search procedures are provided in Appendix I

(MEDLINE), Appendix II (CINHAL) and Appendix III (Web of Science).

Articles published in English, Portuguese, French and Spanish were considered. As time limits, evidence published since 2015 was considered, given that the topic of using new information technologies as a source of health information is relatively recent.

In the third stage, the list of references of the selected articles was analysed, in order to identify any interesting articles for the subject under study.

Source of evidence screening and selection

The process of evidence screening and selection is outlined in the following flowchart:

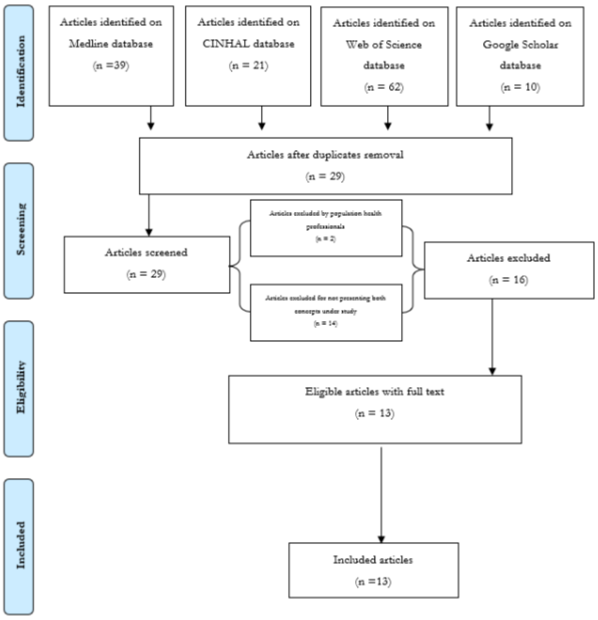

Figure 1 – Flowchart of the scoping review process. Adapted from: Moher, D; Liberati, A; Tetzlaff, J & Altman, D. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Ann Intern Med. [Internet]. 2009,151 (4), 264-269. Available from: https://doi.org/10.1371/journal.pmed.1000097.

The search to identify unpublished literature carried out in the database of the Open Access Scientific Repository of Portugal, did not identify any results. In the databases used after the initial identification of articles through the search for the defined keywords, the title, abstract and keywords were read and analysed. Duplicate articles were then screened, resulting in a total of 29 articles. Subsequently, the list of references of the identified articles was analysed, and no article was identified that met all the selection criteria. The articles to be included in the scoping review were then selected according to their relevance to the subject under study, through the analysis of the title and abstract. In articles whose relevance was not clear by reading the abstract, an analysis of the full text was performed.

During the evidence source selection stage, 16 articles were excluded for not meeting the defined selection criteria; two articles were excluded because their population was health professionals who care for pregnant women who use the internet, and the rest were excluded because they only presented one concept and not both simultaneously.

Then, both authors, independently, selected thirteen articles to be included in this scoping review.

Data extraction

The extraction of data from the selected articles was done through a table, elaborated according to the JBI[17] methodology, with the objective of extracting relevant data from the identified articles, mapping the existing evidence on the relationship between the use of the internet as a source of health information and the level of health literacy of pregnant women. Ethical aspects were preserved throughout the data extraction process, with all authors duly referenced and the content of the included articles presented in a reliable manner.

Results

In order to present the synthesis of the main characteristics of the included studies, a table was elaborated, presented in Appendix IV. Considering the existing asymmetries between different levels of Health Literacy (HL) and the use of the internet as a source of information [6,9,13], the key results of the present scoping review were coded into higher and lower levels of health literacy, and are presented in the following chart:

Chart 3 - Coding of the key results of the scoping review

Author	Objective	Results		
		Relationship between Health Literacy (HL) level and internet as a source of information		
		Lower level of health literacy	**Higher level of health literacy**	**Implications for practice / for health professionals**
Hussey, L.; Frazer, C. & Kopulos, M. (2016)	Analyse the impact of the HL level of millennial pregnant women on health decision-making during pregnancy.	Less ability to understand and apply the information accessed online; Require support from health professionals to understand and apply the health information they access online.	-	The level of HL must be assessed with validated instruments to personalize the information.
Fredriksen, E.; Harris, J. & Moland, K. (2016)	Understand how online discussion forums influence maternal HL.	Interactions between pregnant women in online forums influence their level of HL, increasing their knowledge and health skills and giving guidance in using the health system.	-	-
Sayakhot, P. & Carolan-Olah, M. (2016)	Investigate how pregnant women use the internet to obtain information related to pregnancy.	Empowerment is needed through the promotion of information search skills.	Greater propensity to search for information online.	Should warn that the information available online does not replace contact with health professionals.
Guendelman, S.; Broderick, A.; Mlo, M.; Gemmill, A. & Lindeman, D. (2017)	Understand the extent of adoption and use of digital tools; to identify the main psychological factors that motivate the use of technology among disadvantaged primiparous pregnant women.	Less use of digital tools.	Increased number of online searches on health information; Greater use of digital tools for managing health issues.	Should inquire about online health information search behaviours and assess skilss in using online tools that require HL; Should define strategies to eliminate inequalities between women with different levels of digital HL.
Vamos, C.; Merrel, L.; Detman, L.; Louis, J. & Daley, E. (2019)	Explore pregnant women's experiences in accessing, understanding, evaluating, communicating and using health information during pregnancy.	3 components of HL were assessed: Comprehension: information in current language; audio-visual elements and personalized information; Evaluation: multiple references; credibility of the source and presence of sponsorships; Application: conducting prior search online allows the formulation of questions before the contact with health professionals and making health decisions on topics such as nutrition and physical exercise during pregnancy.		Pregnancy is a privileged period for promoting HL; Prenatal health education interventions should be developed according to the level of health literacy, ensuring their accessibility, understanding and applicability.
Arcia, A.; Stonbraker, S. & Warner, E. (2019)	Understand how disadvantaged pregnant women characterize their digital information needs and search processes; Identify the inhibiting and facilitating factors in this process.	It is a barrier to the correct interpretation of health information that is accessed online; It is associated with a lower propensity to search for information online; It is associated with the need for support to access reliable online information.	-	Should reference online formal sources of information, especially for women with a lower level of HL.
Chung, K.; Cho, H.; Kim, Y.; Jhung, K.; Koo, H. & Park, J. (2020)	Determine associations between pregnant women's medical help-seeking strategies, changes in medical decision-making, and use of online health information with a focus on the mediating effect of self-efficacy on literacy.	-	Online search for information in formal sources; Greater intention to discuss with health professionals about the information accessed online.	-
Šoštaric, M. &, Jokić-Begić, N. (2020)	Understand the phenomenon of health information search online by pregnant women.	It is associated with greater difficulty in obtaining information online.	It is associated with more online research; Increased skills in assessing the accuracy of online information.	-
Bäckström, C.; Chamoun, S.; Tejani, S. & Larsson, V. (2021)	Explore parents perceptions of digital parenting support	Online support tools should be able to be individualized at different levels of HL;		Must be actively present in online support tools,

	during pregnancy and the first 18 months of parenting.			supporting people with critical levels of HL; Should enhance critical and analytical skills, promoting HL.
Donelle, L.; Hall, J.; Hiebert, B.; Jackson, K.; Stoyanovich, E.; LaChance, J. & Facca, D. (2021)	To understand how digital technologies contribute to the experience of transition to parenthood.	The overwhelming amount of information available online makes it difficult to understand; Pregnant women need to raise their HL level to know how to identify reliable online sources.		Should promote digital HL skills; Should know to reference reliable online sources.
Álvarez-Pérez, Y.; Perestelo-Pérez, L.; Rivero-Santana, A.; Torres-Castanõ, A.; Toledo-Chávarri, A.; Duarte-Díaz, A.; Mahtani-Chugani, V.; Marrero-Díaz, M.; Montanari, A.; Tangerini, S.; González, C.; Perello, M.; Serrano-Aguilar, P. (2022)	To determine the influence of creating online courses on improving the digital health literacy of pregnant and breastfeeding women.	Lesser use of online information sources of reference and greater use of sources such as blogs and social networks.	It is potentiated by taking online courses.	Should promote skills to assess the quality and accuracy of information available online; Online courses can be a tool to empower pregnant women, allowing access to valid and reliable information.
Bäckström, C.; Carlén, K.; Larsson, V.; Mårtensson, L.; Thorstensson, S.; Berglund, M.; Larsson, T.; Bouwmeester, B.; Wilhsson, M.& Larsson, M. (2022)	To explore the use of digital information sources by expecting parents and how their health during pregnancy its influenced.	Lower level of HL is related to individual difficulties in searching for online information.	-	Should consider the level of HL to provide personalized support; Should develop online information adapted to different levels of HL.
Lu, Y.; Barret, L.; Lin, R.; Amith, M.; Tao, C. & He, Z. (2022)	To identify research gaps in information needs related to pregnancy and information available from different sources.	Is associated with less online searches; Associated with more difficulties in accessing health information available online.	-	The health information available online should be formulated for a basic level of understanding, in order to be comprehensible to all levels of HL.

Discussion

This scoping review allowed mapping the existing scientific evidence on the relationship between the two concepts under study: internet and health literacy in the defined population, pregnant women, concluding that the level of health literacy of pregnant women has a decisive influence on the use of the internet as a source of information. The authors state that it is in pregnant women with a lower level of HL that is verified less use of digital tools to search for health information, [18, 19, 20] possessing less ability to understand and apply the information accessed online, as well as individual difficulties in search for information, [21, 22] requiring support from health professionals. [18, 23] It is also in pregnant women with a lower level of HL that there is less use of online formal sources and greater use of sources such as blogs and social networks. [24]

On the other hand, pregnant women with a higher level of HL, carry out more searches for online health information, [19, 22, 25] having better skills in assessing the accuracy of the information they access. [22] They tend to resort to formal online sources and have greater intention of discussion with health professionals about the health information they have accessed. [26]

Towards the existing asymmetries between pregnant women with different levels of HL, strategies must be defined by health professionals to eliminate the inequalities that emerge in the use of the internet as a source of health information. [19] In the first instance, they should assess the level of HL with validated instruments to provide personalized support [21, 23] and ask questions about online health information search behaviours of pregnant women whom they care for. [19] They should promote skills for evaluating the quality and accuracy of information available online [21, 24, 27] and be actively present in online support tools, [21] developing health information in current language and with audiovisual elements, [18] which is adapted to different levels of HL. [21]

As a limitation of the present scoping review, the location of most of the included articles emerges, which come from studies carried out in the United States of America, with a smaller number of studies carried out in Europe, emphasizing the lack of studies carried out in Portugal. Given the relevance and timeliness of the topic, research on the use of the internet as a source of health information and the level of health literacy of pregnant Portuguese women emerges as a need.

Conclusions

The articles included in this scoping review allowed mapping the existing scientific evidence on the relationship between the use of the internet as a source of health information and the level of health literacy of pregnant women, something that should not be overlooked by health professionals who provide care for this population. The level of health literacy of pregnant women has a decisive influence on the use of the internet as a source of information, being positively related to greater frequency of use, recurrence to formal sources and discussion of the information accessed with health professionals. In contrast, a lower level of health literacy is associated with less use of digital tools to search for health information, greater use of informal online sources and greater difficulty in evaluating and understanding the information accessed, requiring support from health professionals. The level of health literacy of pregnant women should be considered for the personalized recommendation of valid and reliable online

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information. Considering the relevance of the subject, there is an urgent need to carry out further research, with the aim of guiding health professionals to provide care that is sensitive to the specificities of pregnant women in the 21st century.

Authors' contributions

IND: Conception and design of the study; Data collection; Data analysis and interpretation; Drafting the manuscript.
MHBF: Critical review of the manuscript.

Conflicts of interest

The authors declare that there is no conflict of interest.

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Review Article

Virtual reality as a strategy for labour pain relief: scoping review protocol

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Introduction

During labour, pain can affect the health of the mother and the foetus, and its relief is a right of the mother and a duty of the professionals. In the promotion of a positive experience of labour, it is crucial that nurses specialised in maternal and obstetric health give priority to pain assessment and the use of non-pharmacological methods for pain relief, providing the necessary resources and empowering parturients to use them. Among said methods, virtual reality stands out due to its ease of use and for allowing the reduction of pain levels by diverting attention from the real world, using computers and other devices. Since it is a new approach that is not yet implemented in delivery rooms in Portugal, it is important to map the facilitating factors and barriers associated with its use, so that the dissemination of existing knowledge and its transfer to skilled nursing care during the first stage of labour can be planned.

Objective

To map the research evidence on the facilitating factors and barriers in the use of VR as a non-pharmacological strategy for pain relief during labour in hospital settings.

Methods

This protocol follows the guidelines published by the Joanna Briggs Institute. The databases MEDLINE, CINAHL, Cochrane Database of Systematic Reviews and MedicLatina through the EBSCOhost platform, the Joanna Briggs Institute EBP Database, through the Ovid platform are considered for the search and, the grey literature is also included. As inclusion criteria, qualitative, quantitative and mixed studies that address virtual reality as a pain relief strategy during labour in hospital settings (based on the mnemonic PCC - Population, Concept and Context), published in Portuguese, French, Spanish or English language between 2017 and 2022 are considered. The titles and abstracts of identified references will be independently reviewed and assessed for eligibility by two reviewers. In the event of a tie, a third reviewer will be used. Full text studies and data will be extracted using a form. The data extraction table will show the mapped data in a descriptive way answering the research questions.

Discussion

The results will allow summarising the barriers and facilitating factors in the use of Virtual Reality for pain relief during labour and thus contribute to decision making in planning the dissemination of this strategy to pregnant women and health professionals and its implementation in delivery rooms.

Systematic Review Record

Open Science Framework : osf.io/4b2sj

Keywords

Virtual Reality; Pain in Labour; Obstetric Nursing; Parturient.

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Introduction

Pain during labour is an individual experience.[1] The way pain is experienced by the parturient includes physiological and psychosocial processes[2] that depend on prepartum and intrapartum factors.[3] These include physical, psychological (fear, anxiety, confidence), prenatal education, parity, the position adopted by the woman, genetic and clinical factors, the mother's level of education, socioeconomic and cultural level, and the model of care during childbirth (e.g. presence of a caregiver).[4] Although pain during labour is a natural and physiological condition, it can affect the well-being and health of the woman and the foetus, the woman's emotional relationship with the new-born, as well as her prospects for future births.[5]

National and international guidelines on the positive birth experience or respected motherhood advocate that pain relief is crucial to the provision of quality care. The World Health Organization[6] states that pain relief should be based on scientific evidence and made available in a timely manner, according to the woman's choices, its culture and its needs. In this context, non-pharmacological pain relief strategies that do not entail the risk of adverse effects of pharmacological strategies such as increased duration of labour and the need for instrumental deliveries, are highlighted.[1,7] These strategies have the potential to reduce the side effects of epidural analgesia, increase the rate of adherence to breastfeeding, increase shared decision-making and control over labour, facilitate interaction with professionals, and ultimately increase the satisfaction of the parturient woman and its family. [8-9]

Among the non-pharmacological strategies for pain relief during childbirth, virtual reality (VR) stands out as a non-invasive method, presenting several benefits (increased satisfaction and decreased pain, duration of labour and anxiety), being effective and easy to use.[4,10-11] Musters et al.[12] consider that there has been an increase in scientific evidence that VR is effective in reducing pain during childbirth, and that its use may contribute to reducing the use of pharmacological pain control methods and, concomitantly, the side effects associated with them.

VR is a new technology that uses computers and other devices, which allows the parturient to experience a sense of presence in an immersive three-dimensional and interactive environment, which contributes to reducing the perception of pain, diverting attention away from the real world.[13] This abstraction and sensory experience can also be used simultaneously with other techniques, which is an advantage that should be taken into consideration. [14]

Pain perception is (in part) related to the attention paid to painful stimuli[15] and distraction techniques take the attention away from a noxious stimulus, requiring limited attention from the user. Although distraction through watching movies, listening to music, and having non-clinical conversations has become more common during medical procedures, VR systems may provide a more effective alternative. Distraction may be a very promising analgesia technique that can be used safely and effectively for the reduction of pain and discomfort during medical procedures.[16] In recent years, several researches have explored the effectiveness of immersive VR distraction in reducing pain related to different medical procedures and also labour. [15]

Some of the most recent distraction techniques use advanced audio-visual technology, which combines visual and auditory stimuli in two- or three-dimensional videos. These techniques are called audiovisual VR systems, goggle systems or simply audio visual distraction and do not use kinetic stimuli. VR uses sophisticated equipment such as 3-D monitors (*Head Mounted Displays*) placed on the head, which have a large field of view, and motion detection systems which allow users to interact with the virtual environment. There is a multiplicity of features and components that can be added to or removed from the equipment, which translates into the costs involved for its use.[17]

The use of VR as an analgesia technique offers more immersive images due to occluding headsets that project the images right in front of the user's eyes and, depending on the model used, block real-world stimuli (visual, auditory or both).[16] McCaffery and Pasero[17] have designated this phenomenon as sensory shielding. In the latter, the user is protected from pain by the distraction resulting from immersion, which is particularly increased in VR through the use of *Head Mounted Displays* that direct the focus of attention to what is happening in the virtual world.[16]

In the first phase of labour, VR is of particular interest due to its non-invasive nature, its contribution to pain relief and the absence of significant side effects.[11]

In the studies conducted by Baradwan *et al.*[4], Akin *et al.*[1], and Carus *et al.*[18], the benefits of VR were highlighted as being: the reduction in the perception of pain in parturients, the decrease in anxiety levels, the increase in the satisfaction of women and significant others, the absence of adverse effects, as well as the decreased risk of complications for the foetus and postpartum disorders for women. In this context, it is also important to mention the qualitative study conducted by Wong *et al.*[19], in which the perceptions of parturients during the use of virtual reality were analysed and in which they concluded that women felt calmer and more relaxed, with decreased levels of anxiety and more focused on breathing. This study also showed significant improvements in self-efficacy through the use of VR.

Health professionals, with their knowledge and skills, remain the most important factor in promoting a labour that meets women's expectations[20], ensuring a safe environment, designing, implementing and assessing interventions for pain prevention and control.[21-22] During pregnancy and childbirth, pain relief stands out in the professional practice of obstetric nurses and is based not only on medical reasons, but also on human reasons.[23]

The sharing of knowledge for the innovation of nursing care, strategies and interventions is essential, as well as the acquisition of resources and the training of professionals to provide safe, accessible and effective alternatives[24] for the relief of pain in parturients.[25] The implementation of VR in the first stage of labour requires obtaining information on the preferences of parturients and how they perceive pain.[12] In prenatal care, these aspects can be clarified and the

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development of the birth plan can be a good opportunity to do so.

Despite its effectiveness in pain relief and the safety that its application allows,[26] VR is still not used in delivery rooms in Portugal. In this context, it is essential to identify the facilitating factors and barriers to the dissemination of the available know-how, in order to promote its dissemination during pregnancy in childbirth preparation courses and its accessibility to parturients.

Methods

A search of MEDLINE (EBSCOhost), the Cochrane Database of Systematic Reviews (EBSCOhost), and the Joanna Briggs Institute EBP (Ovid) was performed and no scoping reviews or systematic reviews on the topic were identified.

Objectives and Research Questions

The aim of this scoping review (ScR) is to map the evidence on the facilitating factors and barriers in the use of VR as a non-pharmacological pain relief strategy during labour in hospital settings.

The research questions are:

What are the barriers to using virtual reality as a pain relief strategy during labour?

What are the facilitating factors in the use of virtual reality as a strategy for pain relief during labour?

Following the methodology proposed by JBI, this scoping protocol is presented according to the guidelines for systematic review protocols provided by the Preferred Reporting Items for Systematic review and Meta-Analysis Protocols (PRISMA-P) checklist (Appendix 1).[28] The planned review will be presented according to the PRISMA Extension for Scoping Reviews (PRISMA-ScR) Checklist (Appendix 2).[28]

This protocol will be conducted to include all studies that address virtual reality as a non-pharmacological strategy for pain relief during labour. Ensuring a systematic and replicable work, the structure of this ScR protocol, will follow the following steps: define and align the objective with the questions for the review, develop and align the inclusion criteria with the objectives/questions; describe the planned approach for the search, selection, data extraction and presentation of evidence; search and select the evidence; extract and analyse the evidence; present the results and summarise the evidence in relation to the review objective, reach conclusions and note any implications of the results.[29]

This protocol has been registered in the Open Science Framework (registration no. osf.io/4b2sj)

Eligibility Criteria

Participants: this ScR protocol includes studies on the use of virtual reality for pain relief during labour.

Concept: the phenomenon of interest defined for this ScR concerns the facilitating factors and barriers to the use of virtual reality as a non-pharmacological strategy for pain relief during labour. The identification of these aspects will make it possible to prevent the impact of barriers and promote the successful implementation of this strategy in birth units in Portugal.

Background: hospital (Delivery Rooms).

Types of Studies

This protocol includes primary (quantitative, qualitative and mixed) or secondary (systematic literature reviews and ScR) studies and grey literature. Studies published in Portuguese, French, Spanish and English will be considered, since they are the languages of the researchers. The timeline considered will include the last 5 years of publication, starting in 2017.[29]

Information sources

To identify potentially relevant documents for the ScR two types of information sources will be used.

Electronic databases through the EBSCOhost platform: CINAHL Complete, MEDLINE Complete, MedicLatina and Cochrane Database of Systematic Reviews, and through the OVID platform: JBI EBP.

Other documents from sources such as the Open Access Scientific Repository of Portugal and from organisations issuing guidelines on health care during childbirth.

Research strategy

The research strategy defined for this ScR will involve three stages.

An initial search in relevant databases: MEDLINE, CINAHL. Through this search, the most commonly used descriptors (natural and indexed language) in the titles and abstracts of the searched articles and the indexing terms used to identify the articles related to the facilitating factors and barriers in the use of virtual reality as a non-pharmacological strategy for pain relief during labour are defined.

The natural language search expression to be used in the MEDLINE database includes truncation and wild cards and will be: (Parturient OR Pregnan* OR Wom?n in Labo?r) AND (Virtual Reality OR User-Computer Interface) AND (Pain Management OR Pain Measuring OR Pain Relief OR Labo?r Pain) AND (Hospital OR Obstetric Units).

The search expression in indexed language to be used in the same database will be: (MH "Labour, Obstetric" OR "Pregnancy") AND (MH "Virtual Reality" OR MH "User-Computer Interface") AND (MH "Pain Management" OR MH "Pain Measurement" OR MH "Analgesia, Obstetrical" OR MH "Labor Pain") AND MH "Hospital Units".

As limiting factors, the date of publication (from 2017 to 2023) and language (English, French, and Portuguese) will be used.

Secondly, a search will be conducted by adapting the terms described in the previous section for each of the sources mentioned. The search strategy will be based on the mnemonic "PCC" according to the JBI recommendations. The Participants were the parturient women; the Concept was virtual reality as a non-pharmacological strategy for pain relief and the Context was the hospital (delivery rooms).[30]

The reading of the titles and abstracts by both reviewers independently (using previously established questions) will allow them to select those that meet the eligibility criteria and that will be chosen to be read in full.

For refinement, the bibliographic references of all identified articles and studies will be reviewed to include additional studies.[30]

Data mapping process

After the search, all selected studies will be sent to the Mendeley reference management program and duplicates will be removed. Subsequently, a detailed assessment of the studies will be performed, and their selection will be based on the inclusion criteria and the guiding questions of the review. Two reviewers independent of each other will be used for identification, selection, eligibility and inclusion criteria. In case of doubt, divergent issues will be discussed, and a third reviewer will be contacted for clarification.

Selected articles will be downloaded into the Covidence programme, which, in partnership with Cochrane, allows interaction between reviewers and optimises the systematic review process, based on JBI recommendations. The extracted data will include specific details on population, concept and context, study methods and key findings relevant to the study question.

Summary of Results

The results will be presented in the PRISMA flowchart (Annex 3). The data extraction table will show it in an organized and descriptive way, considering the review questions. Thus, it is essential to identify the facilitating factors and barriers in the use of VR in pain relief during labour. These results will be presented in a descriptive and analytical way, in a table where the characteristics of the studies and documents considered in the ScR will be described.

Discussion

VR is a non-pharmacological alternative for pain relief[31] and mapping the facilitating factors and barriers to its use during labour allows planning interventions for the dissemination and transfer of the knowledge produced involving nurses, physicians and women/companions so as to promote the use of this strategy by enhancing the facilitating factors and minimising the barriers.

Authors' contributions

Coelho, M: Rationale for the protocol, methodological options and writing the manuscript.

Tereso, A: Rationale for the protocol, methodological options and writing the manuscript.

Conflicts of interest

The authors declare that there is no conflict of interest.

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Unitary Caring Science: Caritas Compassion Transpersonal Theory

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Abstract (written by editors)

This article presents a transformative perspective on contemporary nursing, emphasizing unity and interconnectedness in the post-Covid world. Prof. Jean Watson introduces "Unitary Caring Science" as a holistic approach to nursing, rooted in three ethical principles: The Ethic of Belonging, The Ethics of Face, and The Ethics of Hands. These principles guide the paradigm shift in nursing philosophy and practice.
Dr. Watson discusses the "Ten Caritas Processes®," a foundational language for understanding and practicing human care. She highlights the importance of "Transpersonal Caring Moments," where nurses' presence and authenticity influence patient experiences.
The article aligns this approach with the American Nurses Association's new definition, emphasizing compassion and presence in nursing care, and advocates for a holistic, interconnected nursing approach to uphold human dignity and compassion.

Keywords
Ethics Nursing; Holistic Nursing; Nursing Care.

Resumo (escrito pelos editores)

Este artigo apresenta uma perspetiva transformadora sobre a enfermagem contemporânea, enfatizando a unidade e a interligação no mundo pós-Covid. A Prof. Jean Watson apresenta a "Ciência Cuidadora Unitária" como uma abordagem holística para a enfermagem, fundamentada em três princípios éticos: A Ética da Pertença, A Ética do Rosto e A Ética das Mãos. Estes princípios orientam a mudança de paradigma na filosofia e prática da enfermagem.
A Dra. Watson discute os "Dez Processos Caritas®", uma linguagem fundamental para compreender e praticar o cuidado humano. Ela destaca a importância dos "Momentos de Cuidado Transpessoal", onde a presença e autenticidade das enfermeiras influenciam as experiências dos doentes.
O artigo alinha esta abordagem com a nova definição da Associação Americana de Enfermagem, enfatizando a compaixão e a presença no cuidado de enfermagem, e defende uma abordagem holística e interligada à enfermagem para preservar a dignidade e a compaixão humanas.

Palavras-chave
Ética em Enfermagem; Enfermagem Holística; Cuidado de Enfermagem.

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Introduction

Tumultuous times in our world require a new/old unitary worldview; an evolving consciousness about converging ideas of nursing, because we dwell in the sacred circle of life and death and beyond. Post Covid has awakened us to the reality of oneness of all, encompassing a quantum leap for a new worldview, a worldview of unity and connectedness of all things.

In my writing I refer to this shift as unitary caring science for nursing, caring, healing and health care. We are faced with one world/ one humanity/ one Planet.[1,2]

The framework of unitary caring science and transpersonal theory includes the following principles: The Ethic of Belonging; The Ethic of Face; and the Ethic of Hands. Each one of these informs the transformative unitary paradigm for Nursing and specifically my work in philosophy and science of caring as well as transpersonal caring theory.

The Ethic of Belonging

The Ethic of Belonging was posed by French philosopher Levinas in 1969[3] and submitted that we all 'Belong to the Infinite Field of Universal Cosmic Love', before our Separate Being. This worldview of unity and oneness of all reflects a quantum universe of connectedness, which transcends our separate ego physical self. This ethic also represents the reality of the sacred circle of life and death to which we all belong, before birth and after death, awakening the sacred science of caring. Further, Levinas posed Ethic of Belonging as the first principle of science. Thus, it is a foundational starting point and worldview for unitary caring science and my most current theoretical philosophical perspective.

The Ethics of Face

The Ethics of Face, likewise was posited by Levinas[3] as a core principle of human evolution and survival of humanity. His work on Ethics of Face acknowledged that humanity either evolves further as infinite evolution to higher consciousness – Or – we totalize our humanity and each other. The view is in spite of the paradox of virtual reality; in that "the only way we can survive as humans at this point in human history is through *the Face -to-Face* connection". 'When we look into the face of another person, we are looking into the mystery and infinity of human soul; when we look into the mystery and infinity of other, it mirrors back the infinity of our own soul. The Face to Face connection also reflects the Ethic of Belonging that unites us across time and space.

The Ethics of Hands

The third principle of Unitary Caring Science is posited by Ethicist Logstrup,[4] a Danish philosopher. His philosophy highlighted the metaphorical and literal reality that we hold another person's life in our hands. This ethic is core to nursing and human caring practices. In his words he noted: "*The life in our hands* is *a sovereign expression of life as given to us, before and beyond ego; with expressions of trust, love, honesty, forgiveness, gratitude - beyond feelings that are negative expressions of life...*".[4(p18)] He referred to this view as an Ethical Demand, to take care of the life which is in our hands. Within caring science and the infinite energy of love, it is important to highlight that our hands are connected with our heart; the heart is the very source of love, caring, compassion and our inner truth. So the ethics of hands takes on important meaning for nursing and the use of our hands in healing.

10 Caritas Processes®

The Ten Caritas Processes of the transpersonal caring theory, provide core language of the universals of human caring, which nurses are offering every day. However, because Caring has not been named, it has been invisible, without acknowledging, naming, documenting, researching. Further caring language has not been used as the foundational ethical, philosophical guide to micro and macro caring practices, contributing to patient and nurse caring-healing and health outcomes. It must be acknowledged in this postmodern time, that any profession without its own language does not exist. It is also important to know that these 10 Caritas Processes are located within the larger unitary caring science paradigm, the most mature level for honoring nursing's phenomenon and vicissitudes of human experiences.

Transpersonal Caring Moment

The nurse-patient relation in any given moment is affected by the presence, intentionality, consciousness, authenticity of the nurse in a given moment. Each caring moment is informed by nurse's theory, philosophy, ethic and authentic use of self in a given moment. Unitary Caring Science is context for any and each transpersonal caring moment, guided by the professional nurse's evolution and consciousness. Such mature practice at micro and macro level can be framed as Caring Praxis, beyond usual practice of *Doing,* transformed toward a Relational Ontology *of Being.* The ten Caritas Processes provide the language and theoretical foundation and structure of nursing. However, where the theory lives is in a Caring Moment, which is transpersonal, in that each moment is unique and goes beyond two individuals; rather beyond ego of nurse or even ego of nursing profession; rather nurse being authentically

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present, open and receptive to 'see', 'to hear' and to honor with dignity each individual.

Caritas Process 1: Embrace - Practice of Loving Kindness, Compassion and Equanimity, for Self-first: before one is able to offer another authentic caring. Professional theory-guided practice requires informed moral action, such as honoring each of the Caritas Processes as guide for self as well as other.

Caritas Process 2: Inspire - Faith and Hope, through authentic presence. Honoring the subjective beliefs and inner life world of other; appreciating sacred presence. Staying within other's frame of reference. There is so much research and knowledge about the role of faith and hope; the role of religion and one's inner belief system which affects outcomes. In this process the nurse honors the whole person and their inner world beliefs even if they differ from mainstream medicine. Here the nurse works strictly from patient/family beliefs, not judging or attempting to impose own beliefs; while inspiring and enabling patient/family practices.

Caritas Process 3: Trust - Transpersonal Self-being sensitive to self/ others-going beyond ego to transpersonal presence. Trust is immediately detected by the nurses' presence, intentionality, heart-centered awareness; holding space for pausing, listening, *hearing* beyond words. As soon as the nurse walks into a patient's room, the patient will know whether they can trust this nurse or not.

Caritas Process 4: Nurture - Relationship. Heart to heart authentic relation via trust and loving presence. Holding Caritas Consciousness in relation with other. Everything is in-relation and here the nurse moves beyond *Doing Nursing* to *Being* authentically presence. Caritas Process 3 and 4 go hand in hand.

Caritas Process 5: Forgive - All – Allow for expression of positive and negative feelings; non-judgmental acceptance, holding sacred space to listen to another's story. Listening to other's story may be the greatest healing gift – where for perhaps for the first time, they hear themselves beyond the usual inner script; Nurse is there holding sacred space allowing patient to hear self; result they often come up with new solutions and new options for self; for self-care; self-knowledge, even self-healing approaches.

Caritas Process 6: Deepen - Creative self; nurse and patient move beyond 'problems' to strengths and creative solutions; allow for creative emergence. Invite an Expanded epistemology – allowing for multiple and all ways of knowing to be considered, not just empirical data alone. It is unethical to limit our knowledge and ways of knowing to only one form of knowledge. Subjective meaning and inner life experiences also count as knowledge, as well as personal, intuitive, aesthetic, ethical, spiritual as well as empirical-scientific knowledge.

Caritas Process 7: Balance - Learning with authentic teaching; appreciating inner listening and subjective meaning for understanding one's inner life world, leading to heart-centered wisdom. This process results in 'coaching' other in self-caring; self-knowledge; self-control; self-choices; and self-healing approaches. Without learning, there is no teaching. It requires realizing that information is not knowledge; knowledge alone is not understanding; understanding is not same as internalizing; internalizing leads to wisdom.

Caritas Process 8: Co-create - Caritas Field; create healing environment, by 'being' the caritas field of loving-trusting, heart-to-heart connections. The Caritas Conscious nurse is the Healing environment. We can have the most beautiful physical environment, but if the humans in the field are not caring the environment can be toxic or biocidic for nurse as well as patients/families.

Caritas Process 9: Minister - Humanity and basic needs with reverence as sacred acts; sustaining human dignity; viewing bodyspirit as one. Helping another with basic human needs when they are unable to do for self, is one of greatest healing acts nurses offer to humanity. A Caritas Conscious Nurse knows they are not just touching the body, but also the mind, the heart and the soul of patient. Requiring a Caritas loving Consciousness to minister to another as a sacred gift.

Caritas Process 10: Open - To infinity and evolution of consciousness; allowing to spiritual existential unknowns, beyond conventional medical science, open to miracles and mystery of caring-healing and infinite possibilities. Conventional science and Western mindsets of medical science do not have all the answers to human health and healing. Nurses experience miracles and mystery in patient outcomes every day.[5]

Summary Note on Caritas Processes®

It is important to note that the Caritas Processes are not linear. They are a gestalt of the whole Caritas Consciousness in any given moment. It is like a hologram. The whole Caritas Consciousness is present in any given moment. Transpersonal caring moment represents any of the Caritas Processes which transcend time, space, and physicality. A transpersonal caring moment of any of the Caritas processes lasts with the patient and the nurse as long as they life, informing the next moments of their life. Thus, the Ethic of Belonging, the Ethic of Face and Ethic of Hand are present through Transpersonal Caritas in any given moment. This dynamic is a life-giving and life-receiving exemplar of Caritas Praxis.

As a transition from overview of Caring Science Caritas Processes and Transpersonal Moment it is helpful to examine the congruence between Unitary Caring Science/Caritas Processes and Transpersonal with the latest definition of Nursing from American Nurses Association (ANA).

Current Definition of Nursing: American Nurses Association ANA (2021-22)

Nursing integrates the ***art and science of caring*** and focuses on the protection, promotion, and optimization of health and *human functioning*; prevention of illness and injury; ***facilitation of healing***; and **alleviation of suffering** through ***compassionate presence***. Nursing is the diagnosis and treatment of human responses and advocacy in the care of individuals, families, groups, communities, and populations ***in recognition of the connection of all humanity.***

The highlighted areas with the latest ANA definition reflects a Unitary Caring Science Paradigm and Transpersonal Caring values as part of the evolved definition of nursing. It is the first time ANA has included caring in its definition; previously the definitions were medicalized-clinicalized views of nursing and humanity, e.g. diagnosis and treatment language.

Together Unitary Caring Science and Transpersonal Caring Theory provide a mature disciplinary foundation for Nursing for this time of change, so needed to sustain human caring and human dignity for both nurses and patients alike. Identifying the Ethics and Quantum Transformative thinking for Unitary Caring Science provide a universal timeless framework for nursing past, present and future.

In summary I have identified the essence and advantages of expanding Nursing and Unitary Caring Science Paradigm and Transpersonal Caritas as a way forward to sustain nursing's global covenant with humanity.

Watson Essence Of Unitary Caring Science

- Brings infinity of LOVE back into Nursing and Health Care/ Science
- Provides Universal Nursing Language for Universals of Caring Phenomena
- Introduces Transpersonal - Metaphysical – Sacred
- Integrates ancient and contemporary Energetic Caring Healing Arts
- Provides a Full Circle of Caring Science evolution: E.G. Unitary Philosophy - Ethic – Theory – Micro/macro Caritas Praxis/Education-Measurements and Research.

Final Summary

Unitary Caring Science: Transpersonal Human Caring provides a full circle of knowledge to guide the practice, research, education and leadership for Nursing's' future: The core Philosophy; the Ethical principles of Unitary Caring; Core Values that guide Caritas Processes as theoretical frame for micro and macro practices; combined with Measures and outcomes of Caring as essential to all healthcare. Philosophy/ Ethic/ Values/ Theory/ Practice/ Research-Measures/ Outcomes Without nursing advancing within its own philosophical - ethical – theoretical framework, it is doomed to remain as very good technicians of a totally new quantum universe, required for caring healing and health for all.

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Cost of oncological palliative care in home care service: integrative review

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Abstract

Objective
Investigate scientific articles related to the cost of the Home Care Service for patients undergoing oncology palliative care.

Methods
Integrative literature review, which included primary articles indexed in the PubMed, Scopus, Virtual Health Library (VHL), Embase, Science Direct and Scielo databases, using the descriptors: neoplasms; oncology; home care; palliative care; cost analysis; costs.

Results
Ten studies were included, three from the United Kingdom, three from Spain, followed by two from Italy, one from the United States of America and one from Canada. Studies have shown lower costs for home hospitalization with monitoring by healthcare teams, including when analyzing terminally ill cancer patients and disease prognosis.

Conclusion
It was evidenced that the costs of care provided to patients undergoing oncological palliative care are lower in a home environment than at a hospital level.

Keywords
Medical Oncology; Home Care Services; Palliative Care; Costs and Cost Analysis.

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Introduction

Cancer is among the main Chronic No Communicable Diseases (NCDs) and represents the second leading cause of death in the world, with one in every six deaths being related to the disease. Among the most common types of lung cancer (2.09 million cases), breast (2.90 million cases), colorectal (1.8 million cases), prostate (1.28 million cases), non-melanoma skin cancer (1.04 million cases) and stomach cancer (1.03 million cases).[1]

Regarding the severity of NCDs, an analysis by the World Economic Bank estimated that countries such as Brazil, China, India, and Russia lose, annually, more than 20 million productive years of life due to NCDs.[2] From this perspective, Oncological diseases represent a major public health problem, due to the significant cost of treatment, hospitalization, and the need for continuity of care for individuals in palliative care.

According to the World Health Organization (WHO), in a concept defined in 1990 and updated in 2002 and 2017,[3] palliative care refers to actions that improve the quality of life of patients and families facing problems associated with life-threatening illnesses. It aims to prevent and alleviate suffering, through early identification, correct assessment, and treatment of pain and other physical, psychosocial, or spiritual problems.

It is noteworthy that contingency plans focused on de-hospitalization, and optimization of financial resources are extremely relevant, as they constitute strategies that aim to analyze resources and health actions that favor adequate planning, as well as targeting to the various levels of health care.[4]

Assistance or home care (HC) corresponds to the set of health actions, integrated into the Health Care Network (HCN), to guarantee the continuation of care for the individual who needs care. This service is available in Brazil through the Unified Health System (SUS), through multidisciplinary teams and is also offered by other private service providers, known as home care services.[5]

Within this scenario and perspective, in Brazil, Resolution No. 41/2018 defined together with the Tripartite Intermanagers Commission of the National Council of Health Secretaries (CONASS) and municipal secretariats, provided for guidelines for the organization of palliative care, in light of continued care integrated, within the scope of the Unified Health System (SUS). According to Article 5, palliative care must be offered anywhere in the health care network, at no cost to the patient and their family, notably in primary care, home care, outpatient care, urgent/emergency care, and hospital care.[6]

Across the world, healthcare costs are expensive. When it comes to hospital care, it is even higher. Depending on the evolution of the disease, patients undergoing oncology palliative care undergo several readmissions. When it is possible to decrease readmission rates and shift care to home care, it can lead to a significant difference in hospital expenses.[7]

The cost is the sum of expenses with personnel, material, physical structure, and equipment used and must be understood as an important management tool for analyzing performance, productivity and quality of services.[8]

The first stage of the process consists of verifying the costs of health services, procedures, and treatments. According to the analysis carried out, pharmacoeconomic evaluations have different denominations, including: cost-minimization, cost-effectiveness, cost-utility and cost-benefit.9 In this sense, economic evaluation in health plays a prominent role, requiring managers to face new challenges in the continuous search for efficiency and effectiveness of activities. Quality associated with the rational use of resources must be the new challenge for health service managers.[10-11]

Therefore, it is essential to measure health costs, for a careful analysis of the service scenario to support decision-making by managers in the selection of tools and management models that qualify the care provided to the population involved, especially people with cancer in palliative care. In view of the above, the objective of this study was to investigate scientific articles related to the cost of the Home Care Service for patients undergoing oncology palliative care.

Methods

This is an Integrative Literature Review that followed six standardized steps:[12] in step I, the definition of the research problem and the guiding question were established, using the acronym PICo,[13] where the “P” refers to the population study or the patient, or the problem addressed (Population/Patient/Problem), which in this review refers to cancer patients; the “I” is the phenomenon of Interest (Interest), which were the costs of the home care service for palliative care and the “Co” to the context (Context), what was home care. Therefore, the guiding question of the research was: “What is the cost of home care for patients undergoing oncology palliative care?”

In stage II, the inclusion criteria were defined, which were indexed articles, complete texts without definition of temporality or country of publication, in Portuguese, Spanish and English, related to the guiding question and developed in human beings, without restriction on age range in palliative oncology care.

Studies that addressed palliative care in the hospital area, letters to the editor, duplicates, opinion and review articles of any nature, theoretical reflection, comments, essays, preliminary notes, editorials, letters, theses and dissertations, course completion works, manuals, summaries in annals or periodicals, dossiers, official documents, health policies, hospital management reports, books and book chapters were excluded.

Data collection took place in October 2021 in databases and electronic libraries: Scopus; BASIS; Science Direct, PubMed (MedLine), Scielo, Web of Science and the Virtual Health Library (VHL), with the descriptors presented by the search strategy in Table 1.

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Table 1 – Search string to identify studies on the costs of palliative oncology care in Home Care Services

Database and Libraries	Descriptors	Search strategy	Initial number of articles
PubMed (Medline)	MeSH	*"Cost analysis AND home care AND palliative cancer patients"*	**2**
Scopus	MeSH	*"Cost analysis AND home care AND palliative cancer patients"*	**11**
BVS	DeCS	*(Home visit OR Home care) AND (Palliative treatment OR Palliative care OR Palliative care) AND (Oncology OR Cancer OR Neoplasia) AND (Cost analysis OR Costs)*	**9**
Embase (Elsevier)	MeSH	*'Cost analysis' AND ' home care' AND palliative AND care*	**29**
Scielo	MeSH	*(Cost analysis) AND (home care) AND (palliative care)*	**3**
Science Direct	MeSH	*Cost analysis' AND 'home care' AND palliative AND care*	**30**

The studies were analyzed descriptively using tables. The classification regarding the level of evidence was carried out according to Melnyk and Fineout-Overhol,[14] which establishes levels from 01 to 07: level 1, the evidence comes from a systematic review or meta-analysis of all relevant randomized controlled clinical trials or clinical guidelines based on systematic reviews of randomized controlled clinical trials; level 2, evidence derived from at least one well-designed randomized controlled clinical trial; level 3, evidence obtained from well-designed clinical trials without randomization; level 4, evidence from well-designed cohort and case-control studies; level 5, evidence from a systematic review of descriptive and qualitative studies; level 6, evidence derived from a single descriptive or qualitative study; level 7, evidence from the opinion of authorities and/or the report of expert committees.

As it is an integrative review, the research was not submitted to the Research Ethics Committee.

Results

Identified 84 articles according to the initial search strategy. Of these, five were duplicates, resulting in a total of 79. There were 18 articles that addressed the research question; and after reading the full texts, ten studies were selected to be part of this review. The search, selection and analysis process of studies was carried out by two independent reviewers, with the help of the Rayyan reference manager software and any disagreements were resolved by a third reviewer.

Figure 01 represented by Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)[15] presents the study selection flow.

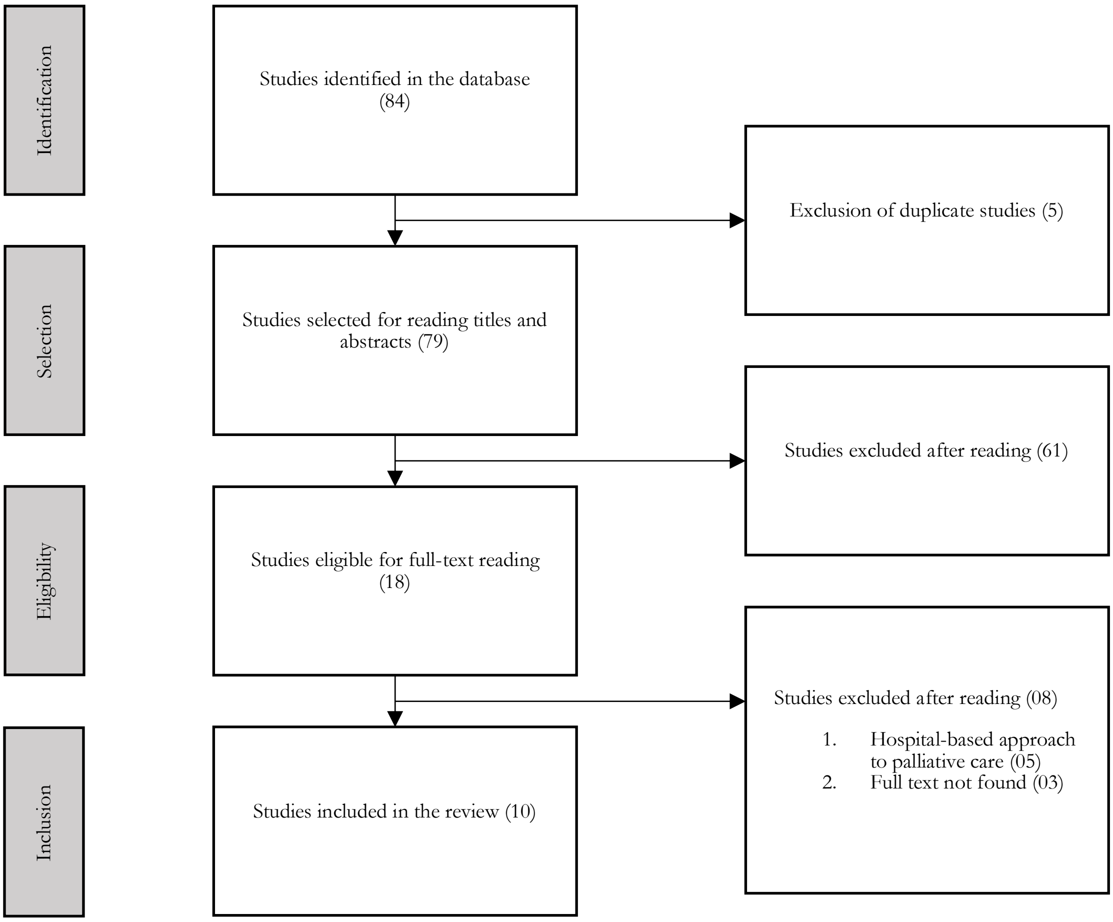

Figure 1 – Flowchart of the process of identification, selection, eligibility, and inclusion of studies. Source: Adapted from PRISMA 2020

For the analysis and synthesis of the ten selected articles, a synoptic table was used containing title, year and country and another with objective(s), method, results and recommendations/conclusions (table 2).[16]

The articles were categorized by theme: comparison of the cost of home care versus hospital service; cost in the last days-months of life; and cost according to the prognosis of the disease. The number of articles published internationally stands out: three from the United Kingdom,[17-19] three from Spain,[20-22] one from the United States of America,[23] two from Italy,[24-25] one from Canada,26 starting publications in 1986.

Table 3 presents data relating to the cost analysis of cancer patients in home care services.

Table 2 – Characterization of the ten primary articles included in the integrative review according to title, year, and country.

Title	Ano	País
A comparative assessment of home versus hospital comprehensive treatment for advanced cancer patients.	1986	USA*
A comparative cost analysis of terminal cancer care in home hospice patients and controls	1987	United Kingdom
A cost-minimization study of cancer patients requiring a narcotic infusion in hospital and at home	1991	United Kingdom
Home palliative care as a cost-saving alternative: Evidence from Catalonia	2001	Spain
Cost analysis of a domiciliary program of supportive and palliative care for patients with hematologic malignancies.	2007	Italy
Use of resources and costs of palliative care with parenteral fluids and analgesics in the home setting for patients with end-stage cancer	2010	United Kingdom

Resource utilization and cost analyses of home-based palliative care service provision: The Niagara West End-of-Life Shared-Care Project	2012	Canada
Actividad asistencial y costes en los últimos 3 meses de vida de pacientes fallecidos con cáncer en Euskadi	2017	Spain
Comparación directa de los costes sanitarios en los 2 últimos meses de vida en pacientes oncológicos a partir de certificados de defunción en un área periurbana según reciban o no atención en su domicilio por un equipo de cuidados paliativos	2018	Spain
Early Palliative Home Care versus Hospital Care for Patients with Hematologic Malignancies: A Cost-Effectiveness Study	2020	Italy

Note: USA* – United States of America

Table 3 – Selected publications referring to the cost analysis of cancer patients in home care services compared to hospital services.

Base	Title / Level of Evidence	Periodical/ Year/Country/DOI	Objective	Main results
Scopus	A comparative assessment of home versus hospital comprehensive treatment for advanced cancer patients. Evidence - IV	J Clin Oncol. 1986. United States DOI: https://doi.org/10.1200/JCO.1986.4.10.1521	Prospectively compare the costs of home and hospital treatment for patients with advanced cancer	Home treatment had a daily cost of US$256 lower than the hospital cost
Science Direct	A comparative cost analysis of terminal cancer care in home hospice patients and controls. Evidence - IV	Journal of Chronic Diseases. 1987. United Kingdom DOI: https://doi.org/10.1016/0021-9681(87)90132-9	To compare the costs of the last 90 days of life in 98 terminal cancer patients treated by a home care service versus hospital care	The costs of 24-hour medical and nursing care at home and support for their families had an average cost of US$6,477 versus US$6,502 for the hospital daily rate
Scopus	A cost-minimization study of cancer patients requiring a narcotic infusion in hospital and at home. Evidence - III	Journal of Clinical Epidemiology. 1991. United Kingdom DOI: https://doi.org/10.1016/0895-4356(91)90043-9	Compare the cost in Canadian dollars of cancer management in patients who required narcotic infusions in the hospital and at home	Medical costs averaged C$369.72/day of hospital stay and C$150.24/day of home care (saving C$219.48/day in 1988). Narcotic costs were the same for any patient in both settings
PubMed	Use of resources and costs of palliative care with parenteral fluids and analgesics in the home setting for patients with end-stage cancer. Evidence - IV	Ann Oncol. 2010. United Kingdom DOI: https://doi.org/10.1023/A:1008364401890	Identify the cost of home care and the cost of hospitalized patients	The daily cost for each patient was between US$250 and US$300, half of which is for hospital expenses. A hypothetical control group (n=25) was constructed based on current practice and chart review cost approximately $750/day. With an average treatment period of 16 days, this means savings of US$8,000 per patient
Scopus	Resource utilization and cost analyses of home-based palliative care service provision: the Niagara West End-of-Life Shared-Care Project. Evidence - IV	Palliative Medicine. 2012. Canada DOI:10.1177/0269216311433475	Analyze the cost of cancer patients receiving home care	Costs for all patient-related services (in 2007) were C$1,625,658.07 or C$17,112.19/patient, being C$117.95/day. It was observed that home care is less expensive than hospital care
Scopus	Early Palliative Home Care versus Hospital Care for Patients with Hematologic Malignancies: A Cost-Effectiveness Study.	Journal of palliative medicine 2020. Italy DOI: https://doi.org/10.1089/jpm.2020.0396	Compare costs and outcomes between early palliative home care and hospital care for early or terminally ill hematological palliative patients	Home care generated weekly savings of €2,314.9 for the healthcare provider, at a cost of €85.9 for the family, and was cost-effective for preventing infections

	Evidence - III			

Table 4 presents publications according to categorization, referring to palliative patients at the end of life, compared to the costs of palliative patients in the hospital.

Table 4 – Selected publications referring to cost analysis in the last days-months of life of patients with oncological diseases in home care services.

Base	Title / Level of Evidence	Periodical/Year/Country/ DOI	Objective	Main results
Scopus	Home palliative care as a cost-saving alternative: Evidence from Catalonia. Evidence - IV	Palliative Medicine. 2001. Spain DOI: https://doi.org/10.1191/02692160167832025 0	Compare the care resources consumed during the last month of life of patients undergoing palliative treatment who died of cancer	The costs of hospital care were 71% higher than home care
Scielo	Actividad asistencial y costes en los últimos 3 meses de vida de pacientes fallecidos con cáncer en Euskadi. Evidence - IV	Gaceta Sanitaria. 201. Spain DOI: https://dx.doi.org/10.1016/j.gaceta.2016.06.00 5	Analyze the use of health resources and budget in the last months of life of the population who died of malignant neoplasia in the Basque Autonomous Country (Spain)	People who died in hospital had an average cost of €14,794 approximately double that of people who died at home, and €7,491
Science Direct	Comparación directa de los costes sanitarios en los 2 últimos meses de vida en pacientes oncológicos a partir de certificados de defunción en un área periurbana según reciban o no atención en su domicilio por un equipo de cuidados paliativos Evidence - IV	Medicina Paliativa. 2018. Spain DOI: 10.1016/j.medipa.2017. 05.003	To compare the healthcare costs of care in the last two months of life for patients with advanced cancer, based on death certificates, in a metropolitan area of Madrid, depending on whether or not they were monitored at home by a home palliative care team	The average cost per patient was €3,158, regardless of whether or not they were monitored by a palliative care team.

Table 5 describes the study that addressed the cost according to the prognosis of the disease.

Table 5 – Selected publication referring to cost analysis according to the prognosis of oncological disease in home care services.

Base	Title / Level of Evidence	Periodical/Year/Country/DOI	Objective	Main results
Scopus	Cost analysis of a domiciliary program of supportive and palliative care for patients with hematologic malignancies. Evidence - IV	Haematologica. 2007. Italy DOI: https://doi.org/10.3324 /haematol.10324	To analyze the use of resources and costs of a home palliative care program for four different groups, subdivided according to the status of hematological malignancy	The cost of the home care program was less than charges but exceeded district rates for cancer patients. In hematology patients, costs differ according to disease status and transfusion requirements.

Discussion

The results of the studies demonstrate that the de-hospitalization of patients in palliative care must be predicted through descriptive and qualitative economic aspects. It needs to be based on the exchange and discussion of cases in multidisciplinary teams, with the participation of the patient and family, in the period prior to hospital discharge, seeking to address possible needs, thus characterizing a continuous, organized, and structured process. Thus, the use of these procedures would make it possible to meet all the necessary elements to implement the procedure and resolve the expectations of the patient and their family regarding home care.[27]

Some studies also reinforce that cost-effectiveness and utility costs are greater when comparing home and hospital care, both for the patient and the family, emphasizing that the quality of life of patients and family support are greater.[25]

There is evidence that the costs of home palliative care are lower than the costs of hospital care, as it has been observed that care provided by teams at home contributes to reducing hospital readmission rates and the average length of stay of patients in hospital, in addition to reducing the number of interventions and complications resulting from hospitalization, such as nosocomial infections.[28]

A study carried out in Italy demonstrated that the costs of home palliative care for patients with hematological malignancies are also lower than the costs of standard hospital care.[26]

It is important to highlight that, for this type of care, the consent of the patient and/or family member is extremely important and, despite the possibility of death occurring at home, it is necessary that, during the period of care, the patient and family are capable of developing the ability to deal with such a situation.

The care plan, prepared by the team, must guide the family and caregivers on how to care for the patient, as one of the great advantages observed in home care is the fact that it allows the individual to have their needs met according to their preferences, without having to follow the strict rules and schedules of a hospital, in addition to being able to enjoy family life.[2]

In cities in Spain, the average cost per patient in a Home Care Program and Support Equipment (*Programa d'Atenció Domiciliària i Equips de Suport* - PADES) is substantially lower than in the non-PADES group, with an increase of 71%.19 Just like monitoring, the cost of patients who died in hospital was €14,794, almost double that of those who died at home, according to the cost assessment carried out (€7,491).[21]

In a study carried out in Brazil, relating the profile of patients assisted with the costs of home care and in the case of hospital stays, the results suggest that the average patient/day cost of home care was R$ 28.26-DP4.10 (US$ 12.03 – DP1.74), while the cost of the patient/day of hospitalization was R$294.46 - DP308.69 (US$ 125.30 – DP131.36), or we reaffirm that the patient is in home care. Generally speaking, it tends to be less.[29]

The modality of home care related to palliative care is part of the health policy discussion agenda for Latin American countries that, being justified by the high costs of hospital inpatient care, seeks a way to optimize two financial resources. On the one hand, home care can reduce hospital expenses, on the other hand, it can increase family health care costs. Research shows that Latino families that exclusively use public systems for medical care are those with the greatest economic vulnerability.[30]

The verified data in our studies favor non-home oncological palliative care, because also two costs will be minors, or the patient finds himself in a family environment, with his loved ones, where he will be able to feel more comfortable and safer when receiving care. Likewise, it is important that future health professionals be trained based on their training to perform home care of patients in oncological palliative care, with a vision for the health process as well, and understand it in its biopsychosocial context.

It is suggested that new research may be developed, through more open studies, that compare the costs of home and hospital care for patients in oncological palliative care, to subsidize the formulation of effective public policies that reinforce home care and de-hospitalization.

Conclusion

The results of the two studies presented in this review suggest that the costs of care for cancer patients in the home environment are less than when we are hospitalized, regardless of the treatment phase.

Home assistance can also be efficient in the quality of accompaniment to the patient in his last days of life, since it is possible for the family (caregiver) to offer emotional support and adequate infrastructure, as well as having adequate accompaniment from a multidisciplinary team, favored by Public Policies that reinforce home care and de-hospitalization of patients in oncological palliative care.

Limitations of the study

As a limitation for the development of this review we can highlight the lack of publications addressed to the costs related to oncological palliative care in home care, impacting the generalization of two results for other regions that perform this type of care.

Authors' contributions

PCV: Conception and design of the study; Data collection; Data analysis and interpretation; Writing the manuscript; Critical revision of the manuscript.

PA: Conception and design of the study; Analysis and interpretation of the data; Writing of the manuscript; Critical revision of the manuscript.

MFCB: Conception and design of the study; Analysis and interpretation of the data; Writing of the manuscript; Critical revision of the manuscript.

TSMM: Conception and design of the study; Analysis and interpretation of the data; Writing of the manuscript; Critical revision of the manuscript.

MCFLH: Conception and design of the study; Data collection; Data analysis and interpretation; Writing the manuscript; Critical revision of the manuscript.

Conflicts of interest

The authors declare that there is no conflict of interest.

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Quality indicator in nutritional therapy in oncology and the interface with nursing: integrative review

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Abstract

Objective

To analyze the evidence of the Indicator of Quality in Nutritional Therapy "prescribed *versus* infused volume in nutritional therapy" in hospitalized adult cancer patients and the prospects for nursing practice.

Methods

An integrative review conducted in the Portal Biblioteca Virtual em Saúde, Nursing Database, Cumulative Index to Nursing & Allied Health Literature, Excerpta Medica dataBASE, Google Scholar, Latin America and the Caribbean Literature on Health Sciences, U.S. National Library of Medicine, SciVerse Scopus Web of Science. This research included studies published in Portuguese, English, or Spanish from 2008 to 2021.

Results

Of the nine studies included most of the authors were nutritionists and/or nutrition academics (53.8%), followed by nurses and/or nursing academics (30.8%). Most studies (67%) did not reach the indicator target, being investigated in clinical and/or surgical wards (27.3%) and adult/general Intensive Care Units (27.3%). The reasons for not meeting the indicator goal were related to clinical and mechanical complications of the use of nutritional therapy.

Conclusion

The goal of the indicator in "nutritional therapy prescribed *versus* infused volume" was not achieved in most studies, and the adult cancer patient presents clinical difficulties in achieving it.

Keywords

Quality indicators in Health Care; Quality Indicators in Nutritional Therapy; Enteral Nutrition; Hospitalization; Neoplasms; Nursing.

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Introduction

The hospitalized adult cancer patient due to the clinical conditions that the disease triggers, such as metabolic changes, hormonal disorders, and inflammatory responses, becomes more susceptible to nutritional deficits, which are related to multifactorial aspects associated with the type of tumor, clinical staging, therapeutic modality, individual characteristics of the patient and human and physical resources of the inpatient unit.[1,2] Studies[3,4] reveal that the hospitalized cancer patient is a population at nutritional risk with a degree of malnutrition of 20% to 80%, especially in the older people in the advanced stage of the disease.[5]

Guidelines[6,7,8] advise conducting nutritional screening within a maximum of 48 hours of hospitalization for all people to monitor the nutritional status of the cancer patient. Thus, to meet the nutritional demand, Nutritional Therapy (NT) is used, with Enteral Nutritional Therapy (ENT) as one of the therapeutic modalities. In Brazil, the ENT development requires a Multidisciplinary Nutritional Therapy Team (MNTT)[8] consisting of a doctor, a nurse, a nutritionist, and a pharmacist. The nurse in the MNTT has, among her attributions, to choose the route of administration of the ENT together with the doctor; to proceed and ensure the placement of the naso/orogastric or transpyloric tube; to guide the patient, the family or the legal responsible regarding the use and control of the ENT; and to ensure the clear and accurate recording of information related to the administration and the evolution of the patient.[9,10]

However, ENT has risks and complications, and based on this, the Indicators of Quality in Nutritional Therapy (IQNT) were developed,[11] which aim to identify failures in the performance of procedures to generate improvement in the assistance provided when there is deficits quality.[12] In Brazil, the International Life Sciences Institute (ILSI)[13] listed 36 IQNTs, aiming to measure the assistance provided through indicators that translate the actions and operationalize them for observation and evaluation, providing correction, redefinition, and improvement of the established goals. In Spain, the European Society for Clinical Nutrition and Metabolism (ESPEN),[14] one of the leading NT societies, also provides instruments to measure the quality of ENT both in clinical nutrition units, and in any situation where a patient requires the use of this therapy. The periodic application of the IQNT stands out as one of the main ways to measure the ENT quality in public and private hospitals. The Brazilian Society of Parenteral and Enteral Nutrition (BRASPEN)[9] guides the application of at least three IQNT in health services to monitor therapy, regardless of the size and human resources of hospitals, including: nutritional screening, frequency of patients with NT-related complications and prescribed and infused volume of ENT.

The IQNT "NT prescribed *versus* infused volume" aims to evaluate patients in ENT who have not reached the estimated nutritional goal, and it is the responsibility of Nursing to record their infused volume. In 2018, ILSI-Brazil[13] updated the list of IQNT, adding the indicator "frequency of days of adequate administration of the NT prescribed *versus* infused volume" to find out the frequency of days of adequate volume supply in patients on ENT. The goal of this IQNT is for at least 80% of the prescribed volume of ENT to be infused.[13] A study conducted by ILSI-Brazil [13] with hospital, clinical, and research institutions highlights that one of the most used IQNT is the "NT prescribed *versus* infused volume," represented in 81% of the institutions participating in the survey.

Given the above, the study identified that hospitalized adult cancer patients present nutritional risks due to their clinical condition and present nutritional risks, making them vulnerable to treatment and possible interventions. Despite the scientific knowledge that the values of the NT prescribed *versus* infused volume in the oncological patient are discrepant in clinical practice,[15,16] professionals must pay attention to the fact that, in addition to defining the diet appropriate to the cancer patient's needs, it is necessary to guarantee the form and condition in which this diet will be infused. To this end, many of the activities that nursing undertakes in hospital health services are included, with the nurse being responsible for recording the IQNT "frequency of days of administration appropriate to the prescribed *versus* infused volume in patients on ENT." This reality supports the importance of exploring this theme and its interface with nursing.

Methods

This is an Integrative Review (IR),[17] held in May and June 2022, which structure is based on the International Recommendations of the Preferred Reporting Items of Systematic reviews and Meta-Analyses (PRISMA).[18]

Initially, based on the acronym PICO:[19] (P) hospitalized adult cancer patient; (I) NT; (O) IQNT "NT prescribed *versus* infused volume" (the comparator element 'C' was dismissed), the review question was formulated: "what does the literature refer to the IQNT NT prescribed *versus* infused volume of responsibility of the nursing in the care of hospitalized adult cancer patients?" The review protocol has not been published.

Regarding the eligibility criteria, the study defined the original articles; free available online in full; in Portuguese, English, or Spanish languages; indexed in the Portal Biblioteca Virtual em Saúde (BVS), Nursing Database (BDENF), Cumulative Index to Nursing & Allied Health Literature (CINAHL), Excerpta Medica dataBASE (Base), Google Scholar, Latin America and the Caribbean Literature on Health Sciences (LILACS), U.S. National Library of Medicine (PubMed), SciVerse Scopus (SCOPUS), and Web of Science; conducted with adult oncological patients hospitalized and under EN, and published from 2008 to 2021. The temporal cut is justified by the incorporation of the IQNT "prescribed *versus* infused volume" in 2008 by ILS,[11] even if possibly, the volume of NT has been monitored by other studies in years prior to the one stipulated in this review. Then, the study identified the descriptors or associated terms according to the acronym PICO [20] and adapted the search strategy for each source of information, according to Chart 1.

Chart 1 - Search strategies according to each source of information. Uruguaiana, RS, Brazil, 2022.

Information Base	**Strategy**
BVS	(“Enteral Nutrition” OR “Enteral Feeding” OR “Feeding Tube, Gastric” OR “Feeding Tubes, Gastric” OR “Feeding, Enteral” OR “Feeding, Tube” OR “Gastric Feeding Tube” OR “Gastric Feeding Tubes” OR “Nutrition, Enteral” OR “Tube Feeding” OR “Tube, Gastric Feeding” OR “Tubes, Gastric Feeding” AND (“nutrition therapy” OR “medical nutrition therapy” OR “nutrition therapy, medical” or “therapy, medical nutrition” OR “therapy, nutrition”) and (volume or prescription or administration) AND (db:(“IBECS” OR “LILACS” OR BDENF” OR BIGG” OR “LIPECS” OR “colecionaSUS”)) AND (year_cluster:[2008 TO 2021])
BDENF	(“nutrição enteral” OR “alimentação enteral” OR “alimentação por sonda” OR “alimentação por tubo” OR "Terapia Nutricional") AND ("Indicador de Qualidade" OR “Indicadores de Qualidade em Assistência à Saúde”)
CINAHL	TX (enteral nutrition or enteral feeding or tube feeding) AND TX (quality indicators or qi) AND TX (neoplasms or oncology or cancer)
Embase	(neoplasms OR ‘benign neoplasm’ OR ‘benign neoplasms’ OR cancer OR cancers OR malignancies OR malignancy OR ‘malignant neoplasm’ OR ‘malignant neoplasms’ OR ‘neoplasm OR ‘neoplasm, benign’ OR ‘neoplasm, malignant’ OR ‘neoplasms, benign’ OR ‘neoplasms, malignant’ OR ‘medical oncology’ OR ‘oncology, medical’) AND (‘enteral nutrition’: ti,ab,kw OR ‘enteral feeding’: ti,ab,kw OR ‘feeding tube, gastric’: ti,ab,kw OR ‘feeding tubes, gastric’: ti,ab,kw OR ‘feeding, enteral’: ti,ab,kw OR ‘feeding, tube’: ti,ab,kw OR ‘gastric feeding tube’: ti,ab,kw OR ‘gastric feeding tubes’: ti,ab,kw OR ‘nutrition, enteral’: ti,ab,kw OR ‘tube feeding’: ti,ab,kw OR ‘tube, gastric feeding’: ti,ab,kw OR ‘feeding tube’: ti,ab,kw) AND (‘quality indicators, health care’: ab,ti OR ‘quality indicators’: ab,ti OR ‘quality indicator’: ab,ti OR ‘healthcare quality indicator’: ab,ti OR ‘healthcare quality indicators’: ab,ti OR ‘indicator, healthcare quality’: ab,ti OR ‘indicators, healthcare quality’: ab,ti OR ‘quality indicator, healthcare’: ab,ti OR ‘quality indicators, healthcare’: ab,ti)
Google Scholar	(neoplasias OR câncer OR tumor) AND ("nutrição enteral" OR "Alimentação por Sonda" OR "Alimentação por Tubo" OR "Sondas Gástricas") AND (“Indicador de qualidade" OR “Indicadores de qualidade”)
Lilacs	(“Enteral Nutrition” OR “Enteral Feeding” OR “Tube Feeding” OR “Feeding, Tube” OR “Feeding Tube, Gastric” OR “Feeding Tubes, Gastric”) AND (“Quality Indicators” OR “Quality Indicator” OR “Quality Indicators, Healthcare” OR “Quality Indicator, Healthcare”) AND (db: (“LILACS”) AND (year_cluster: [2008 TO 2021]
PubMed	(“Quality Indicators, Health Care” OR “Quality Indicators, Healthcare” OR “Healthcare Quality Indicator” OR “Healthcare Quality Indicators” OR “Indicators, Healthcare Quality”) AND (“Enteral Nutrition” OR “Enteral Feeding” OR “Feeding, Enteral” OR “Tube Feeding” OR “Feeding, Tube” OR “Gastric Feeding Tubes” OR “Feeding Tube, Gastric” OR “Gastric Feeding Tube” OR “tube, gastric feeding”)
Scopus	(ALL (neoplasms OR neoplasm OR cancer OR cancers OR tumor OR tumors OR oncology) AND TITLE-ABS-KEY (“Enteral Nutrition” OR “Enteral Feeding” OR “Tube Feeding” OR “Feeding, Tube” OR “Feeding Tube, Gastric” OR “Feeding Tubes, Gastric”) AND TITLE-ABS-KEY (“Quality Indicators” OR “Quality Indicator” OR “Quality Indicators, Healthcare” OR “Quality Indicator, healthcare”)
Web of science	(“Enteral Nutrition” OR “Enteral Feeding” OR “Tube Feeding” OR “Feeding, Tube” OR “Feeding Tube, Gastric” OR “Feeding Tubes, Gastric”) (all fields) AND (“Quality Indicators” OR “Quality Indicator” OR “Quality Indicators, Healthcare” OR Quality Indicator, Healthcare”) (Topic)

The titles and abstracts were then read twice to select the articles that met the eligibility criteria. Two academic reviewers from Nursing course analyzed the studies to qualify the methodological process who, after the selection, discussed and compared their results. A third reviewer, a researcher in the EN area, was consulted in cases of disagreement between the initial reviewers. Finally, the articles were analyzed integrally, concluding the study selection phase. The database of studies was organized in Microsoft Excel®.

Researchers prepared a characterization table to present the studies that drawn up the analytical *corpus*, containing title, reference, objective, design, and level of evidence. [19] Also, a chart with the results of the IQNT “NT prescribed *versus* infused volume” is described, with the aim of summarizing for nursing the characteristics of the studies according to whether or not they achieved the indicator’s goal, including the information: type of cancer, hospital unit, structure for therapy, characteristics of the NT, length of application of the ENT, goal of the adopted indicator, values of the indicator and reasons for stopping the NT (when mentioned).

Results

According to the search strategies defined for each information base, researchers identified 602 publications. After the exclusion of 96 duplicates, 506 studies remained

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and, of these, 238 were evaluated according to the eligibility criteria, and 24 were selected for full reading. Of the 24 studies, 11 were excluded, leaving nine studies included for review. The description and selection of studies was based on the PRISMA[15] and is illustrated in Figure 1.

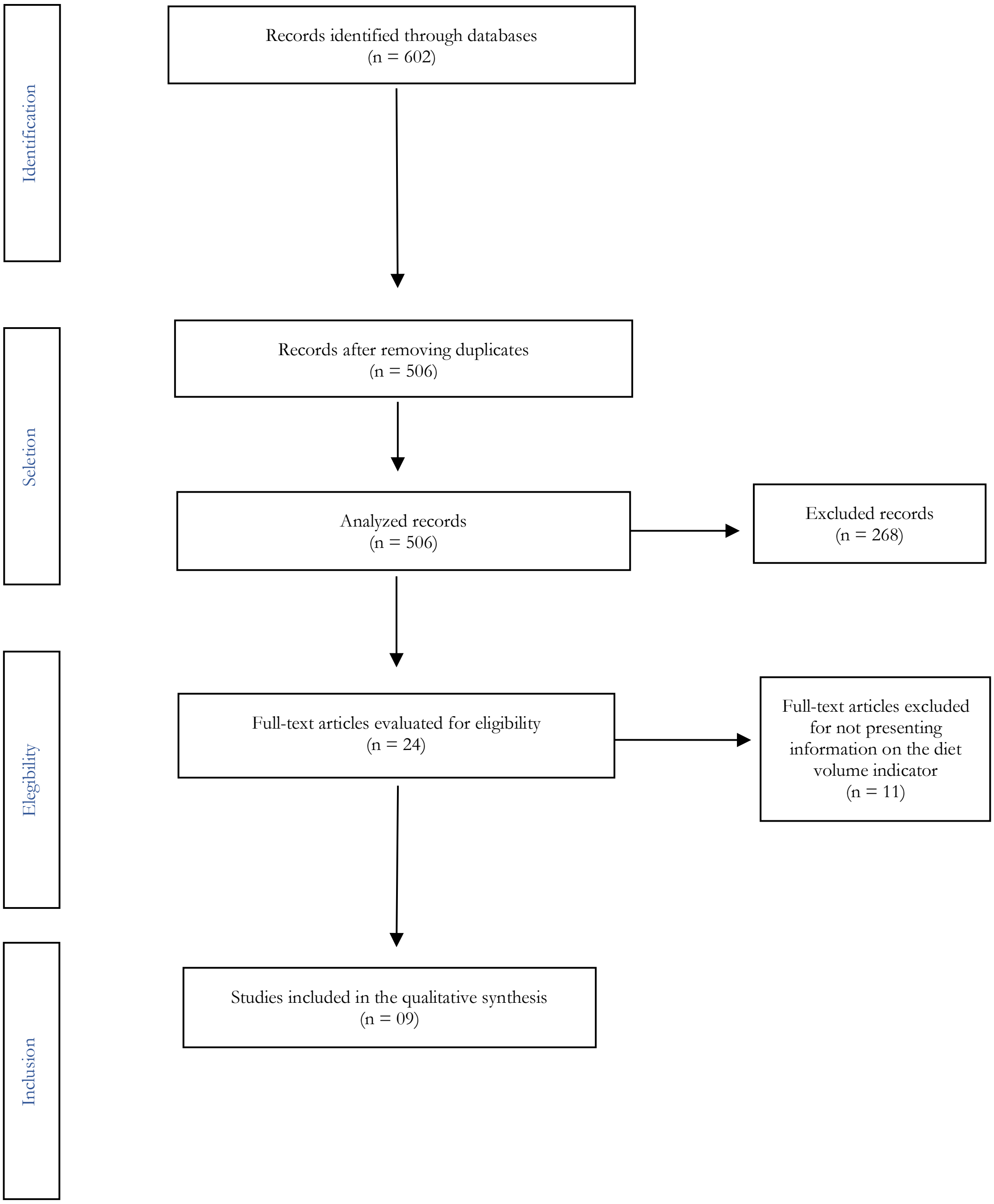

Figure 1 - Flowchart of the of studies selected in the review. Uruguaiana, RS, Brazil, 2022.
From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097
For more information, visit www.prisma-statement.org .

Of the nine studies selected, researchers identified that the years of publication with the highest records were 2017 (n=4) and 2020 (n=2). The authors' profile was mainly nutritionists and/or nutrition academics (n=7; 53.8%), nurses and/or nursing academics (n=4; 30.8%), and physicians (n=2; 15.4%). Most of the studies were prospective (n=6; 66.7%) and retrospective (n=3; 33.3%), descriptive (n=4; 44.4%), and/or observational (n=5;

55.6%), with evidence level N6 (n=8; 89%). The study participants totaled 1,371 patients, 438 of whom were cancer patients, since most of the studies included patients with other clinical conditions in their sample, as shown in Chart 2.

Chart 2 - Characterization of the studies selected for the review. Uruguaiana, RS, Brazil, 2022.

Title/Year/ country of origin of the study	**Profile of the authors**	**Objective**	**Design/level of evidence**	**Sample**
Caloric and Protein Infusion versus Dietary Prescription in Enteral Nutritional Therapy for Cancer Patients/ 2021/ Brazil (21)	Nutritionists and nutrition academics	To compare caloric and protein infusion with dietary prescription in oncological patients under ENT	Retrospective analytical observational N6	120 records of cancer patients
High Frequency of Non-Compliance with Quality Indicators of Enteral and Parenteral nutrition Therapy in Hospitalized Patients/ 2020 / Brazil (22)	Nutritionists	To evaluate the frequency of adequacy of the IQNT in clinical and surgical patients during NE or NP	Prospective descriptive N6	727 patient records 7 cancer patients
Are quality indicators of enteral nutritional therapy useful tools for monitoring patients with advanced cancer in palliative care? cancer patients in palliative care?/ 2020 / Brazil (23)	Nutritionists	Apply the quality indicators of ENT in patients with advanced cancer in palliative care	Prospective descriptive observational quantitative N6	51 cancer patients
Accidental enteral feeding tube dislodgement with the use of a dedicated feeding tube attachment device versus adhesive tape as the securing method: a randomized clinical trial/2019 / Brazil (24)	Teaching nurses and doctors	To evaluate the impact of the use of the feeding tube affixation device (FTAD) compared to the traditional method of fixation with adhesive tape on the occurrence of accidental displacement of the enteral feeding tube	Prospective randomized, single-center, non-blinded clinical trial N3	104 patients 29 cancer patients
Prescribed enteral diet versus infused diet/2017 / Brazil (25)	Nutritionists	Evaluate the prescribed volume of enteral diet versus the infused volume, identifying the causes of interruption of the diet and expenses generated by these interruptions	Retrospective observational N6	27 patient records 1 cancer patient
Quality control of enteral nutrition therapy in cancer patients at nutritional risk/ 2017 / Brazil (26)	Nutritionists and doctors	To analyze the adequacy and quality of ENT used in patients diagnosed with cancer and undergoing treatment in specialized public hospitals applying IQNT	Prospective observational descriptive N6	211 records of cancer patients
Cause of interruption of enteral nutrition in intensive care units/ 2017 / Brazil (27)	Nutritionists and nurses	To identify the causes of interruption of the administration of EN in patients admitted to ICUs of University hospital	Prospective, observational quantitative N6	53 patient records 6 cancer records
Monitoring of Enteral Nutritional Therapy in Intensive Care Unit: Calorie-protein adequacy and survival/ 2017 / Brazil (28)	Nutritionists	To assess the nutritional status in patients admitted to the ICU to monitor the ENT to identify the causes of interruption of the enteral diet	Prospective observational N6	32 patients 1 cancer patient
Adverse events related to use of Enteral Nutritional Therapy/ 2014 / Brazil (29)	Academic nursing, teaching nurse	To verify the occurrence of adverse events related to the use of EN in patients of a public hospital	Retrospective longitudinal exploratory descriptive N6	46 records 12 cancer records

ENT: Enteral Nutritional Therapy; NE: Enteral Nutrition; PN: Parenteral Nutrition; ICU: Intensive Care Unit; IQNT: Quality Indicator in Nutritional Therapy.
Source: own elaboration.

When summarizing the studies that did or did not reach the goal of IQNT "NT prescribed *versus* infused volume," researchers identified that most studies (n=6; 67%) did not reach their goal. Among the reasons for not meeting the goal, gastrointestinal, mechanical, and respiratory complications are described using NT, as shown in Chart 3.

Chart 3 - Characterization of the IQNT "frequency of days of adequate administration of the prescribed *versus* infused volume in patients on nutritional therapy," according to the goal (ILSI, 2018). Uruguaiana, RS, Brazil, 2022.

	Study	**Type of cancer**	**Hospital unit**	**Structure for ENT**	**Characteristics of ENT**	**ENT application time**	**Target of the indicator applied by the institution**	**Indicator results**	**Reasons for the interruption of ENT***
Reached the target of the indicator	(23)	Head and neck, GIT, Breast, Lung	Palliative care unit	It has a MNTT	Transpyloric probe	488 days	≥ 80%	Adequacy of prescribed and infused volume: 92.6%	Gastrointestinal complications, Mechanics, Respiratory, Other**
	(27)	Not described	General and Cardiological ICU	It has a MNTT	Transpyloric probe	16.6 ± 12.2 days	≥ 70%	Adequacy of prescribed and infused volume: 82.7%	Complications gastrointestinal Mechanics, Metabolic, Other**
	(28)	Not described	Adult ICU	It has a MNTT	Transpyloric and nasogastric tube	Average 20.5 days	≥ 70%	Adequacy of prescribed and infused volume: 72.6%	Complications gastrointestinal, Mechanics, Other**
Did not reach the target of the indicator	(21)	Head and neck, Gastrointestinal tract, Gynecological and breast, Male reproductive system	Adult ICU	Does not have a MNTT	Transpyloric probe	4 days	≥ 80%	Average (difference in volumes) Day 1: -477.0 Day 2: -298.0 Day 3: -261.4 (peak) Day 4: -445.9 Adequacy of prescribed and infused volume: 62.5%	Gastrointestinal complications, Mechanics
	(24)	Not described	Clinical Ward	Does not have a MNTT	Transpyloric probe	16 days	≥ 70%	Adequacy of prescribed and infused volume: 58.5%	Complications mechanics
	(25)	Laryngeal cancer	Adult ICU	Does not have a MNTT	Industrialized diet by infusion pump	5 days	≥ 70%	Day 1: 741.5 - 498.6; Day 2: 741.5 - 587.3; Day 3: 923.1 - 472.5; Day 4: 846.2 - 401.2; Day 5: 769.2 - 351.5. Average prescribed volume: 804.3/462.2	Gastrointestinal complications, Mechanics

	(26)	Head and neck, Gastrointestinal, Thoracic, Gynecological, Urological, Lymphoma / leukemia / myeloma	Clinical Ward (Treatment for complications of cancer and / or chemotherapy and radiotherapy)	It has a MNTT	Transpyloric probe Closed system diet, by infusion pump	9.7 ± 7 days	≥ 80%	Adequacy of prescribed and infused volume: 74.3%	Gastrointestinal complications
	(29)	Not described	Adult ICU and medical clinic	It has a MNTT	Naso/orogastric tube Infusion pump diet	3-30 days	≥ 70%	Average difference of the received diet volume (estimated - received): 176.4 ml	Gastrointestinal complications, Mechanics
	(22)	Not described	Clinical and surgical ward	It has a MNTT	Transpyloric probe	7.41 ± 14.22 days	≥ 90%	Adequacy of prescribed and infused volume: 66.7%	Gastrointestinal complications, Mechanics

ENT: Enteral Nutritional Therapy; EN: Enteral Nutrition; ICU: Intensive Care Unit; MNTT: Multidisciplinary Nutritional Therapy Team.
*Reasons for the interruption of the EN described in the studies were classified as: (a) gastrointestinal complications: vomiting, abdominal distension, diarrhea, reflux, emesis, gastric residue fasting for tests or procedures, bulky bleeding, melena, gastrointestinal intolerance; (b) mechanical complications: tube obstruction, inadvertent exit of the tube, extravasation of the diet, delayed delivery of the NE, extubation, procedures/examinations/surgeries and errors in the administration of the diet; (c) respiratory complications: bronchoaspiration; (d) metabolic disorders: hemodynamic instability.
** Others: patient refusal, clinical worsening, lack of net protocol, end-of-life care, and death.

Discussion

Following the purpose of this review, the IQNT "NT prescribed *versus* infused volume" in oncology has been little investigated in the literature, and hospitalized adult cancer patients have clinical difficulties in achieving their goal. For nursing, summarizing the information of the investigated IQNT becomes essential in the sense of strategically directing care to the need for the nutrition of the oncological patient to optimize treatment and ensure better quality of life.[30]

The review identified that the authors' profile was composed mostly of nutritionists,[21-23,25-28] although nursing is responsible for monitoring the indicator under analysis.[13] In Brazil, specific legislation[31] standardizes the performance of the nursing team in the oro/nasogastric and transpyloric probing and highlights the crucial role of the nurse in the process of installing the device, choosing the route of administration together with the doctor, in addition to registration, patient evaluation and monitoring of complications. However, when it comes to the EN area, there is a growing line of research conducted by nurses aimed at care in relation to assertive probe positioning techniques,[32] safe administration of EN,[33] monitoring of complications,[34] and nursing protocols for ENT.[35]

The scientific literature already describes that hospitalized cancer patients have some degree of malnutrition,[5,36] and ENT is one of the principal therapeutic resources for their treatment and prognosis.[37,38] In addition, cancer is one of the main underlying diseases of hospitalized adult patients in Brazil.[39]

In analytical *corpus* in which the IQNT goal was not met[21-26,29] the most prevalent cancers were head and neck[21,26], gastrointestinal tract[21,26], gynecological[21,26] and urological.[21,29] In those who have reached the goal[23,27,28] the most identified cancers were head and neck[23] gastrointestinal tract[23,27], breast[23,28] and lung.[23,24] These findings corroborate with other Brazilian studies[40,41] which also identified the prevalence of these cancers in hospitalized patients. This situation reflects the statistics and estimates of the oncological scenario in Brazil, which identifies breast and gastrointestinal cancers as the most prevalent in the Brazilian population.[42]

The analysis also identified that most of the studies failed to achieve the goal of the investigated IQNT.[21-26,29] This reality allows us to reflect that, could it be the specific characteristics of the tumor and the treatment, as well as the nutritional repercussions triggered in cancer patients[37,38] that could condition the prognosis of the treatment and its repercussions? This review found that the nutritional supply for the cancer patient hospitalized by enteral route has not guaranteed the adequate/total infusion of the prescribed volume of EN, and therefore, this route is not the most appropriate for these patients, and the parenteral route may be more effective, given the clinical weakness of the cancer patient throughout his treatment. Therefore, it is essential that nursing, together with MNTTs, be able to recognize such specificities, and direct a singular care plan to provide adequate nutritional support.[43] This result is relevant in the context of nursing practices since, when assisting cancer patients within their basic human needs, food should be prioritized to contribute to treatment.[38,44]

The IQNT "NT prescribed *versus* infused volume" reflects the evolution and quality of nutritional care, and for the oncological patient to be able to receive the prescribed volume of EN, several factors are fundamental, such as the suitable dietary prescription, the appropriate route of administration of EN, the quality of the EN device, the monitoring and control of complications.[13]. Given this, research[32,33,35] reveals the engagement and protagonism of Nursing in EN area, with promising results regarding good practices in the administration of EN (GPAEN). [45] In a study developed in Israel,[46] nurses conducted a protocol to address and correct the deficiencies of EN in an ICU, and the feeding of the patient was started significantly earlier ($p = 0.007$) in the intervention group (52.3 hours; SD, 42.6) than in the control group (70.3 hours; SD, 65.2). The use of the protocol resulted in a significant increase in nutritional intake in 90% in the intervention group.

Studies that did not reach the IQNT goal[21-26,29] identified that the investigated hospital units were clinical and/or surgical,[22,24,26] adult/general ICU,[21,25,29] and medical clinic, [29] and only three of these institutions[22,26,29] owned MNTT. Hospitals that reached the indicator's goal were general/adult ICU,[27,28] Cardiologic ICU,[27] and palliative care unit.[23]. In these scenarios, the oncological patient is already in a state of metabolic stress that triggers numerous nourishing supplements *deficits*, which result in increased nutritional needs.[1,2] Thus, the research analyzed that, even in closed/controlled hospital units, such as the ICU, and the fact that the hospital institution has MNTTs, the effectiveness of ENT for adult cancer patients is not guaranteed, which minimally generates a movement to (re)think nursing practices in ENT in these care units. Therefore, especially in specific populations, the goal of the IQNT "NT prescribed *versus* infused volume" can be presented above what the cancer patient can receive, and the patient's clinical conditions should be evaluated for the measurement of the indicator goal.

Regarding the length of application of the EN and the IQNT, the research found that in studies that did not reach the goal, oncological patients used the EN, on average, for more than five days,[22,24,26,29] corroborating with a study [47] in an oncology hospital, which identified that none of the patients (n=96) managed to reach the prescribed volume of EN, on seven days of exclusive EN. Indicator goals for these studies alternate between ≥ 70%,[24-26] ≥80%,[21,26] and ≥ 90%,[22] indicating that sometimes Brazilian institutions follow the ILSI Brazil guidelines,[13] sometimes they stipulate their own targets according to the characteristics of the hospital unit. For institutions that adopt different goals (higher) than recommended in the guideline,[13] planned care structure, good health practices, and implementation of protocols are necessary.[13] Thus, one of the fundamental elements for good results is to have MNTTs, which perform the appropriate nutritional assessment[36], choosing the adequate device,[48] the early onset of EN,[39] monitoring for complications of EN,[34] the application of IQNT,[49] and continuing education actions.[35,43,50]

Among those studies that were able to achieve the goal, the length of application of EN in cancer patients was greater than five days,[23,27,28] evidencing the existence of a proportional relationship between time and the ability to achieve the adequacy of the prescribed volume.[47] This situation can be explained because, in the first days of hospitalization, cancer patients tend to present an unstable clinical picture, greater exposure to health procedures and interventions, and a care plan still in definition and adaptation.[48] Therefore, establishing the number of days for EN requires more time for its administration. The goals adopted by these institutions ranged from ≥70%[27,28] and ≥ 80%,[26] following the guidelines of ILSI-Brazil and its reformulations.[13]

The clinical repercussion in cancer patients who receive a lower volume of EN is raised in different studies, [3-6] which demonstrate that not reaching the goal of EN is correlated with worse clinical outcomes, such as infection [4] issues and complications[3,5,6] during hospital stay. In this sense, there must be a reflection to try to minimize the discrepancy between nutritional planning and the effectiveness of this plan. For nursing, it is necessary to ensure that the prescribed volume is adequately infused, and, for this, it is required to train the nursing team regarding the skills and competencies that subsidize qualified care with EN and patient safety.[51]

One of the reasons why the prescribed volume of EN is not entirely infused in the adult oncological patient is associated with gastrointestinal, metabolic, mechanical, and respiratory character complications. Both in the studies that reached and in those that did not reach the goal of the indicator, the reasons for the major complications of EN were gastrointestinal.[21-23,25-29] Therefore, the analysis observed that the main element that makes the cancer patient unable to reach the prescribed volume of ENT is linked to its clinical fragility that triggers gastrointestinal complications, directly affecting the volume that the patient should receive. That is, the clinical difficulties of the cancer patient directly affect the volume of infused EN, and not only the IQNT processes themselves.

For more than a decade, nurses have been conducting research on different patient profiles[39-40,50-51] to monitor complications on the use of EN. In a prospective cohort,[52] 157 ICU patients were followed daily during the first ten days of hospitalization and, among those who received and did not receive EN, complications such as diarrhea and the need for gastric decompression were more frequent in the EN group (39.7 % *vs.* 11.7 %, $p < 0.001$ and 34 % *vs.* 13.3%, $p = 0.004$, respectively). Therefore, it is necessary to constantly reevaluate EN care practices, from the evaluation of diet formulation, the characteristics of EN administration, the correct positioning of the tube, and the continuous infusion mode.[53]

Among the limitations of the present review are the search only in the Portuguese language performed in Google Scholar and the eligibility criteria of complete original studies available online may have limited the number of studies reviewed and/or included.

Conclusion

This study allowed us to analyze the evidence of the IQNT “NT prescribed *versus* infused volume” in the hospitalized adult cancer patient, revealing that in most studies, the indicator’s goal was not reached, and that the patient has clinical difficulties in achieving it. The quality of nutritional care to this population stratum permeates the articulation between nursing care and the analyzed indicator.

In short, the results of this review point to the aspects of the IQNT “NT prescribed *versus* infused volume” in hospitalized adult cancer patients that weaken their adequacy, and reflections on nursing care that can be performed in the hospital setting, to improve GPAEN, assisting nurses in the development of skills necessary for clinical decision-making. In addition, the evidence raised in this study about the interface of nursing practices with the investigated IQNT can contribute to the planning of individual nutritional support throughout the disease, promoting the importance of Nursing in the various aspects of care for oncological patients using ENTs. New research must be developed to evaluate, through the IQNT “NT prescribed *versus* infused volume,” what institutional difficulties contribute so that the oncological patient does not receive the adequate volume of EN.

In addition, the IQNT “NT prescribed *versus* infused volume” has been presented in the literature with different results (sometimes percent, sometimes average), which makes it difficult to compare them. Another question refers to the studies that included in their sample patients with other clinical conditions, not exclusively oncological, in which, at times, it was not possible to fragment/select the values of the indicator by disease, which may have indicated a more significant negative impact on the results of the IQNT investigated.

Authors’ contributions

L. S. E - Conception and design of the study; data collection; data analysis and interpretation; statistical analysis; drafting the manuscript; critical review of the manuscript.
B. S. S - Conception and design of the study; drafting the manuscript; critical review of the manuscript.
M. C. S. A - Critical review of the manuscript.
J. B - Critical review of the manuscript.
B. S - Conception and design of the study; data collection; data analysis and interpretation; statistical analysis; obtaining funding; rafting the manuscript; critical review of the manuscript.

Conflicts of interest

No conflict of interest has been declared by the authors.

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The role of grandparents in the transition to parenting: a scoping review

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Abstract

Introduction
The transition to parenthood involves a set of intra and interpersonal changes, which affect not only the woman and her partner, but also the entire family system. Grandparents are highlighted as prominent figures in the contemporary family, constituting the main source of support for the family in this process. Therefore, it is extremely important to understand how grandparents can influence or not the transition to positive parenting, acting as facilitating agents or as hinderances in this process.

Objective
To map the available scientific evidence regarding the role of grandparents in the transition to parenthood of their children, encompassing the period of pregnancy, childbirth and the postpartum period up to 3 years.

Methods
This scoping review was developed according to the methodology of the Joanna Briggs Institute (JBI), 2020, with research carried out in April and May 2022 and updated in July 2023. Qualitative, quantitative or mixed studies were included, as well as review articles, published in English and produced between 2015 and 2023.

This scoping review includes articles that address the role of grandparents in the context of the transition to parenting of their children, including the time of pregnancy, childbirth and the postpartum period up to 3 years.

Results
11 articles that met the inclusion criteria were included. Four categories emerged: grandparents as a source of support; grandparents and their influence on family nutrition and exclusive breastfeeding; the ambivalence of feelings and the role of health professionals.

Conclusion
Grandparents can stand out as prominent elements of the family during the transition to parenting of their children, developing instrumental, emotional, informational and financial support roles; may influence exclusive breastfeeding and family nutrition. When concepts and beliefs about fundamental aspects relating to children differ, ambivalent feelings can arise and that lead to intergenerational conflicts. There is a gap in health care regarding the inclusion of meaningful people in the care of the couple and the child, in this case the grandparents.

Keywords
Grandparents; Role; Parenthood Transition; Pregnancy; Childbirth; Post-Partum

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Introduction

Parenting can be understood as one of the most demanding and challenging aspects of a person's life. Becoming a mother and father is an important milestone and can simultaneously be a period of great joy, but also a stressful life event.[1] Thus, parenting can be understood as a set of emotional bonds, knowledge, attitudes, and behaviors of mothers and fathers, which is influenced by several factors, such as previous experiences (from their own childhood), personal and sociocultural circumstances, expectations and beliefs.[2] It is also influenced by the sense of personal competence, marital relationship or the relationship established with the other parent, the support network (namely the family), available social services, as well as other situations of inequality or vulnerability.[2] The concept of parenting therefore refers to the set of activities and attitudes and the way of interacting in relationships with children.[3]

According to Meleis[4], the transition to parenthood is a multidimensional concept that presupposes changes in roles, definitions and redefinitions of the self and the very transition, which is considered a passage or movement from one state, condition or place to another.

The transition to parenthood is a complex process of various physiological, psycho-emotional, social, and cultural changes and adjustments. It is a demanding process, characterized by constant learning, skill and relationship development, and deep identity reconstruction.[5] Parental experience depends on parenting strategies and responses, and these include cognitive components of learning and decision-making, relational components such as family support, and operational components such as task sharing, routine reorganization, and role reconciliation.[5] Having support, whether emotional or physical, can be seen as a crucial aid in this process, decreasing the perception of stressful events, and helping parents cope with them more effectively.[6] Thus, the nature of the transition to parenthood affects not only the woman, but her partner, and the entire family system, and in turn involves a set of intra- and interpersonal changes.

Dessen[7] highlights grandparents as prominent figures in the contemporary family, constituting the main source of support and support for the family in this process, promoting emotional, material and financial support.

Parents will be faced with a set of new and unexpected situations for which experience, or lack thereof, does not yet provide effective or convincing answers. At this point, the support provided by grandparents, whether instrumental or emotional, if provided properly, becomes a protective factor in the adaptation of parents to the new task that is required.[8]

To understand these transitions, it is essential to know the structure and functions of the family support network, since they vary according to the socio-cultural context, time and stage of life of the individual and the family as a group.[9]

It is therefore extremely important to understand how grandparents can influence or not the transition to parenthood, acting as facilitators or barriers in this process.

Finally, and after consulting the JBI database, it was confirmed that there is no scoping review on this topic, which further accentuates its relevance. With that in mind, the objective of this scoping review is to map the available scientific evidence on the role of grandparents in the transition to parenthood of their children, encompassing the period of pregnancy, childbirth and the postpartum period up to 3 years.

The research question of this scoping review is: what is the role of grandparents in the transition to parenthood of their children?

Methods

In order to guide this scoping review, a protocol was developed, published on the Open Science Framework (OSF) platform, with the identification DOI 10.17605/OSF.IO/KJC2Y.

Inclusion Criteria

Population Type: This scoping review will include articles addressing grandparents who have experienced the transition to parenthood of their children and other community members who have witnessed the experience of grandparents transitioning to parenthood of their children.

Concept: This scoping review will include articles that address the role of grandparents who have experienced the transition to parenthood of their children.

Background: This scoping review will include articles that address the role of grandparents in the context of the transition to child parenting, including the timing of pregnancy, childbirth, and the postpartum period. The postpartum period was considered up to 3 years after delivery, since it is intended to cover the physical, emotional, psychological, social and cultural developments and adjustments that this transition comprises. This longer period thus highlights the importance of considering the transition to parenthood as a continuous, complex and demanding process, promoting a more comprehensive and holistic approach.

Types **of information sources**: This scoping review will consider all studies of a qualitative, quantitative or mixed nature, as well as review articles, published in Portuguese, English or Spanish, that meet the inclusion criteria described. Regarding the temporal issue, it is decided to define as inclusion criteria the studies published in the last 8 years (2015 to 2023), with the purpose of gathering the latest scientific evidence.

Research Strategy

The research strategy of this scoping review aims to identify articles published in Portuguese, English or Spanish in the last eight years that portray the role of grandparents in the transition to parenthood of their children.

According to the strategy defined by JBI[10], this was planned in three distinct stages.

As a first step, a search was carried out limited to the CINAHL, MEDLINE databases, through the EBSCOhost platform, and the Scopus database, to identify articles on the subject. To this end, the keywords extracted from the natural terms of the research question were used. Then, an analysis of the words used in the titles and abstracts and the identification of the indexed terms corresponding to each database was carried out.

In this sense, a table was prepared referring to the keywords, natural terms and respective indexed terms (table 1), in order to organize the first stage.

Table 1 – Systematization of the inclusion criteria, natural terms and respective terms indexed in the CINAHL, MEDLINE and Scopus databases

Keywords	Natural terms	CINAHL indexed terms	MEDLINE Indexed terms	Scopus terms
Grandparents	Grandparents	Grandparents	Grandparents	Grandparents
Role	Role	Role	Role	Role
Transition to parenthood	Parenthood transition	--	--	Parenthood transition
	Parenting transition		--	Parenting transition
	Childbirth	--		Childbirth
	Pregnancy			Pregnancy
	Post-partum	Childbirth	Parturition	Post-partum
		Pregnancy	Pregnancy	
		Postnatal period	--	

In a second stage, a search was performed using all the natural and indexed terms identified in table 1, in the databases separately.

In the CINAHL database, a search of the natural terms as well as the respective indexed terms was done, later crossing with the Boolean operator OR. After aggregation between the natural terms and the respective indexed terms, a new search was carried out associating the results obtained previously, with the Boolean operator AND. This process is depicted in Appendix I and with the search expression:

((grandparents OR (MM "Grandparents") OR "grandparents")) **AND** ((role OR (MM "role+) OR "role")) **AND** ((parenthood transition OR parenting transition OR "transition to parenthood" OR "parenting transition") OR (childbirth OR (MM "childbirth+") OR "childbirth") OR (pregnancy OR (MM "Pregnancy+") OR "pregnancy") OR (postpartum OR (MM "Postnatal Period+") OR "postpartum")).

The same steps were followed in the MEDLINE database, with the respective terms identified in Table 1. This process is presented in Appendix II.

Regarding the Scopus database, only the natural terms were searched, since this database does not present indexed terms, crossing the terms *childbirth, pregnancy and post-partum,* with the Boolean operator OR, as well as with the terms *parenthood transition* and *parenting transition* and the remaining terms with the Boolean operator AND. This process is depicted in Appendix III.

Finally, in the third stage of the research strategy, an analysis of the bibliographic references of the selected articles was carried out, looking for more evidence, especially primary evidence.

This survey was conducted between April and May 2022 and updated in July 2023, extending its time limit to 2023.

Study Selection

The articles found were analyzed by two independent reviewers, taking into account the relevance of the title and the abstract. Duplicates and those that did not meet the previously defined inclusion criteria were removed.

Subsequently, the selected articles were fully analyzed through full-text reading, meeting all the inclusion criteria, and none were excluded. This step was also carried out by two independent reviewers, and the disagreements between them were resolved through discussion.

An article was integrated by analyzing the bibliographic references of the previously selected articles.

Data extraction

A data extraction tool was built by an independent reviewer as per JBI[10] indications. This tool was tested in order to ensure its clarity and accuracy of the extracted data. The data of the selected articles were extracted using this tool.

Thus, the extracted data detail with clarity and specificity, aspects about the phenomenon of interest, population, objectives, study method and significant results for the research question.

Data presentation

The data extracted from the selected articles are presented in narrative form, as well as in a table (Appendix IV), which organizes the studies according to the title, authors, year of publication, country of origin, language, type of study, objectives, sample and results relevant to the research question. The discussion of results is elaborated in narrative form.

Results

Search Results

The search in the three databases identified 63 articles. After the duplicates were removed, 57 articles remained for analysis of titles and abstracts according to the defined inclusion criteria. At this stage, 47 articles were excluded because they did not meet one or more inclusion criteria, leaving 10 articles for full-text analysis. All 10 articles were analyzed and none were excluded. The bibliographic references of the 10 selected articles were also consulted and another full-text article was integrated, in a total of 11 articles included in this scoping review. This process is schematized in the *Prisma* diagram to which figure 1 refers.

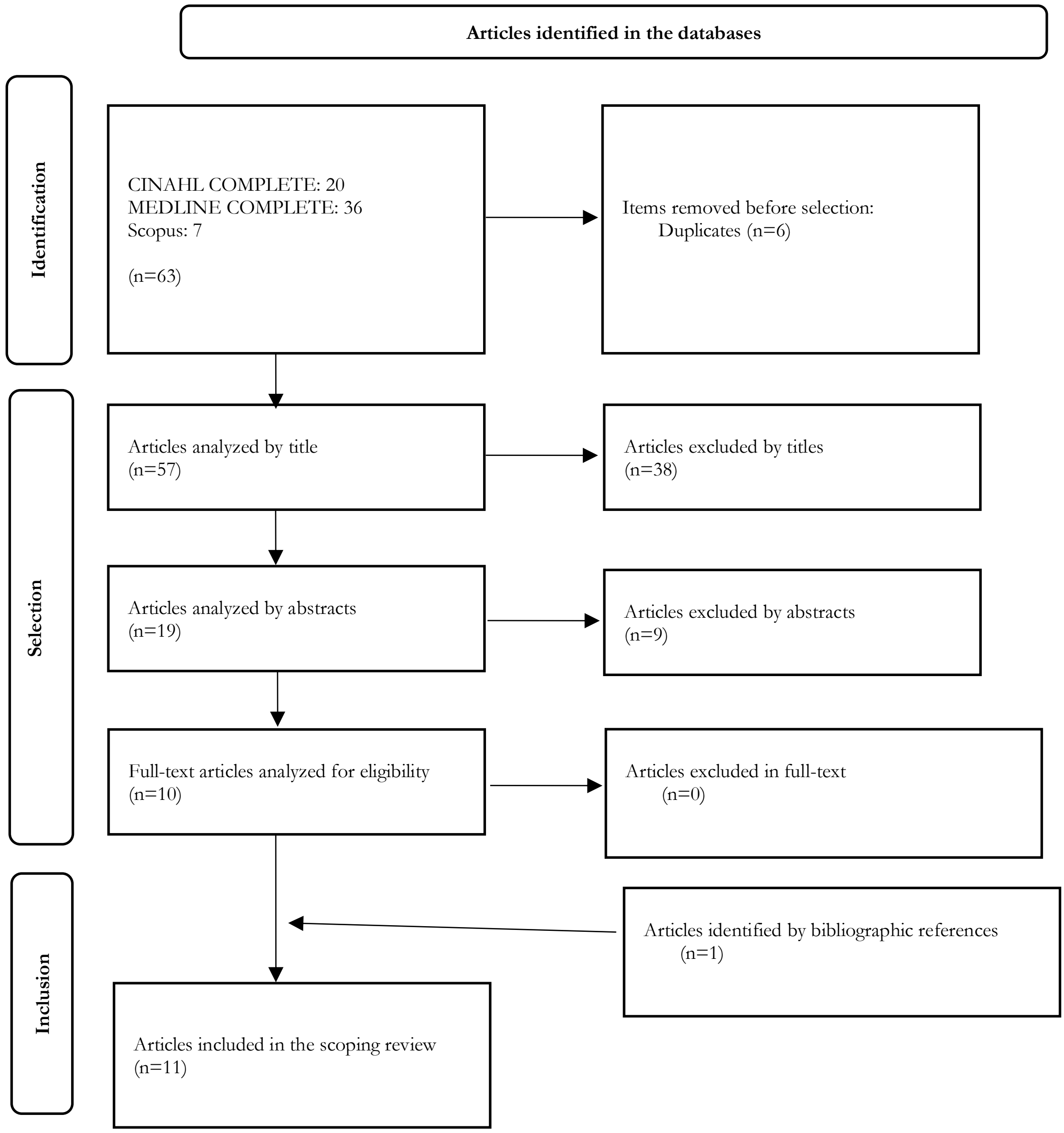

Figure 1- PRISMA diagram: research results and selection of studies to be included in the scoping *review. Adapted* JBI.[10]

Characteristics of sources of evidence

The articles selected in this scoping review were published between 2015 and 2023, and 72% (n=8) were published in the last six years. They are all articles published in international journals, such as the Journal of Family Issues (n=1), Nursing Inquiry (n=1), Global Public Health (n=1), Maternal & Child Nutrition (n=1), International Journal of Childbirth Education (n=1), Midwifery (n=2), Breastfeeding Review (n=1), BMC Pregnancy and

Childbirth (n=1), Human Nature (n=2). All articles are written in English. Two articles are from China, another two from the United States of America (USA), followed by Austria, Ghana, Colombia, New Zealand, Australia, France and Namibia, with one article each. Four literature reviews and seven primary studies with a qualitative or mixed approach were then included.

The population of articles is diverse, including couples who have been parents, grandparents, health professionals, as well as community leaders.

Seven studies used in-depth semi-structured interviews as a methodology and most studies aim to evaluate and explore the experiences of parents and grandparents in the transition to parenthood.

Review Results

In order to organize the results that emerged from the research, we grouped them into four categories: grandparents as a source of support; grandparents and the influence on family nutrition and exclusive breastfeeding; the ambivalence of feelings; and the role of health professionals.

Grandparents as a source of support

Many grandparents play a vital role in the lives of pregnant women or women/mothers and their grandchildren and represent a source of support, whether instrumental, emotional, informative or financial.[6.11,12] Geographical distance, culture, maternal and paternal relationship with parents and in-laws, as well as the age of grandparents can change the role that grandparents play and subsequently change the influence they have on the parenting of children. The interconnected nature of the different generations can affect parenting styles, baby safety, as well as parenting role performance.[6]

Grandmothers were identified as the main support of pregnant women, providing them with information, guidance and emotional support.[11,12] Grandmothers are the ones who have the role of preserving cultural traditions related to this period, they are repositories of knowledge about local medicine and decision-makers in health-seeking behaviors, that is, they decide where childbirth takes place and the need to resort to health services.[11] In a study conducted in an African country, Namibia,[13] three domains were identified in which grandmothers contribute, namely: a) learning to be mothers, through representations of care and examples, as well as information; b) support in breastfeeding; and c) health and well-being in the postnatal period. It is concluded that the informational, emotional and instrumental support provided to mothers and their newborns during the perinatal period can help establish the mother-child bond, promote maternal energy balance and improve the nutritional outcomes of babies.

The instrumental and emotional support provided by grandparents, although dependent on the type of relationship between parents and children, when not intrusive, is a protective factor for the development of maternal mental health problems in the first postpartum year.[14] Beneficial effects for the child are also reported, as mothers without mental health problems are more emotionally available and actively respond to the child's needs.

Another article[15] also mentions that the role of grandparents is as a support network, taking care of both mother and baby, preparing meals, and doing other household chores. The role of grandparents also involves the intergenerational transmission of roles, in which mothers learn either by observation, advice or imitation of care.

Grandparents and the influence on family nutrition and exclusive breastfeeding

The culture of breastfeeding in a family plays a significant role in supporting new mothers to breastfeed exclusively and the practice of exclusive breastfeeding for six months is not limited to the intentions or actions of the mother-child dyad; it is a relational behavior influenced not only by family networks around the mother, but also by cultural, historical and social contexts.[16]

Grandmothers have the ability to influence exclusive breastfeeding. A grandmother's positive opinion about breastfeeding has the potential to influence a mother up to 12% to initiate breastfeeding.[17,18] On the other hand, it can also have a negative influence, having the ability to decrease the likelihood of breastfeeding up to 70%.[17] Wagner et al,[18] suggest that mothers who were breastfed as infants were more likely to initiate and continue breastfeeding than non-breastfed mothers. The mother's mother and the mother's previous breastfeeding experience have a strong influence on breastfeeding practices. [18]

Concha and Jovchelocitch,[19] suggest that grandmothers play a central role in the nutrition of many families during the prepartum, postpartum, breastfeeding or complementary feeding periods, namely in the preparation of meals.

The ambivalence of feelings

Ambivalent feelings arise when the involvement of grandparents in one or more domains, whether affective, cognitive or behavioral, does not correspond to the wishes and expectations of parents.[12] This ambivalence also exists when there are divergent views of parents and grandparents in relation to concepts and convictions about pregnancy, education, childcare, nutrition, or other fundamental aspects in raising children. In the same study, these ambivalent feelings also occurred when grandparents questioned the roles and attitudes of parents and there were critical judgments of grandparents about their parenting abilities. Another aspect related to ambivalent feelings in the involvement of grandparents is at the behavioral level, when the grandparents do not respect the limits imposed by the parents and, at the affective level, when it involves disappointment with emotional aspects of the relationships, namely feelings of competition between parents and grandparents.[12]

A study conducted in China[21] identifies that grandparents are expected to support parents during the transition to parenthood, even without parents asking for it. The study mentions that, regarding postpartum and newborn care, parents identify a significant gap between their beliefs and those of their grandparents, noting that the approaches of the older generation are outdated and unscientific. On the other hand, the older generation believes they have the experience of having children and the wisdom already passed on for years. This discord creates family strife. The study also identifies that parents appreciate the support received by grandparents, for allowing time off from the demands of care; however, they criticize them for potentially causing harm to the baby, for their traditional approaches. The same study also argues that clear and direct communication leads to a better family relationship and mutual understanding, rather than criticism. On the other hand, there were conflicts whenever family members expressed ineffective or non-existent communication and insisted on doing it their way, which led to precarious family relationships. If family members did not speak up and hide their conflicts or communicate in a vague way, they were more likely to trigger feelings of anger and silent aggression. Families with well-established boundaries tend to have more harmony in this transition period.[15] Most of the interviewed grandparents recognized their role and boundaries and refrained from expressing their views on parental decisions. In some families there was competition among their members for control and, when this competition was strong, conflicts arose. This study[15] also refers to generational limits, that is, the expectations of perceived limits and rules of interaction of all family members, involving the regulation of the behavior of parents and grandparents. Clear boundaries require grandparents to respect parental authority and avoid offering too much advice regarding their parenting decisions. Unwanted advice from grandparents is the most ineffective form of communication and can be perceived as a critique of parental care, affecting trust in one's own parental skills.[15] Thus, the involvement of grandparents in the parental role can threaten the autonomy of parents and may not be well received by them.

The role of healthcare professionals

Parents and grandparents attribute a relevant role to health professionals as mediators of family conflicts.[21] The former claim that the latter are in a better position to mediate family conflicts related to the clarification of roles, division of tasks, communication and establishment of limits in the puerperium and in the care of the newborn. The need for knowledge and development of parental skills, the need for information and education in the postpartum period and psychological support for mothers are also identified.[21]

There is a potential gap between health education campaigns that target mothers as autonomous decision-makers and the reality of a more collectivist community structure in which mothers rarely make these decisions without the support of other community members. Burgess[6] argues that it is important for health professionals preparing for childbirth and promoting adaptation to parenting to recognize the role of grandparents and work to assess their knowledge of current care practices and child safety, including their role in caring for the baby. A thorough evaluation will allow health professionals to provide appropriate educational and support interventions and resources for both parents and grandparents. The birth of a new baby is not only an isolated experience for the future mother, but also a transition for the grandparents.[6] In this sense, the provision of support by health professionals can improve self-efficacy, as well as the growth of grandparents as individuals. As educators, they should be mindful of what this transition can mean and help families embrace the interconnectedness that the birth of this new baby brings to all.[13]

Discussion

In the last eight years, 11 articles were found that identify the various roles of grandparents in the transition to parenthood of their children, thus providing an answer to the research question initially formulated. This scoping review therefore allows us to understand that grandparents can play a vital role in the lives of children and their grandchildren and represent a source of support, whether instrumental, emotional, informative or financial,[6,11,12] by providing information and guidance.[11] This informational, emotional and instrumental support during the perinatal period can help establish the parent-child bond, promote maternal energy balance, improve child's nutritional outcomes[13] and improve maternal mental health.[14]

It is also identified the influence that grandmothers represent in the nutrition of the whole family in the perinatal period, namely in the preparation of meals,[19] as well as their influence on exclusive breastfeeding. We know that breast milk is the best food for the baby until food introduction and that it is exclusively recommended until 6 months of age;[20] however, several factors contribute to influence its practice. Thus, the practice of exclusive breastfeeding during the first 6 months of the baby's life is a relational behavior influenced by the mother's intentions, family networks and cultural, historical and social contexts.[16] There is scientific evidence that corroborates the ability of grandmothers to influence exclusive breastfeeding.[17,18] Although there are differences in the type of breastfeeding outcome and how the influence of grandmothers was measured, the overall effect on breastfeeding was positive when the attitudes or experiences of older female generations in relation to breastfeeding were favorable. A grandmother's positive opinion of breastfeeding had the potential to influence a mother up to 12% to initiate breastfeeding. On the other hand, a negative opinion has the ability to reduce the probability of breastfeeding up to 70%.[17] In this sense, it is pertinent to allow and encourage the presence and participation of grandmothers in the health care provided to pregnant women and parents, if desired, especially in the perinatal period.

The ambivalence of parents' feelings towards their grandparents was another aspect highlighted in this scoping review. If, on the one hand, parents appreciate and recognize the importance of grandparents' support in the transition to parenthood, on the other hand, when there are divergent views regarding concepts and convictions related to children, through questioning parental attitudes and roles and through critical judgment about their abilities, there is an ambivalence of feelings, which can lead to intergenerational conflicts.[12,21] Clear and direct communication leads to a better family relationship and mutual understanding, to the detriment of criticism.[21] On the other hand, the most ineffective form of communication translates into the unwanted advice of grandparents, which can be perceived as a criticism of parental care, affecting confidence in their own parental skills.[15] In this sense, health professionals can assume a role as mediators of conflicts, through the clarification of points of view, based on the latest scientific evidence. According to a qualitative exploratory study,[21] all participants expressed the wish that health professionals could help them, believing that they are in a better position to mediate family conflicts.

Several articles also mention a gap in health care regarding the inclusion of significant people in the care of women, namely grandparents, who represent a crucial source of support in the transition to parenthood.[6,11,21] It is important that health professionals, namely those who prepare for childbirth and who promote adaptation to parenthood, recognize the role of grandparents, making a complete assessment, which will allow them to provide appropriate care for both parents and grandparents, adopting a more inclusive approach.

Conclusion

The various articles analyzed identified many roles that grandparents can have in the transition to parenthood of their children in the most different places in the world, meeting the objective of this scoping review, as well as answering the research question formulated. In addition to identifying the roles of grandparents in the transition to parenthood of their children, we also identified the possible feelings and conflicts that may arise between them and their children in this period, suggesting that it is through clear and assertive communication that they can be resolved. It also identified gaps in relation to health care and the integration of grandparents into it, suggesting that health professionals include grandparents in their approach to care.

As nurses are one of the main providers of health care to women and couples in the transition to parenthood, it is important to incorporate the results of this scoping review, in order to envisage a continuous improvement in the care provided by them, in different contexts. Thus, the nurse should involve significant people in the care process, also integrating them as care clients and establishing partnerships with them.

By understanding the different roles that grandparents can play in the transition to parenthood, we will better understand the importance of integrating them into the health care of women/couples and children in this process. However, this aspect implies an individual and personalized evaluation, as each person is unique. We live in an increasingly multicultural society with specific health care needs. We emphasize as a strong point of this scoping review, the multiculturalism of the various studies included, allowing to broaden the vision of care and alerting to the different perspectives and specificities of each individual as a social, cultural and spiritual being. On the other hand, we emphasize as limitations this same multiculturality of the studies, which does not allow a generalization of the results; as well as most of the selected studies focus only on women/pregnant women and grandmothers in the transition to parenthood. Although a vital role is increasingly being attributed also to male figures in relation to parenting, still today, in many cultures this is experienced especially by the female gender. It is therefore important to consider that sometimes couples may prefer to include fathers, namely mothers, in their health process during the transition to parenthood.

More research on this topic is considered necessary, particularly in Portugal, in order to raise awareness among health professionals, namely nurses, about the importance of family integration in health care. Thus, future primary studies are suggested in order to discover the Portuguese reality of the role of grandparents in contemporary society.

Authors' contributions

IS: Conception and design of the study; Collection of data; Analysis and interpretation of data and Writing of the manuscript.
HB: Data collection; Data analysis and interpretation; Critical revision of the manuscript.

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Effectiveness of therapeutic showering in pain relief during the first stage of labor

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Abstract

Introduction
Pain prevention and effective control is emphasized as a priority for the obstetric unit's humanization. The therapeutic shower it's an easy-to-deploy non-pharmacological alternative whose effectiveness has not been recognized by nurses.

Objective
The aim of this study was to evaluate the effectiveness of therapeutic showering for pain relief during the first stage of labor.

Methods
Quasi-experimental study with the following research question: Is the therapeutic shower effective in relieving pain during the first stage of labor? Convenience sampling (n=81) was used. Data were collected in the two maternity wards. Labor pain was assessed using a Numeric Scale before water application as a comparative standard of pain level before and after warm water application (immediately after, 10 and 20 minutes after). Data analysis was performed using SPSS®, v.27.

Results
Repeated measurement ANOVA showed statistically significant results. Contrast analysis between the first and second measurements revealed significant differences between the mean level of pain immediately and 10 minutes after water application. However, post hoc analysis revealed that after 20 minutes, the differences between the means were not statistically significant.

Conclusion
Therapeutic showering is effective in pain reduction immediately and 10 minutes after application.

Keywords
Hydrotherapy; Labor Pain; Pain Management; Pain Measurement.

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Introduction

Pain can significantly influence the development of labor and interfere with the decisions and satisfaction of women. Anxiety and pain can be associated with longer labor, higher levels of stress hormones, and greater use of pharmacological analgesia.[1-5] As privileged caregivers of parturients, fetuses, and families, obstetric nurses can play an essential role when considering pain as the fifth vital sign and promoting the use of non-pharmacological strategies for its relief.[6]

Providing non-pharmacological alternatives that facilitate women's autonomy and decision-making in pain management during labor can minimize fear and anxiety and facilitate the release of hormones that favor the birthing process.[7] In the first stage of labor, several studies have reported that conventional pharmacological approaches may not be beneficial for the physiological evolution of labor.[8] Obstetric nurses can use their skills and contribute objectively to prevent the unwanted effects of pharmacological strategies, improve physical sensations, and mitigate the psychological and emotional perception of pain in parturients.[9]

Among existing non-pharmacological labor pain relief alternatives, hydrotherapy (defined as the external application of water for therapeutic purposes) has been considered by several national and international institutions as an option that can provide significant pain relief and optimize the positive delivery experience of women, fetuses and families.[6, 9-12]

In Portugal, the Board of the Obstetric and Maternal Health Nursing Specialty College of the Council of Nursing[9] has a project called Maternity with Quality in which, one of the indicators of the relevance of the project and measurement, highlights the importance of promote and apply non-pharmacological pain relief measures in labor and delivery. The project maintains that the use of water during labor for pain relief, in the first and second stages, promotes the well-being of women and contributes to lowering the incidence of episiotomies and cesarean deliveries. Two of the core concepts of maternal health and obstetric nursing care are woman-centered care and the promotion of normal childbirth.[13] In this context, making therapeutic showers available to women and supporting them in decisions regarding labor pain management can contribute to the recognition of the role of women in childbirth and its depathologization.[14]

The Portuguese Council of Nursing[15] states that the therapeutic use of warm showers results in a statistically significant reduction in the use of epidural analgesia during the dilation period and does not present adverse effects with implications for the duration of labor, the rate of surgical births, and neonatal well-being. Providing hydrotherapy in Portuguese hospitals, in this case in the form of showers with warm water, means providing women with an empowering environment and instituting adequate care policies that include non-pharmacological strategies for pain relief in obstetric units. In this context, and taking into account its beneficial effects, it is essential to encourage the use of therapeutic showers, given how easy they are to apply and that they do not require large investments in resources. Despite the contributions mentioned above, in practice, the use of showers is not widespread. Stark and Miller[16] described some of the barriers to this implementation. These authors consider it important to develop research on such barriers, including strategies to overcome them.

Stark[17] tested the effectiveness of therapeutic showering during labor in a study with 32 parturients in active labor, in which water was applied for 30 minutes. The study found that in relation to the control group, there was a statistically significant reduction in pain, and that therapeutic showering was effective in reducing pain, discomfort, anxiety, and tension, while improving relaxation and supporting labor.

Despite this evidence, in Portuguese maternity hospitals, the use of hydrotherapy is far from widespread and often neglected in relation to pharmacological strategies. If on the one hand, material resources (in the case of immersion baths or showering) are essential, on the other hand, producing research and disseminating results about the effectiveness of the strategy can help motivate nurses and develop evidence-based practices.

Stark[18] considered it important to distinguish therapeutic showering from hygienic showering, which usually includes active effort and movement to wash and cleanse. Therapeutic showering is mainly passive, allowing the flow of water to achieve the intended effect. Therapeutic reasons for showering may include heating, cooling, humidifying, relaxing, revitalizing, and massage, as well as pain relief.[19] To obtain the desired benefit of showering, exposure to a warm shower requires more time than what is needed for hygienic showering.

Although there have been some studies that evaluate the effectiveness of hydrotherapy, the available scientific evidence focuses on hydrotherapy performed with immersion baths. In some countries, warm showers during labor are commonly used, but have not been subjected to scientific study and are not discussed.[20] In this context, it is necessary to assess its effectiveness to establish evidence-based practice that promotes a healthier and more rewarding childbirth experience.

The aim of this study was to evaluate the effectiveness of therapeutic showering for pain relief during the first stage of labor in Portuguese hospitals.

Methods

The methodological options chosen based on the nature of the research problem and objectives are foundational to ensuring the reliability and quality of research results. This was a quasi-experimental study which investigated a specific population, in this case, women who reported pain in the first phase of labor, with the following research question: Is the therapeutic shower effective in relieving pain during the first stage of labor?

The evolution of pain levels was evaluated before applying water vs. three times after water application (immediately after, 10 minutes after, and 20 minutes after), in the pelvic area, in the lower back, or in more than one location. Data analysis was performed using the repeated measures ANOVA. The assumptions were analyzed using the Kolmogorov-Smirnov and Mauchly's tests[21] which analyze the normality of distributions and the sphericity of the matrix of variances-covariances, respectively. The variable "pain level" presented normal distribution in the first two assessments after application, immediately after application and 10 minutes after application, with $p>0.05$. The variable "pain level", in the third application did not present normal distribution, homogeneous variances, or zero covariances ($W=0.974$; $X2(2)=1.933$; $p=0.380$), indicating sphericity. Multiple comparisons were made using contrasts with the first measurement (immediately after water application) as a reference and conducting the Fisher's LSD post-hoc test. The data were analyzed using IBM SPSS®, v. 27 (IBM Corp., Armonk, N. Y., USA).

Participants

Sampling was non-random, accidental, casual or convenient[21] and included 81 observations (n=81). Participants included all women in labor who met the inclusion criteria: parturients in the first stage of labor who verbalized pain; were 18 years old or older; had a low-risk pregnancy, were at full term pregnancy, and had a single fetus; and expressed an interest in participating. The study established clinical criteria that guaranteed the safety of the intervention and its evaluation. Ethical and legal requirements for studies with human subjects were followed, and participants signed free and informed consent forms. Women who were submitted to other pharmacological or non-pharmacological pain relief strategies were excluded.

The study was conducted in two Portuguese maternity wards (one in a public hospital and the other in a private hospital) in Lisbon, between June 2018 and December 2021. It is worth emphasizing that the data collection period was extended because of the restrictions imposed by the SARS-CoV-2 pandemic in Portugal.

Risks/Benefits for participants

The intervention (therapeutic showering) did not imply predictable risks for the parturients or fetuses. According to the American College of Nurse-Midwives[22], high-quality research validates the use of hydrotherapy for pain relief during labor, which does not increase risks for healthy women during childbirth or neonates when evidence-based clinical guidelines are followed. Obstetric nurses who were caring for the parturients were responsible for verifying their clinical conditions to ensure their safety. The use of this strategy involved reorganizing spaces and equipment to provide the necessary physical resources for access to and application of therapeutic showers, to preserve the privacy and intimacy of the participants, and to ensure safety during the procedure, especially by preventing sudden changes in water temperature and preventing falls. The benefits for participants in this study were related to pain relief as a result of the proposed intervention.

Data collection instrument

A two-part questionnaire was created for this study. The first part gathered sociodemographic and obstetric information about the participants and included the following items: age, level of education, nationality, obstetric index, location of prenatal care, preparation/negotiation of a birth plan, attendance at childbirth and parenthood preparation course, and whether therapeutic showering was included in this course. The second part included questions about the location of pain (pelvis, lower back or more than one location), duration and location of therapeutic shower application, and assessment of pain level at four times (before the intervention, immediately after, 10 minutes after, and 20 minutes after). An 11-point numerical scale was used to assess pain. This scale consists of a ruler divided into eleven equal parts, numbered sequentially from 0 (which corresponds to no pain) to 10 (which corresponds to maximum pain).[23] The horizontal version of the ruler was use. The pain intensity was always that reported by the participants, and it was recorded by the obstetric nurses at the different assessment times. All parturients received an explanation about the scale using simple and accessible language and confirmed that they had correctly understood its meaning and how to use it.

Ethical aspects

This study was approved by the Health Ethics Committees of the institutions involved (RNEC: 20170700050). Informed consent forms were signed by all the participants, who were told that they could withdraw their participation at any time without any consequences and without having to explain their reasons. The participants were also informed that the data collected would be confidential, coded and entered into a database for statistical analysis, and would only be used for the purpose of this study. Secrecy and anonymity were guaranteed, as well as privacy and intimacy during the intervention. All procedures were carried out in accordance with Declaration of Helsinki and relevant guidelines and regulations.

Intervention

Therapeutic showering was the intervention. All potential participants were informed about the intervention by the obstetric nurses and asked about their availability to participate in the study. In all situations, the evolution of labor was assessed, and auscultation of the fetal heart rate was performed before and after the intervention.

The participants were free to choose where to apply water, and the nurses recorded where the water touched their bodies. The duration of water application was recorded in time intervals: less than 10 minutes, between 10 and 20 minutes, and more than 20 minutes. Warm water was made available, and each parturient adjusted the temperature to best suit their well-being and comfort.

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Results

The parturients who participated in this study were between 18 and 45 years old, with a mean age of 30 years (M=29.96) and a standard deviation of 6 (SD=5.54). Regarding country of origin, 77% were Portuguese, 11% Brazilian, 5% Cape Verdean, 4% Angolan, and the remaining 3% were Australian, Italian, and Russian (1% each). In terms of level of education, 50% had a higher education degree (undergraduate degree 3%, graduate degree 47%), 35% had studied up to year 10 and 12 of secondary school, and the remaining participants, up to year 4 of elementary school.

Of the participants, 69% were primiparous (first-time parturients) and had not attended a childbirth preparation course. The remaining 31% had attended a preparation course, and 26% reported that the course had covered hydrotherapy.

Pain was assessed before the intervention, to establish a comparative level of pain before water application, and after application (immediately after application, 10 minutes after, and 20 minutes after) (Figure 1).

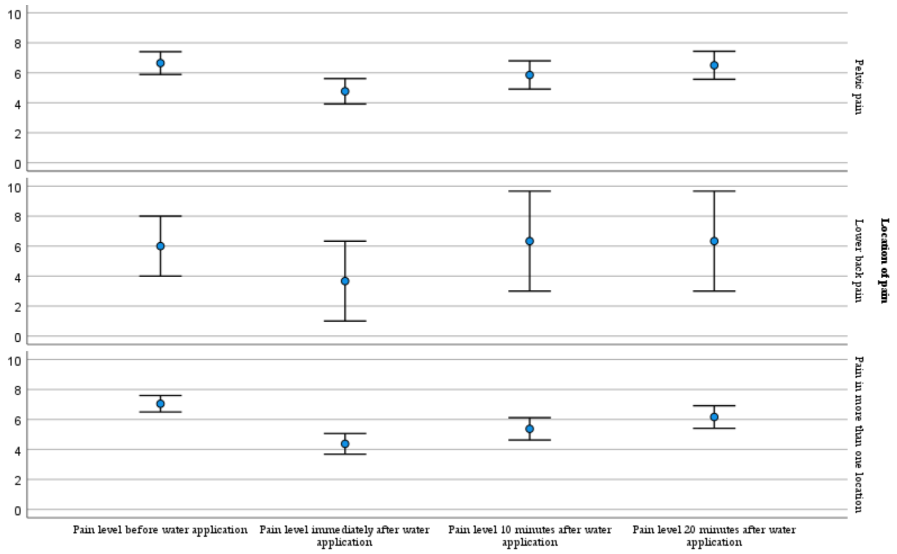

Figure 1 - Pain level distribution by location of pain [Mean+-2 Standard Error (SE)]

To analyze the mean pain levels at the different times after water application, the mean value of pain before its application was used as a baseline (Mean=6.85, SE=0.22). Figure 2 shows that the average pain level decreased immediately regardless of time after water application, with a progressive increase at 10 and 20 minutes. However, the water application time in minutes shows a greater dispersion of data when it is less than 10 minutes and more than 20 minutes, compared to the intermediate time between 10 and 20 minutes.

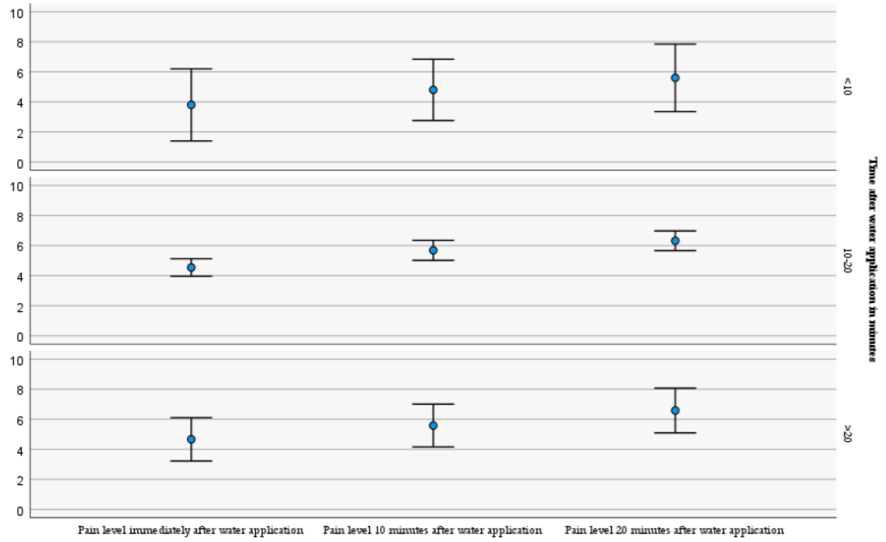

Figure 2 - Distribution of pain level according to time after water application

The data for the three pain assessment times were also analyzed in terms of location of water application (pelvis, lower back, or more than one place).

As shown in Figure 1, increased pain levels (pelvic, lower back, and in more than one location) occurred immediately after the application of water, and at 10 and 20 minutes post-intervention, although with greater data dispersion when the pain was in the lower back.

The repeated measures ANOVA showed that the results were statistically significant [$F(2.10)=23.12$; $p<0.001$; $\eta 2p=0.236$ and $\pi = 0.878$]. The contrast analysis between the first measurement (before the water application) and the other measurements showed no statistically significant differences, with the exception of contrast analysis between the first and second measurements that revealed significant differences between mean level of pain assessed immediately after water application and 10 minutes after application [($F(1.5)=15.324$, $p<0.001$, $\eta 2p= 0.170$ and $\pi=0.972$]. However, the post-hoc analysis revealed that after 20 minutes, the differences between the means were not significant ($p>0.05$).

Discussion

In most studies of the therapeutic application of water, a large number of authors, are used as references or used in the discussion of their results, have only investigated the effect of hydrotherapy applied through immersion baths, such as in Benfield et al.[4], Simkin and Bolding[20], Eckert et al.[24], Cluett et al.[25], Silva et al.[26] and Gallo et al.[27] Of these, Eckert et al.[24] stands out because, unlike the others, it concluded that immersion in warm water does not confer any clear benefits to parturients and that when the water temperature is above 37 °C, it can be harmful to the fetus.

When considering hydrotherapy for pain relief during labor, it is important to highlight that therapeutic showering has characteristics and contributions that differ from those of immersion baths. Johnson et al.[28] asserted that women usually shower in upright positions, including standing, rocking, swaying, squatting or sitting, and that they can change their position in the shower to direct water wherever it is needed to provide pain relief or a soothing effect. Therefore, showering provides numerous benefits during labor that are provided by movement as pain relief, increased sense of self-efficacy, calming and comfort, and perception of control over the environment and the birthing experience.[28]

Stark[18] also stated that therapeutic showering promotes and facilitates physiological labor: the rhythmic impact of warm water can provide a pleasant sensory distraction, the shower allows freedom of movement, and showering involves ambulation because of the necessary walking to get into and out of the shower.

Gayeski et al.[29] assessed the application of non-pharmacologic methods to relieve pain during labor, from the point of view of the primiparous women (n=188), on the day they were discharged from the hospital. They found that warm showers were the second-most-used non-pharmacologic method (91.5%) (emotional support provided by the parturients companion was the first [97.3%]). In this context, it is also important to mention that some authors consider that there is a shortage of scientific evidence to support warm showers as a therapeutic intervention. Of these, emphasis goes to Simkin and O'hara[30], and Stark[18], who contend that while showering is considered an effective coping strategy during labor, research about it is lacking and its effectiveness has not been tested.

Of the studies that assessed the effect of therapeutic showering for pain relief during the first phase of labor, we highlight the work of Davim et al.[31], who observed significant pain relief in parturients after the application of water from a shower at room temperature, and a study conducted by Barbieri et al.[32] in which a warm shower with water at 37ºC was used on the lower back region for 30 minutes, showing no significant difference in the pain score evaluated before the intervention and 1 hour after. As concluded by Barbieri et al.[32], Stark in his study published in 2013[18], highlighted that therapeutic showering did not significantly reduce the perception of pain in participants. In that study, the direction of the flow of the water and the temperature of the water could be adjusted by the parturients and, for safety reasons, they remained seated during the procedure.[18] Pain measurements were carried out 10 minutes after the intervention. The author noted that if pain had been measured before leaving the shower, there might have been a more evident reduction and the results could have been different.

A study by Santana et al.[33] presented different results, pointing to the benefits of therapeutic showering, and concluding that, in the active phase of labor, a 20-minute shower between 37 ºC and 39 ºC was effective in reducing intensity of pain. Similarly, a 2017 study by Stark[17] highlighted that after 30 minutes of therapeutic showering (this length of time was selected based on research conducted by Benfield et al.[34], whose findings with immersion baths showed significant changes after 15 minutes), the intervention group presented statistically significant decreases in pain, discomfort, anxiety and tension, and a significant increase in relaxation, and they concluded that therapeutic showering was effective in reducing pain.

Lee et al.[8] found that average pain was less at 10 minutes post-shower than at 20 minutes post-shower. Although they did not evaluate pain immediately after water application and did not record the location of pain or of water application, they presented results similar to those found in this study that pointed to the effectiveness of therapeutic showering, at least at two times after application. However, at the third time (20 minutes after application), there was a decrease in its effectiveness. Lee et al.[8], who defined 37°C as the appropriate temperature for the intervention for 20 minutes, affirmed that the parturients in the intervention group, who were submitted to warm showers, reported significantly lower scores on the Visual Analog Scale for pain at 4cm and 7cm cervical dilation, and better birth experiences than the control

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group. Regarding water application sites, after a 5 minute full-body or lower-back shower, participants were permitted to direct shower water anywhere that felt most comfortable, although they did not record location of pain or of water application after 5 minutes.

Despite the studies that mention only the beneficial effects of therapeutic showering, it is also important to mention research that does not corroborate these findings. Henrique et al.[1] and Cavalcanti et al.[35] found an increase in pain scores and a shorter labor duration in the group of participants submitted to the intervention.

In terms of research developed to evaluate specific aspects of therapeutic showering, namely temperature, duration of application, and location of application, Hecox et al.[36] argued that the effect of water for pain relief was greater when the temperature varied between 37 °C and 40 °C and was applied in 20-30minute sessions, and Lee et al.[8] maintained that 37 °C was the ideal water temperature.

In the present study, the results showed that time after application in minutes impacted level of pain. Although the pattern for the three times was similar in the interval between 10 and 20 minutes, there was a decrease in the level of pain that was more pronounced immediately after water application, and the results also seemed more consistent because there was lower data dispersion.

Conclusions

Therapeutic showering is a non-pharmacological strategy that, in the first stage of labor, contributes to safe but temporary pain relief, with pain levels that are lower at the time of application (pelvis, lower back and in more than one place) and that increase over time at 10 and 20 minutes, although with greater data dispersion when the pain was located in the lower back region.

It is essential that the benefits of this strategy become accessible to parturients as one of the dimensions of humanized childbirth, and obstetric nurses should promote the exercise of women's right to self-determination, which includes free and informed decisions about non-pharmacological pain relief strategies during the first stage of labor.

This pain relief strategy does not require previous training of women or a need for specific physical resources, since most Portuguese maternity hospitals have warm water showers available in the bathrooms that are accessible to parturients. Nevertheless, it may have some impact on the allocation of human resources, because it implies the availability of nurses to accompany women during the procedure, and there may be some limitations related to personnel restrictions in the context of the SARS-CoV-2.

More research is needed about therapeutic showering that allows it to be evaluated, not only in terms of its effect on pain relief, but also on the evolution of labor and the satisfaction of women and families. Producing and disseminating such knowledge will increase the visibility of therapeutic showering in obstetric nursing practice guidelines, parenting preparation courses, and the standardization of non-pharmacological pain relief methods available in labor and delivery units in Portugal.

Considering that the results show an increase of pain over time, and taking into account other studies that have observed higher levels of pain when measurements were not taken immediately post-intervention, it would be interesting to always assess pain immediately after the intervention and at shorter time intervals, namely 5 and 10 minutes.

Study limitations

Limitations of this study include the sample size, the type of sampling, restrictions due to the SARS-CoV-2 pandemic, and lack of evaluation of shower water temperature, since each participant regulated the temperature based on their preferences.

Authors' contributions

AT: Conception and design of the study; data collection; data analysis and interpretation; statistical analysis; drafting the manuscript; critical review of the manuscript.
FL: Conception ad design of the study; data collection.
RG: Conception ad design of the study; data collection.
HB: Conception ad design of the study; drafting the manuscript; critical review of the manuscript.
LC: Conception ad design of the study; data collection.
AC: Conception and design of the study; data collection; data analysis and interpretation; statistical analysis; drafting the manuscript; critical review of the manuscript.

Conflicts of interest and Funding

The authors declare that they have no conflicts of interest with respect to the authorship or publication of this article. The authors state that the opinions expressed in this article are their own and not from an official position of the institutions or financial agent.

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Training hypocoagulated users and their families in disease management: a community nursing intervention

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Abstract

Introduction
Brain and cardiovascular diseases require regular and specialized follow-up, including pathologies that require oral anticoagulants, in order to reduce hospitalizations due to clinical decompensation, maintain the person active, and reduce their degree of dependence. This requires a professional/patient/family partnership in their management. This project was based on Dorothea Orem's Self-Care Deficit Theory.

Objective
To train hypocoagulated users and their families in disease management.

Methods
The health planning methodology was applied. The situation diagnosis was developed using questionnaires applied to the patient to validate their knowledge about disease management and a second one applied to the family to understand their knowledge about their relative's needs. The non-probability convenience sample was composed of 18 patients and five family members in the consultations performed during the internship period.

Results
The situation diagnosis revealed a deficit of knowledge about disease management: in self-care, therapeutic regimen, and their interaction, as well as a deficit of the family's role in monitoring their family member and perceiving their needs. Health education was used as a strategy to improve the problems identified through the empowerment of users and families. After intervention, there was an increase in knowledge in all the addressed points: self-care (92.85%), therapeutic regimen and its interaction (85.71%). As for the family intervention, we found that participants are family members who live with hypocoagulated patients and have already taken over the role of caregiver.

Conclusion
This project contributed to the knowledge of hypocoagulated patients and family, through the intervention of community nursing, as well as the reflection on how to develop strategies with families, to empower them in the early detection of intervention in the self-care of their family member and in the management of family roles.

Keywords
Patients; Family; Oral Anticoagulants; Health education; Community nursing.

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Introduction

Cardiovascular diseases are the main cause of death in the member states of the European Union, amounting to 36% of deaths in 2010, as reported by the PNDCCV.[1.] Brain and cardiovascular diseases require effective, specialized follow-up during their management in order to reduce hospitalizations due to clinical decompensation, maintaining patients alive, and reducing their degree of dependency. The cardiovascular diseases that require oral anticoagulants (OAC) are included, which requires a more regular health vigilance and a professional/user/family partnership during disease management. There has been a decrease in hospitalizations due to circulatory system disease, 8.1% in 2016 in relation to 2011, and an increase in hospitalizations due to cardiac arrest, 20.3% in 2016 in relation to 2011.[1]

Community and public health nursing "Contribute to the process of training groups and communities"[2(p.8667)], promoting interventions through education-for-health actions (EfH) in the community, doing follow-up with families in their health project. This transforms them into partners and decision-makers in their care with the aim of improving quality of life and making gains in health. EfH, as an intervention strategy, shall devise an interactive process "focused on utilizing strategies that help individuals and the community to either adopt or modify behaviors that allow better health levels".[3(p.1)] The literature review shows the importance of EfH sessions in order to train users in performing self-care and managing their disease more safely and effectively.

This project was guided by the Otawa[4(p.3,4)] letter, int he basic condition – Training "is centered on seeking equality in health," in order to contribute to reducing existing inequalities; there must be "a solid implementation in a favorable environment, access to information, lifestyles, and opportunities that allow healthy options." The intervention focused on a community action in which "health promotion is developed through concrete, effective intervention in the community, establishing priorities, making decisions, planning strategies, and implementing them in order to achieve better health," to build up personal skills via access to information, EfH, thus improving their self-care skills. Moreover, in the Dorothea Orem's Self-Care Deficit Theory, whose premise is that "every person has the potential, in different degrees, to take care of themselves and the others who are under their responsibility"[5(p.614)].

It must be understood that family is a complex system, with a specific structure that is developed and transformed throughout the life cycle according to one's life experiences. In this intervention community, it was found that the participating families were in the last stage of the life cycle, as stated by Figueiredo.[6] This is a transformative stage, as it helps understand the fragilities of those who need care, as well as those who provide it. Thus, nursing plays a key role in doing follow-up with families, identifying transformations throughout the life cycle, providing information, supporting them in their decision-making, collaborating in strategies in order to maintain them trained to perform self-care, managing their familial roles through positive, effective, and efficacious communication.

This article aims to briefly expose a community intervention project developed throughout an internship that was part of the researcher's master's degree in nursing, in the Community Nursing specialization area.

Methods

"Health planning must be adequate to reality, catering to needs and/or problems experienced in the community or any health organization in an assertive and pragmatic way, supposedly in service for this community".[7(p.67)] It was through the health methodology planning that project intervention was devised. All the formative and interventional route of the community being followed-up was described, analyzed and assessed according to several development stages: situation diagnosis, priority identification, goal setting, strategy selection, project and program creation, execution and assessment preparation. These stages allowed to steer a sustained, systematized path, as this "requires a logical, rational methodology ".[7(p.29)] This is a descriptive, exploratory study, devised after a favorable opinion from the Ethics for Health Commission with reference 6272/CES/2021.

Target Audience and Sample

This project target audience consisted in the users registered at the FHU, amounting to a total of 52 users, as per the following inclusion criteria: hypocoagulated patients with need for INR, who received follow-up in consultation throughout the internship period and were able to understand, read and write well enough to answer a questionnaire and accepted to participate in this project. Of these, a total of 18 users were included in a nonprobability, convenience sample.

Data Collection Instrument

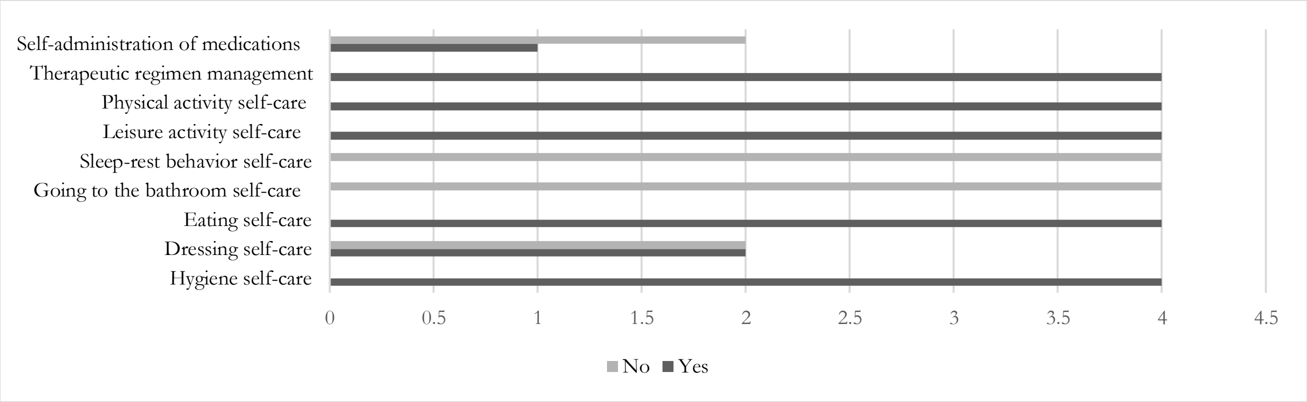
To begin the first stage of the health planning methodology – Situation Diagnosis, a questionnaire was devised and validated by experts. A pre-test was carried out in order to understand the hypocoagulated users' and their families' knowledge, which consisted in: Part A – sociodemographic variables that enable us to understand the study sample; Part B – motivational variables, which enable us to understand commitment/knowledge of users regarding their disease management, and Part C – socio-relational variables, which enable us to analyze the user/nurse relationship. To understand the family role of the hypocoagulated user, the Dynamic Model of Family Assessment and Intervention (MDAIF), operative matrix, in its functional dimension, was applied on the users' families who accompanied them in their hypocoagulation nursing consultations in order to identify intervention areas performed by their families as caregivers. The functional dimension assesses the dependency of several types of self care described by ICN (2002b): dressing, eating, drinking, going to the bathroom, sleep-rest behavior, leisure and physical activities, as well as knowledge about the dependency on management of the therapeutic regimen, self-vigilance, and self-administration of medicines, as stated by Figueiredo.[6(p.92)] This helped assess the needs of both family members and caregivers. Data collection was carried out between October and November 2021 after authorization from the Ethics for Healthcare Commission.

Results

The users' ages in the sample vary between 55 and 88 years, with an average of 73.61 years. It was found that 67% of them are males, while 44% of them are females; of these, 67% completed basic education. Regarding family households, it was found that 72% of the interviewees live with their partners, 22% of them live with a relative, and 6% of them live alone.

Regarding disease knowledge, 100% of the interviewees can identify the name of the prescribed medicine, while 72% can identify the therapeutic interval that is adequate for them. However, 28% of the interviewees do not know why they are taking anticoagulant medication. Regarding medication interactions with OAC, 89% of the subjects cannot identify medicines that may interfere with it, but regarding food and health situations, 50% of them can give some examples that may alter therapeutic value or even foods that they might have to suspend. Finally, there is the importance of the nursing consultation, in which 100% of the interviewees refer that this is an accessible consultation, and it is important for monitoring and surveillance of one's health state.

Graph 1 - Analysis of self-care dependency areas



Three relatives and a non-family-related caregiver answered the family-focused questionnaire. It was found that the hypocoagulated users present a dependency of several self-care areas: Therapeutic Regimen Management, Self-Care Physical Activity, Self-Care Leisure Activity and Self-Care Hygiene, in which the caregiver, mostly a relative, takes over these functions as their, as shown in graph 1. Regarding use of the MDAIF operative matrix, there was low family adherence to follow-up and supervision of family member's needs.

According to the results obtained in the health diagnosis stage. Identification and preparation of nursing diagnoses according to CIPE taxonomy, 2015 version: Deficit in knowledge about the pathological process and their diet regimen; Compromised self-care ability; Compromised disease self-management; Compromised knowledge about their families' role; and Compromised relative's ability to manage the disease.

From Situation Diagnosis to Execution

After identifying the health problems and preparing nursing diagnoses, their hierarchization was carried out. Priority definition, the second phase of the health planning methodology, was carried out by using a group of experts as a resource and it was based on the analysis grid criteria, which was adapted from Hartz.[8] According to our results and with a view to either minimize or solve the problems we found, the first four priorities were focused: Deficit in knowledge about their diet regimen; Compromised disease management; Compromised relative's ability to manage the disease; and Deficit in knowledge about the pathological process.

Based on the prioritized problems, the general and specific objectives were set; setting objectives is the next stage, which enables us to carry out the project so that "it is possible to devise a path for intervention strategies (...) from the current state of a certain community, what state we intend to achieve, where and until when"[7(p.23)] Thus, the main objective of this study is to train hypocoagulated users and their families in disease management. The following specific objectives were set: Identify foods that interfere with OAC the most; Acknowledging danger situations for users who take OAC; Relating danger situations with actions to be taken in order to reduce risks; Support families in identifying the areas where their family needs support; and Understand the pathological process. Activity, adherence, and quality indicators were set in order to quantify and qualify the activities to be devised.

The fourth stage of the Health Planning Methodology – Strategy Selection, whose function is "a set of specific techniques, organized in order to achieve a certain objective, thus resolving one or more health problems".[9(p.65)] The following strategies were set according to Dorothea Orem's Self-Care Deficit Theory: Involving the nursing team; presenting the project to the nursing team; informal meetings with colleagues to maintain them informed about project developments and ask for their opinions. Information and Communication, participation of the masters' degree candidate in hypocoagulation consultations to establish a relationship with users/family and inform them about the project; Exposing information at a visible location about the activities to be performed; Information about the activities to be developed by reinforcing it with their family nurses; Self-Care Promotion, doing two EfH sessions at the FHU (Family Health Unit); presenting a checklist to help register changes in patients' daily well-being; presenting a pamphlet with a summary of care measures to be taken so as to have good health; Proximity of Nursing Care, making a manual of good practices in nursing in on-line consultations. These strategies aimed to provide a timely answer to the difficulties pointed out by the users and their families. Maintaining users able to self-care and improve "performance or the practice of activities that individuals carry out to their own benefit to maintain their lives, health and well-being"[10(p.84)] is to make them autonomous regarding their self-care.

The EfH sessions that were carried out aimed to promote health in the community under intervention, facilitating its development and improving knowledge about the disease. As stated in the Ottawa (1986), "it is a process that aims to increase the capacity of individuals and their communities to control their health in order to improve it, understanding health as (a resource for life and not as a life end."[8(p.160)]

Assessment

After intervention execution, the project assessment was carried out based on preset goals. The goals were set based on the situation diagnosis. At the end of each EfH session a checklist was used to assess the addressed themes. Thus, the knowledge of users and families who participated in the sessions regarding the themes addressed in the two sessions, adding to the objectives and result indicators defined for this intervention project, as exposed in Table 1.

Table 1 – Assessment of Prioritized Nursing Diagnoses applied to 14 participants, of which four are relatives who participated in the two EfH sessions.

Nursing Diagnosis: Deficit in knowledge about their diet regimen		
Result Indicator	**Goal**	**Result**
Percentage of users/family who received intervention able to identify five foods that interfere with OAC the most.	80%	85.71%
Nursing Diagnosis: Compromised disease self-management		
Result Indicator	**Goal**	**Result**
Percentage of users/ family who received intervention able to identify three danger situations. Percentage of users/ family who received intervention able to identify two actions to reduce risk.	90%	92.85%
Nursing Diagnosis: Family's knowledge about patients' relatives' ability to manage the disease is compromised.		
Result Indicator	**Goal**	**Result**
Percentage of family who received intervention able to identify three areas where their relative needs support.	50%	100%
Nursing Diagnosis: Deficit in knowledge about their pathological process		
Result Indicator	**Goal**	**Result**
Percentage of users/ family who received intervention able to identify the reason for taking the anticoagulant.	70%	92.85%

Table 1 shows that the proposed goals were achieved despite the difficulties perceived in families' adherence to the project and motivation of all users who responded to the questionnaire to participate in EfH sessions. The two programmed sessions presented more user adherence because the sessions had been carried out on the day of their consultations, thus the number of participants was smaller than that of questionnaire responders. It was found that the users, who were mostly older persons, remain alone during their vigilance and monitoring consultations in order to maintain disease management within their physical and mental abilities.

Discussion

This project aimed to strengthen mapping carried out via scoping review. As stated by Madrid,[12(p.463)] "The education level and patients' knowledge have a direct influence on the global management of the anticoagulation."; Alphonsa[13(p.668)] says that "Patient's knowledge about OAT was suboptimal." The findings support the need for educational interventions to improve the knowledge regarding OAT and, thereby, achieve an appropriate and safe secondary prevention of stroke." Moreover, Viola, Fekete and Csoka[14(p.1265)] say that "The lowest frequency of correct answers regarded the questions on drug interactions (10.2%) and diet (11.4%).” There is also a need for “(…)developing new strategies for patient education to improve knowledge on the treatment with oral anticoagulants.”. The questionnaires used in this project found an older population (mode equal to 87 years of age), with low education level (67% completed basic education), where 28% of the sample is not able to justify why they take OAC, and 78% of them do not acknowledge the medication interaction; on the other hand, regarding the foods that may interfere with it, 50% of them can identify five foods. After intervention with this group, EfH showed that new knowledge about the disease was acquired, along with alert signals and actions to take in order to minimize risk and promote self-care improvement. These sharing moments, organized by the nurses who take care of this community, create moments of great learning. Not only does the target group participates actively in them, but also raises questions and identifies difficulties to train themselves in disease management. All articles highlight the education factor as a key point for the users’ understanding and participation in disease management, thus demonstrating the importance of the EfH sessions and how pertinent they are regarding user training. This is an intervention area of the nursing community specialist, where they must invest in these actions to improve health literacy in the community and develop and document it through clinical investigation. No articles written by Nursing professionals were found in this intervention area.

Conclusion

The community intervention nursing specialists play a central role in doing follow-up and guide the community in managing their health project. EfH fostered moments of learning and growth in order to improve the community’s health state. By making use of on the health diagnosis and the Dorothea Orem's Self-Care Deficit Theory and the support-education system, it was possible to identify the self-care deficiencies of the hypocoagulated users and their families in disease management, as well as outline strategies to train them in order to improve their self-care skills. The EfS sessions made learning moments possible through the users’ sharing knowledge and experiences, and a debate that improved their skills regarding their disease, medication and food interaction, as well as their identifying risk situations and measures to be taken in order to minimize risks and maintain a healthy, balanced life. The community interventions that were carried out during this project were very enriching due to the engagement of the whole multidisciplinary team. This helped divulge information and stimulate the users’ and their families’ participation, thus, all together will improve health literacy in the hypocoagulation area. However, we must focus on families due to a difficulty we noticed in integrating them in participating in the project and the health care intervention. The families’ time availability difficulty was one of the limitations we noticed in the intervention project. The available internship time to make interventions with users and their families is also minimal because only after a favorable opinion from the ethics commission can we interview and engage them in the project.

Making interventions in this community, improving their self-care skills, engaging a multidisciplinary throughout their route contributed to promote knowledge and develop investigation in Nursing. However, other questions emerged during community intervention. Noticing that this community has a high percentage of older persons who manage their health project on their own, led the team to the following questions: How to make an early detection of cognitive decline and intervene to promote better nursing care? How to alert families to a new reality and intervene in family readaptation in advance? How to support families in rearranging functions or even taking over new roles?

Authors’ contributions

RR: Study conception and design; Data collection; Data analysis and interpretation; Statistical analysis; Manuscript writing.

ES: Study conception and design; Data analysis and interpretation; Statistical analysis; Critical revision of the manuscript.

FP: Data analysis and interpretation; Critical revision of the manuscript.

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The authors declared that there is no conflict of interest.

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Hospitalization experiences: the perspective of individuals admitted to the medical clinic

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Abstract

Introduction

Contemporary society is witnessing a population that struggles to look after their health due to the relentless pace of their lives, consequently rendering them susceptible to the experience of hospitalization. Within this context, individuals relinquish their autonomy and are confronted with a plethora of reactions and emotions, requiring an individualized and humane approach for a prompt and effective recovery.

Objective

To comprehend the lived experience of hospitalization, from the perspective of individuals admitted to the medical clinic.

Methods

This is an exploratory study, with a qualitative approach, and draws upon partial data from a matrix research project, rooted in the theoretical framework of Health Promotion. The manuscript has been organized in adherence with the consolidated criteria for reporting qualitative research (COREQ). It was conducted with a cohort of 15 inpatients from the medical clinic department of a public hospital in the Southern region of Brazil. Data was collected by the authors, using a semi-structured questionnaire, between September and October 2021. Thematic content analysis was used to organize and interpret the data.

Results

Two categories emerged: the first highlighted the experiences lived during hospitalization. While some participants felt secure and supported by the multi-professional team, others perceived the hospital environment as a place associated with pain and suffering. The second category emphasized the sentiment of longing experienced during hospitalization, such as for spending time with family, friends, leisure activities, and daily routines.

Conclusion

The experience of the hospitalization process triggers feelings of security, vulnerability, and longing. The importance of qualified professionals to facilitate moments of effective and compassionate care within the hospital setting is evident.

Keywords

Hospitalization; Humanization of Care; Health Promotion; Nursing.

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Introduction

In contemporary times, people demand swift and effective solutions, aiming to save time and accomplish numerous tasks. To achieve this goal, individuals often resort to various practices, some of which may be inadequate, such as the consumption of ultra-processed foods and self-medication to alleviate certain conditions. Such practices seem to offer effective solutions at first glance. This results in numerous long-term detriments, such as the marked increase in chronic diseases, an alarming trend in society.[1]

Thus, it is evident that due to the fast-paced routine, many individuals lack the time to indulge in leisure or to prioritize and promote their health. Consequently, they fail to contemplate the pleasures of daily life, such as freedom, autonomy, and well-being, rendering daily existence even more exhausting and demotivating,[2] subjecting themselves to the risk of illness and occasionally requiring hospitalization.[3]

The hospitalization process can pose a threat to the autonomy and social roles enacted prior to admission, as the individual shifts from an active role to that of a patient, relinquishing their independence, privacy, and interaction with their support group.[4] These circumstances can provoke diverse reactions and feelings, given the uniqueness of each individual; however, certain sentiments are recurrent, including longing for home or family, alongside the potential perception of the hospital environment as an unpleasant place. Conversely, being present in an environment that is reminiscent of pain, suffering, and fear tends to evoke an appreciation for what was experienced previously. Therefore, the individual, vulnerable in this situation, requires a holistic, humanized, and multi-professional approach to achieve a prompt and satisfactory recovery.[5]

In this context, humanization emerges as a means to preserve the basic rights of the hospitalized individual, reinforcing the need for dignified and respectful treatment while safeguarding their agency and autonomy. Humanization in the healthcare domain has received a great deal of attention in recent years, given the imperative of this practice across all procedures and protocols. As a result, in 2003, the Brazilian Ministry of Health published the National Humanization Policy (NHP) with the aim of implementing the principles of the Brazilian Unified Health System (SUS) in the routine of health services. Furthermore, it is crucial to emphasize that the NHP is applicable across all sectors, regardless of the level of complexity, as it is grounded in the qualification of care.[6]

Therefore, to ensure humanization, it is imperative to attend to the patient with a multidisciplinary team, with professionals such as nurses, physicians, physiotherapists, nutritionists, speech therapists, among others. Teamwork is essential to guarantee more effective and higher-quality care across all areas of healthcare services, especially in the medical clinic, where patients are admitted with various and sometimes impactful diagnoses, requiring more complex procedures and treatments.[7]

It should be highlighted that multidisciplinary teamwork can contribute to enhancing empathy among professionals, making them more efficient and compassionate in providing healthcare to the hospitalized individual and their family. However, it is essential that collaborative efforts are undertaken by all and not merely a subset of professionals within a specific unit or sector.[8] Additionally, nurses are indispensable during the hospitalization process, as they accompany the patient from admission to discharge, and are responsible for managing the nursing team, which will carry out all the care and procedures necessary to assist the individual's health, ensuring their comfort and significantly contributing to their recovery. Moreover, it is crucial to attend to each patient in an integral and holistic manner, continuously evaluating both the environment and the individual, considering not only physical aspects but also psychological, emotional, social, cultural, and spiritual dimensions, ensuring greater well-being and quality in the provision of healthcare.[9-10]

Furthermore, in line with humanized care, the principle of comprehensiveness, which, along with others, underpins the SUS in Brazil, is valued in the NHP and was further emphasized in the National Health Promotion Policy (NHPP). In the NHPP, comprehensiveness is defined as the articulation and harmony among health services, as well as the broadening of the workers' and health services' listening capacities towards patients, considered universal citizens deserving of care without prejudices or privileges. This comprehensive approach is applied in the spheres of health promotion, prevention, protection, and recovery.[11]

In this context, the Social Determinants of Health are essential in healthcare, as they consider aspects of an individual's life that extend beyond illness and the biological body, such as work, the environment in which the person lives, social, cultural, economic, ethnic, and behavioral issues, among others.[12]

Health promotion, an essential aspect of the SUS and the backdrop of the aforementioned policies, can be seen as a promising strategy to produce health and address related challenges. This notion was further emphasized in the Ottawa Charter, a document born out of the First International Conference on Health Promotion. The charter defined health promotion as a process of empowering individuals, communities, and society to have greater control and autonomy, utilizing personal and social resources, in pursuit of improvements in quality of life and health.[13-14]

The Charter outlined five action areas which concern healthy public policies, environments favorable to health, community action, autonomy and development of personal skills, and reorientation of health services in the light of health promotion. The document emphasizes the importance of collectively building health, self-care, and caring for others. Specifically, it indicates that these items, in addition to holism, which is related to comprehensiveness, and ecology, are indispensable for the development and implementation of health promotion strategies.[13-14] The document also outlines commitments for participating countries in pursuit of effective health promotion. In Brazil, the NHPP highlights the five axes derived from the Charter and aims to fulfill these commitments related to the development of public policies, equity, valuing the individual/community in their health-disease process, the reorganization of health services to achieve health promotion, among others.[13,15]

Based on the foregoing, the following research question emerged: What is the experience of the hospitalization process like from the perspective of individuals admitted to the medical clinic? It is believed that by shedding light on the demands of those experiencing hospitalization, it is possible to reflect upon and implement strategies to qualify healthcare assistance in the hospitalization process. Moreover, considering the diversity of the population served in the hospital network, both in terms of age and culture, it is essential to perceive the factors involved in recovery during this process, so as to make the hospital environment more welcoming and pleasant. Therefore, the objective of the study was to comprehend the experience of the hospitalization process from the perspective of individuals admitted to the medical clinic.

Methods

This is an exploratory study with a qualitative approach, grounded in the theoretical assumptions of Health Promotion. The manuscript was organized following the consolidated criteria for reporting qualitative research (COREQ).

The research took place in a referral public hospital in the West of Santa Catarina, Brazil. Participants were 15 individuals, selected for convenience from those who met the inclusion criteria: aged over 18 and hospitalized in the medical clinic at the time of data collection. Lack of physical and communicative aptitude to respond to interview questions was the exclusion criterion. The participants were intentionally selected, and all those approached accepted to be part of the study.

Data collection was conducted through semi-structured interviews carried out by the authors in the participants' rooms, between September and October 2021. Each interview had an average duration of 40 minutes and followed a guide encompassing questions about the experience of the hospitalization process and the feelings evoked during the admission. All interviews were recorded and subsequently transcribed into digital files.

Thematic content analysis was employed to organize and interpret the data, which aims to uncover the central significance that constitutes communication, prioritizing interpretative approaches over statistical interference. In the preliminary analysis stage, the transcribed data was briefly skimmed to organize the content and define the units of analysis. In the second stage of material exploration, the data were coded to attain a comprehensive understanding of the text. In the third stage, the data were categorized and sub-categorized through classification and interpretation.[16] Two categories emerged from the analysis: 1) Experiencing hospitalization; 2) Longings evoked during hospitalization, which will be discussed subsequently.

The study was approved by the Research Ethics Committee of a public university in Santa Catarina, under opinion No. 4,960,473/2021, on September 9, 2021. It is emphasized that, prior to data collection, all participants read and signed the Informed Consent Form (ICF). To ensure anonymity, the interviewees were labeled according to basic human needs, based on the content of their testimonies. Hence, the following pseudonyms were used: Food, Shelter, Rest, Family, Friendship, Work, Self-esteem, Clothing, Health, Hydration, Exercise, Safety, Spirituality, Sleep, Resilience.

Results

Participants' age ranged from 39 to 82 years, which included four females and 11 males. The period of hospitalization at the time of the interview varied from 2 to 30 days. In the first category, the interviewees reported that they received adequate care and were well looked after during their hospitalization. Additionally, they mentioned that while at home, they experienced a feeling of impending death, but upon receiving hospital care, they noticed an improvement in their condition, which put them at ease.

"For me, it's good to be in the hospital. They are treating me well, and I've already improved [...]" (Food)

"Now I'm fine, I feel better here. In fact, the doctor told me I'd only be heading home tomorrow, and I felt at ease." (Shelter)

"As I was at home [...] I thought I was going to die [...] Being here in the hospital, I received all the care and I'm fine [...]" (Rest)

The participants also discussed the administration of pain-relief medications and the multi-professional work for physical well-being in hospital care.

"...The medications are being administered correctly, so I feel good." (Friendship)

"It's good because you don't feel pain, you're being taken care of in the best possible way..." (Family).

"[...] The staff's visits can be entertaining, there are physiotherapists, speech therapists, the whole team here, the team of pharmacists, very good nurses, their care is very good [...] It's clear, in these 6 days here, what good patient treatment looks like [...]" (Work)

On the other hand, they revealed their dislike for the hospital space, as it represents an environment visited during illness, in a more serious state of health, leading

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them to associate hospitalization with something unpleasant and a tiring period.

"It's bad because we're here all the time, lying down." (Family)

"I don't like being in the hospital because whoever comes here is because they're not well, they're sick, so it's bad." (Self-esteem)

"Oh, it's tiring [...]" (Clothing)

In the second category - longings evoked during hospitalization -, the interviewees mentioned missing the comfort and routine of their lives at home, along with the freedom experienced in their households, as the hospital environment imposes various restrictions.

"I miss everything: my bed, the food. Everything is different here. At home, we feel more at ease." (Friendship)

"Oh, I like being at home, walking, having visitors over, and now I have nothing here in the hospital." (Health)

"Oh, we miss home, of course, because it's freer there, there are no restrictions. Here, everything is regulated, and if you don't follow orders, you won't get better." (Food)

Hospitalization led the participants to miss being with their families. Missed conversing with them, taking care of them, and having them close, revealing their concern for them:

"My husband [is alone], I'm very worried about him." (Hydration)

"I miss looking after my granddaughters [...], miss my daughter. [...]" (Shelter)

"I miss my daughters and my mother." (Clothing)

Moreover, the interviewees mentioned feelings of longing related to their contact with neighbors, friends, and colleagues, as well as the work activities they engaged in before hospitalization:

"[I miss] my neighbors because we used to visit [each other]. I always took some time out for everyone, to help people too, and now I've been here for almost 30 days." (Family)

"Chatting with my colleagues, I miss that." (Exercise)

"Working, for sure, I miss it a lot [...]" (Family)

Additionally, the participants reported missing the leisure moments that were part of their daily lives, in which they set aside time to promote self-care, have fun, attend church services, and experience the freedom of life.

"Going to the [beauty] salon, dressing up." (Safety)

"Oh, being free, drinking mate. I miss it very much..." (Exercise)

"I wanted to be having a beer [...] and singing [...] That's what we used to do, right?" (Rest)

"[...] I can't attend the worship service." (Health)

It was clear, in the interviewees' testimonies, the deprivation of various significant aspects of their lives due to the hospitalization period, as they expressed longing for their routines, frequented environments, their families, friends, and leisure activities. It became evident that the hospital environment is perceived as a place that evokes pain and suffering, as well as a space that provides security and support due to the care routines performed by the professionals.

Discussion

The hospital environment is complex and demands knowledge and efficiency from professionals to provide quality care. In this context, safety within the hospital setting is essential. It contributes to minimizing harm associated with health care to an acceptable level for the institution. This consideration includes the infrastructure, professionals' expertise, and material resources of the respective health service.[17]

Medication management is crucial in this setting and requires professional responsibility, which is tasked with addressing doubts and treating each need individually to provide comfort and well-being. It is known that the use of medications is not limited to a therapeutic practice based on the biomedical model. When used correctly and rationally, they become important mechanisms for the prevention, maintenance, and recovery of health, reducing symptoms, and providing physical and mental well-being.[18]

Another critical element in the hospitalization process is the promotion of a suitable and humanistic environment. This encompasses the building's physical structure, which is developed through architectural design. The design aims to meet criteria for enhancing patient satisfaction and comfort. This involves the implementation of organizational methods that facilitate their stay and integration within the hospital. The architectural design aims to harmonize and seeks to meet the different realities of the hospital setting, promoting well-being and creating spaces that provide physical and psychological support to patients, as the environment is essential to the quality of care.[19]

Furthermore, hospital environments can induce stress and tension. And sometimes, physical structures do not provide the comfort of human sensitivity, attention, and care, despite being an important aspect in the recovery of patients. Humanizing the environment is significant, as it contributes to improved patient experiences and outcomes. This approach should be practiced in the training of professionals, ensuring they develop effective strategies to meet the individual needs of each person in a comprehensive and humanized manner. This effort makes each sector as welcoming and pleasant as possible for patients, their families, and co-workers.[20]

Moreover, professional training and interdisciplinary work are essential for promoting effective health care.[21] Both ensure greater resolution, shorter durations, and reduced health spending, enabling comprehensive and humanized care.[9] As a tool for ensuring professional qualification, continuing education is mentioned, encompassing specialization and ongoing professional development, along with permanent education, addressing work process demands, aiming for more qualified health care.[22] To encourage multi-professional practice, there are residency programs in this field, which combine theoretical-practical knowledge with teamwork and intense insertion in health services.[23]

Another critical consideration for professionals working in the hospital environment is that, during the experience of hospitalization, patients commonly feel longing, whether for work, habitual activities as a means to occupy time and ensure financial support, friends and family, or gatherings for leisurely conversation and distraction. Furthermore, there is the longing to attend religious centers, participating in worship, and strengthening spirituality. Thus, longing signifies the absence felt from what was experienced before hospitalization.

Longing is understood as a human feeling that is difficult to define and can symbolize the experience of pain or joy related to the deprivation or distance from a beloved object or person.[24] Within the hospital environment, this sentiment is common and can be evaluated to ascertain its influence on the patient's treatment and recovery.[4,25]

These everyday activities that generate longing, when restricted, can significantly impact the well-being of hospitalized individuals, as they evoke feelings of helplessness due to the loss of control over their own bodies, as well as the inability to engage in daily activities, along with feelings of anguish and anxiety resulting from the disruption of routines, leisure moments, and contact with family, all crucial for quality of life.[26]

Longing also arises from the hospital environment itself, which typically evokes pain, suffering, and sadness, in addition to subjecting patients to invasive procedures, the loss of privacy, and autonomy. Therefore, it is essential that each patient is seen as a unique individual, with a comprehensive approach, considering each of their statements, complaints, or feelings, in pursuit of an effective and healthy recovery. Furthermore, through dialogues with patients and attending to their complaints, it is possible to improve the service, considering that they benefit from daily care and are the most qualified to suggest changes.[4,25]

To this end, the healthcare professional, especially in nursing, plays an important role in ensuring a humanized care that brings a sense of security and comfort in the hospital setting.[27] In addition to the safe administration of medications, care in the hospital environment, and multi-professional work, communication with patients promotes a more welcoming space, as mentioned by the interviewees. Communication enables moments of sharing knowledge and feelings, strengthening the relationship and bond between the professional and the patient. It is also important for this bond to be established with the family during the hospitalization period, as they provide important support in increasing the patient's confidence and security.[28]

Dialogue with the hospitalized patient helps them to choose the most appropriate course of action for their health condition, contributing to the reduction of hospital stay, as well as pain and risks to their well-being.[28] These behaviors can make the hospital environment more humanized, allowing for less uncomfortable experiences for both patients and their families who also experience this period. Therefore, it is essential that professionals can provide care while striving to enhance communication continually throughout the work process, thus reflecting the provision of safe and quality care.[27]

Conclusion

Considering the above, it is possible to understand the hospitalization process from the perspective of patients admitted to the medical clinic, who experience moments of satisfaction and security when they feel cared for. Therefore, good care and a welcoming environment directly impact their well-being, providing comfort, hope, and significantly facilitating their recovery.

On the other hand, they feel vulnerable, mainly due to sudden changes in their routine and being deprived from carrying out their daily activities, relying on the help and care of the multi-professional team and others. This situation is related to the perception of the hospital as a place of suffering, anguish, restrictions, which evokes longing for family, home, work, friends, and leisure activities.

Thus, the significant importance of the multi-professional work by professionals aligned with the principles of comprehensive care becomes evident, willing to implement new care strategies in the hospital environment. This approach is essential to promote a humanized, qualified, and efficient service, considering the needs and individualities of each individual, recognizing all aspects of the patient's life rather than just the illness. These aspects will broaden the possibilities for effective recovery and make hospitalization more bearable for the patient and their family.

Among the limitations of the study is the focus on people hospitalized in the hospital's medical clinic, most of whom were living with chronic health conditions. The focus on this cohort excluded other units of hospitalization, such as the surgical clinic, which receives many people with acute health conditions requiring other interventions. As a contribution, the study demonstrates some of the feelings experienced by hospitalized individuals regarding their own condition, their stay in the hospital, and the multi-professional team, providing insight into possibilities for health promotion in situations such as the one presented here. It also contributes to the development of a holistic perspective in health care, seeking to address more unique and individual patient concerns and needs. It emphasizes the importance of hospital ambiance, as well as contributing to the discussion of multi-professional work in health and comprehensive care, all important aspects of the NHP and the NHPP.

Authors' contributions

JBS: Conception and design of the study; drafting the manuscript; critical review of the manuscript.
RATB: Conception and design of the study; data analysis and interpretation; drafting the manuscript; critical review of the manuscript.
KCPP: Conception and design of the study; data analysis and interpretation; drafting the manuscript; critical review of the manuscript.
SKM: Conception and design of the study; data analysis and interpretation; drafting the manuscript; critical review of the manuscript.
ER: Conception and design of the study; drafting the manuscript; critical review of the manuscript.
KMO: Conception and design of the study; drafting the manuscript; critical review of the manuscript.
VM: Conception and design of the study; drafting the manuscript; critical review of the manuscript.

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