The construction of the health professional in palliative care contexts: a scoping review on caring for the person at the end of life

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Abstract

Aim: The aim of the study was to map of the literature on the elements contributing to the construction of the health care professional in the context of palliative care.

Methods: Scoping review based on Arksey and O'Malley framework. PubMed, Embase, CINAHL, Scopus databases, and gray literature were the sources searched (2005–2015), completed by reference searching, hand searching, and expert consultations. Primary studies focusing on different professionals working in palliative care units or hospice centers were eligible for inclusion.

Results: From a total of 3632 articles, 22 met the inclusion criteria. The content of the studies was described and classified in 5 elements: (i) construction and application of the concept of care; (ii) psychosocial effects that the daily care produces; (iii) working conditions that influence the caregiving provided; (iv) knowledge mobilized in the provision of care; and (v) strategies adopted by health care professionals to build relationships. Data about nurses, physicians, and psychologists were found, but no data were found about social workers. Gaps identified in the publications were as follows: relationship competencies and strategies adopted; the real needs from educational programs; and the view of other professionals.

Conclusions: Key elements identified in the concept of the construction of the health care professional should be addressed in future interventions: prevention of emotional exhaustion, depersonalization, and achievement of a greater personal accomplishment. In addition, none of the articles retrieved offered the different perspectives of all the disciplines in a multidisciplinary team.

Keywords: end of life care, health care worker, literature review, palliative care, staff attitude

Introduction

As a result of medical advances, life expectancy is progressively increasing. Consequently, the number of people living with a chronic disease has increased. This has contributed to a growing need for palliative care (PC), and therefore, more health care professionals (HCPs) will provide care at the end of life (EoL).[1] The World Health Organization defines PC as "an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[2]

However, along with the perception that science has all the answers, doubts and restlessness arise on how to implement some of the knowledge when we come across patients at the EoL. Literature has shown that PC has been proven to be more effective than standard approaches, improving the quality of life of patients and their families at a lower cost.[3–7] Nevertheless, contact with people at EoL is conducive to feeling intense emotions that evidence the fragility and limitations of human life. The important role of emotions in human life becomes even more important as death approaches.[8]

Hospital experiences that produce the greatest emotional impact are related to death, suffering, and caring for patients at the EoL.[9] Taking into account that the above statement is significant because most people in developed countries die in hospitals; therefore, attention to the quality of life in these contexts has increased.[10–13]

Previous studies conclude that the HCPs who feel more competent and face the EoL with more personal resources provide more effective care[14,15] and those who have more knowledge in PC score higher with regard to control of negative emotions and fear of death.[16]

Previous personal experience related to death can provide the HCPs with a better perception of the EoL of their patients and with better personal resources.[17] In addition, HCPs who spend a greater percentage of time in contact with patients in EoL situation reported more positive attitudes toward death.[18]

It is known that effective communication is an element that allows the delivery of excellent health care, being an essential

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factor to face EoL care. In fact, patients at EoL valued HCP trained in communication skills.[19] HCPs play a key role supporting the informal caregivers, providing them with knowledge and evaluating their needs.[20,21]

Although previous studies provide a representation of what happens at the EoL, they do not explain the elements involved in the construction of the HCP that provide EoL care. Moreover, if we want to achieve the main goals of PC,[2] we must have highly qualified HCPs. It is therefore important to understand what factors are involved in the construction of this caregiver.

As the population continues to age and PC becomes more present in health care practice, having an understanding of the necessary elements of HCPs, who effectively manage care in EoL, is essential.

HCPs in PC are working daily with people who are dying and are exposed to intense emotional reactions. Therefore, it is essential to understand the elements that contribute to the construction of the HCP in this unique context.

To date, despite the unique nature of this context, no review has examined the specific elements that contribute to the construction of the HCP in the context of the PC, which supports the need for this scoping review.

Aims

The aim of this scoping review is to examine the extent, range, and nature of the research activity around which elements contribute to the construction of the HCP in the context of the PC and to identify research gaps in the existing literature.[22]

Methods

This scoping review was guided by the methodology proposed by the Joanna Briggs Institute Scoping Reviews, and is based on the framework by Arksey and O'Malley[23] for conducting scoping reviews. It takes into account the works by Levac et al[24] and Daudt et al,[22] which included: (i) identifying the research question; (ii) finding relevant studies; (iii) selecting appropriate studies; (iv) charting the data; and (v) collating, summarizing, and reporting the results.

Inclusion criteria

This scoping review considered quantitative and qualitative primary studies published in English, Spanish, Catalan, and Portuguese during the last 10 years that focus on HCPs (physicians, nurses, social workers, and psychologists) working in palliative care units (PCUs) or hospice centers and caring for inpatients >18 years at the EoL.

Search strategy

According to different terms and rules for searching in each database, the effective combination of search terms was designed by one reviewer (RPP) (librarian expert in health science) and discussed with 3 other reviewers (VOP, AAR, and JBB).

Once relevant material was selected from electronic literature databases (CINAHL Plus, PubMed, Embase, Scopus, DART-Europe, OpenGrey, Grey Literature Report), relevant websites were searched, key journals were hand-searched, and reference lists were retrieved from articles, to increase our capture of relevant material. Finally, recommendations from experts in the field were also used to identify further published, unpublished,

and ongoing studies. The process was documented in detail to enable the study to be replicated by others (Table 1).

The Mendeley software was used to manage the list of all the articles retrieved and any duplication was removed.

Selection criteria

The review pursues to identify all the published research about which elements contribute to the construction of the HCP in the context of the PC. Articles searched were assessed for relevance by 2 independent reviewers (VOP and ANC). Those that meet the inclusion criteria, based on the information provided in the title and abstract, were included. When the relevance of a study was unclear in the abstract, the full article was reviewed.

The full article was retrieved for all studies that met the inclusion criteria. Based on full texts, 2 reviewers (VOP and ANC) examined independently whether the studies met the inclusion criteria. The disagreements that arose between the reviewers were resolved through discussion, or with a third reviewer (MGS).

Data extraction

Quantitative and qualitative data were extracted from papers in the review using a data extraction table, taking into account the review question (Table 2). In this process, 2 reviewers (VOP and ANC), independently of one another, charted the "first five to ten studies using the data-charting form and met to determine whether their approach to data extraction was consistent with the research question and purpose," as suggested by Levac et al.[24] Any disagreement was resolved through discussion, or with a third reviewer (MGS). In addition, when it was necessary, primary authors were contacted for further information/clarification of data.

Results

After the duplicates were removed, 3632 records were identified for study selection. A total of 163 documents met the inclusion criteria, based on the titles and abstracts; therefore, the full-text articles were obtained. Full-text articles were read, after which 22 fulfilled the inclusion criteria. As a result, 22 studies were analyzed.

The stages of the scoping review process can be seen in the PRISMA flow diagram (Fig. 1).

The overview of the reviewed material is presented and discussed in narrative form. Tables and figures are included to aid in data presentation.[23] The overview of the studies included is presented in Table 2.

About the geographical source 9 studies were conducted outside Europe (n=9): the United States, Brazil, and Japan.[25–29] The other 14 were from the United Kingdom, Spain, Belgium, Norway, Scotland, Sweden, and Portugal.

Regarding the year of publication, most of the articles had been published between 2007 and 2014 (n=21), 1 had been published in 2006,[30] and none had been published in 2005 or 2015 (until April). Regarding the research methods used, the majority of the studies were qualitative (n=12), 4 collected quantitative data, and another 4 studies used mixed methods.

Data about nurses were found in twenty out of the twenty two articles included, four articles had data about physicians, one had data about psychologists, and no data were found about social

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Table 1

Final database search strategy

Database: PubMed

Filters: Languages; Publication Dates

Total: <u>1995</u>

Strategy (April 2015):

(End of Life[Title/Abstract] OR hospice[Title/Abstract] OR hospices[Title/Abstract] OR palliative[Title/Abstract] OR palliatives[Title/Abstract] OR Palliative Care[Majr] OR Hospices [Majr] OR terminal care[Majr]) AND (Nurse[MeSH Terms] OR Physicians[MeSH Terms] OR Social worker[MeSH Terms] OR "formal caregiver"[Title/Abstract] OR "professional caregiver"[Title/Abstract] OR "formal caregivers"[Title/Abstract] OR "professional caregivers"[Title/Abstract] OR Psychologists[MeSH Terms] OR Patient Care Team[MeSH Terms]) AND (Portuguese[lang] OR Spanish[lang] OR Catalan[lang] OR English[lang]) AND "last 10 years"[PDat] NOT (paediatric*[Title/Abstract] OR child[MeSH Terms] OR pedriatic*[Title/Abstract] OR minors[MeSH Terms] OR Adolescent[MeSH Terms] OR infant[MeSH Terms])

Database: CinahlPlus

Filters: Languages; Publication Dates

Total: 985 (<u>242</u> excluding MEDLINE)

Strategy (April 2015):

(TI ("end of life" OR hospice OR hospices OR palliative OR palliatives) OR AB ("end of life" OR hospice OR hospices OR palliative OR palliatives) OR ((MM "Palliative Care") OR (MM "Hospices") OR (MM "Terminal Care"))) AND (TI ("formal caregiver" OR "professional caregiver" OR "formal caregivers" OR "professional caregivers") OR AB ("formal caregiver" OR "professional caregiver" OR "formal caregivers" OR "professional caregivers") OR ((MH "Nurses+") OR (MH "Physicians+") OR (MH "Social Workers") OR (MH "Psychologists") OR (MH "Multidisciplinary Care Team"))) NOT (TI paediatric* OR AB paediatric*)

Database: EMBASE

Filters: Languages; Publication Dates; Adult

Total: 2095 (<u>103</u> excluding MEDLINE)

Strategy (April 2015):

(("end of life" or "hospice" or "hospices" or "palliative" or "palliatives" or "palliative care" or "terminal care") and ("nurse" or "nurses" or "physicians" or "social workers" or "formal caregivers" or "professional caregivers" or "psychologists")).ti,ab.

Database: Scopus

Filters: Languages; Publication Dates

Total: 5102 (<u>1514</u> excluding MEDLINE)

Strategy (April 2015):

TITLE-ABS ("end of life" OR "hospice" OR "palliative") AND TITLE-ABS ("nurse" OR "physician" OR "social worker" OR "formal caregiver" OR "psychologist") AND NOT TITLE-ABS (adolescent OR pediatric* OR paediatric* OR infant* OR child) AND (LIMIT-TO(PUBYEAR,2015) OR LIMIT-TO(PUBYEAR,2014) OR LIMIT-TO(PUBYEAR,2013) OR LIMIT-TO(PUBYEAR,2012) OR LIMIT-TO(PUBYEAR,2011) OR LIMIT-TO(PUBYEAR,2010) OR LIMIT-TO(PUBYEAR,2009) OR LIMIT-TO(PUBYEAR,2008) OR LIMIT-TO(PUBYEAR,2007) OR LIMIT-TO(PUBYEAR,2006) OR LIMIT-TO(PUBYEAR,2005)) AND (LIMIT-TO(SUBJAREA,"MEDI") OR LIMIT-TO(SUBJAREA,"NURS") OR LIMIT-TO(SUBJAREA,"HEAL")) AND (LIMIT-TO(LANGUAGE,"English") OR LIMIT-TO(LANGUAGE,"Spanish") OR LIMIT-TO(LANGUAGE,"Portuguese")) AND NOT (PMID (1*) OR PMID (2*))

Database: DART-Europe

Filters: Languages; Publication Dates

Total: <u>19</u>

Strategy (April 2015):

("End of Life" OR hospice OR palliative OR "Palliative Care" OR "terminal care") AND (Nurse OR Physician OR "Social worker" OR "formal caregiver" OR "professional caregiver" OR "formal caregivers" OR "professional caregivers" OR Psychologist)

Database: OpenGrey

Filters: Languages; Publication Dates

Total: <u>5</u>

Strategy (April 2015):

("End of Life" OR hospice OR palliative OR "Palliative Care" OR "terminal care") AND (Nurse OR Physician OR "Social worker" OR "formal caregiver" OR "professional caregiver" OR "formal caregivers" OR "professional caregivers" OR Psychologist)

Database: Grey Literature Report

Total: <u>0</u>

Strategy (April 2015):

("End of Life" OR hospice OR palliative OR "Palliative Care" OR "terminal care") AND (Nurse OR Physician OR "Social worker" OR "formal caregiver" OR "professional caregiver" OR "formal caregivers" OR "professional caregivers" OR Psychologist)

workers. From the 22 articles identified, 14 were conducted in PCUs and the other 8 in inpatients hospices.

The content of the studies was described and classified in 5 main elements identified in the articles: (i) construction and application of the concept of care (including what caring for HCPs means, how they provided this care, and with what objectives. It also includes the factors that intervened in the development [construction] of this meaning, provision, and purpose); (ii) psychosocial effects that daily care produces (including the personal, professional, emotional, and psychological repercussions that come from working in PC); (iii) working conditions that influence the caregiving provided (including facilitating factors and difficulties that are extrinsic to the professional, but that influence the care provided, such as the time available for caring, teamwork, or the paradigm of healing still prevalent in some professional teams); (iv) knowledge mobilized in the provision of care (including not only academic knowledge but also the knowledge that derived from the professional experience and the personal experience of each professional; and (v) strategies adopted by HCP to build relationships (including the strategies adopted to build relationships with the team and the patient). All these elements are interrelated and mutually influential, and none of these elements is absolutely distinct from others, existing the possibility of a cross between them.
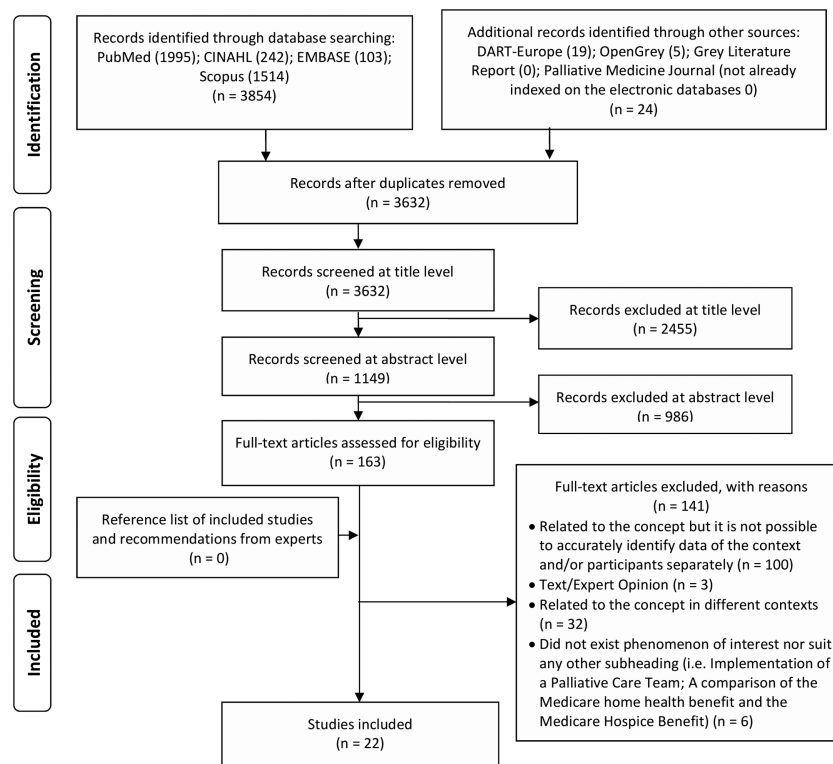
Figure 1. PRISMA flow diagram of the scoping review process.

Construction and application of the concept of care by HCPs

HCPs mention that for them care means a sense of purpose and honor and devote a high degree of commitment to their role.[29,31] The findings of the studies included mention that the goal of care is to provide a peaceful death. They also mention total pain as a reason for PC sedation and that the care provided should ensure that the bereaved would not have memories of their loved ones dying in distress.[32]

Therefore, to achieve freedom from pain is one of the priorities of comfort care, but pain relief and minimizing the pathophysiological symptoms were insufficient for the patients' fully experience of comfort.[33] Care means to provide calm and relaxation, sometimes with a silent compassion and caring touch, a feeling of rest and freedom from the mental and emotional distress. It is about alleviation of patient suffering, relief from mental and emotional distress, and the different ways in which people express their spirituality and their fear of death and dying. It means providing care in a physical, emotional, and spiritual way, not only helping patients to live but also helping patients to die serenely. The mental focus of care has shifted from doing something for the patient to being with the patient and enhancing their quality of life. The focus is now on the individual, and the concept of care has a holistic approach.[31,33–35]

HCPs report not considering death as a failure but as something that needs to be lived; this perspective gives them a motivation to find the meaning of care in their work. This sense of commitment also influences caregiving.[36] HCPs were still concerned about life as the most valuable commodity, regardless of the time remaining.[33] Furthermore, considering death as a part of life became an expression of their consideration for life itself as a cycle.[29] HCPs' experiences of care contributed to greater understanding of death as a part of life[37]; death was not seen as something aggressive, and they did not feel powerlessness before death.[30] The explanation could be the experience that nothing could be done to change the outcome of the disease.[34]

Such reality shows that it is possible to care for patients at the EoL differently and make death more human while fostering one's personal development.[36] Comforting the patients in their vulnerable EoL situation, recognizing patient autonomy, and providing a care sustained by ethics were the motivation that guided their work; they feel passion for their work in this context even when it is seen as stressful.[29,37–39]

Psychosocial effects that the daily care of people at EoL produces in HCPs

The daily care of EoL patients spurs an awareness of the HCPs' own spirituality, mortality, and finitude of their own existence.[31,34,37,38] Findings show that this perception led to reflect about the meaning of life and death. Accompanying the patients at the moment of death brought on less anxiety about their own death. Participants expressed that this experience makes them more aware and understanding, and leads them to bringing up the subject of death when talking with their own families.[35] Through this experience, HCPs gain greater human and communication competency. Moreover, their close witnessing of death becomes a reminder of the importance and meaning of taking care of their health.[34,37] They perceive positive changes in their thinking on the subject of death since their work in PC.[30] We need also to be aware that facing patients' suffering could sometimes trigger feelings of uncertainty and vulnerability.[35]

Gama et al[40] show that PC nurses had a statistically significant higher Purpose in Life score (112.00) compared with internal

Table 2

Extraction instrument

Author; year; country	Aims	Study design	Context	Participants	Main findings	Elements
Ablett and Jones (2007); UK [31]	To understand the factors that help to promote resilience and mitigate the effects of workplace stress.	Qualitative methodology (Grounded Theory)	Hospice	Nurses (n = 10)	HCP mentioned a high degree of commitment to their role. An active election to work in PC. Meaning to their work, and a sense of purpose. Some saw the challenge associated with their work as a significant factor in gaining a sense of satisfaction and achievement and some stated that that they disliked change and preferred a degree of stability. An awareness of their own mortality and spirituality led them to perceive aspects of their work as comprehensible. Cope strategies as have a proper support system at home, social life, talk to colleagues and actually discuss feelings. HCP acquire knowledge through past personal experience (close relative dying, previous experience working in hospitals) and nursing training.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Bezerra do Amaral et al (2012); Brazil [44]	To analyze ethic and bioethics dilemmas experienced by nurses who take PC for hospitalized elderly.	Qualitative methodology (Explanatory-Descriptive)	PCU	Nurses (n = 10)	Participants do not issue information, nor do they wish to inform patients on their state of health and closeness of death. Adequately structured PC, with guidelines established for difficult decision making, is of fundamental importance. It is impossible to disassociate the historical and cultural aspects in the daily lives of HCP. The influence of curative training is still strongly linked to the difficulties found in the credible comprehension of the principles and philosophies of PC.	Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Dee and Endacott (2011); UK [45]	To identify factors that clinicians consider when a patient is dying.	Qualitative methodology (Husserlian Phenomenological study)	Hospice	Nurses (n = 5) Doctors (n = 5)	Participants mentioned the importance of multidisciplinary teamwork. However, some nursing staff may have felt their opinions were somewhat ignored. Experienced clinicians would recognise when a patient was close to death, but not necessarily know when death would occur. When carers accepted that the patient was dying, this was a positive factor. HCPs might be avoiding talking about the difficult issue of death to relatives who are in denial about their loved one's imminent death. Managing staff may need to ensure that clinical staff receives suitable training to improve their communication skills.	Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care Strategies Adopted by HCP to Build Relationships
Evans and Hallett (2007); UK [33]	To explore the meaning of comfort care for hospice nurses. To examine the means by which hospice nurses provide comfort to hospice patients.	Qualitative methodology (Hermeneutic Phenomenological study)	Hospice	Nurses (n = 15)	Many participants referred to pain relief as a priority and an important goal for nurses to provide comfort. Pain relief and minimizing physio-pathologic symptoms were insufficient to achieve patients' total comfort. Spiritual comfort was a relief from emotional anguish and the expression of their spirituality. Comfort was also about helping people deal with the heavy burden of a near death. Nurses are aware that life is a valuable commodity, regardless how long or short the time remaining. Effective comfort requires time. Attention to patients and relatives should take time.	Construction and Application of the Concept of Care Working Conditions that Influence the Caregiving Provided Strategies Adopted by HCP to Build Relationships
Källström Karlsson et al (2008); Sweden [37]	To explore five nurses' experiences of regularly having to face patients' incurable illnesses, dying, and death.	Qualitative methodology (Interpretive descriptive)	Hospice	Nurses (n = 5)	Dealing with dying patients had a great impact on nurses' daily work and their private lives. Supporting patients in such a vulnerable situation was inspiring for nurses in their work, but was also experienced as a stress factor. The feeling of reward for the work done compensated for the difficulties encountered. Nurses' experiences contributed to a deeper understanding of life and death. Dealing with dying patients, being present and caring for them at the time of their death seemed to make them feel less anxious about their own death.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Knowledge Mobilized in the Provision of Care

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Table 2

(continued).

Author; year; country	Aims	Study design	Context	Participants	Main findings	Elements
					This reality became a reminder to better care for their own health, and led them to talk about the topic of death with their own relatives. As a means to prevent pain and anxiety, most HCPs tried not to think too much or too often about their patients when not at work. The capacity to establish a border between work and leisure time improved with time in the job.	
Martins and Basto (2011); Portugal [34]	To understand the nursing intervention process used in relieving the suffering of end-of-life inpatients.	Qualitative methodology (Grounded Theory)	PCU	Total (n = 47) nurses (n = 19) patients (n = 9) relatives (n = 19)	Patient pain relief at the EoL is achieved through the nurse's accompaniment. Nurses help patients die serenely by providing support for their EoL comfort and spiritual needs, and by facilitating relatives to be present. Nothing can be done to alter the course of the illness. Close contact with suffering provides nurses with skills to enable more humane relationships and helps them deal better with their own grief and that of others. When facing suffering and death, nurses become aware of the finitude of their own existence. The state of almost permanent suffering makes nurses more mature, energetic and able to deal with suffering and death.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Oliveira et al (2007); Brazil [38]	To analyze the nursing concept of autonomy of terminal patients and what is the nurse perspective in the presence of autonomy while has being structure in Brazil.	Qualitative methodology (Content Analysis)	PCU	Nurses (n = 7)	The care of PC patient requires that HCP is responsible for articulating the relationships within patient; family; heath professional and to communicate effectively with them. Patient autonomy challenges nurses in their work routine because it confronts them with their own mortality. Some nurses react with judgments and neglect the patient's autonomy, faced with a Care model in which the paradigm of healing is prevalent.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided
Oliveira and Silva (2010); Brazil [39]	To analyze the concept the health team applies relating to autonomy of patients and identify what is the attitude of such professionals before the manifestation of this autonomy.	Qualitative methodology (Descriptive exploratory)	PCU	Physicians (n = 4) Psychologist (n = 1)	HCPs in this area allow sufficient autonomy to establish a solid trajectory in treating EoL patients, making sure that physical conditions such as decreased levels of consciousness are not a limiting factor in developing a care plan sustained by ethics. Verbal and non-verbal communication was reported as key for human relationships, sustainability and autonomy according to the individual's expectations. Communication in health care environments, PC in particular, is seen as a natural principle.	Construction and Application of the Concept of Care Working Conditions that Influence the Caregiving Provided Strategies Adopted by HCP to Build Relationships
Shimoinaba et al (2014); Japan [29]	To describe Japanese PC nurses' experience of loss and grief.	Qualitative methodology (Grounded Theory)	PCU	Nurses (n = 13)	Witnessing death in the daily work led nurses to recall personal losses and to experience grief again. It is not always possible to optimally meet the needs; there is ground for reduced confidence and self-esteem and a sense of failure. Grief could only be accepted when nurses acknowledged their own emotions related to loss. It was helpful when the multidisciplinary team was open to share feelings. Most participants expressed their passion for their work at PCU and their sense of honour in caring for dying patients and their relatives. Participants expressed gratitude and feeling privileged at helping a person in the last moments of their life.	Construction and Application of the Concept of Care Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care

(continued)

Table 2
(continued).

Author; year; country	Aims	Study design	Context	Participants	Main findings	Elements
Tornøe et al (2014); Norway [35]	To describe the meaning of hospice nurses' lived experience with alleviating dying patients' spiritual and existential suffering.	Qualitative methodology (Phenomenological hermeneutical)	Hospice	Nurses (n = 8)	The nurses' frame of mind had shifted from "doing something for the patient" to "being with the patient". Past experiences and personal beliefs also have an impact on well-being. Advanced PC treatment sometimes caused nurses to spend less time with the patient, which created ethical dilemmas. Facing patient's suffering could sometimes bring memories of past grief to nurses and feelings of powerlessness, vulnerability and uncertainty. Support meetings with work colleagues were helpful in coping with the stress of caring for dying patients.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Zinn and Moriarty (2012); Scotland [32]	The aim of this study was to explore the knowledge, perceptions, and experiences of hospice nurses with palliative sedation.	Qualitative methodology (Exploratory cross-sectional design)	Hospice	Nurses (n = 5)	Nurses explain palliative sedation as a proportionate response to terminal suffering. They reported patients' fear and anxiety, along with physical symptoms and overall pain as reasons for palliative sedation. Nurses acknowledged team support as important to cope with the decision of using palliative sedation. They saw palliative sedation as a brave and collaborative initiative, while they also acknowledged the ethical implications. Nurses described team support and clinical and practical supervision as key to improving their coping strategies. All nurses agreed that the goal was to help patients die in peace and comfort.	Construction and Application of the Concept of Care Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Gama et al (2014b); Portugal [40]	To identify professional exposure to dying, training degree and personal factors relevant to burnout dimensions in nurses coping with death issues.	Quantitative, descriptive and correlational (Maslach Burnout Inventory, Death Attitude Profile Scale, Purpose in Life Test and Adult Attachment Scale).	Department: Internal medicine Oncology Hematology PCU	Nurses (n = 360) 52.8% 13.6% 19.4% 14.2%	Significant differences were found between medical departments in burnout scores when comparing those with PCU. In medical units there are a higher percentage of nurses with undergraduate training in PC and in PCU a higher percentage of nurses with postgraduate training in PC.	Psychosocial Effects that the Daily Care of People at EoL Produce Knowledge Mobilized in the Provision of Care
Gama et al (2012); Portugal [41]	To identify the most frequent attitudes that nurse have toward death and to see which sociodemographic, professional, and training factors significantly affect attitudes toward death.	Quantitative, descriptive, Cross-sectional and correlational (Death Attitude Profile, Adult Attachment Scale).	Department: Internal medicine Oncology Hematology PCU	Nurses (n = 360) 52.8% 13.6% 19.4% 14.2%	The PC nurses had significantly lower levels of the fear of death, death avoidance, and escape acceptance dimensions than the other groups, a significantly higher score for neutral acceptance, and similar scores for religious acceptance. The study suggests that nurses with more work experience with terminally ill patients show higher escape acceptance and religious acceptance. Background/personal experience with death appears as a facilitator to dealing positively with new confrontations, whether work-related or personal, which is to say that more work experience leads to less anxiety toward death and to more positive attitudes toward caring.	Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Gama et al (2014a); Portugal [36]	To identify which factors can positively impact the construction of meaning of life in nurses.	Quantitative, descriptive correlational (Purpose in Life test and Adult Attachment Scale).	Department: Internal medicine Oncology Hematology PCU	Nurses (n = 360) 52.8% 13.6% 19.4% 14.2%	PC nurses had a statistically significant higher Purpose in Life score (112.00) compared with internal medicine nurses (107.46), oncology nurses (105.37) and hematology nurses (104.51). Positive statistically significant correlations exist between Purpose in Life scores and PC training. The higher Purpose in Life scores found in PC departments tend to show that PC nurses do not consider death as a failure but as	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care

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Table 2
(continued).

Author; year; country	Aims	Study design	Context	Participants	Main findings	Elements
					something that needs to be lived.	
Henoch et al (2014); Sweden [43]	To compare Attitude Toward Care of the Dying among Swedish nurses and nursing students with those from other languages, and to evaluate influences of experiences on attitudes toward care of dying patients.	Quantitative, descriptive, cross-sectional, and predictive (FATCOD).	Department: 3 Hospices Oncology Surgical Palliative home care Students	Nurses (n=213) (n=46) (n=23) (n=27) (n=17) (n=100)	With regard to place of work, hospice registered nurses had the most positive attitudes. There were significant differences on Attitude Toward Care of the Dying between nurses at hospices compared with nurses in surgical wards and in oncology. This may be explained by the culturally different attitudes toward care in hospices and hospital wards. More emphasis on the care of dying patients is deemed necessary in nurse training, at theoretical and practical levels, preferably by HCPs with experience and positive attitudes toward the care of dying patients.	Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care
Martens (2009); USA[42]	To determine the perceived stress factors of inpatient and home hospice nurses and their correlation to perceived self-efficacy.	Quantitative, descriptive cross-sectional (Nursing Stress Scale).	Department: Home hospice Hospice	Total nurses (n=146) (n=79) (n=63)	Research has shown that excessive workload demands and conflicting expectations are examples of stressful working conditions.	Working Conditions that Influence the Caregiving Provided
Miyashita et al (2008); Japan [25]	To clarify nurses' views of discussions among nurses and physicians regarding artificial hydration for terminally ill cancer patients.	Quantitative survey (Questionnaire developed and validated by the Japan Palliative Oncology Study Group).	Department: Oncology PCU	Total nurses (n=3328) (n=2735) (n=593)	Only 68% of palliative care nurses report being heard on artificial hydration. Nurses deem their influence on decision-making as insufficient. Eo patients tend to reject medical treatment, which puts nurses in a difficult position when artificial hydration is prescribed for symptom relief. PC nurses evaluate discussion in the units as positive.	Working Conditions that Influence the Caregiving Provided Strategies Adopted by HCP to Build Relationships
Nakazawa et al (2013); Japan [27]	To clarify physicians' practices and attitudes regarding advance care planning in PCU in Japan.	Quantitative nationwide cross-sectional survey (Questionnaire developed and validated by the authors).	PCU	Physicians (n=99)	Physicians who had negative practices regarding Advance Care Planning and Advance Directives experienced significantly more difficulties in assessing patients' decision-making capacity (p= 0,005) and in listening to patients regarding their EOL care wishes (p=0,026), compared with physicians with positive practices. Physicians who had negative practices showed significantly less trust in the guided decision making by the Advance Directives in a catastrophic situation (p=0,020).	Working Conditions that Influence the Caregiving Provided
Murakawa and Nihei (2009); Japan [26]	To understand differences in how Japanese cancer care staff perceive a "good death."	Mixed method (28 components of a "good death," identified in a previous study); One freely question.	Cancer Centre:PCU Non PCU	Physicians (n=14) surgeons (n=15) nurses (n=13) nurses (n=122)	When asked how they would help patients prepare for dying, doctors mainly used talking approaches; palliative ward nurses mainly used listening and discussing approaches. Nurses of both types were more likely to use more concrete means (for example, 'help to have time with family and friends' and 'ask for the help of a psychotherapist').	Strategies Adopted by HCP to Build Relationships
Santisteban Etxeburu and Mier (2006); Spain [30]	To know what stressors impact on each profession directly dealing with end-stage patients.	Mixed method (Death Anxiety Scale; Maslach Burnout Inventory; questionnaire developed by the authors).	PCU	Physicians (n=4) nurses (n=4)	HCPs perceive positive changes in their thinking on the subject of death since they started working in PC. No HCPs considered seeing death as more aggressive or felt powerless before death. The most marked stressors are team relationships (communication, feeling valued, recognition tasks, decision making). All nurses recognized viewing the death of patients in a more natural manner.	Construction and Application of the Concept of Care Psychosocial Effects that the Daily Care of People at EoL Produce Working Conditions that Influence the Caregiving Provided

(continued)

Author; year; country	Aims	Study design	Context	Participants	Main findings	Elements
Shimoinaba and Lee (2007); Japan[28]	To identify the personal support needs of general nurses and PC nurses caring for PC patients in Kyushu, Japan.	Mixed method (Questionnaire developed by the authors).	Department: 6 PCU 6 General Hospitals	Total nurses (n=207) (n=90) (n=117)	There was a statistically significant difference between the 2 groups regarding 'anxiety' (p=0.029), with general nurses claiming significantly more 'anxiety' while caring for PC patients than PC nurses. Family and friends were valued support for both groups too. PC nurses ranked the need for support from staff/colleagues more highly than general nurses. Low confidence about the care they are providing leads to lower job satisfaction.	Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care Strategies Adopted by HCP to Build Relationships
Timmermann et al (2009); Belgium[46]	The relationship between defence mechanisms, coping strategies, palliative attitude, and the well-being of caregivers in PCU.	Mixed method (semistructured interview; Thematic Apperception Test; COPE inventory; Ways of Coping and Defence Style Questionnaires; Palliative Care Attitude and Well-being Scales)	PCU	Nurses (n=18)	HCP prefer to use mature defence mechanisms (humour, altruism, affiliation). The older a caregiver is, the more he or she uses the defence mechanism of self-assertion and the coping strategy of acceptance. The longer his or her experience, the more the caregiver uses the defence mechanism of self-assertion through the expression of feelings. A weak score for well-being is predicted by high number of defence mechanisms (narcissistic, denial and distortion, and acting out) and of coping strategies (disengagement, around problem coping, and humour).Anxiety is also decreased by group exchange.	Working Conditions that Influence the Caregiving Provided Knowledge Mobilized in the Provision of Care

Table 2 (continued).

medicine nurses (PIL 107.46, $t=2.07$, $P < .040$), oncology nurses (PIL 105.37, $t=2.52$, $P < 0.013$), and hematology nurses (PIL 104.51, $t=2.98$, $P < 0.003$), and also lower burnout scores when comparing those medical departments with PCUs (significant lesser levels of emotional exhaustion [$t=2.71$; $P < 0.008$], depersonalization [$t=3.07$; $P < 0.003$], and higher levels of personal accomplishment [$t=2.24$; $P < 0.027$]).[36] This is in accordance with the article which mentions that palliative HCP had significantly lower levels in the fear of death, death avoidance, and escape acceptance dimensions than the other departments, a significantly higher score for neutral acceptance, and similar scores for religious acceptance.[41]

Working conditions that influence the caregiving provided

Excessive workload demands and conflicting expectations are examples of stressful working conditions for nurses.[25,42] Studies mentioned that past personal experience, professional experience (more work experience leads to less anxiety toward death and to more positive attitudes toward caring), and the establishment of personal and professional boundaries help to deal with these issues when providing care.[31,35,41,43] HCPs become skilful in coping with the suffering of others and their own,[34] and gain awareness of how meaningful the relationships established through their role can become.[29]

Nonetheless, it is impossible to disassociate the historical and cultural aspects in the daily lives of HCPs, and it is a constant challenge due to their own prejudices and values.[38,43,44] The influence of curative training is still strongly related with the difficulties found for the real understanding of the principles and philosophies of PC.[36,44] In a health care model in which the paradigm of healing is prevalent, some professionals react with judgments and neglect the patient's autonomy.[38]

The importance of multidisciplinary teamwork was mentioned too. However, 2 of the articles suggested that some HCPs may feel that their opinions are not considered, which could be frustrating and affect the caregiving.[29,45] One study even mentioned that team relationships are the most marked stressors,[30] instead of being an opportunity for sharing experiences and looking for support.[36]

In addition, communication skills were mentioned as a factor that could improve the care provided. Communication, particularly in PC, is viewed as a natural principle, and communication skills training should be provided by the managers.[32,35,39,45]

Other fundamental factors that influence the caregiving in PC are as follows: an adequately structured PC, with guidelines established for difficult decision making[44]; the participation in the decision-making process, and how the professional is closely involved[25]; and time because comfort care takes time. Time is needed to develop a sense of dependability with patients and families, to establish meaningful communication, and to deliver sensitive and effective clinical care. Taking the time to be present, ensuring that people are made to feel that they "matter" when they reach the point of greatest overcoming vulnerability.[33,35,36]

Physicians, who displayed negative practices regarding advance care planning and advance directives, found significant added difficulties in appraising the patient's decision-making capacity ($P=.005$), letting the patients express their wishes for EoL care ($P=.026$) and lower confidence in treatment decisions in a catastrophic situation ($P=.020$), compared with physicians with positive practices.[27]

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One of the studies mentioned that low confidence in the care provided leads to lower job satisfaction.[28] As it is not always possible to address a numerous variety of needs to fully satisfy patients, trust is likely to be reduced, as self-esteem, and sometimes one may experience a feeling of failure as a palliative professional. This could cause doubts as to whether or not the full professional ability has been displayed to support patients, and could influence the way care is provided.[29] Confidence, trust, and experience are necessary in the provision of care,[32] meaning that it seems essential that HCPs use defense mechanisms and coping strategies simultaneously.[32,46]

The last factor mentioned by the included studies was the support from staff, including the unit manager, educator (supervisor) colleagues,[28,32,35] family and friends.[28]

Knowledge mobilized in the provision of care

In the provision of care, HCPs need to possess several coping strategies such as having a good support system at home, social life, psychological strength, balance of mind and body, and assuming responsibility in caring for their own feelings by talking to colleagues and discussing their feelings or how to manage cases.[28,31] Furthermore, as previously mentioned, the HCP knowledge and personal experiences have an important influence in the care provided,[29,32,43,44] for example, being able to use silence for therapeutic and comforting purposes.[35]

In fact, HCPs with more work experience with terminally ill patients had higher escape and religious acceptance, which is explained by the developed strategies in dealing with their emotional response to death and dying.[41]

For example, after having worked for an extended period, they improved the ability to clearly differentiate between work and leisure time.[37] An experienced clinician would acknowledge when a patient's EoL is near and take the necessary action to accompany a patient during the last hours of their life.[29,34,45] Personal experience with death appears as a facilitator to dealing positively with new confrontations, whether work-related or personal.[41,46]

A study shows that there is a higher percentage of nurses with undergraduate training in PC in medical units such as hematology; internal medicine; and oncology, than in PCUs, where there is a higher percentage of nurses with postgraduate training. Further training seems to provide more coping strategies in dealing with EoL care, as PC professionals had less levels of burnout compared with other departments.[40] As a positive statistically significant correlation between Purpose in Life scores and PC training was also found, knowledge about coping strategies seems to be important.[36]

Strategies adopted by HCPs to build relationships

Dee and Endacott[45] and Shimoinaba and Lee[28] mentioned that seeking the support of colleagues could be a way to develop a strong relationship between team members. One way to build relationships was to help people "to deal with the heavy burden of death awareness by entering into their world in a compassionate and connected interpersonal relationship."[33] HCPs also recommend more active communication between team members.[25] Verbal and nonverbal communication was considered key in mediating between relatives, individuals, and professionals.[39] Palliative HCPs mainly used listening and discussing approaches to help patients prepare for death. They were more likely to use more concrete means than nonpalliative professionals.[26]

Discussion

This scoping review identifies 5 key elements around the construction of the HCP concept in the context of PC: construction and application of the concept of care; psychosocial effects that daily care produces; working conditions that influence the caregiving provided; knowledge mobilized in the provision of care; and strategies adopted by HCP to build relationships; and it also identifies research gaps in the existing literature such as the absence of the perspective of all the members of the multidisciplinary team.

As mentioned by HCPs in the studies included care means a sense of purpose and honor with a high degree of commitment to their role.[29,31] Nevertheless, other studies showed that the experience of witnessing patients' dying and death overtime had a great impact on the professionals' day-to-day work and in their private lives, and is also seen as stressful. In a way of preventing grief and anxiety, most professionals "tried to avoid thinking too much, too often, or too intensely about their patients when they were not at work."[37] However, it seems that the feeling of reward and recognition obtained through their commitment compensated for any difficulties and was even the inspiration that guided their work.[37]

From the analysis of the included articles, it seems that the daily care of people at EoL is not affecting the HCP at a high level compared with other units. The levels of burnout are lower in PC professionals,[40] as they undergo positive changes in their perception of the subject of death from their work in a PC context. However, it is necessary to interpret the data (self-reported questionnaires), through the participants' contribution.

Miyashita et al[25] mention that sometimes PC nurses are put in uncomfortable situations by physicians. However, data were gathered retrospectively on nurses' views only, which might be subject to incomplete or mistaken recalling and does not take into consideration the view of other professionals. Further studies should address which strategies should be adopted to deal with such an uncomfortable situation. In this sense, it is important to mention that the sample of most included studies is constituted by nurses, which is perhaps justified by nurses constitute the HCP that remains more time with patients, ensuring its caring 24 hours a day.[47–49]

HCPs might be avoiding talking about the difficult issue of death to relatives who are in denial about their loved one's imminent death, and therefore appropriate communication skills training is required.[45] Even mentioning the importance of these programs, it is still not clear which are the real needs or strategies that need to be adopted. As mentioned in Henoch et al,[43] a first step could be to take into consideration that both theoretical and practical education should be provided, preferably under the supervision of HCPs with positive attitudes toward care of dying patients.

HCPs seem to acquire greater human and communication capacities[34]; however, the literature did not mention precisely those relationship competencies. HCPs are responsible for articulating the relationships between patient, family, and other HCPs, and to communicate effectively with them, but the reality is that the strategies they use in this process are not clear.[38]

The most marked stress factors, however, seem to be team relationships. It seemed that some nursing staff were feeling somewhat ignored in their opinions, which could be a source of frustration.[30,45] Further investigations should try to provide understanding on which strategies should be adopted to avoid this element of stress.

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The element of communication is considered as a natural element of team cohesion and a means of influencing others.[39] HCPs should enter into their patients' worlds in a kind-hearted way and have an interpersonal relationship; they therefore need time for meaningful communication.[33]

Another aspect to be discussed is the fact that this scoping includes studies conducted in 10 countries; however, the countries with the most articles included are Japan (5 studies) and Portugal (4 studies). This data is curious given that Japan was one of the first countries which emerged PCUs (70s)[50] and is one of the countries that has PC well integrated into his health care system.[51] Portugal, for its part, where CP started only in the 90s,[50] is recognized for actively developing PC in the country.[51] Perhaps this data (although distinct) justifies the high research activity in these 2 countries. Although in all the included studies the elements can be considered universals, in these 2 countries it is noteworthy that none of the studies published in Japan addresses the element "Psychosocial Effects that the Daily Care of People at EoL Produce," and none of the studies published in Portugal addresses the element "Strategies Adopted by HCP to Build Relationships," which is possibly due to cultural issues.

This study is unique in including publications not only in English but also in Spanish, Catalan, and Portuguese, thus broadening the scope and enabling these cultural comparisons.

Limitations of the scoping review

This scoping review has some particularities that limited our capacity to comprehensively understand the problem under analysis.

In the articles mentioning social workers these had been included in larger samples with participants who did not fit our inclusion criteria and had not followed the analysis separately.[30] Most of the studies analyzed in this scoping review were not carried out taking into account all team members of the multidisciplinary team. In 18 articles data were only gathered retrospectively on nurses' views. Although we use the term HCPs because our study is centered upon the multidisciplinary team, most of the data relate to nurses. Therefore, this limits any possible generalization among other HCPS involved in the EOL care.

It was not the main purpose of this scoping review to examine which palliative team members were the focus of the studies; however, our results suggest that it would be positive to incorporate other team members' perspectives into PC team discussions to inform about their work and to have an input in drawing up multidisciplinary team planning.

In addition, the scoping review included studies with imbalanced sample sizes and concerns exist about the rigor of study designs. However, a clear research question, a clear research strategy, and appropriate and strong inclusion criteria provide validity to its findings.[52]

Finally, due to the fact that the number of included studies is high, and a broader description would have repercussions on a table of high dimensions, the findings presented in Table 2 are only the main findings; however, in "Results" section we presented a more detailed exploration in narrative form.

Implications for research

The analysis of the existing evidence does identify gaps in the literature, resulting in recommendations for future research.

It seems necessary in future research to understand whether the impact of care at EoL and the stress and anxiety suffered by HCP are ever compensated by the satisfaction, sense of commitment, and purpose of the work they do, compared with other health care departments. It is also important to understand whether the lower levels of burnout reported by PC professionals are specific to Portugal or they could be generalized to other countries. A systematic review of the literature focused on the prevalence of burnout could help in this understanding.

The state of the science on HCPs' concerns and needs is evolving. Research evidence requires further research in these areas to find the best strategies and theories on how to provide this care in the most possibly efficient manner. An intentional focus on understanding the elements that contribute to the construction of the HCP in the specific context of PC is needed to improve not only the welfare of the HCP but also the care provided to the patient at EoL. This assumes a role of significant relevance for the caregiver and the patient who receives care at this singular moment.

It is also recommended the realization of studies that address the element "psychosocial effects that daily care produces" in the Japanese context, and studies that address the "strategies adopted by HCP to build relationships" element in the Portuguese context. This could be an important theme of analysis in future research because this lack of evidence incurs caregiving costs that may not be tangible. The empirical knowledge that facilitates the professional growth of PC teams should become a priority.

Finally, the literature reveals that working in PC leads to feelings of intense emotions, evidencing the fragility and limitations of human life, which could lead to several stressful and demanding challenges. However, comparing to nurses in other contexts, nurses working in PC have lower levels of burnout.[53] This ambiguity demonstrates the importance to develop more primary studies to understand how nurses experience the caring in PC.

Conclusions

This scoping review examined the extent, range, and nature of the research activity around which elements contribute to the construction of the HCP in the context of the PC and identifies 5 key elements: construction and application of the concept of care; psychosocial effects that daily care produces; working conditions that influence the caregiving provided; knowledge mobilized in the provision of care; strategies adopted by HCP to build relationships.

This scoping review contributes to the generation of a solid body of empirical knowledge that facilitates the professional growth of PC teams becausre it identifies key elements in the concept of the HCP construction, revealing the importance of developing specialized training programs and adding new elements to define strategies of action, showing the necessity of promoting interpersonal skills and emotional management mechanisms. It also reinforces the need to incorporate all team members' perspectives, such as social workers, in PC team discussions, evidencing that none of the articles retrieved offered the perspective of all the disciplines of the multidisciplinary team.

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Author contributions

VOP participated in the design of the study, carried out the study and had the main responsibility for writing the manuscript. ANC, AAR, and MGS participated in conceiving the study and writing the manuscript. RPP, JAA, and JBB supported data analysis and writing the manuscript. All authors helped in revising and making substantial contributions to the manuscript, and also read and approved the final manuscript.

Conflicts of interest

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