

Social work in palliative care: the necessary intervention with the family in Galicia, Spain

Andrea Fernández-Álvarez 



Social Worker

UTE ContactNova. Ourense, España
andrea.fernandez.564564@gmail.com

Carmen Verde-Diego 

Ph.D. in Philosophy and Educational Sciences. Social Worker

Universidad de Vigo. Ourense, España
carmenverde@uvigo.es

Paula Frieiro-Padín  

Ph.D. in Social Work. Social Worker

Universidad de Santiago de Compostela. Compostela, España
paulafrieiropadin@hotmail.com

Abstract

Palliative care is understood as the set of health interventions coordinated from a multidisciplinary and integral perspective, based on the analysis of the patient's preferences and needs, with the aim of improving his or her quality of life and that of his or her family members in the face of a life-threatening disease through the prevention and relief of suffering at all levels of care. The present research article shows the perception that relatives of patients who have been in palliative care units have of the intervention carried out by social work professionals with them in these devices. The research has gathered this information through semi-structured interviews with six family members who have used palliative care services and who have been the main caregiver of their sick family member. After contrasting the arguments of the literature review and the interviews with the family members, the results show that families are a fundamental element in palliative care units, so that carrying out an appropriate intervention with them is of vital importance when it comes to accompanying and intervening throughout the process.

Keywords: Accompaniment; Palliative care; Family; Death; Social Work.

Received: 07/05/2023 | Evaluated: 18/08/2023 | Accepted: 01/09/2023 | Published: 01/01/2024



This work is under a Creative Commons License: Attribution-NonCommercial-ShareAlike 4.0 International.

✉ **Correspondence:** Paula Frieiro-Padín, Universidad de Santiago de Compostela, Praza da Inmaculada N° 5. CP 15702. Santiago de Compostela, España, Email: paulafrieiropadin@hotmail.com

¿How to quote this article?

Fernández-Álvarez, A., Verde-Diego, C., & Frieiro-Padín, P. (2024). Social work in palliative care: the necessary intervention with the family in Galicia, Spain. *Prospectiva. Revista de Trabajo Social e intervención social*, (37), e20312948. <https://doi.org/10.25100/prts.v0i37.12948>

El Trabajo Social en cuidados paliativos: la necesaria intervención con la familia en Galicia, España

Resumen

Se entiende por cuidados paliativos el conjunto de intervenciones sanitarias coordinadas desde una perspectiva multidisciplinar e integral, basadas en el análisis de las preferencias y necesidades del paciente, con el fin de mejorar su calidad de vida y la de sus familiares frente a una enfermedad que compromete la vida a través de la prevención y alivio del sufrimiento desde todos los niveles de atención. El presente artículo de investigación muestra la percepción que tienen familiares de pacientes que han estado en unidades de cuidados paliativos sobre la intervención realizada por profesionales del Trabajo Social con ellos en estos dispositivos. La investigación ha recopilado esta información a través de entrevistas semiestructuradas a seis familiares que han recurrido a servicios de cuidados paliativos y que han sido la cuidadora o el cuidador principal de su familiar enfermo. Tras contrastar los argumentos de la revisión bibliográfica realizada y las entrevistas a los/as familiares, los resultados muestran que las familias son un elemento fundamental en las unidades de cuidados paliativos, por lo que llevar a cabo una intervención adecuada desde el Trabajo Social con ellas es de vital importancia a la hora de acompañar e intervenir a lo largo del proceso.

Palabras clave: Acompañamiento; Cuidados paliativos; Familia; Muerte; Trabajo Social.

Summary: 1. Introduction, 2. Methodology, 3. Findings, 3.1. Timing of Disease Diagnosis, 3.2. Care and Decision Making, 3.3. Relationship with Multidisciplinary Care Team, 3.4. Relationship with Social Work Professional in Palliative Care Units, 3.5. Perception of Family Members Regarding the Palliative Care Experience, 4. Conclusions, 5. Bibliographic references.

1. Introduction

Social Work at the end of life

Death is a natural phenomenon that is part of the life cycle of every living being. In recent decades, significant technical and scientific advances, along with social progress and improvements in the population's quality of life, have significantly influenced the increase in life expectancy and the changing conditions and causes that lead to life's end. All of this has fostered the idea in society that death is a situation that should be postponed as much as possible. Against this background, palliative care stands out for its holistic approach and emphasis on improving the quality of life for patients and families facing potentially life-threatening illnesses. In this context, the role of Social Work in palliative care services becomes of prime importance (Toh *et al.*, 2018).

It should be noted that since 1987, at the European level, the "Association of Social Workers in Palliative Care" has existed to cover various areas. Among its objectives are to elevate the profile of Social Work in palliative care to provide support and advice to social workers working in end-of-life care, to promote excellence by sharing best practices, and to encourage high-quality research and evaluations to improve end-of-life care and the grieving process (Novellas-Aguirre de Cárcer, 2017). More recently, the Scientific-Technical Advisory Unit Avalia-t has fostered the design of health programs and the development of individualized care plans that guarantee continuity of care through the analysis and study of disease trajectories. After a diagnosis of an incurable illness with a limited and uncertain life prognosis, an intervention from clinical practice must be initiated from the outset through a palliative care approach. In this way, palliative care becomes a model of multi-professional and cross-cutting care, ensuring continuity of care and adequate planning of interventions (Agencia Gallega para la Gestión del Conocimiento en Salud [ACIS], 2021).

Palliative care was initially conceived to alleviate the symptoms of individuals diagnosed with advanced-stage cancer. The World Health Organization (WHO, 2020) definition of palliative care refers to it as a set of coordinated healthcare interventions through comprehensive, patient-focused care and analysis of their preferences and needs in order to improve their quality of life and that of their loved ones in the face of a life-threatening illness; and this is achieved through the prevention and relief of suffering on physical, psychosocial, or spiritual levels. The existence of non-oncological, disabling, and progressive diseases with diagnoses leading towards death has made them prone to attention within palliative care units because these types of diseases share much of the symptomatology with advanced oncological diseases on physical, social, psychological, and spiritual levels (Alonso *et al.*, 2010). Hence, patients receiving palliative care will include advanced oncological patients; patients with organic pathologies - cardiopulmonary, hepatic, or renal diseases - who experience a slow decline with exacerbations and partial recoveries; and patients with dementia - mainly neurodegenerative diseases - with an

unpredictable evolution characterized by a final stage of significant deterioration (Royo-Sierra *et al.*, 2021).

The scarcity of resources must be considered and kept in mind, as it can lead to detrimental behaviors and attitudes, such as tensions in relationships, patient abandonment, stress, and difficulties in overcoming grief. Therefore, Social Work becomes crucial. Through skills such as empathy and active listening, the discipline provides support, guidance, and counseling, contributing to the well-being of the patient and their environment (Pérez-Bandera, 2021). Likewise, palliative care must address each patient and their family as unique individuals, taking into account their life history, relationships, and culture. Thus, the unit of care within palliative care units is made up of the patient and their family (Munuera-Gómez, 2016), who will express different sensations and needs throughout the care process, which must be considered from an integral and individual perspective (De la Rica-Escuín, 2017; Lima-Fernández & González-Rodríguez, 2017). It is essential when providing support from a social perspective not to forget the person accompanying the patient throughout the process (Jauregui-Virto & Arza-Porras, 2023; Munuera-Gómez, 2016; Pérez-Bandera, 2021).

The Spanish Society of Palliative Care (SECPAL, 2014) action guide differentiates the need to address communication aspects with family members about the illness as different clinical situations progress toward the end of life. De la Rica-Escuín (2017) revisits this, as observed in table 1.

Table 1. Clinical Situations at the End of Life

	Advanced Incurable Disease	Terminal Illness	Situation of Distress
Disease Course	Progressive and gradual	Irreversible symptoms	Preceding death
Symptomatology	Various degrees of autonomy and quality of life	-Multiple symptoms. --High emotional impact. -Loss of autonomy.	-Intense physical deterioration. -Extreme weakness. -Cognitive and consciousness disorders. -Difficulty in relationships. -Difficulty with food intake.
Response to treatment	Variable	None	None
Outcome	Medium term	Weeks or months	Days or hours

Source: prepared by the authors.

The relevance of incorporating the family in these moments derives from considering it to be the first support network and the responsible unit for its members' education and socialization, making it an institution of great personal and social value. In crises, such as terminal illnesses, changes occur in family organization and roles, justifying the inclusion of the family in palliative care. Therefore, Social Work teams must offer support to cope with psychosocial suffering and, communicate honestly and respect the dignity of individuals with diseases and their families (Espíndola *et al.*, 2018).

In situations of distress preceding death, it is of great importance to provide all possible means to face the process in the least traumatic way possible: knowing all the needs and concerns of the family, offering maximum information, and ensuring that the intervention is carried out with each member of the care unit fits their individual needs at each moment. This intervention should be carried out through balanced communication, avoiding overstimulation, and respecting moments of rest (Vílchez-Palacios, 2016). It is worth noting that Social Work, as a discipline committed to human rights, is also responsible for ensuring that individuals with illnesses can express their will and priorities. This also implies providing guidance and support while respecting their principle of autonomy and self-determination regarding the right to die with dignity without prolonging their lives. Social Work must be close to those who need to live and present for those who want to die with dignity (Carbonell *et al.*, 2021).

The grieving process begins the moment that the diagnosis of an adverse disease progression is confirmed (SECPAL, 2014). From this perspective, information and proposals about the measures to be applied and the care of the body will be provided to promote positive thinking for all individuals within the care unit. Efforts will be made to prevent paralyzing and disabling fears, which are typical in these moments and could hinder a proper farewell and cause difficulties in facing grief shortly (Jauregui-Virto & Arza-Porras, 2023).

Considering the multidisciplinary perspective from which intervention in palliative care units should be addressed (Bermejo-Higuera *et al.*, 2014), the social Work professional will intervene in two critical stages throughout the evolution of the disease (Carmona-Sánchez, 2016). Firstly, there is the *acute phase*, characterized by initiating the first outreach to the family, where assessment will begin: family nucleus, identification of individuals responsible for primary care, environment, housing, and available resources. Secondly, there is the *chronic phase*, in which the social Work professional will guide the family as the support figure who will analyze the situation while also working in conjunction with primary care, palliative, and municipal services.

Specifically, social work intervention within palliative care services focuses on assessing, advising, planning, and intervening in crises. More specifically, this includes assessing the psychosocial risks for the family unit; supporting, accompanying, and understanding the situation; mediating between the family, the medical team, and the patient to meet the needs of all involved parties; guiding the patient and their family about the most appropriate resources

for each moment; supporting family reorganization, mediating in family conflicts that may arise, providing guidance on handling information with the most sensitive family members, advising and managing essential resources such as home help, telecare, family respite programs, etc.; coordinating all necessary health services and resources and monitoring cases throughout the disease (Head *et al.*, 2019; Moro-Yerpes & Lerena-Tejón, 2011). As emphasized by Rine (2018), cultural competence regarding racial, ethnic, and social differences in end-of-life care is also vital to take into account. Thus, the social support provided by the social work department of palliative care units is understood as a cornerstone of interventions tailored to the patient and the family (Jauregui-Virto & Arza-Porras, 2023; Vanzini, 2010).

In conclusion, the functions performed by social work professionals in palliative care units are a significant responsibility and encompass a large number of activities and management of material resources (orthopedic material for the home, management of accessible transportation for home/hospital transfers) as well as management of human resources (managing hospital-at-home care and serving as liaison and spokesperson for the palliative care team with families), as well as management of emotions (Arranz *et al.*, 2003; Vanzini, 2010). However, the profession still needs help, such as in gaps in research and defined protocols, which can lead to the discipline being relegated to secondary roles in legislative and disease processes (Buarfa-Mohamed, 2019).

6

The research context

The research presented in this article was conducted in the Autonomous Community of Galicia,¹ in northwestern Spain.

In Galicia, public health services are organized through the *Galician Health Service* (Servizo Galego de Saúde - SERGAS), a constituent part of the National Health System. SERGAS coordinates and organizes all the public centers, services, and establishments in Galicia that promote the population's health, protect it against possible risks, and assist in case of illness. The system plans and manages healthcare throughout the Galician territory, divided into seven health areas.

To better understand the research, it is essential to note that palliative care in Galicia is addressed through two main types of care and resources, according to the Galician Health Service (SERGAS, 2014). On the one hand, there are indirect services composed of:

¹ According to Law 1/2018, of April 2, which amends Law 8/2008, of July 10, on health in Galicia, the seven health areas are delimited as follows: A Coruña and Cee; Santiago de Compostela and A Barbanza; Ferrol; Lugo, A Mariña, and Monforte de Lemos; Ourense, Verín, and O Barco de Valdeorras; Pontevedra and O Salnés; and Vigo.

- The Galician Commission on Palliative Care² The official body in this field is responsible for developing guidelines and protocols on palliative care, advising the Ministry of Health and SERGAS, and issuing reports and research.
- The Technical Health Committees on Palliative Care are composed of physicians, nurses, social workers, and clinical psychologists who adapt healthcare processes, evaluate activities, and make proposals to improve the development of the palliative care plan in each specific health area.
- The Palliative Care Reference Points in Primary Care are embedded in a primary care professional whose role is to provide support and information to other professionals in palliative care matters and to serve as a link and coordinator between the management of each health area and the existing material and human resources for palliative care.

On the other hand, SERGAS identifies the other type of care in the direct services constituted by:

- Primary Care Services is composed of multidisciplinary teams with physicians, nurses, social workers, psychologists, and physical therapists who treat patients in their homes. The service comprehensively responds to all patient needs, including pain relief and psychological, social, and spiritual care.
- Conventional hospital services cover the comprehensive needs of the patient and their affective environment from the hospitalization area corresponding to the patient's primary pathology: oncology, nephrology, internal medicine, etc.
- Support Teams in Palliative Care are configured as hospital care teams for patients with highly complex cases. These "palliative care teams" carry out their Work both in the hospital environment (in the "Palliative Care Units" themselves) and in the "home hospitalization" service. These home services are composed of at least one physician and one nurse caring for patients requiring specific monitoring of their health conditions while remaining in their homes until death.

There is specific legislation in the Autonomous Community of Galicia regarding palliative care (Galician Health Service, 2007) and end-of-life care (Galician Health Service, 2012). However, it seems essential to conclude this section by referring to Law 5/2015, of June 26, *on the rights and*

² Decree 181/2016, of December 9, amending Decree 181/2010, of October 21, which creates the Galician Commission on Palliative Care. Official Gazette of Galicia, No. 243, dated December 22, 2016.

guarantees of the dignity of terminally ill people, which, in its "Explanatory Memorandum," recognizes the right of individuals to a dignified death and states:

Today, most people understand a good death as one that occurs without suffering, feeling like a person until the end, surrounded by loved ones, and, if possible, at home. The end of life thus confronts us with the evidence that medicine has limits and that there are processes beyond cure that need to be addressed, processes to which society and the healthcare system must pay attention to offer people comprehensive care focused on achieving the highest possible quality of life. (p. 85013)

In this research, we share the premises of this law specifically from the perspective of the social work field, where we aim to provide support not only to clients wanting to extend and lead a good life but also to those seeking a "good death" as well as to their families throughout their process.

2. Methodology

2.1 Design

8

The objective of this research has been to discover the perception that relatives of patients in palliative care units have about the intervention carried out by social work professionals in these facilities—an exploratory. An empirical study was conducted using semi-structured interviews to collect qualitative data. This choice was made because of the delicate nature of this topic and its many associated taboos. We considered it very important for the interviewees to be able to share their personal experiences in their own words (Vallés, 2009). Thus, quality outweighs quantity, as we obtained rich, nuanced information about the participants' complex experiences that helps us to understand the experience of death by caregivers of deceased patients. As Olivier de Sardan (2018) states, if conducted rigorously, qualitative research can have the same methodological advantages as quantitative research with large sample sizes, providing the possibility of generalizable results (p.63). In this sense, the validity of qualitative research can be increased through theoretical saturation, on the one hand, and triangulation through other methods, such as document analysis and review of previous studies. In summary, validity can be achieved by identifying possible narratives about a single problem in a specific space and time and, secondly, by contrasting the information with different types of data pertinent to the content of the narratives. Both complementary strategies provide sufficient methodological guarantees regarding the obtained information, which must be coded and interpreted by the researcher.

2.2 Inclusion criteria for participants

Participants were required to meet the following inclusion criteria: a) they had to be family members of patients; b) the patients had to have been diagnosed with an incurable disease with a limited life prognosis; c) the patients had to be deceased at the time of data collection; d) the patients had to have been recipients of palliative care services in any health area of the Autonomous Community of Galicia (Table 2); finally, e) the participants had to have been the primary caregivers for their relatives until their death.

Given the peculiarities of the sample, it was located using the snowball sampling technique, reaching a total of six informants who met all the inclusion criteria.

Table 2. Characteristics of participants in the research.

Subject ID	Gender	Age	Rural/Urban Residence	Relationship with the patient	Start Date of Care by the Caregiver	Health Area
Subject 1	Female	37	Rural	Sister	January 2021	Pontevedra and O Salnés
Subject 2	Female	23	Urban	Niece	November 2018	Ourense, Verín and O Barco de Valdeorras
Subject 3	Female	26	Rural	Daughter	April 2021	Pontevedra and O Salnés
Subject 4	Male	54	Urban	Spouse	May 2021	Ourense, Verín and O Barco de Valdeorras
Subject 5	Female	43	Rural	Sister	July 2021	Pontevedra and O Salnés
Subject 6	Female	22	Rural	Daughter	March 2021	Pontevedra and O Salnés

Source: prepared by the authors.

2.3 Instrument

A semi-structured interview was used as the data collection technique (Keats, 2009; Vallés, 2009). It relied on a pre-established script of open-ended questions that allowed each participant to elaborate on the topic as they saw fit. This script was developed from the specific objectives of the research study (Table 3).

Table 3. Question Guide based on the Research Objectives.

Objectives	Interview Questions
Analyze how the social worker's intervention with the family is carried out.	Was there a social worker within the care teams?
	Which professional from the care team provided counseling and support to you?
	Did the social worker collaborate with you throughout the process?
	What services were offered to you at the diagnosis of the illness and throughout its course?
Describe, from the family's perspective, the social worker's role in palliative care units.	Were you the primary caregiver throughout the process? Did you have a family support network for your care?
	Did you feel supported by the professional team responsible for caring for your family member?
Identify at what moment the social worker started the intervention with the family.	In what aspects did you find it helpful to have the presence of a social worker?
	At what point did the social worker start their intervention with you?
Contrast the current opinion of the family about the intervention carried out with their perceived feelings during the process.	Who made the decisions regarding the care and services focused on your family member?
	How do you remember the moment of diagnosis and the subsequent progression of the illness?
	Could the team caring for your family member have collaborated or advised you better?
	How do you currently feel about the treatment and support you received from the palliative care team?

Source: prepared by the authors.

2.4 Procedure

After conducting the relevant literature review, participants were recruited based on the inclusion mentioned above criteria and using the non-probabilistic snowball sampling technique. Initial contacts were made with the individuals who agreed to participate in the research study in February and March of 2022. Before conducting the interviews, one of the researchers met with the prospective participants to establish a relationship of trust that would enable them to share their experiences and freely express themselves on a topic as sensitive as the death of close relatives.

Before the interviews, informed consent was obtained per Law 3/2018, of December 5, on Personal Data Protection and Guarantee of Digital Rights. Mutually agreed-upon locations (usually the participants' homes) were chosen, and the first author traveled to these sites in April of 2022.

Due to the highly emotional nature of the topic for the interviewees, the interviews were conducted with great care, always respecting the timing and silence of the participant, resulting in an average duration of approximately an hour and a half for each interview.

All interviews were recorded and transcribed, amounting to nearly ten hours of recorded speech. The narratives were then analyzed, classified, and coded manually using Microsoft Word, based on the following thematic categories previously defined by the authors: a) moment of disease diagnosis; b) care and decision-making; c) relationship with the multidisciplinary care team; d) relationship with the social worker of the palliative care unit; and e) perception of family members regarding the palliative care process. Although the coding was not initially limited to the system above, the five categories corresponded appropriately to the data; thus, no *post hoc* categories were included.

3. Findings

As previously indicated, the results obtained from this empirical study have been grouped around different thematic categories that correspond to the prevalent narratives expressed by the participants and that we present here.

3.1 The Moment of Disease Diagnosis

The moment of diagnosis of an incurable disease with a limited and uncertain life prognosis, in the case of the relatives of the interviewed individuals, was a diagnosis of advanced metastatic cancer. This diagnosis represented a moment of shock and uncertainty for all of them. Most of the patients who ended up in palliative care units had previously experienced a successful cancer diagnosis (n=4). However, the emergence of COVID-19 resulted in a delay in routine check-ups, as the healthcare system prioritized its fight against the pandemic over regular screenings of patients with other diseases.

My mother's check-ups were suspended from the beginning of the pandemic, and after several months, she fainted at home. We knew something was wrong, but in the tests conducted by the doctors, they assured us that everything was fine and attributed it to the stress of the situation we were experiencing. A few weeks later, we took her to the emergency room due to severe back pain. They told us it was just sciatica [brief pause]. After weeks of insisting and finally getting all the necessary tests done, they confirmed that the cancer had returned. The back pain was caused by a tumor located in the pelvis that had already spread to the ribs, skull, and thoracic vertebrae 2 and 3. (Subject 6, personal communication, March 12, 2022).

For subject 2, their relative's diagnosis of cancer occurred before the onset of COVID-19, but difficulties in obtaining a proper diagnosis and referral to the appropriate professional prolonged the time until the actual diagnosis:

At every appointment with her primary care doctor, the diagnosis was a neck strain. He even rudely spoke to my aunt, accusing her of being overly dramatic [long silence] until we managed to change doctors, and he urgently referred us to the Ourense hospital for all the tests. The final diagnosis was stage IV breast cancer with metastasis in the spine. (Subject 2, personal communication, February 24, 2022).

3.2. Care and decision-making

All participants except for subjects 2 and 3 assumed the role of the primary caregiver throughout their relative's illness. Subjects 2 and 3 could not fulfill this role due to work commitments, although they still actively participated in decision-making regarding their family member and contributed to their care. Subject 4 was the only participant who did not have a family support network for the care and accompaniment of their family member:

12

We did not have a support network as such, only my daughter and I, as my wife had no relationship with her family and did not want us to inform them of what was happening. (Subject 4, personal communication, March 7, 2022).

Regarding decision-making throughout the illness, most interviewees stated that decisions were always made collectively within the family, including the patient, with input from the medical team to "coordinate ourselves to take care of her in the best possible way" (Subject 5, personal communication, March 9, 2022).

Similarly, subject 2 stated that their relative was the sole decision-maker during their illness: "My aunt made all the decisions alone; even the final decision to be sedated and pass away in the nursing home was her decision" (Subject 2, personal communication, February 24, 2022).

However, not all experiences demonstrated respect for the patient's autonomy. Subject 3 stated that:

The doctor in charge was the only one deciding on the treatment to be taken and whether she would go home or stay in the hospital; they did not consider us at all (Subject 3, personal communication, February 27, 2022).

Additionally, subjects 1, 3, and 6 mentioned that their relatives also used the home hospitalization service in addition to the hospitalization service in the palliative care unit for as long as the evolution of their disease and related care allowed.

In summary, regarding the role of the primary caregiver, four of the interviewees assumed this role, whereas it was impossible for the remaining two for work reasons. All primary caregivers had a support network throughout the process, except for one person who respected their family member's decision not to share their diagnosis with the rest of the family.

3.3 Relationship with the Multidisciplinary Care Team

When referring to the multidisciplinary care team, as stated by the interviewees, the first professionals who offered guidance and support to the patients and their families were the oncology professionals who provided the decisive diagnosis.

Subsequently, all of them except subject 3 received the support of other team members, such as psychologists and social workers.

Moreover, the services offered to all the interviewees and patients included home hospitalization, ambulance transfers from home to and from the hospital for medical treatments, and psychological care, which was also offered by the Cancer Fight Association of their city (Subject 3, personal communication, February 27, 2022; Subject 6, personal communication, March 12, 2022).

Of these available resources, all but one interviewee made use of the psychological services, and three patients used the home hospitalization service for as long as their illness allowed it.

The patient's autonomy in decision-making regarding the situation and the services offered was respected by palliative care teams except in one case (Subject 3, personal communication, February 27, 2022). This particular participant expressed feeling that the doctor should unilaterally make decisions about the treatments throughout her daughter's illness. In other cases, the patient's and family's opinions were considered when initiating, discontinuing, incorporating, or modifying clinical guidelines and services.

3.4 Relationship with the Social Worker in Palliative Care Units

In terms of the figure of the social worker within the care team, all family members affirmed that, within the teams that cared for their family members, there was a social worker who collaborated with them throughout the process. Subject 3 was the only one who indicated not having contact with the social worker:

I never could attend a meeting with the social worker who was assigned to us, but I know she worked with my family. (Subject 3, personal communication, February 27, 2022).

In addition, subject 6 stated:

At the first hospital, the social worker never met with us. When we started therapy in Vigo, the social worker from that hospital did talk to us and helped us. (Subject 6, personal communication, March 12, 2022).

Thus, all interviewees, except subject 6, affirmed that the intervention of the social worker with their family and with them began shortly after they were informed of the diagnosis of the illness. Likewise, the interviewees stated that the presence of the social worker throughout the disease was beneficial and that this professional served as "a support figure that helped us better understand the situation and what was yet to come" (Subject 4, personal communication, March 7, 2022).

For some of the interviewees, the figure of the social worker in palliative care units was crucial, providing support and assistance to families:

Having someone on the team who generates confidence, helps you, and understands you is essential for understanding everything that is happening and will happen and all the paperwork to be done. (Subject 2, personal communication, February 24, 2022).

In summary, all palliative care units had a social worker, whose intervention in most cases began shortly after the diagnosis of the disease and who was remembered by all interviewees except subject 3, who could not contact her as "a support figure."

3.5 Perception of Family Members Regarding the Palliative Care Process

The interviewees expressed various opinions about the treatment received from the teams in the palliative care units. On one hand, half of them (Subject 2, personal communication, February 24, 2022; Subject 4, personal communication, March 7, 2022; Subject 5, personal communication, March 9, 2022) said they feel grateful for all the treatment received by the family and the patient, stating that they needed to have a team that rose to the occasion and that they never felt abandoned during the process. On the other hand, the experience was not favorable for the other half of the interviewees, which was sometimes due to the (poor) treatment received from a professional, specifically:

I am sad and angry about the way my sister was treated in many cases. I mean the aggressiveness with which they said things to her [brief silence]. The hardest thing was seeing how my sister wanted to fight, even though she knew perfectly well what awaited her... they left her out... Nevertheless, I am pleased with the oncology doctor who initially treated her and the social worker from the second hospital where she received treatment. They treated us very well, both my sister and I. (Subject 1, personal communication, February 19, 2022).

One of the last times we were able to talk with her doctor, he told us that continuing to give my mother blood transfusions was a waste and that other people needed it [long silence]. (Subject 1, personal communication, February 19, 2022).

In some situations, the narratives focused on staff-related deficiencies in the hospital environment, which can raise legitimate concerns about the care and services provided to patients:

In the palliative care ward, all they did was give her food and clean; a doctor hardly ever came to see her. Home hospitalization was much better; at least we had updated reports on her progress, and she had everything she needed. (Subject 3, personal communication, February 27, 2022).

Likewise, participants also reported situations of professional abandonment or neglect in the follow-up of diagnoses of loved ones, adding a layer of anguish to an already difficult situation:

A sad room where only one person could go in to see her...; very few times did they come to check her blood pressure [brief silence]. We experienced palliative care hospitalization as if she were parked there, waiting to see how long her body would last [long silence]. (Subject 1, personal communication, February 19, 2022).

It was the worst; my mother spent three months lying in bed face up because her wound level was so high that any other position was dangerous [brief silence]. Since everything coincided with the pandemic, only one of us could go in to be with her; it was very depressing when they kept coming to close the door because another person had died... (Subject 3, personal communication, February 27, 2022)

Furthermore, a negative experience was expressed that seemed to involve a situation of medical negligence:

The worst of all was when we met again with the doctor who had made my sister's initial diagnosis, and he confessed to us that he had reviewed her file and that my sister's case had been mishandled. (Subject 1, personal communication, February 19, 2022).

Finally, we do not want to silence the expressions of profound pain from some family members who could not accompany their family members and support each other at the time of death because the palliative care process coincided with the COVID-19 pandemic:

Even after she had died, the treatment was terrible. When we notified them that we were present when she died, after begging a thousand times for them to let more than one of us in to spend her last moments together as a family, two nurses came and sent us out of the room; they removed the medication IV from her and did not care that she kept bleeding, they told

us she was already dead and that it did not matter. (Subject 6, personal communication, March 12, 2022).

4. Conclusions

The results highlight the importance of multidisciplinary interventions with patients and their families by professionals in palliative care units, as advocated by Pérez-Bandera (2021) and Jauregui-Virto and Arza-Porras (2023). All services involved in the comprehensive care of the individual should be coordinated to provide individualized care according to the psychosocial needs that arise throughout the process, from a perspective focused on each family - in line with what Munuera-Gómez (2016) emphasized - and based on the personal preferences of each patient. All participants considered this coordination of care essential, echoing the findings of Bermejo-Higuera et al. (2014).

All interviewees stated that the presence of the family in the final moments of life is of great importance, both for the patient and the family, through collaboration in care and decision-making throughout the process. Thus, within palliative care teams, as most interviewed family members stated and consistent with Munuera-Gómez (2016), decisions regarding care and resources are made jointly and based on objective criteria between the family and the patient to carry out proper planning and coordination of care among all involved parties. When this does not happen, and families are separated from patients in the final moments of their lives, great pain ensues, as expressed by some of the interviewees, even if these circumstances arise due to external factors, such as COVID-19 precautions.

Similarly, family members of patients in palliative care units expressed mixed opinions about the treatment provided by the professionals who carried out the interventions. Half expressed gratitude for the treatment, personally and for their family member. These individuals stated that their care team was prepared to face such situations and never felt abandoned. In contrast, the other three interviewees reported that their experience in palliative care units was not optimistic due to the treatment received from some professionals, staff shortages during the palliative care hospitalization phases, and situations of abandonment of their relatives by the teams following the poor progression of their relatives' illnesses. In terms of the latter, the care teams did not perform the crucial tasks assigned to them, nor did they properly introduce families to the grieving process, in contrast with the recommendations of Bermejo-Higuera et al. (2014) and the SECPAL guidelines (SECPAL, 2014). These three participants in the study described their experiences with professionals negatively. They expressed frustration and anger about the treatment received, both for themselves and their now-deceased family members.

Within palliative care teams, the social worker's role in caring for the patient and their family throughout the illness process is especially significant. Interviewees identified the

functions performed by social work professionals, which focus on accompanying, supporting, mediating, and guiding the family, as pointed out by Moro-Yerpes and Lerena-Tejón (2011) and Lima-Fernández and González-Rodríguez (2017). In this regard, most study participants sincerely appreciated the social worker's involvement in this process. Only two interviewees remarked that their process lacked the presence of a social worker to accompany them, and one of those two participants was aware that the rest of the family did have support from a social worker.

The limitations of this research primarily relate to the sample size and the geographical scope of the study. Therefore, it would be appropriate to expand this research to other regions and interview more participants (families) in future studies. Additionally, it would be fascinating to investigate patients' perceptions about the palliative care they receive. However, we know the challenges of conducting this kind of research.

Funding

The authors state they received no resources to write or publish this article.

Authors' Contribution statement

Andrea Fernández-Álvarez: conceptualization, data curation, formal analysis, research, methodology, writing (original draft), writing (review of the draft and revision/correction); Carmen Verde-Diego: conceptualization, methodology, writing (review of the draft and revision/correction); Paula Frieiro: supervision, validation, writing (review of the draft and revision/correction).

Conflicts of interest

The authors unequivocally state that there is no conflict of interest in the writing or publishing of this article, reinforcing the integrity and impartiality of the research.

Ethical statement

The authors do not have any type of ethical implication to be stated in writing and publishing this article.

5. Bibliographic references

- Agencia Gallega para la Gestión del Conocimiento en Salud [ACIS]. (2021). *Guía de Práctica Clínica sobre atención paliativa al adulto en situación de últimos días*. Ministerio de Sanidad; Agencia Gallega para la Gestión del Conocimiento en Salud (ACIS); Unidad de Asesoramiento Científico-técnico, Avalia-t. https://portal.guiasalud.es/wp-content/uploads/2021/09/gpc_612_atencion_paliativa_avaliat_compl.pdf
- Alonso, A., Gisbert, A., & Rexach, L. (2010). Cuidados paliativos en enfermedades no oncológicas. *Medicina Paliativa*, 17(3), 156-160.
- Arranz, P., Barbero, J. J., Barreto, P., & Bayés, R. (2003). *Intervención emocional en cuidados paliativos. Modelo y protocolos*. Ariel.
- Bermejo-Higuera, J. C., Lozano-González, B., & Villacieros-Durbán, M. (2014). La atención psicosocial con perspectiva integradora en cuidados paliativos. *Documentos de Trabajo Social. Revista de trabajo y acción social*, (54), 240-250.
- Buarfa-Mohamed, N. (2019). Trabajo social y muerte digna. *Servicios sociales y política social*, (121), 57-67.
- Carbonell, A., Navarro-Pérez, J. J., & Botija-Yagüe, M. (2021). El derecho a morir dignamente: una oportunidad para el impulso ético del Trabajo Social. *Trabajo Social Global – Global Social Work*, 11, 1-29. <https://dx.doi.org/10.30827/tsg-gsw.v11.11453>
- Carmona-Sánchez, M. (2016). Ámbitos de atención. Expectativas, efectos y particularidades. En A. Novellas, M. Munuera, J. Lluch y X. Gómez-Batiste (Coords.), *Manual para la atención psicosocial y espiritual a personas con enfermedades avanzadas. Intervención social* (pp. 121-129). Obra Social “La Caixa”. https://fundacionlacaixa.org/documents/10280/846215/manual_atencion_psicosocial_intervencion_social_es.pdf/1fb7d782-1865-453c-8c86-f82601e138f6
- De la Rica-Escuín, M. L. (2017). *El sentido de la dignidad del paciente oncológico al final de la vida* [Tesis Doctoral, Universidad de Zaragoza]. Archivo digital. <https://zaguan.unizar.es/record/63069/files/TESIS-2017-088.pdf>
- Decreto 181/2016, de 9 de diciembre, por el que se modifica el Decreto 181/2010, de 21 de octubre, por el que se crea la Comisión Gallega de Cuidados Paliativos. *DOG*, 243, del 22 de diciembre de 2016. https://www.xunta.gal/dog/Publicados/2016/20161222/AnuncioC3K1-161216-0001_es.html
- Espíndola, A. V., Quintana, A. M., Farias, C. P., & Bade-München, M. A. (2018). Relaciones familiares en el contexto de los cuidados paliativos. *Revista Bioética*, 26, 371-377. <https://doi.org/10.1590/1983-80422018263256>
- Head, B., Peters, B., Middleton, A., Friedman, C., & Guman, N. (2019). Results of a nationwide hospice and palliative care social work job analysis. *Journal of social work in end-of-life & palliative care*, 15(1), 16-33. <https://doi.org/10.1080/15524256.2019.1577326>

- Jauregui-Virto, A., & Arza-Porras, J. (2023). El acompañamiento, una oportunidad para fortalecer la humanización de la intervención social. *Cuadernos de Trabajo Social*, 36(1), 49-60. <https://doi.org/10.5209/cuts.82015>
- Keats, D. M. (2009). *Entrevista. Guía práctica para estudiantes y profesionales*. McGraw Hill.
- Ley 5/2015, de 26 de junio, de derechos y garantías de la dignidad de las personas enfermas terminales. (2015). *BOE*, 228, de 23 de septiembre. https://www.boe.es/diario_boe/txt.php?id=BOE-A-2015-10200
- Ley 1/2018, de 2 de abril, por la que se modifica la Ley 8/2008, de 10 de julio, de salud de Galicia. (2018). *BOE*, 96, de 20 de abril de 2018. <https://www.boe.es/buscar/doc.php?id=BOE-A-2018-5392>
- Ley Orgánica 3/2018, de 5 de diciembre, de Protección de Datos Personales y garantía de los derechos digitales. (2015). *BOE*, 294, de 7 de diciembre. <https://www.boe.es/buscar/act.php?id=BOE-A-2018-16673>
- Lima-Fernández, A. I., & González-Rodríguez, R. (2017). La intervención social en el final de la vida. *Servicios Sociales y Política Social*, (114), 2-18. <https://www.serviciosocialesypoliticassocial.com/-11>
- Moro-Yerpes, M. P., & Lerena-Tejón, I. (2011). El trabajador social como agente de cambio en cuidados paliativos. *Documentos de trabajo social: Revista de trabajo y acción social*, (49), 270-276. <https://dialnet.unirioja.es/servlet/articulo?codigo=4111523>
- Munuera-Gómez, M. P. (2016). Entorno sociofamiliar facilitador de bienestar en situaciones de final de vida. En A. Novellas, M. Munuera, J. Lluch y X. Gómez-Batiste (Coords.), *Manual para la atención psicosocial y espiritual a personas con enfermedades avanzadas. Intervención social* (pp. 47-72). *Obra Social "La Caixa"*. https://fundacionlacaixa.org/documents/10280/846215/manual_atencion_psicosocial_intervencion_social_es.pdf/1fb7d782-1865-453c-8c86-f82601e138f6
- Novellas-Aguirre de Cárcer, A. (2017). La atención de situaciones de final de la vida desde el Trabajo Social. *RTS. Revista de Treball Social*, (210), 37-53. <https://www.revistarts.com/article/latencio-de-situacions-de-final-de-vida-des-del-treball-social>
- Olivier de Sardan, J. P. (2018). *El rigor de lo cualitativo. Las obligaciones empíricas de la interpretación socioantropológica*. CIS. Centro de Investigaciones Sociológicas.
- Pérez-Bandera, M. (2021). Trabajar con la muerte desde el Trabajo Social. Implicaciones antropológicas, psicológicas, bioéticas y legales. *Trabajo Social hoy* (92), 7-26. <https://www.trabajosocialhoy.com/articulo/308/trabajar-con-la-muerte-desde-el-trabajo-social-implicaciones-antropologicas-psicologicas-bioeticas-y-legales>
- Rine, C. M. (2018). Is social Work prepared for diversity in hospice and palliative care? *Health & Social Work*, 43(1), 41-50. <https://doi.org/10.1093/hsw/hlx048>
- Royo-Sierra, L. C., Pagés-Lanau, L., Otal-Cajal, B., Oto-Gracia, I., & Redondo-Hernández, R. (2021). Paciente paliativo no oncológico. *Ocronos*, 4(2), 67-71. <https://revistamedica.com/paciente-paliativo-no-oncologico/>

- Servizo Galego de Saúde. (2007). *Plan gallego de cuidados paliativos*. Xunta de Galicia Consellería de Sanidade. Servizo Galego de Saúde.
- Servizo Galego de Saúde. (2012). *Los cuidados al final de la vida. Documento de recomendaciones*. Xunta de Galicia Consellería de Sanidade. Servizo Galego de Saúde. https://www.sergas.es/Docs/Bioetica/Cuidados%20CAST_240912_link.pdf
- Servizo Galego de Saúde. (2014). *Recursos do Plan Galego de Coidados Paliativos*. [https://www.sergas.es/Asistencia-sanitaria/Documents/645/Informaci%C3%B3n%20sobre%20recursos%20asistenciais\(galego\).pdf](https://www.sergas.es/Asistencia-sanitaria/Documents/645/Informaci%C3%B3n%20sobre%20recursos%20asistenciais(galego).pdf)
- Spanish Society of Palliative Care [SECPAL]. (2014). *Atención al duelo en cuidados paliativos: guía clínica y protocolos de actuación*. <https://www.redpal.es/wp-content/uploads/2018/12/MONOGRAFIA-duelo-.-secpal.pdf>
- Toh, Y. P., Karthik, R., Teo, C. C., Suppiah, S., Cheung, S. L., & Krishna, L. (2018). Toward mentoring in palliative social Work: a narrative review of mentoring programs in Social Work. *American Journal of Hospice and Palliative Medicine*, 35(3), 523-531. <https://doi.org/10.1177/1049909117715216>
- Vallés, M.S. (2009). *Entrevistas Cualitativas*. Centro de Investigaciones Sociológicas.
- Vanzini, L. (2010). El Trabajo Social en el ámbito de los cuidados paliativos: una profundización sobre el rol profesional. *Documentos de trabajo social: Revista de trabajo y acción social*, (47), 184-199. <https://dialnet.unirioja.es/servlet/articulo?codigo=3655799>
- Vílchez-Palacios, M. (2016). La familia frente a síntomas y situaciones complejos o imprevistos. En A. Novellas, M, Munuera, J. Lluch y X. Gómez-Batiste (Coords.), *Manual para la atención psicosocial y espiritual a personas con enfermedades avanzadas. Intervención social* (pp. 89-99). Obra Social “La Caixa”. https://fundacionlacaixa.org/documents/10280/846215/manual_atencion_psicosocial_intervencion_social_es.pdf/1fb7d782-1865-453c-8c86-f82601e138f6
- World Health Organization [WHO]. (August 20, 2020). Palliative care. WHO. <https://www.who.int/es/news-room/fact-sheets/detail/palliative-care>