CIÊNCIAS DA VIDA E DA SAÚDE
LIFE AND HEALTH SCIENCES
CIENCIAS DE LA VIDA Y LA SALUD

millenium 41

Millenium, 2(17), 41-51.

en

FATORES QUE INFLUENCIAM A SATISFAÇÃO DOS CLIENTES E FAMÍLIA COM OS CUIDADOS PALIATIVOS: SCOPING REVIEW

FACTORS THAT INFLUENCE CUSTOMER AND FAMILY SATISFACTION WITH PALLIATIVE CARE: SCOPING REVIEW

FACTORES QUE INFLUYEN LA SATISFACCIÓN DEL CLIENTE Y FAMILIA CON LA ATENCIÓN PALIATIVA: REVISIÓN DE ALCANCE

Igor Pinto[1] https://orcid.org/0000-0003-3739-2020
Sónia Novais[2] https://orcid.org/0000-0002-4328-3755
Maribel Carvalhais[2] https://orcid.org/0000-0002-2206-2582
Sara Gomes[1] https://orcid.org/0000-0003-4599-7345
Custódio Soares[3] https://orcid.org/0000-0002-8629-4411

[1] Universidade Católica Portuguesa, Instituto de Ciências da Saúde, Porto, Portugal
[2] Escola Superior de Saúde Norte da Cruz Vermelha Portuguesa, CINTESIS, Universidade do Porto, Oliveira de Azeméis, Portugal
[3] Escola Superior de Saúde Norte da Cruz Vermelha Portuguesa, Oliveira de Azeméis, Portugal

Igor Pinto - isp.igor@gmail.com | Sónia Novais - sonia.novais@essnortecvp.pt | Maribel Carvalhais - maribel.carvalhais@essnortecvp.pt | Sara Gomes - saramrgomes@gmail.com | Custódio Soares- sergio.soares@essnortecvp.pt

Corresponding Author
Igor Emanuel Soares Pinto
Rua António Patrício, nº 68, 3º esq traseiras
4460-204 Matosinhos - Portugal
isp.igor@gmail.com

RECEIVED: 19th August, 2021
ACCEPTED: 22th October, 2021

RESUMO

Introdução: A auscultação da satisfação com os cuidados paliativos (CP) na ótica dos seus principais beneficiários é essencial e consolida-se com o dever ético dos profissionais de saúde de providenciarem os melhores cuidados.

Objetivo: Sintetizar a evidência científica sobre os fatores que influenciam a avaliação da satisfação dos clientes com os CP e identificar os instrumentos utilizados para a sua avaliação.

Métodos: Revisão de acordo com o método do Joanna Briggs Institute para a realização de uma scoping review. A pesquisa foi realizada nas bases de dados da Scopus, na CINAHL Complete e Web of Science, bem como no OpenGrey e Dart-Europe, em julho de 2021. A seleção foi executada por dois investigadores independentes e os dados foram reunidos em temas de acordo com os seus conteúdos.

Resultados: Foram incluídos 40 estudos. Da análise efetuada concluiu-se que os fatores que influenciam a avaliação da satisfação podem ser agrupados em cinco temas: Disponibilidade dos Cuidados, Cuidados Físicos, Cuidados Psicossociais, Comunicação da Informação e Cuidados ao Doente em Morte Iminente.

Conclusão: A FAMCARE é o instrumento de medida utilizado com maior frequência para avaliar a satisfação dos clientes face aos CP. O conhecimento dos fatores influenciadores permitem que tanto as organizações como os profissionais promovam uma melhor personalização dos cuidados, assegurando a segurança e qualidade, ajustando-se às expectativas dos clientes e cuidadores.

Palavras-chave: cuidados paliativos; satisfação do paciente; enfermagem de cuidados paliativos na terminalidade da vida; cuidadores familiares

ABSTRACT

Introduction: The assessment of satisfaction with palliative care (PC) from the perspective of its primary beneficiaries is essential and is consolidated with the ethical duty of health professionals to provide the best care.

Objective: To synthesize the scientific evidence on the factors that influence the assessment of customer satisfaction with PC and identify the instruments used for its assessment.

Methods: Review according to the Joanna Briggs Institute method for carrying out a scoping review. The search was carried out in Scopus, CINAHL Complete and Web of Science databases, and in OpenGrey, and Dart-Europe in July 2021. The selection was carried out by two independent researchers and the data were grouped into themes according to their contents.

Results: Forty studies were included. From the analysis carried out, researchers concluded that the factors that influence the assessment of satisfaction were grouped into five themes: Availability of Care, Physical Care, Psychosocial Care, Communication of Information and Care for the Patient in Imminent Death.

Conclusion: FAMCARE is the most widely used measurement instrument to assess customer satisfaction with PC. Knowledge of influencing factors allows both organizations and professionals to promote better personalization of care, to ensure safety and quality, and to adjust to the expectations of clients and caregivers.

Key words: palliative care; patient satisfaction; hospice and palliative care nursing; caregivers

RESUMEN

Introducción: La valoración de la satisfacción con los cuidados paliativos (CP) desde la perspectiva de sus principales beneficiarios es fundamental y se consolida con el deber ético de los profesionales de la salud de brindar la mejor atención.

Objetivo: Sintetizar la evidencia científica sobre los factores que influyen en la evaluación de la satisfacción del cliente con los CP e identificar los instrumentos utilizados para su evaluación.

Métodos: Revisión de acuerdo con el método del Instituto Joanna Briggs para realizar una scoping review. La búsqueda se realizó en las bases de datos Scopus, CINAHL Complete y Web of Science, así como en OpenGrey y Dart-Europe, en julio de 2021. La selección fue realizada por dos investigadores independientes y los datos se agruparon por temas según su contenido.

Resultados: Se incluyeron 40 estudios. Del análisis realizado se concluyó que los factores que influyen en la valoración de la satisfacción se pueden agrupar en cinco temas: Disponibilidad de Atención, Atención Física, Atención Psicosocial, Comunicación de Información y Atención al Paciente en Muerte Inminente.

Conclusión: FAMCARE es el instrumento de medición más utilizado para evaluar la satisfacción del cliente con los CP. El conocimiento de los factores influyentes permite tanto a las organizaciones como a los profesionales promover una mejor personalización de la atención, garantizando la seguridad y la calidad, ajustándose a las expectativas de los clientes y cuidadores.

Palabras clave: cuidados paliativos; satisfacción del paciente; enfermería de cuidados paliativos al final de la vida; cuidadores

INTRODUCTION

Due to the increase in disabling and irreversible chronic diseases, it is essential to adopt clinical and therapeutic strategies that offer the population a more adequate approach to their problems, including management of signs and symptoms, intervention in advanced disease and at the end of life (Grande et al., 2009). For the World Health Organization (WHO) by 2060 the number of people in need of this level of care will double, with approximately 56.8 million people needing this type of care worldwide and 25.7 million in the last year of life (World Health Organization, 2020). It is estimated that in Portugal, on average 82737 people need palliative care (Comissão Nacional de Cuidados Paliativos (CNCP), 2019).

Palliative care is a clinical approach whose objective is to improve the quality of life of people with advanced or end-of-life disease throughout their life cycle as well as their families in light of the problems inherent to their clinical condition (World Health Organization, 2020). The aim of this approach is to prevent and alleviate suffering with early detection, correct assessment and therapeutic intervention of pain and other problems, whether physical, psychosocial or spiritual; and, access to this care must be strengthened in health systems (World Health Organization, 2020). This care is organized around ten structuring pillars: self-help and support, the involvement of beneficiaries, facilitation of information, psychological support, symptom control, social support, rehabilitation, access to complementary therapies, spiritual support, and end-of-life care and throughout the grieving process (Rosser & Walsh, 2014).

In a culture of quality assessment, it is important to define indicators of quality of care in palliative care that allow for continuous improvement and benchmarking (Capelas, 2014).

The strategy of assessing the quality of palliative care involves the development of a culture of safety, assuring the health team is staffed with properly trained members, preventing avoidable deaths, being proactive in non-maleficence, improving the experience of beneficiaries of palliative care towards better outcomes, and ensuring that people with advanced disease or end-of-life care receive care at the most appropriate location (NHS Finance and Operations, 2016).

Considering the ethical duty of health professionals to provide the best care, whether to people with advanced disease or at the end of life, or to family members and significant others, as well as their interdisciplinary nature, it is imperative to listen for satisfaction with palliative care from the perspective of its main beneficiaries (Capelas, 2014; Parker et al., 2013). This assessment is also considered one of the indicators of quality of care provided in a context of accountability and continuous improvement (Ornstein et al., 2017; Parker et al., 2013).

Quality monitoring is based on eight domains, and the assessment of satisfaction from the perspective of the person with advanced disease or at the end of life or of their family members is present as an indicator of results in three domains, namely: the Structure and Process of Care, the Psychological and Psychiatric Aspects of Caring, and Caring for the Patient in Imminent Death (Capelas, 2014).

There is no clear definition of what is meant by satisfaction with care, as palliative care is organized into different levels and teams, leading to differences in the components of care and in the dimensions of quality of care (Observatório Português de Cuidados Paliativos, 2018). However, the studies carried out show that this is affected by relationships with the team, education and knowledge, the perception of emotional support, the individuality of care, the recognition and competence of the team, communication, and coordination of care (D'Angelo et al., 2017; McDarby & Carpenter, 2019). It is known that the assessment of this indicator with people with advanced disease or at the end of life can be difficult due to their clinical status, or the side effects of medication (Ornstein et al., 2017; J. A. Teresi et al., 2014).

Considering the reality of palliative care in Portugal in the Structure and Process of Care domain, it is essential to understand the satisfaction related to care/response to the patient's needs/problems, the human care with which the patient was approached, the proximity of the supervision that was carried out to the patient, the conditions offered, the coordination of the information made available, the methodology of information transmission, listening, availability of the team, keeping the person and family informed about their clinical situation, respect for the patient's therapeutic preferences, coordination of care, and waiting time for admission/consultation. Looking at the Psychological and Psychiatric Aspects of Caring domain, family satisfaction with controlling their loved one's anxiety/sadness is a result indicator (Capelas, 2014). As for the Care for the Imminent Death Patient domain, it is important to monitor the family's satisfaction with the continuity of the information provided about the evolution of the patient's clinical status, and with the information provided by the team regarding therapeutic approaches for symptomatic control of the patient during the phase of agony (Capelas, 2014).

Given the above, and the gaps found concerning the factors that influence the assessment of customer satisfaction with palliative care, the aim of this scoping review is to synthesize the scientific evidence on the factors that influence the assessment of customer satisfaction with palliative care and identify the instruments used for its assessment.

This review follows the recommendations of the Joanna Briggs Institute (JBI) (Peters et al., 2020). The questions that guide this review are: how the evidence on the assessment of customer satisfaction with palliative care is presented (number of studies, their characteristics and data collection instruments used); and what is known about the factors that influence the assessment of customer satisfaction with palliative care (what this phenomenon means and what factors influence customer satisfaction).

1. METHODS

Taking into account the review question and its aims, a scoping review was performed. Considering the protocol and standardization of elaborating a scoping review, which assumes methodological rigour, transparency and reproducibility, the JBI recommendations for this type of review were followed (Peters et al., 2020). Moreover, this article is organized following the PRISMA-ScR checklist (Tricco et al., 2018).

The PCC (Population, Concept and Context) mnemonic was used, according to the JBI recommendations for scoping reviews to define the inclusion criteria of the articles (Peters et al., 2020).

P – The review includes studies carried out with people or relatives of people at the end of life or advanced disease, over 18 years of age. No restrictions on gender, ethnicity, clinical diagnosis or other personal characteristics were applied.

C –The review focuses on studies on the assessment of beneficiary satisfaction with palliative care.

C – The review is limited to inpatient palliative care settings, palliative care community support teams and with hospital palliative care support teams. There will be a restriction imposed on studies carried out in the context of paediatric palliative care. Primary studies of the qualitative, quantitative and mixed type, and secondary studies of the systematic literature review type and narrative reviews that answer the research question were considered. Text and opinion documents were also searched for inclusion in the review. Only references written in Portuguese, English, and Spanish without time restriction were considered.

Before identifying potentially relevant studies, the search terms were determined according to the investigation question. In this respect, the electronic research was performed on Scopus, CINAHL complete and Web of Science using the following terms ("family satisfaction" OR “Patient Satisfaction”) AND (“Palliative Care” OR Hospice and “Palliative Care Nursing” “Palliative Medicine”). The bibliographic search was carried out in July 2021. A search of the bibliographic references as well as a search of the grey literature in OpenGrey and Dart-Europe was conducted using the same terms.

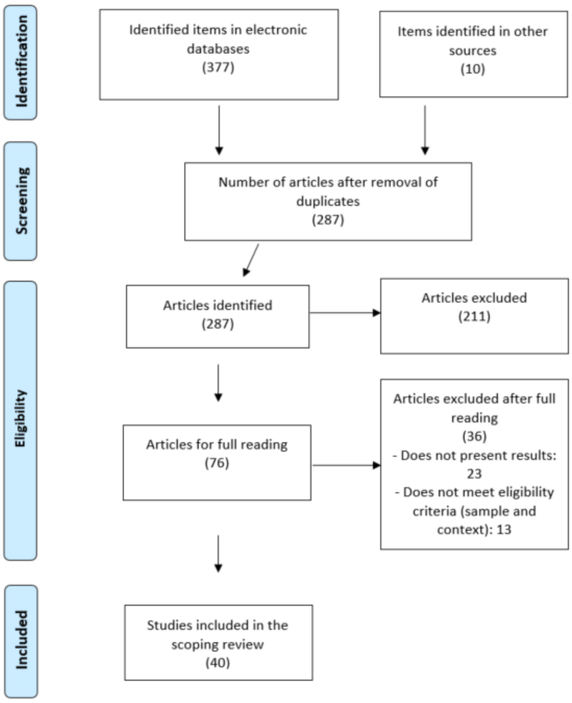
The search was carried out independently by two researchers and 387 articles were found. After the research, the studies were exported to the Zotero software where duplicates were eliminated.

The selection of articles was carried out in two phases. In the first, the titles and abstracts were analysed and those that did not meet the inclusion criteria were eliminated. In the second phase, the articles that apparently met the inclusion criteria were retrieved in full and the details of the studies, characteristics and results were extracted to the JBI extraction table (JBI SUMARI). This phase was carried out independently by two researchers who carried out the complete analysis of the texts to assess the consistency of the results with the research questions and the objectives defined.

2. RESULTS

We identified 377 references in the databases and 10 references in the grey literature repositories, as evidenced in the PRISMA flow diagram (Figure 1).

Figure 1 - The process of researching and selecting articles



Forty articles were considered for data extraction. Analysing the published articles, it appears that the year with the most publications was 2015, with five articles, followed by 2020, 2017, 2018 and 2013 with two articles each year.

Regarding the countries where the studies were carried out, the United States of America leads publications with 12 articles (Gade et al., 2008; Gelfman LP et al., 2008; Huen et al., 2019; Miceli PJ & Mylod DE, 2003; Ornstein et al., 2015, 2017; Paramanandam et al., 2020; Parker et al., 2013; Roza et al., 2015; Strasser F et al., 2004; J. Teresi et al., 2015; J. A. Teresi et al., 2014). In Europe, 12 articles were published, one of which was a multicentre study and only one was carried out in Portugal (D'Angelo et al., 2017; Flöther et al., 2021; Korfage et al., 2020; London & Lundstedt, 2007; Parpa et al., 2017; Proot I et al., 2006; Ribeiro et al., 2020; Ringdal et al., 2003; Sandsdalen et al., 2019; Thery et al., 2021; van Soest-Poortvliet et al., 2015; Vitacca et al., 2019). The remaining studies are distributed geographically across Oceania, the Middle East, Canada and Asia.

From the methodological analysis of the articles, most studies presented are methodological studies (eight articles), followed by randomized controlled and quasi-experimental studies, both with five articles. The remaining methodologies focus on retrospective, exploratory, observational, correlational, mixed, descriptive, transversal, qualitative studies and systematic literature review.

Below, a simplified data extraction instrument is presented, in the form of a table, which includes the most relevant data that were mapped based on the question and objectives of this review.

Table 1 - Articles included for data extraction, instruments used and factors associated with satisfaction with palliative care

Reference	Instruments for assessing satisfaction with palliative care	Factors that influence the assessment of satisfaction with palliative care
(Morita et al., 2002)	60 questions about the level of satisfaction with the care they received	● Facility ● Information provided ● Availability of the team ● Family care ● Cost ● Symptom management
(Fakhoury, 1998)	Does not assess	● Physical environment \ Accessibility \ Availability \ Continuity of care ● Accompanying the family during grieving by palliative care nurses and community
(Tierney et al., 1998)	Modified Picker–Commonwealth Scale Specific questions aimed at relieving symptoms especially pain	● Quality of life ● Symptom management ● Communication between patients and physicians
(Morita T et al., 2002)	Scale of satisfaction for family members of patients receiving care Palliative care – *Satisfaction scale for Family members receiving Inpatient Palliative Care* (Sat-Fam-IPC)	● Nursing care ● Night shift nursing staff ratio ● Multidisciplinary team (nurses, physicians, social workers, nursing assistants) ● Patient and family age ● Symptom management ● Physical conditions of the unit ● Length of stay ● Costs per approved room ● Occupation of the family – occupation
(Miceli PJ & Mylod DE, 2003)	Questionnaire: Hospice Care Family Survey	● Availability of the team ● Keeping family members informed ● Empathy (sensitivity of professionals to the difficulties caused by the family member's disease) ● Teaching and training on how to take care of the family
(Ringdal et al., 2003)	FAMCARE Scale - Applied 1 month after death	Does not identify
(Strasser F et al., 2004)	7-item questionnaire – The patient answers on a scale from 1 (not satisfied) to 5 (very satisfied)	● Multidisciplinary assessment ● Symptom management
(Proot I et al., 2006)	Maastricht Instrument on Satisfaction with Terminal Care (MITTZ)	Does not identify
(London & Lundstedt, 2007)	Likert-type questionnaire with 17 questions about satisfaction, 3 demographic questions and 3 open answer questions	● Compassion and dignity ● Communicating information to family and friends ● Pain management ● Identifying and responding to care wishes
(Gade et al., 2008)	Modified scale from the City of Hope Patient Questionnaire	NA

Reference	Instruments for assessing satisfaction with palliative care	Factors that influence the assessment of satisfaction with palliative care
(Gelfman LP et al., 2008)	After-Death Bereaved Family Member Interview	● Systematized hospital palliative care programs
(Zimmermann et al., 2008)	Scale adapted from Ware Specific satisfaction assessment instruments for terminally ill patients are not referenced	● Specialized palliative care ● Symptom management
(Lo C et al., 2009)	FAMCARE-P16	● Symptom management ● Depression ● Anxiety
(Detering et al., 2010)	5 questions on patient satisfaction with hospital admission	● Systematized hospital palliative care programs ● Meeting the patient’s goals, values and beliefs and their future health care choices
(Heyland et al., 2013)	CANHELP Questionnaire	Does not identify
(Parker et al., 2013)	Satisfaction assessment scale constructed for that aim	Does not identify
(Chan et al., 2014)	Interview	● Structured palliative care program
(J. A. Teresi et al., 2014)	FAMCARE	Does not identify
(Ozcelik et al., 2014)	Customer and family satisfaction assessment form	● Symptom management
(J. Teresi et al., 2015)	FAMCARE	● Caucasian race ● Symptom management – pain
(Ornstein et al., 2015)	Short version of FAMCARE	Does not identify
(Ozcelik et al., 2015)	FAMCARE	● Sex ● Differentiated profession ● Communication of information
(Roza et al., 2015)	Bereaved Family Survey	● Emotional support ● Availability ● Respect for patient and family preferences ● Dying in a palliative care unit ● Specialized palliative care
(van Soest-Poortvliet et al., 2015)	Care satisfaction scale – End-of-Life in Dementia	● Comfort
(Mehdinezhad et al., 2016)	FAMCARE-P16	● Symptom management, including pain management ● Emotional support
(Wentlandt et al., 2016)	Not identified	● Hospital infrastructure ● Quality of care ● Customer and family experience
(D’Angelo et al., 2017)	FAMCARE-2	● Advanced age of patients ● Female sex ● Higher education level ● Death in hospital
(Ornstein et al., 2017)	FAMCARE-5	● Caucasian race ● Level of education ● Older age of the patient ● Higher education level
(Parpa et al., 2017)	FAMCARE-P13	● Medical care
(A. Ng & Wong, 2018)	Institutional questionnaires to assess satisfaction with care	● Management of signs and symptoms, including pain
(Naoki et al., 2018)	FAMCARE	● Communication of information ● Including the family in therapeutic decisions
(Huen et al., 2019)	*Patient Satisfaction Short-Form* Questionnaire (PSQ-18)	● Service ● Communication domains (physician’s interpersonal form, technical quality, communication, time spent with the physician) ● Domains related to the functioning of the system (financial aspects, accessibility and convenience)

Reference	Instruments for assessing satisfaction with palliative care	Factors that influence the assessment of satisfaction with palliative care
(Sandsdalen et al., 2019)	Emotional Stress Reaction Questionnaire	● Person-related conditions (e.g., patients' perception of coherence and perceptions of the subjective importance of quality) ● Conditions related to the organization (e.g., doctors' competence and type of care services)
(Vitacca et al., 2019)	Satisfaction questionnaire with 7 questions	● Quality of care ● Having responded to the need for the patients' (and caregivers') information ● Professional support ● Preferred ways to access health services
(Alshammary et al., 2020)	Questionnaire with 4 questions (5 response options), applied at the end of each consultation	● Waiting time for the consultation ● Adequacy of the information provided in the consultation ● Dignity with which they were treated during the consultation
(Korfage et al., 2020)	EORTC IN-PATSAT	● Information provided by physician ● Information provided by nurses
(Paramanandam et al., 2020)	Questionnaire consisting of 5 questions and administered by volunteers to patients/relatives 60 days after admission to the program	● Information provided about the disease ● Support and education for the family/caregiver ● Team response to patient concerns ● Providing support and information to the patient about their goals
(Ribeiro et al., 2020)	FAMCARE Scale	● Psychosocial care ● Physical care ● Communication of information ● Availability for care
(Flöther et al., 2021)	FAMCARE-6	● The worries and sadness that the patient feels ● Symptom management
(Thery et al., 2021)	EORTC Out Patient Satisfaction Core 33 questionnaire (PATSAT C33) Out-patient satisfaction 7 (OUT-PATS AT7) questionnaires.	● Care provided by doctors and nurses

3. DISCUSSION

In this review, we have tried to understand how the scientific evidence on assessing customer satisfaction with palliative care is presented, finding that the population included in the different studies, mostly people with advanced or end-of-life disease, had oncological diseases, with only one study being carried out with relatives of people diagnosed with dementia (van Soest-Poortvliet et al., 2015) and another with people diagnosed with chronic obstructive pulmonary disease in an advanced stage (Vitacca et al., 2019). Palliative care is mostly associated with oncological disease, so the results suggest a need for a paradigm shift.

Regarding the factors influencing the assessment of satisfaction, they can be grouped into five themes, four of which are included in the customer satisfaction assessment scale most often used in studies, FAMCARE, including Availability of Care, Physical Care, Psychosocial Care, and Communication of Information (Ribeiro et al., 2020). We also found that the meaning of satisfaction with palliative care in most studies presents results in line with Capelas (2014) in the domain of Structure and Process of Care, with the most evident dimensions of meaning relating to therapeutic preferences (symptom management), care/response to the patient's needs/problems, team availability, waiting time for admission/consultation and communication (Alshammary et al., 2020; Huen et al., 2019; Paramanandam et al., 2020; Vitacca et al., 2019). However, the most widely used measurement instrument for the assessment of satisfaction, FAMCARE, does not allow one of the domains mentioned by Capelas (2014), with regard to Caring for the Patient in Imminent Death to be assessed. Only one study referring to the assessment of this domain was found (Fakhoury, 1998).

This domain that needs evaluation is a key element in the relationship between health professionals, people with advanced or end-of-life disease and their families, and in the moment of agony, communication based on the truth is essential to strengthen the therapeutic relationship (Andrade et al., 2013). Among all the barriers to communication in palliative care, the most frequently identified are related to health professionals' lack of time, the ambivalence or lack of openness to discuss the diagnosis and prognosis by the parties involved, the feeling of a lack of honesty on the part of health professionals regarding these same issues, and the demonstration of health professionals' difficulty in talking about death, as it is a factor that influences satisfaction with care, particularly from the perspective of family members (Slort et al., 2011). It is known that about half of the relatives of people with advanced or end-of-life disease would like to have more information about possible scenarios or outcomes, including the possible death of the patient. And those with initial resistance, later stressed that they would have liked to have obtained this information and would have benefited at the time of mourning (Krawczyk & Gallagher, 2016). In the long term, these results led to the positive experience of mourning, in the feeling of well-being and absence of feelings of guilt.

It is worth noting that from the analysis of the articles, in addition to the three domains of satisfaction with palliative care identified by Capelas (2014), we identified a new domain of influence on satisfaction, namely the personal characteristics of the person with advanced disease or at the end of life and of family caregivers. With regard to this domain, the articles show that characteristics such as gender, age, race and educational level influence satisfaction with palliative care. In this sense, the female gender, the Caucasian race, the older age of the person and caregiver, and higher educational level are associated with greater satisfaction with palliative care (D'Angelo et al., 2017; Ornstein et al., 2017; J. Teresi et al., 2015).

From an in-depth analysis of the articles, and crossing with the three satisfaction domains identified by Capelas (2014), it appears that the domain of Psychological and Psychiatric Aspects of Caring is one of the domains mentioned with less satisfaction (Lo C et al., 2009; Ribeiro et al., 2020), demonstrating that from the perspective of family caregivers and even of people with advanced disease, symptom control is one of the dimensions of greatest satisfaction, overshadowing the psychological dimension of care (Flöther et al., 2021; Ng & Wong, 2018).

Integration in structured palliative care programs centred on managing signs and symptoms and communication is crucial to improving satisfaction with palliative care and is referred to in the literature as having a positive impact, not only on satisfaction with care, but also on quality of life and in mourning. Monitoring the person at the end of life by a specialized multidisciplinary team is associated with better satisfaction as there is better monitoring, greater availability, recognition of skills and, consequently, an improvement in the management of signs and symptoms (Chan et al., 2014; Detering et al., 2010).

The results of this review must be analysed considering some limitations. Regarding the research keywords, only the terms widely used in the literature were considered; however, some relevant terms may have been excluded, leading to the exclusion of other studies. The inclusion of articles only in English, Portuguese and Spanish potentially excluded relevant studies in other languages.

CONCLUSION

In the present review, we found that the most widely used measurement instrument to assess quality of life in palliative care is FAMCARE.

The domains of satisfaction with palliative care included in the literature include the *Structure and Process of Care*, the *Psychological and Psychiatric Aspects of Care*; however, the domain of *Care for the Imminent Death Patient* is practically absent from the objectives and results of the articles found.

It was possible to identify a new domain that influences satisfaction with palliative care, the *personal characteristics of people with advanced or end-of-life disease and family members*, which should be considered not only in the assessment of satisfaction, but also in the adequacy and personalization of palliative care.

REFERENCES

Alshammary, S., Duraisamy, B., Salem, L., & Altamimi, A. (2020). Integration of Palliative Care Into Primary Health Care: Model of Care Experience. *CUREUS*, *12*(6). https://doi.org/10.7759/cureus.8866

Andrade, C. G. de, Costa, S. F. G. da, & Lopes, M. E. L. (2013). Cuidados paliativos: A comunicação como estratégia de cuidado para o paciente em fase terminal. *Ciência & Saúde Coletiva*, *18*, 2523–2530. https://doi.org/10.1590/S1413-81232013000900006

Capelas, M. (2014). *Indicadores de Qualidade para os Serviços de Cuidados Paliativos*.

Chan, C. W., Chui, Y. Y., Chair, S. Y., Sham, M. M., Lo, R. S., Ng, C. S., Chan, H. Y., & Lai, D. C. (2014). The evaluation of a palliative care programme for people suffering from life-limiting diseases. *Journal of Clinical Nursing (John Wiley & Sons, Inc.*, *23*(1–2), 113–123. https://doi.org/10.1111/jocn.12094

Comissão Nacional de Cuidados Paliativos (CNCP). (2019). *Plano Estratégico para o desenvolvimento dos Cuidados Paliativos para o biénio 2019/2020*. Retrieved from: https://apcp.com.pt/152795/aprovacao-do-plano-estrategico-para-o-desenvolvimento-dos-cuidados-paliativos-para-o-bienio-2019-2020

D'Angelo, D., Punziano, A. C., Mastroianni, C., Marzi, A., Latina, R., Ghezzi, V., Piredda, M., & De Marinis, M. G. (2017). Translation and Testing of the Italian Version of FAMCARE-2: Measuring Family Caregivers' Satisfaction With Palliative Care. *Journal of Family Nursing*, *23*(2), 252–272. https://doi.org/10.1177/1074840717697538

Detering, K., Hancock, A., Reade, M., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *BMJ-British Medical Journal*, *340*. https://doi.org/10.1136/bmj.c1345

Fakhoury, W. (1998). Satisfaction with palliative care: What should we be aware of?. *International Journal of Nursing Studies*, *35*(3), 171–176. https://doi.org/10.1016/S0020-7489(98)00026-1

Flöther, L., Pötzsch, B., Jung, M., Jung, R., Bucher, M., Glowka, A., & Medenwald, D. (2021). Treatment effects of palliative care consultation and patient contentment: A monocentric observational study. *Medicine*, *100*(12), e24320–e24320. https://doi.org/10.1097/MD.0000000000024320

Gade, G., Venohr, I., Conner, D., Mcgrady, K., Beane, J., Richardson, R., Williams, M., Liberson, M., Blum, M., & Della Penna, R. (2008). Impact of an inpatient palliative care team: A randomized controlled trial. *Journal of Palliative Medicine*, *11*(2), 180–190. https://doi.org/10.1089/jpm.2007.0055

Gelfman LP, Meier DE, Morrison RS, Gelfman, L. P., Meier, D. E., & Morrison, R. S. (2008). Does palliative care improve quality? A survey of bereaved family members. *Journal of Pain & Symptom Management*, *36*(1), 22–28. https://doi.org/10.1016/j.jpainsymman.2007.09.008

Grande, G., Stajduhar, K., Aoun, S., Toye, C., Funk, L., Addington-Hall, J., Payne, S., & Todd, C. (2009). Supporting lay carers in end of life care: Current gaps and future priorities. *Palliative Medicine*, *23*(4), 339–344. https://doi.org/10.1177/0269216309104875

Heyland, D. K., Jiang, X., Day, A. G., & Cohen, S. R. (2013). The Development and Validation of a Shorter Version of the Canadian Health Care Evaluation Project Questionnaire (CANHELP Lite): A Novel Tool to Measure Patient and Family Satisfaction With End-of-Life Care. *Journal of Pain & Symptom Management*, *46*(2), 289–297. https://doi.org/10.1016/j.jpainsymman.2012.07.012

Huen, K., Huang, C., Liu, H., Kwan, L., Pannell, S., Laviana, A., Saucedo, J., Lorenz, K., Bennett, C., & Bergman, J. (2019). Outcomes of an Integrated Urology-Palliative Care Clinic for Patients With Advanced Urological Cancers: Maintenance of Quality of Life and Satisfaction and High Rate of Hospice Utilization Through End of Life. *American Journal of Hospice & Palliative Medicine*, *36*(9), 801–806. https://doi.org/10.1177/1049909119833663

Kingsley, C., & Patel, S. (2017). Patient-reported outcome measures and patient-reported experience measures. *BJA Education*, *17*(4), 137–144. https://doi.org/10.1093/bjaed/mkw060

Korfage, I. J., Carreras, G., Arnfeldt Christensen, C. M., Billekens, P., Bramley, L., Briggs, L., Bulli, F., Caswell, G., Červ, B., van Delden, J. J. M., Deliens, L., Dunleavy, L., Eecloo, K., Gorini, G., Groenvold, M., Hammes, B., Ingravallo, F., Jabbarian, L. J., Kars, M. C., & Kodba-Čeh, H. (2020). Advance care planning in patients with advanced cancer: A 6-country, cluster-randomised clinical trial. *PLoS Medicine*, *17*(11), 1–16. https://doi.org/10.1371/journal.pmed.1003422

Krawczyk, M., & Gallagher, R. (2016). Communicating prognostic uncertainty in potential end-of-life contexts: Experiences of family members. *BMC Palliative Care*, *15*(1), 59. https://doi.org/10.1186/s12904-016-0133-4

Lo C, Burman D, Rodin G, Zimmermann C, Lo, C., Burman, D., Rodin, G., & Zimmermann, C. (2009). Measuring patient satisfaction in oncology palliative care: Psychometric properties of the FAMCARE-patient scale. *Quality of Life Research*, *18*(6), 747–752. https://doi.org/10.1007/s11136-009-9494-y

London, M., & Lundstedt, J. (2007). Families speak about inpatient end-of-life care. *JOURNAL OF NURSING CARE QUALITY*, *22*(2), 152–158. https://doi.org/10.1097/01.NCQ.0000263105.08096.b1

McDarby, M., & Carpenter, B. D. (2019). Barriers and Facilitators to Effective Inpatient Palliative Care Consultations: A Qualitative Analysis of Interviews With Palliative Care and Nonpalliative Care Providers. *The American Journal of Hospice & Palliative Care*, *36*(3), 191–199. https://doi.org/10.1177/1049909118793635

Mehdinezhad, M., Naji, S., & Hazini, A. (2016). Investigate the effect of palliative care on the satisfaction of patients with cancer who referred to Imam Reza Clinic-Seyedoshohada Hospital and Entekhab Center in Isfahan in 2014. *International Journal of Medical Research & Health Sciences*, *5*(11), 199–203.

Miceli PJ & Mylod DE. (2003). Satisfaction of families using end-of-life care: Current successes and challenges in the hospice industry. *American Journal of Hospice & Palliative Care*, *20*(5), 360–1p. https://doi.org/10.1177/104990910302000510

Morita, T., Chihara, S., & Kashiwagi, T. (2002). A scale to measure satisfaction of bereaved family receiving inpatient palliative caret. *Palliative Medicine*, *16*(2), 141–150. https://doi.org/10.1191/0269216302pm514oa

Morita T, Chihara S, & Kashiwagi T. (2002). Family satisfaction with inpatient palliative care in Japan. *Palliative Medicine*, *16*(3), 185–193. https://doi.org/10.1191/0269216302pm524oa

Naoki, Y., Matsuda, Y., Maeda, I., Kamino, H., Kozaki, Y., Tokoro, A., Maki, N., & Takada, M. (2018). Association between family satisfaction and caregiver burden in cancer patients receiving outreach palliative care at home. *Palliative & Supportive CarE*, *16*(3), 260–268. https://doi.org/10.1017/S1478951517000232

Ng, A., & Wong, F. (2018). Effects of a Home-Based Palliative Heart Failure Program on Quality of Life, Symptom Burden, Satisfaction and Caregiver Burden: A Randomized Controlled Trial. *Journal of Pain and Symptom Management*, *55*(1), 1–11. https://doi.org/10.1016/j.jpainsymman.2017.07.047

Ng, Z., Tan, P., Theophilus, M., & Ng, Z. Q. (2017). Stapled Mesh stomA Reinforcement Technique (SMART) in the prevention of parastomal hernia: A single-centre experience. *Hernia*, *21*(3), 469–475. https://doi.org/10.1007/s10029-016-1548-9

NHS Finance and Operations. (2016). *Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care*. gov.uk; London. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf

Observatório Português de Cuidados Paliativos. (2018). *Observatório Português de Cuidados Paliativos partilha Relatório de Outono*. Retrieved from: https://ics.lisboa.ucp.pt/news/observatorio-portugues-de-cuidados-paliativos-partilha-relatorio-de-outono-10066

Ornstein, K., Penrod, J., Schnur, J., Smith, C., Teresi, J., Garrido, M., McKendrick, K., Siu, A., Meier, D., & Morrison, R. (2017). The Use of a Brief 5-Item Measure of Family Satisfaction as a Critical Quality Indicator in Advanced Cancer Care: A Multisite Comparison. *Journal of Palliative Medicine*, *20*(7), 716–721. https://doi.org/10.1089/jpm.2016.0442

Ornstein, K., Teresi, J., Ocepek-Welikson, K., Ramirez, M., Meier, D., Morrison, R., & Siu, A. (2015). Use of an Item Bank to Develop Two Short-Form FAMCARE Scales to Measure Family Satisfaction With Care in the Setting of Serious Illness. *Journal of Pain and Symptom Management*, *49*(5), 894-+. https://doi.org/10.1016/j.jpainsymman.2014.10.017

Ozcelik, H., Cakmak, D., Fadiloglu, C., Yildirim, Y., & Uslu, R. (2015). Determining the satisfaction levels of the family members of patients with advanced-stage cancer. *Palliative & Supportive Care*, *13*(3), 741–747. https://doi.org/10.1017/S1478951514000534

Ozcelik, H., Fadiloglu, C., Karabulut, B., & Uyar, M. (2014). Examining the Effect of the Case Management Model on Patient Results in the Palliative Care of Patients With Cancer. *American Journal of Hospice & Palliative Medicine*, *31*(6), 655–664. https://doi.org/10.1177/1049909113506980

Paramanandam, G., Boohene, J., Tran, K., & Volk-Craft, B. (2020). The Impact of a Hospital-Community Based Palliative Care Partnership: Continuum from Hospital to Home. *Journal of Palliative Medicine*, *23*(12), 1599–1605. https://doi.org/10.1089/jpm.2020.0090

Parker, S. M., Remington, R., Nannini, A., & Cifuentes, M. (2013). Patient Outcomes and Satisfaction With Care Following Palliative Care Consultation. *Journal of Hospice & Palliative Nursing*, *15*(4), 225–232. https://doi.org/10.1097/NJH.0b013e318279f4ce

Parpa, E., Galanopoulou, N., Tsilika, E., Galanos, A., & Mystakidou, K. (2017). Psychometric Properties of the Patients’ Satisfaction Instrument FAMCARE-P13 in a Palliative Care Unit. *American Journal of Hospice & Palliative Medicine*, *34*(7), 597–602. https://doi.org/10.1177/1049909116645511

Peters, M., Godfrey, C., McInerney, P., Munn, Z., Trico, A., & Khalil, H. (2020). Chapter 11: Scoping Reviews. In E. Aromataris & Z. Munn (Eds.), *JBI Manual for Evidence Synthesis*. JBI. https://doi.org/10.46658/JBIMES-20-12

Proot I, Schrijnemaekers V, van Hoef L, Courtens A, & Huijer HA. (2006). Measuring patient and family satisfaction with terminal care: The development and testing of the Maastricht Instrument on Satisfaction with Terminal Care (MITTZ). *Supportive & Palliative Cancer Care*, *3*(1), 7–14. Retrieved from: https://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=106205200&lang=pt-br&site=ehost-live

Ribeiro, O., Lima, S., & Duarte, J. (2020). Satisfação da família com os cuidados paliativos. *Milleniu - Journal of Education, Technologies, and Health*, *5e*, Article 5e. https://doi.org/10.29352/mill0205e.22.00322

Ringdal, G., Jordhoy, M., & Kaasa, S. (2003). Measuring quality of palliative care: Psychometric properties of the FAMCARE Scale. *Quality of Life Research*, *12*(2), 167–176. https://doi.org/10.1023/A:1022236430131

Rosser, M., & Walsh, H. (2014). *Fundamentals of palliative care for student nurses*.

Roza, K. A., Lee, E. J., Meier, D. E., & Goldstein, N. E. (2015). A Survey of Bereaved Family Members To Assess Quality of Care on a Palliative Care Unit. *Journal of Palliative Medicine*, *18*(4), 358–365. https://doi.org/10.1089/jpm.2014.0172

Sandsdalen, T., Wilde-Larsson, B., & Grondahl, V. (2019). Patients’ Perceptions Of The Quality Of Palliative Care And Satisfaction—A Cluster Analysis. *Journal of Multidisciplinary Healthcare*, *12*, 903–915. https://doi.org/10.2147/JMDH.S220656

Slort, W., Schweitzer, B. P. M., Blankenstein, A. H., Abarshi, E. A., Riphagen, I. I., Echteld, M. A., Aaronson, N. K., van der Horst, H., & Deliens, L. (2011). Perceived barriers and facilitators for general practitioner-patient communication in palliative care: A systematic review. *Palliative Medicine*, *25*(6), 613–629. https://doi.org/10.1177/0269216310395987

Strasser F, Sweeney C, Willey J, Benisch-Tolley S, Palmer JL, & Bruera E. (2004). Impact of a half-day multidisciplinary symptom control and palliative care outpatient clinic in a comprehensive cancer center on recommendations, symptom intensity, and patient satisfaction: A retrospective descriptive study. *Journal of Pain & Symptom Management*, *27*(6), 481–491. https://doi.org/10.1016/j.jpainsymman.2003.10.011

Teresi, J. A., Ornstein, K., Ocepek-Welikson, K., Ramirez, M., & Siu, A. (2014). Performance of the Family Satisfaction with the End-of-Life Care (FAMCARE) measure in an ethnically diverse cohort: Psychometric analyses using item response theory. *Supportive Care in Cancer*, *22*(2), 399–408. https://doi.org/10.1007/s00520-013-1988-z

Teresi, J., Ocepek-Welikson, K., Ramirez, M., Kleinman, M., Ornstein, K., & Siu, A. (2015). Evaluation of measurement equivalence of the Family Satisfaction with the End-of-Life Care in an ethnically diverse cohort: Tests of differential item functioning. *Palliative Medicine*, *29*(1), 83–96. https://doi.org/10.1177/0269216314545802

Thery, L., Anota, A., Waechter, L., Laouisset, C., Marchal, T., Burnod, A., Angellier, E., Djoumakh, O., Thebaut, C., Bredart, A., Dolbeault, S., Mino, J., & Bouleuc, C. (2021). Palliative care in day-hospital for advanced cancer patients: A study protocol for a multicentre randomized controlled trial. *BMC Palliative Care*, *20*(1). https://doi.org/10.1186/s12904-021-00754-x

Tierney, R., Horton, S., Hannan, T., & Tierney, W. (1998). Relationships between symptom relief, quality of life, and satisfaction with hospice care. *Palliative Medicine*, *12*(5), 333–344. https://doi.org/10.1191/026921698670933919

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., … Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine*, *169*(7), 467–473. https://doi.org/10.7326/M18-0850

van Soest-Poortvliet, M., van der Steen, J., de Vet, H., Hertogh, C., Deliens, L., & Onwuteaka-Philipsen, B. (2015). Comfort goal of care and end-of-life outcomes in dementia: A prospective study. *Palliative Medicine*, *29*(6), 538–546. https://doi.org/10.1177/0269216315570409

Vitacca, M., Comini, L., Tabaglio, E., Platto, B., & Gazzi, L. (2019). Tele-Assisted Palliative Homecare for Advanced Chronic Obstructive Pulmonary Disease: A Feasibility Study. *Journal of Palliative Medicine*, *22*(2), 173–178. https://doi.org/10.1089/jpm.2018.0321

Wentlandt, K., Seccareccia, D., Kevork, N., Workentin, K., Blacker, S., Grossman, D., & Zimmermann, C. (2016). Quality of Care and Satisfaction With Care on Palliative Care Units. *Journal of Pain & Symptom Management*, *51*(2), 184–192. https://doi.org/10.1016/j.jpainsymman.2015.10.006

World Health Organization. (2020). *Global Atlas of Palliative Care at the End of Life* (London). 2nd ed.; Worldwide Palliative Care Alliance. www.thewhpca.org

Zimmermann, C., Riechelmann, R., Krzyzanowska, M., Rodin, G., & Tannock, I. (2008). Effectiveness of specialized palliative—Care a systematic review. *JAMA- Journal of the American Medical Association*, *299*(14), 1698–1709. https://doi.org/10.1001/jama.299.14.1698