

Diagnostic assessment of the comfort of palliative patients: scoping review protocol

Avaliação diagnóstica do conforto na pessoa em situação paliativa: protocolo de scoping review

Evaluación diagnóstica del confort de la persona en situación paliativa: protocolo de revisión del alcance

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Abstract

Introduction: The competence to evaluate is essential in any profession in the health area. The concept of comfort is intrinsically linked to palliative care, being a concern shared by any health professional. These, when analyzing, must know what they are looking for and what they should expect to find. **Objectives:** To map how health professionals assess people's comfort in palliative and end-of-life situations. **Methods:** will follow the methodology proposed by the Johanna Briggs Institute (JBI) for scoping reviews. Considered studies in Spanish, English and Portuguese, without temporal definition. **Databases to search:** MEDLINE Complete, Academic Search Complete, CINAHL Complete and Mediclatina (EBSCOhost), Scopus and Web of Science Core Collection. For unpublished studies, the RCAAP (open access repository in Portugal) will be used. Two independent reviewers will evaluate the articles and extract the data using a specific tool created. In case of discrepancies, a third reviewer will be requested. **Results:** It is expected to map the data used by health professionals in assessing the comfort of people in palliative care. **Conclusions:** This review will make it possible to identify instruments used to collect data and what is the professional competence of the group that has in its practice the assessment of comfort. This can form the basis for a systematic review and/or help identify gaps where it may be important to invest in the future. This protocol was registered on the OSF platform with the DOI: 10.17605/OSF.IO/UF52X.

Keywords: Patient comfort; Palliative care; Terminal care.

Resumo

Introdução: A competência para avaliar é essencial em qualquer profissão na área da saúde. O conceito de conforto está intrinsecamente ligado aos cuidados paliativos, sendo uma preocupação compartilhada por qualquer profissional de saúde. Estes, quando analisam, devem saber o que estão à procura e o que devem esperar encontrar. **Objetivos:** Mapear como os profissionais de saúde avaliam o conforto das pessoas em situação paliativa e fim de vida. **Métodos:** Esta revisão seguirá a metodologia proposta pela Johanna Briggs Institute (JBI) para scoping reviews. Serão considerados estudos descritos em espanhol, inglês e português, sem definição temporal. As bases de dados a pesquisar serão: MEDLINE Complete, Academic Search Complete, CINAHL Complete e Mediclatina (via EBSCOhost), Scopus e Web of Science Core Collection. Para fontes de estudos não-publicados será usada a pesquisa no RCAAP (repositório de acesso aberto em Portugal). Dois revisores independentes avaliarão os artigos e extrairão

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os dados usando uma ferramenta específica criada. Existindo divergências, um terceiro revisor será requisitado. Resultados: Espera-se mapear os dados utilizados pelos profissionais de saúde na avaliação do conforto das pessoas em situação paliativa. Conclusões: Esta revisão permite identificar a evidência científica sobre os dados que os profissionais de saúde utilizam na avaliação do conforto da pessoa em situação paliativa, quais os instrumentos que são utilizados para a recolha destes dados, e qual o grupo profissional que tem na sua prática a avaliação do conforto. Esta pode ser a base para uma revisão sistemática e/ou ajudar a identificar lacunas onde pode ser importante investir no futuro. Este protocolo foi registado na plataforma OSF com o DOI: 10.17605/OSF.IO/UF52X.

Palavras-chave: Conforto do paciente; Cuidados paliativos; Cuidados de fim de vida.

Resumen

Introducción: La competencia para evaluar es fundamental en cualquier profesión del área de la salud. El concepto de comodidad está intrínsecamente ligado a los cuidados paliativos, siendo una preocupación compartida por cualquier profesional de la salud. Estos, al momento de analizar, deben saber lo que buscan y lo que deben esperar encontrar. Objetivos: Mapear cómo los profesionales de la salud evalúan el confort de las personas en situaciones paliativas y al final de la vida. Métodos: Esta revisión seguirá la metodología propuesta por el Instituto Johanna Briggs (JBI) para las revisiones de alcance. Se considerarán estudios descritos en español, inglés y portugués, sin definición temporal. Las bases de datos a buscar serán: MEDLINE Complete, Academic Search Complete, CINAHL Complete y Mediclatina (EBSCOhost), Scopus y Web of Science Core Collection. Para fuentes de estudios inéditos se utilizará RCAAP (repositorio de acceso abierto en Portugal). Dos revisores independientes evaluarán los artículos y extraerán los datos mediante una herramienta específica creada. En caso de discrepancias, se solicitará un tercer revisor. Resultados: Se espera mapear los datos utilizados por los profesionales de la salud en la evaluación del confort de las personas en cuidados paliativos. Conclusiones: Esta revisión permite identificar las evidencias científicas sobre los datos que utilizan los profesionales de la salud para evaluar el confort de la persona en situación paliativa y al final de la vida, qué instrumentos se utilizan para recoger estos datos, y cuál es el grupo profesional que tiene en su práctica la valoración de la comodidad. Esto podría ser la base para una revisión sistemática y/o ayudar a identificar brechas en las que podría ser importante invertir en el futuro. Este protocolo fue registrado en la plataforma OSF con el DOI: 10.17605/OSF.IO/UF52X.

Palabras clave: Comodidad del paciente; Cuidados paliativos; Cuidado terminal.

1. Introduction

To palliate is to comfort, relieve and try to control symptoms, to listen, respect, share, accommodate and accompany, as early as possible, until the end of the patients' life cycle, and even after their life, likewise their family members and significant persons. From this perspective, palliative care base all of their activities, and always as one of their prime purposes, the promotion of maximum comfort for the person who is cared for (Coelho et al., 2016).

Comfort is a state of relief, a sense of security and satisfaction, which can be described as a complex and multidimensional conception, based on a subjective and positive experience, and that can also be experienced by a patient, being this perception by the client as something expected when receiving health care (Gibaut et al., 2013). This concept, related to the concern about the promotion of well-being by the healthcare professional, is also inherently connected to the respect for human dignity, as well as for the vulnerability that arises from the end-of-life processes (Chochinov, 2006; Konietzny & Anderson, 2017; Sandgren et al., 2021). This has also to do with an attitude based on the principle of prevention of everything that may have the potential to be a disruptor of that same state (Ibidem).

Nursing, as a discipline in the health area, has history in developing the concept of comfort. In the case of Nursing theories, "comfort" was, in an initial phase, simply related to physical processes and pain relief. However, there is already a consensus that this conception encompasses a multidimensional aspect, and where different classifications and taxonomies deriving from various views and theories are integrated and articulated (Pinto et al., 2016).

Among these, the works of both Janice Morse and Katharine Kolcaba, stand out for their systematization and clearer definition in relation to this theme, and their theories are still used today when trying to define or support the most correct perspective regarding comfort. If for Morse (2000) this is the result and final stage of well-being resulting from therapeutic attitudes and Nursing interventions, for Kolcaba (2006) this derives from a holistic experience that is evidenced by those who receive comfort care. In fact, for this same author, fulfilment by acting on needs can only be achieved by satisfying the three

types of comfort needs – relief, tranquility and transcendence – incorporated in the four levels of experience: physical, psycho-spiritual, socio-cultural and environmental (Ibidem).

In the final phase of the life cycle, persons in a palliative situation have specific needs for comfort, which are closely related to the promotion of a calm environment, peace and emotional and spiritual stabilization, conflict resolution and social support, in addition to the obvious repercussions they feel in terms of bodily processes and responses on a physical level.

The causes that have the potential to disturb this state of equilibrium have a multidimensional origin, with interconnection of their properties, so it is easy to understand how it will be more gainful when attending to the greatest possible number of aspects, instead of the particularization and single attention to one isolated issue, once a global comfort will always be greater and more significant than the management or even resolution of each of the separate parts.

Being present, observant and interested in everything that surrounds you and has the potential to interfere with the well-being of the patients you care for are essential assumptions of any healthcare profession, being even more relevant in nursing. This observation and monitoring are processing that Nurses use to obtain, analyze and synthesize assessment data, which will underlie their most relevant care domains, and, therefore, the identification and support of nursing diagnoses that will be acknowledged in care plans (Pfrimmer et al., 2017).

Florence Nightingale, the considered “mother of Nursing”, mentions in one of her best-known works that this vigilance and how to correctly do it is the most important practical lesson that can be taught to Nurses. More specifically, Nurses must be trained in what they should observe, how to do it, what it is the meaning of what is perceived, and how they should adapt their care in the face of this (Nightingale, 1860). This skill to observe, monitor, and evaluate, is considered by Nightingale, as one of the most essential qualities - coming to question herself, if not the most important - in the Nursing profession (Ibidem). In order to carry out a correct assessment, nurses must complement the data that are collected, with the meaning that is attributed to that same information, because only then will they be able to assign importance, distinguish situations and assign priorities (Orem, 2001).

Failing to be aware of the definitions and implications of comfort, to systematically assess it and integrate it as essential part of the palliative care Nursing, will certainly be understood by patients as well as by their families as a negative outcome (Lake et al., 2016; Kitson et al., 2013; Tutton & Seers, 2004). This concern for the comfort of persons in a palliative situation is not, however, an exclusive concern of nursing, being worthy of shared attention by the different professions that constitute a formal and specialized team in the provision of palliative care.

The purpose of this review is to explore the current state of scientific knowledge related to how healthcare professionals assess comfort; which instruments and strategies are applied to collect data, which reveal comfort or lack thereof, of patients in palliative and end-of-life care.

Considering this issue, it was decided that the search would be done through a scoping review strategy, once as according to the JBI, these reviews are done “with the objective of providing a map of the range of the available evidence that can be undertaken as a preliminary exercise prior to the conduct of a systematic review” (Aromataris, 2020, p. 6), allowing to record the available evidences about a certain theme, as well as it also makes it possible to identify the main characteristics or factors related to a concept or idea, including those that are related to the methodological research (Munn et al., 2022).

A preliminary search of Open Science Framework (OSF), Medical Literature Analysis and Retrieved System Online (MEDLINE) – via PubMed – and Cumulative Index to Nursing and Allied Health Literature (CINAHL) – via EBSCO – was executed, using the terms “patient comfort”; “evaluation” and “palliative care”. No relevant or similar to the aims of our search work were found (published or in progress) whereby the construction of this scoping review protocol acquired even more importance.

Review questions

This scoping review will be guided by the following research questions:

- What data are used by health professionals to assess the comfort of patients in palliative and end-of-life care?
- What instruments or strategies are used by health professionals to collect this data and assess the comfort of patients in palliative and end-of-life care?
- What is the professional group that has this concern in their practice to assess the comfort of patients in palliative and end-of-life care?

Inclusion criteria

Following the JBI methodology recommended for scoping reviews (Munn et al., 2022; Aromataris, 2020), the PCC mnemonic was applied to define the following inclusion criteria:

Participants: This review will consider all primary studies that have as a target population health professional who are part of a multidisciplinary palliative care teams that accompany and support adult patients. The professionals part of these formal teams considered for this research will be doctors, nurses, physiotherapists, speech therapists, occupational therapists, nutritionists, psychologists and social workers (Hermes & Lamarca, 2013). Even though this definition may vary by legal rights, country, and/or psychological development, for the purposes of this investigation, by adult patients/users/clients we will contemplate the definition of being 18 years or over. Gender restrictions will not be considered, nor ethnicity or other personal characteristics. For this research, patients in a palliative and end-of-life situation will be considered, by this meaning people who are in an advanced stage of the disease and considered incurable or with little expectation of response to targeted treatments, regardless of the underlying disease (World Health Organization [WHO], 2002; Worldwide Palliative Care Alliance [WPCA], 2014).

Concept: The main concept of this review is related to how health professionals assess people's comfort in palliative and end-of-life care. In addition, this review will also include studies that can address which indicators are evaluated by these professionals to infer about people's comfort in this context of care. By assessment we mean the notion of a process used to learn about a patient's condition by the National Cancer Institute (2023). This can be consolidated in the use of indicators, which, as mentioned by Pereira (2021), *lato sensu*, have the ability to reflect a certain characteristic of something or someone, and which, in the context of health, reveal a state of health condition of someone and can be used as useful tools to monitor, evaluate and understand something.

Context: This review will focus on all contexts where this type of care is provided, palliative care units, hospital inpatient services, hospices, long-term care units and home care. The characteristics of these palliative care contexts will not be differentiated, namely whether they belong to public or private entities, whether they are part of an urban or rural environment, or whether they have specialized certification or accreditation.

Exclusion criteria

All the literature that does not report on how healthcare professionals assess the comfort of patients in a palliative situation will not be included.

2. Methodology

The proposed scoping review will be conducted following JBI methodology (Tricco et al., 2018) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Scoping Reviews Extension for Scoping Reviews (PRISMA-

ScR) checklist (Tricco et al., 2018). This scoping review protocol aims to map the available scientific evidence on the subject under study (Peters et al., 2020).

2.1 Types of sources

This scoping review will consider quantitative, qualitative and mixed methods study projects for inclusion. It will also contemplate analytical observational studies, including prospective and retrospective cohort studies, case-control studies, and analytical cross-sectional studies. In addition, descriptive observational study designs, including case series, individual case reports, and descriptive cross-sectional studies and systematic reviews will also be contemplated. The studies included will be on English, Spanish and Portuguese. Temporal, geographic or cultural limits will not be considered in the research.

2.2 Search strategy

JBIR recommends a three-phase research process that should be used in developing a comprehensive research strategy (Munn et al., 2022; Peters et al., 2020). Thus, a limited initial search was performed through Medical Literature Analysis and Retrieved System Online (MEDLINE), Academic Search Complete; Complete CINAHL and Medicalatline.

The reference list of all included sources of evidence will be screened for additional studies. The Table 1 presents a research strategy proposal in the different databases. The sources of unpublished studies, namely grey literature, was searched on RCAAP (Portuguese Open Access Scientific Repository). This search was done on 28th April of 2023.

Table 1 - Search strategy for published Studies (Search done on 28th April of 2023).

Database	Research strategy	Results
MEDLINE Complete; Academic Search Complete; CINAHL Complete; MedicLatina (EBSCOhost)	S1: TI "patient comfort" OR TI "comfort patient" OR TI "care comfort" OR TI "comfort care" OR TI "comfort measures"	(3,348)
	S2: AB "patient comfort" OR AB "comfort patient" OR AB "care comfort" OR AB "comfort care" OR AB "comfort measures"	(29,999)
	S3: S1 OR S2	(32,115)
	S4: TI "palliative medicine" OR TI "medicine palliative" OR TI "palliative car*" OR TI "terminal care" OR TI "end of life care" OR TI "end-of-life care" OR TI hospice OR TI "terminal*" OR TI dying	(875,147)
	S5: AB "palliative medicine" OR AB "medicine palliative" OR AB "palliative car*" OR AB "terminal care" OR AB "end of life care" OR AB "end-of-life care" OR AB hospice OR AB "terminal*" OR AB dying	(3,437,234)
	S6: S4 OR S5	(3,765,861)
	S7: S3 AND S6	(3,537)
	S8: TI "assess*" OR TI "evaluat*" OR TI "measur*" OR TI "screen*" OR TI "tool*" OR TI techniques OR TI "method*" OR TI "strateg*"	(32,094,995)
	S9: AB "assess*" OR AB "evaluat*" OR AB "measur*" OR AB "screen*" OR AB "tool*" OR AB techniques OR AB "method*" OR AB "strateg*"	(124,536,349)
	S10: S8 OR S9	(136,190,578)
	S11: S7 AND S10	(2,507)
	S12: S7 AND S10 Expanders – Search also in the full text of the articles; Apply equivalent subjects Limiters – Full text; Reviewed by peers; Publication date: 20000101-20231231 Types of sources – Academic journals; Dissertations/Theses Language - spanish; portuguese; english Content provider – MEDLINE Complete; Academic Search Complete; CINAHL Complete; MedicLatina	604
(after automatic duplicate removal)	393	

Scopus	1: Title-abs-key (comfort)	150,310
	2: Title-abs-key (comfort) AND Title-abs-key (palliative AND care)	2,774
	3: Title-abs-key (comfort) AND Title-abs-key (palliative AND care) AND Title-abs-key (end-of-life AND care)	1,226
	4: Title-abs-key (comfort) AND Title abs-key (palliative AND care) AND Title-abs-key (end-of-life AND care) AND Limit-to (Subjarea, "Medi") OR Limit-to (Subjarea, "Nurs") OR Limit-to (Subjarea, "Soci") OR Limit-to (Subjarea, "Psyc") OR Limit-to (Subjarea, "Heal") OR Limit-to (Subjarea "Mult") AND Limit-to (Language , "English") OR Limit-to (Language, "Spanish") OR Limit-to (Language, "Portuguese")	1,181
	5: Title-abs-key (comfort) AND Title-abs-key (palliative AND care) AND Title-abs-key (end-of-life AND care) AND Title-abs-key (assessment) AND (Limit-to (Subjarea, "Medi") OR Limit-to (Subjarea, "nurs") OR Limit-to (Subjarea, "Soci") OR Limit-to (Subjarea, "Psyc") OR Limit-to (Subjarea, "Mult") OR Limit-to (Subjarea, "Heal") AND Limit-to (Language , "English") OR Limit-to (Language, "Spanish") OR Limit-to (Language, "Portuguese")	261
	6: Title-abs-key (patient AND comfort) AND Title-abs-key (palliative AND care) AND Title-abs-key (end-of-life AND care) AND Title-abs-key (assessment) AND Limit-to (Subjarea , "Medi") OR Limit-to (Subjarea, "Nurs") OR Limit-to (Subjarea , "Soci") OR Limit-to (Subjarea, "Psyc") OR Limit-to (Subjarea , "Mult") OR Limit-to (Subjarea, "Heal") AND Limit-to (Language, "English") OR Limit-to (Language, "Spanish") OR Limit-to (Language, "Portuguese")	235
Web of Science Core Collection	1: ALL= (patient comfort)	20,060
	2: ALL= ("patient comfort")	4,301
	3: TI= ("patient comfort")	405
	4: ((TI= ("patient comfort"))) OR AB= ("patient comfort")	4,136
	5: (((TI= ("patient comfort")) OR AB= ("patient comfort"))) AND AB= (palliative care)	53
	6: (((TI= ("patient comfort")) OR AB= ("patient comfort")) AND AB= (palliative care)) and English (language))	45

Source: Authors.

For the search for grey literature was used the term patient comfort, being the search strategy proposal present on the Table 2. The second phase involves carrying out specific searches in each of the bibliographic databases and information sources selected and reported in the protocol. The third phase comprises the inclusion of any relevant additional studies in the reference lists of all articles selected for the review.

Table 2. - Search strategy for unpublished studies (Search done on 28th April of 2023).

Database	Research strategy	Results
Open Grey	"Patient comfort" (All fields)	1
RCAAP - Portuguese Open Access Scientific Repository	"Patient Comfort" (title) OU "Patient Comfort" (All fields) AND "Palliative care" (All fields)	8
CAPES- Theses Base of the Coordination for the Improvement of Higher Education Personnel - Brazil)	"Patient Comfort" (All fields)	12

Source: Authors.

2.3 Study selection

Following this stage, all studies identified through database searching will be retrieved and stored in Mendeley® V1.19.8 (Mendeley Ltd., Elsevier, The Netherlands) and duplicates removed. Then, the articles will be imported into Rayyan QCRI (Qatar Computing Research Institute [Data Analytics], Doha, Qatar) for the following selection process. Subsequent to a pilot test, titles and abstracts will then be screened by two reviewers with the intention of determining if they fit the inclusion criteria and the objectives of this research. Studies with potential and eventually eligible to integrate the scoping review will be retrieved in full text, in order to proceed with their analysis. After this moment, the complete text of the selected citations will be evaluated in detail. If the inclusion criteria are not met, full-text studies will be excluded. Finally, the references of all studies included in the review will be manually analysed. In the event of disagreements between the reviewers, the presence of a third reviewer will be requested at each stage of the selection process. If the full version of a publication is found to be inaccessible, the original authors of the publication will be contacted. The evaluation of the methodological quality of the included studies will not be carried out because it is a scoping review (Munn et al., 2022). The research results will be described in full in the scoping review, and will be presented in the form of a flowchart, using the “preferred reporting items for systematic reviews and meta-analysis extension for scoping reviews (PRISMA-ScR) guidelines (Page et al., 2021; Tricco et al., 2018).

2.4 Data extraction

Pre-defined data extraction forms or instruments can provide consistency in a systematic review, whilst reducing bias and improving validity and reliability (Tricco et al., 2018). Thus, data will be extracted from articles included in the scoping review by two independent reviewers, using a specific data extraction tool developed by the same. In case of any disagreements that may arise between the two reviewers, the same will be resolved through discussion, or the presence of a third person will be requested, as already mentioned. An instrument will be used that considers specific details about the population, concept, context and research methods relevant to the question and the stated purpose of this scoping review, as indicated by the methodology developed by the JBI (Table 3). 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 pertinent changes, according to the conclusions of the pilot test and the emerging needs of the analysis of eligible articles.

Table 3 - Data extraction tool.

<i>Scoping review title</i>
Diagnostic assessment of healthcare professionals in the comfort of palliative patients: a scoping review protocol
<i>Review objective(s)</i>
The purpose of this review is to explore the current state of scientific knowledge related to how healthcare professionals assess comfort; which instruments and strategies are applied to collect data, which reveal comfort or lack thereof, of patients in palliative and end-of-life care.
<i>Review question(s)</i>
-What data are used by health professionals to assess the comfort of patients in palliative and end-of-life care? -What instruments or strategies are used by health professionals to collect this data and assess the comfort of patients in palliative and end-of-life care? - What is the professional group that has this concern in their practice to assess the comfort of patients in palliative and end-of-life care?
<i>Inclusion/ exclusion criteria</i>
<i>Population</i>
This review will consider all primary studies that have as a target population health professional who are part of a multidisciplinary palliative care teams that accompany and support adult patients
<i>Concept</i>
The main concept of this review is related to how health professionals assess the comfort of people in palliative and end-of-life care. It will also include studies that can address which indicators are evaluated by these professionals to infer about people's comfort in this context of care.
<i>Context</i>
This review will focus on all contexts where this type of care is provided, palliative care units, hospital inpatient services, hospices, continuing care units and home care.
<i>Types of evidence source</i>
This scoping review will consider quantitative, qualitative and mixed methods study projects for inclusion. It will also contemplate analytical observational studies, including prospective and retrospective cohort studies, case-control studies, and analytical cross-sectional studies
<i>Author(s)</i>
<i>Year of publication</i>
<i>Country origin of source vidence</i>
<i>Aims/purpose</i>
<i>Types of evidence source</i>
<i>Population</i>
<i>Results extracted from the source of evidence according to the concept under analysis</i>
<i>Data or items used to assess patient's comfort</i>
<i>Strategies or instruments used to assess patient's comfort</i>
Healthcare professionals involved in the assessment of patient's comfort
<i>Other results</i>
<i>Recommendations/ suggestions for research</i>
<i>Relevant bibliography</i>

Source: Authors.

2.5 Data analysis and presentation

In addition to the organization in table format, as already mentioned and explained, a narrative description will also be written that can demonstrate what came out of this large and important methodological phase. If this is justified and interesting, we will also try to organize the data by demographic groups, professionals, or other characteristics that can be clustered and demonstrate differences between groups or classes.

3. Results and Discussion

At this stage, in addition to demonstrating those that were the results of the investigation, and interrelating them in order to comply with the objectives defined at the outset for this work, an attempt will also be made to identify possible limitations that may contribute to the carrying out of future investigations. At this point, we may assume that a limitation of this review may be that will only consider studies published in Portuguese, Spanish and English languages. However, for a

broader approach by mapping all the information described in the literature, studies from any geographical area and without any time restrictions will be included. Once scoping reviews do not seek to assess the methodological quality of the studies included for analysis, recommendations for clinical practice cannot be issued (Arksey & O'Malley, 2005). Nevertheless, it is expected that this work may arise relevant clues for the development of future studies on the topic, whether primary studies or systematic reviews.

4. Conclusion

This review will provide useful insights into the data that healthcare professionals use to describe the comfort, or lack thereof, of patients in palliative care. Strategies or instruments used to assess comfort and the health professionals most involved in assessing patient comfort in palliative care. Comfort is a fundamental element for a dignified death and the result of quality health care. In this perspective, and focusing on the implications for research, the systematization of the evidence can serve as the basis for a systematic review and/or help to clarify gaps where it may be important to invest in the future.

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