RIASE
REVISTA IBERO-AMERICANA DE SAÚDE E ENVELHECIMENTO
REVISTA IBERO-AMERICANA DE SALUD Y ENVEJECIMIENTO

# PALLIATIVE CARE: PERCEPTION OF HEALTH PROFESSIONALS IN COMMUNITY CONTEXT

# CUIDADOS PALIATIVOS: PERCEÇÃO DOS PROFISSIONAIS DE SAÚDE EM CONTEXTO COMUNITÁRIO

# CUIDADOS PALIATIVOS: PERCEPCIÓN DE LOS PROFESIONALES DE LA SALUD EN ENTORNOS COMUNITARIOS

Rui Miguel Tavares Correia[1], Ana Maria Grego Dias Sobral Canhestro[2].

[1]Care Unit in the Infante Community, ACES Barlavento,
[2]School of Health, Polytechnic Institute of Beja.

Received/Recebido: 2022-12-14 Accepted/Aceite: 2023-02-28 Published/Publicado: 2023-06-23

DOI: http://dx.doi.org/10.60468/r.riase.2023.9(2).582.7-28

VOL. 9 NO. 2 APRIL 2023

## ABSTRACT

**Introduction:** The accessibility of citizens to palliative care is today a public health emergency, since it is strongly marked by issues of inequality and inequity. The lack of knowledge of health professionals is one of the biggest barriers preventing users with palliative needs from accessing this care. The aim of this study is to assess the degree of knowledge of health professionals, in community context, on referral to palliative care. This study aims to identify possible gaps in knowledge/training in order to contribute as a change agent to improve health practices.

**Methods:** Simple descriptive study with a qualitative approach. Semi-structured interviews were conducted with seven primary health care professionals and the data obtained were subjected to content analysis.

**Results:** From the analysis, ten subcategories emerged through an inductive logic and five categories through a deductive logic. The categories that emerged are: perception of palliative care; assessment of palliative needs; training; barriers in access to palliative care; promotion of accessibility to palliative care.

**Conclusion:** The lack of knowledge of professionals in this area has an extremely negative impact on users' access to this care.

**Keywords:** Health Personnel; Palliative Care; Skills; Training.

## RESUMO

**Introdução:** A acessibilidade dos cidadãos aos cuidados paliativos constitui-se hoje como uma emergência em saúde pública, uma vez, que esta é fortemente marcada por questões de desigualdade e iniquidade. A falta de conhecimentos dos profissionais de saúde constitui-se como uma das maiores barreiras que impedem os utentes com necessidades paliativas de aceder a estes cuidados. O objetivo deste estudo é avaliar o grau de conhecimento dos profissionais de saúde, em contexto comunitário, no encaminhamento para cuidados paliativos. Pretende-se com este estudo identificar possíveis lacunas no conhecimento/formação, de modo, a contribuir como agente de mudança para melhorar as práticas em saúde.

**Métodos:** Estudo descritivo simples com abordagem qualitativa. Foram realizadas entrevistas semiestruturadas a sete profissionais de saúde dos cuidados de saúde primários e os dados obtidos foram sujeitos a análise de conteúdo.

**Resultados:** Da análise emergiram dez subcategorias através de uma lógica indutiva e cinco categorias através de uma lógica dedutiva. As categorias que emergiram são: perceção dos cuidados paliativos; avaliação das necessidades paliativas; formação; barreiras no acesso aos cuidados paliativos; promoção da acessibilidade aos cuidados paliativos.

**Conclusão:** O desconhecimento dos profissionais nesta área tem um impacto extremamente negativo, no acesso dos utentes a estes cuidados.

**Palavras-chave:** Competências; Cuidados Paliativos; Formação; Profissionais de Saúde.

## RESUMEN

**Introducción:** La accesibilidad de los ciudadanos a los cuidados paliativos es hoy una emergencia de salud pública, ya que está fuertemente marcada por cuestiones de desigualdad e inequidad. El desconocimiento de los profesionales sanitarios es una de las mayores barreras que impiden a los usuarios con necesidades paliativas acceder a estos cuidados. El objetivo de este estudio es evaluar el grado de conocimiento de los profesionales sanitarios, en entornos comunitarios, sobre la derivación a cuidados paliativos. Este estudio pretende identificar posibles lagunas de conocimiento/formación para contribuir como agente de cambio a la mejora de las prácticas sanitarias.

**Métodos:** Estudio descriptivo simple con enfoque cualitativo. Se realizaron entrevistas semiestructuradas a siete profesionales de atención primaria y los datos obtenidos se sometieron a un análisis de contenido.

**Resultados:** Diez subcategorías surgieron del análisis a través de la lógica inductiva y cinco categorías a través de la lógica deductiva. Las categorías que surgieron son: percepción de los cuidados paliativos; evaluación de las necesidades paliativas; formación; barreras en el acceso a los cuidados paliativos; promoción de la accesibilidad a los cuidados paliativos.

**Conclusión:** El desconocimiento de los profesionales en esta materia repercute muy negativamente en el acceso de los usuarios a estos cuidados.

**Descriptores:** Competencia; Cuidados Paliativos; Formación; Habilidades; Profesionales de la Salud.

# INTRODUCTION

The current reality demonstrates that access to palliative care is strongly marked by numerous inequalities and inequities. According to WHO, palliative care only reaches 12% of users who need it, meaning that only about 7 million, out of 56.8 million, people can access it(1). This situation tends to worsen, since demographic and epidemiological changes resulting from population aging are a reality that forces us to rethink health strategies. According to the latest data from the Organization for Economic Co-operation and Development, longevity gains are stagnating and chronic diseases are affecting more and more people. In OECD countries an average person can expect to live up to 81 years, and about one third of the population lives with two or more chronic diseases(2). Forecasts indicate that worldwide, population aging and the increase in non-communicable diseases will increase by more than 100 million in 2060, thus contributing to the scale of unnecessary suffering and increased needs for palliative care(3). Palliative care emerges in response to the suffering experienced by these people and their families. Access to this care is a legal obligation on the part of States, and currently several international organizations claim this care as a human right. Care is based on the principles of the dignity of the human person, the promotion of quality of life, universality and respect for the unquestionable value of human life. The non--access of people with palliative needs to this health care is considered as a cruel, degrading and inhumane treatment(4).

The most recent data show that in Portugal the number of people in need of palliative care is between 81,553 and 96,918. The country has 27 community teams, 43 intra-hospital teams and 31 inpatient units, 17 of which are in hospitals and 14 are incorporated into the National Network of Continuing Care, thus accounting 409 beds(5).

According to the latest report by the Portuguese Observatory for Palliative Care, the national accessibility rate stood at 23.3%. Of the people admitted to the teams, 80.7% were due to oncological disease, 16.8% to non-oncological disease and 2.5% to mixed disease. This study allows concluding that Portugal is far from having a universal coverage of Palliative Care, being the same marked by deep regional asymmetries. Comparing the needs of the population and the people who have access to this care, it appears that the country does not respond to about 70% of the population(6).

There is still a long way to go in terms of ensuring universal coverage, it is essential to create more teams, increase the number of human resources and increase the training needs of health professionals.

Scientific evidence has shown that early provision of palliative care contributes to improving the quality of life and the mood of people with palliative needs(7), increase survival, reduce caregiver burden, improve symptom control management, increase satisfaction levels(8), reduce health system costs (fewer visits to hospital services, fewer hospitalizations and greater likelihood of dying at home) and decrease the number of cases of therapeutic obstinacy at the end of life(9).

Although it is an obligation of States to guarantee the access of their citizens to palliative care, it is urgent to reflect, why they cannot ensure this right. Scientific evidence indicates that one of the main barriers preventing citizens' access to this care is the lack of specific training of health professionals(10). Adequate training for health professionals in this specific area contributes to increased health gains, namely, increased quality of life, decreased levels of suffering and decreased unnecessary spending for the health system(11).

Thus, the research question that was the basis of this study was: What is the degree of knowledge that health professionals present about the referral of patients to palliative care?

We intend with this study to identify possible gaps in the knowledge/training of professionals, in order to contribute as a change agent to improve health practices.

# METHODOLOGY

This is a simple descriptive study with a qualitative approach. The sample consisted of health professionals (doctors and nurses) from a health center (Personalized Health Care Unit and Community Health Care Unit) under the jurisdiction of the Algarve Regional Administration. The following criteria were defined as eligible for inclusion: medical professionals and nurses who are currently employed in the unit and who agree to participate in the study in a free and informed manner, according to the Helsinki declaration. Exclusion criteria: remaining professionals and refusal to participate in the study.

Seven health professionals participated in the study, of which one had advanced training in palliative care (postgraduate) and another, basic training, the rest had no training in the area. The interviewed population is female and the average age is 44.7 years. For the years of service, the average corresponds to 21.1 years. In terms of years in the current service, the average corresponds to 9.8 years.

The information collection instrument that best fit the intended objective was the semi-structured interview (Chart 1↗). For the interview, and after the favorable opinion of the ethics committee of the Regional Health Administration of the Algarve, a script was prepared with open and closed questions, which was validated by experts in the area. Data collection took place during the month of May 2021, with audio recording lasting 45 minutes. Content analysis was used to process the data. According to Bardin, the author proposes that raw data go through a transformation process called coding(12). In the pre-analysis phase and after the full transcription of the interviews, an exhaustive reading of the same and subsequent circumscription of the universe of analysis was carried out. The next phase, exploration of the material, we applied the open coding system, in which we used the words of the interviewees (registration units) and through an inductive logic we built the subcategories. For the codification of the categories, a deductive perspective was chosen, in which the data were grouped according to their similarity and through a process of data condensation, the categories were identified. Thus, we can conclude that the disassembly of the data and the regrouping allowed a new interpretation of the data whose objective is to prove the "theory".

After the full transcription of the interviews, the content analysis technique proposed by Bardin was performed. The author organizes the content analysis in three chronological poles: the pre-analysis; the exploration of the material and the treatment of the results, the inference and the interpretation(12). In the pre-analysis phase, a floating reading of the interviews was carried out and later the circumscription of the universe of analysis. The next stage, exploitation of the material, was the codification, namely the cutting, enumeration and choice of categories and subcategories. For the choice of categories and subcategories, an inductive logic was chosen, since the categories resulted from the thematic blocks present in the script of the interviews and the subcategories resulted from the discourse of the interviewees.

The anonymity of the participants in the study was guaranteed through the codification of the data resulting from the interview, with the letter E, numbered from 1 to 7, according to the interviews (I1, I2,...,I7).

# RESULTS AND DISCUSSION

From the content analysis of the interviews, five categories emerged: perception of palliative care, evaluation of palliative needs, training, barriers in access to palliative care and the promotion of accessibility to palliative care. Ten subcategories represented in Chart 2↗ correspond to these categories.

*Category: Perception of Palliative Care*

The perception of palliative care is composed of the subcategories suffering, dignity and quality of life. These subcategories emerge as a result of the perception/vision that respondents have about palliative care. These three dimensions are closely linked to the philosophy of care. The central concept is the person as a whole, in the appreciation of his Self, as a person and not as a terminal patient or bearer of incurable disease. They are cares that promote a holistic approach contemplating the physical, psychological, social and spiritual aspects, as the objective that people with palliative needs can adapt to their death in a constructive and complete way(13).

- Suffering

Palliative Care is very linked to the issues of suffering, namely pain, despair and hopelessness, very frequent at the end of life. It is important to refer to the concept of total pain, introduced by Cicely Saunders, founder of modern palliative care, who alerts us to the issues of intense suffering that the person and his family members experience at the end of their lives. These questions were corroborated in a recent study conducted in Portugal, where it concludes that about 70% of cancer patients who die in a public hospital were subjected to aggressive treatment at the end of life, eventually dying in excessive suffering(14).

The impact that suffering has on each of us is measured in the light of the values, beliefs, experiences and resources that each one has, which may be different from person to person. It is due to this multiplicity of factors that human suffering becomes a complex reality(15).

This concern for the suffering of the other is well expressed in excerpts from the interviews, which is why we believe that this recognition for the suffering that the other goes through can contribute to the promotion of a more humanized care.

> “(…) these are people who **suffer immensely** and the approach is usually not appropriate (…)” I2, P. 56

> “(…) especially when the person knows that there is **no longer any hope of life**.” I3, P. 117
>
> “(…) people get this feeling of impotence and **despair** of not being able to control the situation (…)” I4, P. 165
>
> “People with enormous resistance to everything that is pain control, **total pain**, surreal (…) need a lot, a lot of daily monitoring (…)” I5, P. 207
>
> “(…) people resort already at a stage when they are already more **desperate**.” I6, P. 240

- Dignity

Dignity is represented by respect for the other, the importance of valuing the person and his well-being being seen as necessary for the person to have a more dignified end of life. According to Chochinov, dignity is defined as the state of being worthy, honored, or esteemed. The concept of dignity is based on the relationship we have with each other. It is about recognizing and valuing the other as a person, respecting their individuality. The author addresses the importance of preserving dignity, through a holistic approach to the person, whose sole purpose is the comfort and well-being of the person, the degree of satisfaction, self-control and sense of belonging translating the quality of care that the other perceives(16).

The category dignity is parallel in the units of registration where the concern for the other stands out, the importance of valuing the person until the end of his life. Respect and concern for those who suffer and who despite having an incurable disease and a more limited life span, remains important.

> “(…) **respect** for human rights... dignity, the person's dignity with whatever they need (…)” I2, P. 58
>
> “(…) that person so that she could continue to be, to **feel like a person**, not just a person who is at the end of her life, but who is here and wants to make the most of something (…) “ I3, P. 119
>
> “(…) health depends on **well-being**, joy, happiness, balance, peace (…)” I4, P. 149

- Quality of life

Quality of life, a central theme in palliative care, is directly related to the degree of control that the person has of his own life, either pain control or other symptoms. In this sense, this subcategory is represented by the importance of caring for the other in a holistic perspective. In the interviewees, there is a constant concern for the quality of life of the other, this balance between the body (pain relief) and “the totality of being” (holistic well-being).

> “(...) as a whole, as a **holistic well-being**.” I1, P.27
>
> “(...) has a lot to do with **comfort** measures, pain control (...)” I2, P.50
>
> “(...) when the person reaches the end of life, they have had **pain relief**, comfort, the presence of significant people (...)” I3, P.91
>
> “(...) to have a minimum of quality of life, of **balance** in terms of well-being, in terms of their(...)” I4, P.137
>
> “(...) mainly to **relieve symptoms** (...)” I6, P.232
>
> “(...) care for its maintenance, that is, **stabilizing** it, giving quality of life, whatever we achieve for the user.” I7, P.269

It is essential that health professionals develop technical and human skills in order to normalize conversations about death and dying. Professionals should promote active listening in order to meet the needs of users. Such conversations allow users a greater control of their health situation, with a positive impact on the promotion of autonomy, preservation of dignity and improvement of quality of life(17). Another study considers that these skills allied to others, such as: pain relief, emotional and psychological suffering; autonomy in decision making; not being a burden; emotional support to the family; choice of place of death; performing cultural rituals, are essential conditions for a good death(18).

*Category: Assessment of palliative needs*

After analyzing the concept of the theme, it is important to analyze how this vision finds parallel in the daily practice of professionals. The importance of carrying out a palliative approach as early as possible goes first through an evaluation of the palliative needs of the population. According to Gómez-Batiste *et al*, people with chronic diseases should receive a comprehensive palliative approach as early as possible in all health services, and the identification of these people is the first step to be taken(19).

- Evaluation Instruments

In this sense arises the subcategory assessment instruments. This subcategory looks at how respondents assess the palliative needs of the people they care for.

In their daily practice respondents make use of their experience, intuition and common sense to help people. It was found that they do not use any palliative needs assessment instrument. As a symptom assessment instrument, only the numerical scale was used to assess pain. The lack of knowledge about the existence of instruments that allow assessing the palliative need of people was common to all respondents.

> “(...) the only scale I have available at SClinico to apply is the pain monitoring scale, the **numeric scale**.” I1, P.19
>
> “I'm not one of those people who uses many scales, instruments... I'm much more **intuitive**, much more in relation to what the person needs (...) it's a lot of contact with what I see and what people end up telling us.” I4, P.151
>
> “It is entirely based on the **experience** and knowledge of the patients, at this moment I do not apply any scale by definition properly (...)” I5, P.195
>
> “Perhaps by **intuition**, the patient is at a stage where we cannot give him quality of life.” I7, P.284

According to Gómez-Batiste *et al*, one of the problems that hinders the implementation of a palliative approach, especially in primary health care is effectively the lack of instruments that can help professionals in detecting as early as possible the palliative needs of the population(19). In another study, the researchers concluded that primary care professionals revealed difficulties in identifying patients with palliative needs. Only 14.3% of the sample identified correctly(20).

- Real needs of the population

This subcategory emerged from the interviewees' need to know the population better, the need to meet people for a better assessment of possible needs.

This was a need we identified, the importance of having the real data of people with palliative needs. In fact, Portugal needs a statistical survey of these real needs of the population and not only estimates, based on causes of death. Locally, the problem intensifies, since according to statistical data, we have the problem of population aging and social isolation. Therefore, this need arises to meet people, regardless of where they are. Only in this way will we be able to identify such needs.

> “(...) I believe that the main intervention is to start doing homework, which is basic work. That is to know how many **users** we have in real terms, who need this intervention (...)” E1, P.21
>
> “(...) is to go far into the field, to **identify people** who are very isolated, to try to understand what are the health problems...” E3, P.103
>
> “(...) we have an aging population, isolated, without access to health and the only way **to find** them is to have a van and go there.” E4, P.153

> "(...) the **proximity** health care, I think may be the ones that most identify some palliative need that teeth may have (...)" E5, P.187

*Category: Training*

The need for training by professionals in such a specific area is of vital importance. The National Program for Palliative Care recognizes the importance of health professionals with differentiated training and training. Only in this way will it be possible to respond to the complexity and management of an intense suffering that people with chronic, advanced and progressive disease go through(21). According to a systematic review of the literature, if health professionals have access to training programs, they have been able to respond more effectively to the suffering of patients. These gains in health go through the management of symptom control, reduction of cases of therapeutic obstinacy and timely referral for palliative care(22).

The training category comprises two subcategories, the need for knowledge and insecurity.

- Need for knowledge

The high degree of lack of knowledge in palliative care was evident in the interviews. Despite knowing the concept, most interviewees reveal difficulties in identifying palliative needs and in referring to specialized teams when necessary. About 71% of respondents do not have any training in this area and recognize that this is a difficulty in responding to the user. Instead, those who had training proved to be better able to respond to the palliative needs (implementation of palliative actions) of the users. It should be noted that untrained professionals will never be able to identify such needs and will never be able to give an effective response. These data are corroborated by another study, which concluded that the lack of knowledge and experience of professionals affect the degree of confidence in the approach to these users thus hindering the transition process to palliative care(23). In another study carried out in the United Kingdom, researchers concluded that about 9000 people with palliative needs end up not being able to access these services(24).

> "(...) we benefited from the **knowledge** of having a person with advanced training in that area, we and the user." I1, P.15
>
> "(...) maximum information or training in this area to be able to **respond** (...)" I2, P.109
>
> "(...) lack of training for teams, health professionals, not knowing the right time to refer, **lack of knowledge** about such teams (...)" I3, P.121
>
> "(...) there is a great **need** for professional training, to begin with." I4, P.145

> "Training is fundamental here, knowing what palliative care is, what palliative care does, what low complexity is, what high complexity is, what teams exist to do that and then all training (...) **if people do not have knowledge they will not identify** (...)" I5, P.197

> "(...) could be of great help to this type of patient. Yes, there could be **strategies** to deal with that situation. Yes, the information is important, I think it would give a more timely response." I6, P.250

- Insecurity

This subcategory encompasses the interviewees' view of the difficulties faced by people with chronic and advanced diseases. The difficulties in responding to these challenges are present in the registration units, namely in the impotence and difficulty of being alone and having to respond to the sick person and the family. These fears or powerlessness about what to do or say probably come from lack of skills and experience in palliative care(25).

For Barbosa, the fears of health professionals before a patient with palliative needs, are manifested by the difficulty that he has in expressing emotions; in feeling powerless or ignorant (for not knowing all the answers); in fear of triggering in the person reactions such as anxiety, anger or sadness; in fear of triggering feelings similar to that of the sick person (suffering for sympathy) and in personal fears about illness and death(26).

> "(...) none of them were in a terminal state of life, so maybe it was **easier** for me (...)" I1, P.33

> "The situation that marked me the most was me being alone and the family being alone. It was me being **alone** with the family in that situation (...)" I2, P.74

> "It's horrible when we are doing a domicile and we see that the person lives in pain and **we don't know** how to control it (...)" I4, P.165

> "I feel **powerless** to take care of a user with palliative needs." I7, P.294

*Category: Barriers to accessing palliative care*

This category is composed of subcategories myths and lack of knowledge of resources. Currently there are still many barriers in access to this care. According to a systematic review of the literature on: What are the barriers to referral of adult cancer and non-cancer patients to palliative care services, concluded that these were due to lack of knowledge and beliefs of professionals, stigma associated with palliative care, lack of preparation of the professionals themselves and the health system(11).

- Myths

Despite the development of palliative care in Portugal, there are still many myths associated with this issue, by both professionals and the population. The association between palliative care and death is still very evident. Most respondents related palliative care to pain and expressed difficulties in dissociating it from death. The interviewees revealed difficulties in modifying certain beliefs by the population, namely the separation between palliative care and death or contradicting the already celebrated phrase that is not possible to do more.

> "(...) because there is still an almost linear association with **death** (...)" I1, P.37

> "(...) people think it is a fatality and that **there is nothing else to do**." I2, P.64

> "I immediately associate palliatives with pain (...) we still live that idea a lot: **we are born to suffer**. I am not criticizing anyone, but I see many doctors saying, there is pain, you have to endure it, this is very cultural (...)" I4, P.145

> "Talking about palliative care, people immediately think they are already **dying**..." I5, P.213

> "(...) it is always thought that palliative care is **associated with death** (...)" I6, P.254

As we contemplate the human being in his multidimensions, we realize how important it is to start a palliative approach as soon as possible. The human being becomes complete only if his life finds a meaning for his existence. Only when all his needs are physiological; security; love/belonging; esteem and self-realization are satisfied will it be possible for a person to find meaning and meaning for his life(27).

- Lack of knowledge of resources

This subcategory represents the difficulties in getting this care to those who need it. We found that although the region has several specialized teams, whether in the community or at the hospital level, most respondents were unaware of their existence and how to get to them. This lack of knowledge is represented by the units of registration, namely, not knowing the existence of these teams going through the difficulty in knowing the referencing procedures for them. This lack of knowledge was justified by the lack of communication by official entities. This represents a serious injury to the populations that could benefit and for one reason or another they cannot access these services.

> "(...) **there is no palliative care team**, so to speak, that responds to palliative situations other than oncology..." I1, P.9

> "**Knowledge is by hearsay**, I didn't hear any communication about it (...)" I2, P.52
>
> "(...) **not knowing the right moment** to refer, the lack of knowledge about such specialized teams (...)" I3, P.121
>
> "Right now, **I don't even know who to refer to**, after that idea of referring to palliative care is to go somewhere..." I4, P.167
>
> "(...) most of the people who work here **don't know the resources they have**. And I also know why I went to do an internship there, that's the reality (...)" I5, P.191
>
> "Disclosure of the team or even coming here and talking, **when you should refer** or other type of support that could be given." I6, P.230

Several studies corroborate that the degree of lack of knowledge of professionals in this area is a factor promoting inequalities and inequities in access to palliative care. The studies concluded that the majority of patients did not have access to this care. There were situations in which references were late. People were only referred at a very advanced stage of the disease, and the waiting time was long, eventually dying without having access(28,29).

*Category: Promoting accessibility to palliative care*

As a way to improve the accessibility of this care to the population, we tried to understand what was the interviewees' view about the possibility of promoting an articulation between primary health care and palliative care teams.

- Optimize the articulation between teams

For the interviewees it is important to meet with the teams, get to know them, share experiences, above all, know which communication channels for a given situation. It is essential to know the procedures to be carried out in the articulation between the units, in order to obtain a faster response to the palliative needs of each user.

> "(...) we can **work in a network**, so that we can share experiences, clarify doubts, optimize knowledge (...)" E1, P.41
>
> "(...) communication, opening a **communication** channel, either with a reference element, or a form of referral and communication with the palliative care team." E2, P.66
>
> "(...) I think it would be important **to meet** with us in a physical space(...)" E3,P.117
>
> "(...) there may be an app, a **sharing** of...but I think face-to-face contact is essential." E4, P.165

> "Having a sharing will at least access that, then with time and with a **consultancy**, the person will also learn and integrate the concepts." E5, P.215
>
> "(...) having these **meetings** with other teams, we ended up acquiring strategies..." E6, P.256

According to Innis *et al*, the differentiated training and contact of primary health care professionals with palliative care can be a facilitating element in the identification and referral of people to palliative care. The study suggests the importance and the need to promote communication between both teams(20).

# CONCLUSION

The present study allowed us to verify that the high lack of knowledge of health professionals in this area calls into question the right of users to access palliative care. The perception that health professionals present on the subject resulted in several categories. These categories supported the need to promote changes in the response to end-of-life care.

Currently, the health center cannot meet the palliative needs of the population. There is a widespread lack of knowledge of the resources that the region has in this area, which causes a lack of articulation with the palliative teams, calling into question the non-direction of more complex patients.

The data obtained showed that the lack of pre, postgraduate and continuous training is one of the major responsible for sub-references, thus constituting an important barrier in the accessibility of citizens to these care. We found that professionals with training were distinguished by the inclusion of palliative actions in their daily clinical practice, compared to those who did not have training. We did not identify differences between those who had basic and advanced training. Due to this lack of training of the interviewees, there is still a very reductive view that associates palliative care only to pain control and its direct relationship to death. This vision represents a strong barrier to the accessibility of palliative care by citizens. We also conclude that not using tools to identify palliative needs by professionals exacerbates the problem.

We consider it essential to increase awareness of early referral to primary health care professionals. Improve communication channels within the institution (dissemination of resources and how to reach them). Develop strategies that facilitate the articulation between the various teams and implement training action programs, so that there is a standardization of care in response to patients with palliative needs.

In the future and in order to promote accessibility to palliative care, It is essential to incorporate tools for assessing palliative needs in computer programs in order to streamline the process of identification and referencing thus allowing the improvement of end-of-life care.

We consider as the main limitation of the study the small sample size, so it would be important to apply this study to other units in the region in order to understand if the needs identified would be similar.

# REFERENCES

1. Boletim da OMS: Implementando a Resolução da Assembleia Mundial da Saúde sobre Cuidados Paliativos 12 de outubro de 2021. [cited 2022 Nov 28]; Available from: https://www.who.int/news/item/12-10-2021-implementing-world-health-assembly-resolution-on-palliative-care

2. OECD. Health at a Glance 2019: OECD Indicators. 2019. [cited 2022 Nov 28]; OECD Publishing, Paris. Available from: https://doi.org/10.1787/4dd50c09-en

3. Sleeman, K., Brito, M., Etkind, S., Nkhoma, K., Guo, P., Higginson, I., Gomes, B. et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. Lancet Glob. Health. 2019; 7(7). Available from: https://doi.org/10.1016/S2214-109X(19)30172-X3

4. EAPC. Toolkit for the Development of Palliative Care in Primary Care. 2019. [cited 2022 Dec 1]. Available from: https://www.eapcnet.eu/wp-content/uploads/2021/03/EAPC-Toolkit-2019.pdf

5. CNCP. Plano Estratégico para o Desenvolvimento dos Cuidados Paliativos. 2021-2022. Lisboa: Ministério da Saúde. Available from: https://www.acss.min-saude.pt/wp-content/uploads/2017/01/PEDCP-2021_2022.pdf

6. Capelas, M., Afonso, T., Durão, S. & Teves, C. Relatório de Outono 2019 do Observatório Português dos Cuidados Paliativos: Secção II Atividade Assistencial das Equipas/Serviços de Cuidados Paliativos. 2020. Available from: https://repositorio.ucp.pt/bitstream/10400.14/30228/4/9789725407158

7. Temel, J., Greer, J., Muzikansky, A., Gallagher, E., Admane, S., Jackson, V., ... Lynch, T. Early palliative care for patients with metastatic non-small-cell lung cancer. The new England journal of medicine. 2010; 363(8), 733-742. Available from: https://doi.org/10.1056/NEJMoa1000678

8. Zimmermann, C., Swami, N., Krzyzanowska, M., Hannon, B., Leighl, N., Oza, A., Lo, C., et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. The Lancet. 2014; 383(9930), 1721-1730. Available from: https://doi.org/10.1016/S0140-6736(13)62416-2

9. Shepperd, S., Gonçalves-Bradley, D. C., Straus, S. E., & Wee, B. Hospital at home: home-based end-of-life care. The Cochrane database of systematic reviews. 2016; 2(2), CD009231. Available from: https://doi.org/10.1002/14651858.CD009231.pub2

10. WHO. World Health Assembly 67.19 Strengthening of palliative care as a component of comprehensive care throughout the life course. 2014. [cited 2022 Nov 30]; Available from: https://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf

11. Alves, J., Marinho, M. & Sapeta P. Referenciação tardia: barreiras a referenciação de doentes adultos oncológicos e não oncológicos para serviços de cuidados paliativos. Revista de Cuidados Paliativos. 2019; 6(1). Available from: https://www.apcp.com.pt/uploads/revista-cuidados-paliativos_vol06_n01_2019.pdf

12. Bardin, L. Análise de Conteúdo. Lisboa: Edições 70; 2019.

13. Twycross, R. Cuidados Paliativos. 2.ª Ed. Lisboa: Climepsi editores; 2003.

14. Martins-Branco D, Lopes S, Canario R, et al. Factors associated with the aggressiveness of care at the end of life for patients with cancer dying in hospital: a nationwide retrospective cohort study in mainland Portugal. ESMO Open. 2020;5(6). Available from: https://doi.org/10.1136/esmoopen-2020-000953

15. Barbosa, A. Ser pessoa, Vulnerabilidade e Sofrimento. In: A. Barbosa, P. Pina, F. Tavares, & I. Neto (Ed.), Manual de Cuidados Paliativos. 3.ª Ed. Lisboa: Núcleo de cuidados paliativos. Centro de bioética. Faculdade de Medicina da Universidade de Lisboa; 2016. p. 665-690.

16. Chochinov H. M. Dignity-conserving care – a new model for palliative care: helping the patient feel valued. 2002; JAMA, 287(17),2253-2260.

17. Sutherland R. Dying Well-Informed: The Need for Better Clinical Education Surrounding Facilitating End-of-Life Conversations. The Yale journal of biology and medicine. 2019; 92(4),757--764.

18. Zaman M., Mohapatra, A., Espinal-Arango S. & Jadad, A. What would it take to die well? A systematic review of systematic reviews on the conditions for a good death. Lancet Healthy Longevity. 2021; 2: e593-e600.

19. Gómez-Batiste, X., Amblàs, J., Costa, X., Espaulella, J., Lasmarías, C., Ela, S., Mir, S., et al. Recomendaciones para la Atención Integral e Integrada de Personas com Enfermadades o Condiciones Crónicas Avanzadas Y Prognóstico de Vida Limitado en Servicios de Salud Y Sociales: NECPAL CCOMS-ICO© 3.1. 2017; Available from: http://ico.gencat.cat/web/.content/minisite/ico/professionals/documents/qualy/arxius/INSTRUMENTO-NECPAL-3.1-2017-ESP_Completo-Final.pdf

20. Innis, M., Capelas, M. & Caldas, A. Capacidade dos Profissionais de Saúde de Medicina e Enfermagem dos Cuidados de Saúde Primários em Identificar Doentes de Cuidados Paliativos. 2017; Gazeta Médica, 4(2),78-85.

21. DGS. Programa Nacional de Cuidados Paliativos. Lisboa: Direção Geral da Saúde. 2005 [cited 2022 Dec 5]; Available from: http://1nj5ms2lli5hdggbe3mm7ms5-wpengine.netdna-ssl.com/files/2015/08/Programa-Nacional-de-Cuidados-Paliativos.pdf

22. Correia, R., Canhestro, A. & Pedro, G. A Importância da Capacitação dos Profissionais de Saúde na Prestação de Cuidados aos Doentes com Necessidades Paliativas: Revisão Sistemática da Literatura. 2021; RIASE, 7(2),217-234.

23. Kim, S., Lee, K., & Kim, S. Knowledge, attitude, confidence, and educational needs of palliative care in nurses caring for non-cancer patients: a cross-sectional, descriptive study. BMC palliative care. 2020;19(1),105. Available from: https://doi.org/10.1186/s12904-020-00581-6

24. Allsop, MJ, Ziegler, LE, Mulvey, MR, et al. Duration and determinants of hospice-based specialist palliative care: a national retrospective cohort study. Palliat Med. 2018;32(8):1322-1333.

25. Corbett C. M. Effecting Palliative Care for Patients with Chronic Kidney Disease by Increasing Provider Knowledge. Nephrology nursing journal: journal of the American Nephrology Nurses' Association. 2018;45(6),525-546.

26. Barbosa, A. Mestrado em Cuidados Paliativos: Módulo V – Comunicação de Más Notícias. 2013. Faculdade de Medicina de Lisboa. Centro de Bioética. Núcleo de Cuidados Paliativos. Lisboa.

27. Zalenski, R. J., & Raspa, R. Maslow's hierarchy of needs: a framework for achieving human potential in hospice. Journal of palliative medicine. 2006;9(5),1120-1127. Available from: https://doi.org/10.1089/jpm.2006.9.1120

28. Vasconcelos, P., Cruz, T. & Bragança, N. Referenciação para Cuidados Paliativos num serviço de Medicina Interna. Revista clin. Hosp. Prof. Dr. Fernando Fonseca. 2015; 14-19. Available from: https://repositorio.hff.minsaude.pt/bitstream/10400.10/1693/1/06%20Referencia%C3%A7%C3%A3o%20para%20Cuidados%20Paliativos.pdf

29. Vilaça, R., Coelho, S. & Terroso, M. Demência Avançada nos Serviços de Urgência. Barreiras à Referenciação para Cuidados Paliativos. Revista Cuidados Paliativos. 2018;1(1),5-12.

Authors
Rui Miguel Tavares Correia
https://orcid.org/0000-0002-3863-248x
Ana Maria Grego Dias Sobral Canhestro
https://orcid.org/0000-0002-5528-3154

Corresponding Author/Autor Correspondente:
Rui Correia – Unidade de Cuidados na Comunidade Infante. ACES Barlavento, Lagos, Portugal.
ruiolhao@gmail.com

Authors' contributions
RC: Study coordination, study design, collection, storage and analysis of data, review and discussion of results.
AC: Study design, data analysis, review and discussion of results.
All authors read and agreed with the published version of the manuscript.

Ethical Disclosures
Conflicts of Interest: The authors have no conflicts of interest to declare.
Financial Support: This work has not received any contribution, grant or scholarship.
Provenance and Peer Review: Not commissioned; externally peer reviewed.

Responsabilidades Éticas
Conflitos de Interesse: Os autores declararam não possuir conflitos de interesse.
Suporte Financeiro: O presente trabalho não foi suportado por nenhum subsídio ou bolsa.
Proveniência e Revisão por Pares: Não comissionado; revisão externa por pares.

Chart 1 – Interview guide.

| Subthemes | Objectives | Questions |
|---|---|---|
| A – Knowledge and perception of health professionals about palliative care. | – Identify knowledge about palliative care. | • What do you mean by palliative care?<br>• What resources (types of teams) does the Barlavento region have in terms of palliative care?<br>• Can palliative care be useful for chronically ill patients? If positive, how? If negative, why not? |
| B – Strategies used for identification and referral to palliative care. | – Know how the identification of palliative needs is carried out.<br>– Identify how the referral for palliative care is carried out.<br>– Identify the advantages and disadvantages of referencing. | • How do you identify the palliative needs of users?<br>• Do you currently know how many users enrolled at the Health Center are monitored by the palliative care teams?<br>• Do you think that the number of chronic patients and those with advanced disease has increased or decreased?<br>• In your opinion, what interventions could be developed for an early identification of the palliative needs of the population?<br>• What are the advantages and disadvantages of referring to palliative care?<br>• Do you know the criteria to refer to palliative care teams?<br>• Do you know the procedure to refer for palliative care?<br>• In your opinion, when should palliative care be referred? |
| C – Importance of articulation between the health center and the specialist teams in palliative care. | – Identify the means used in the articulation between the different teams. | • Can you describe how you establish communication with the palliative care teams?<br>• Which means do you find most facilitating for this articulation?<br>• In your opinion, how should communication with specialized teams in palliative care be articulated?<br>• In your opinion, do you consider it important to have a link between primary health care and palliative care teams? |
| D – Barrier to referral for palliative care. | – Identify the needs felt by primary health care professionals in relation to palliative patients.<br>– Identify possible barriers in the referral process for palliative care. | • What difficulties do you experience when facing a palliative patient?<br>• What are some of the barriers that you believe may be preventing these people from being referred for palliative care?<br>• What situations experienced by people with palliative needs that worried you the most?<br>• Have you ever felt powerless to help a palliative patient? If yes, what would be the desired solution for you? |

Chart 1 – Interview guide.←↖

| Subthemes | Objectives | Questions |
|---|---|---|
| E – Importance of meetings about sharing experiences. | – Promote participation in the meeting of primary health care teams with palliative care teams. | • Do you think it is important to have a meeting to share experiences between palliative care and primary health care teams?<br>• Are you available to participate in the 1st meeting of primary health care professionals with specialized palliative care teams? |

Chart 2 – Summary of categories and subcategories resulting from the analysis.↸

| Categories | Subcategories |
|---|---|
| Perception of palliative care | Suffering |
| | Dignity |
| | Quality of life |
| Assessment of palliative needs | Evaluation instrument |
| | Real needs of the population |
| Training | Insecurity |
| | Need for knowledge |
| Barriers to accessing palliative care | Myths |
| | Lack of knowledge of resources |
| Promoting accessibility to palliative care | Optimize the articulation |