VNIVERSITAT DE VALÈNCIA

Tesis doctoral

HOLISTIC PALLIATIVE CARE NEEDS ASSESSMENT IN OLDER PATIENTS WITH COMPLEX CHRONIC CONDITIONS AND THEIR FAMILIES: CHALLENGES AND OPPORTUNITIES FOR IMPROVED QUALITY OF CARE

Presentada por:

Laura Belén Llop Medina

Dirigida por:

Dr. Jorge Garcés Ferrer
Dr. Francisco J. Ródenas Rigla
Dra. Ascensión Doñate Martínez

Programa de Doctorado en Diseño, Gestión y Evaluación
de Políticas Públicas de Bienestar Social (R.D. 99/2011)
UNIVERSITAT DE VALÈNCIA
Instituto de Investigación en Políticas de Bienestar Social
(POLIBIENESTAR)

VNIVERSITAT DE VALÈNCIA
UJI UNIVERSITAT JAUME I
Programa de Doctorado en **Diseño, Gestión y Evaluación de Políticas Públicas de Bienestar Social**

Dr. Jorge Garcés Ferrer, catedrático de la Universitat de Valencia, Dr. Francisco José Ródenas Rigla, profesor titular de la Universitat de València, y Dra. Ascensión Doñate Martínez, Doctora en ciencias sociales por la Universitat de València, como directores del proyecto de tesis doctoral por compendio de publicaciones de la doctoranda Laura Belén Llop Medina

HACEN CONSTAR:

Que la presente memoria, titulada "Holistic palliative care needs assessment in older patients with complex chronic conditions and their families: challenges and opportunities for improved quality of care", corresponde al trabajo original realizado bajo su dirección por Laura Belén Llop Medina, para su presentación como Tesis Doctoral en el Programa de Doctorado en Diseño, Gestión y Evaluación de Políticas Públicas de Bienestar Social de la Universitat de València.

Y para que conste firman el presente documento en Valencia, a 07 de mayo de 2024.

JORGE|
GARCES
|FERRER
Firmado
digitalmente por
JORGE|GARCES|
FERRER
Fecha: 2024.05.07
14:22:43 +02'00'

Fdo. Jorge Garcés Ferrer

FRANCISCO
JOSE|
RODENAS|
RIGLA
Firmado
digitalmente por
FRANCISCO JOSE|
RODENAS|RIGLA
Fecha: 2024.05.07
15:51:12 +02'00'

Fdo. Francisco Ródenas Rigla

Firmado por DOÑATE
MARTINEZ ASCENSION -
***9198** el día 08/05/2024
con un certificado emitido

Fdo. Ascensión Doñate Martínez

TESIS DOCTORAL

HOLISTIC PALLIATIVE CARE NEEDS ASSESSMENT IN OLDER PATIENTS WITH COMPLEX CHRONIC CONDITIONS AND THEIR FAMILIES: CHALLENGES AND OPPORTUNITIES FOR IMPROVED QUALITY OF CARE

DEPÓSITADA EN MAYO 2024

Presentada por:

LAURA BELÉN LLOP MEDINA

Dirigida por:

DR. JORGE GARCÉS FERRER

DR. FRANCISCO J. RÓDENAS RIGLA

DRA. ASCENSIÓN DOÑATE MARTÍNEZ

Programa de Doctorado en Diseño, Gestión y Evaluación
de Políticas Públicas de Bienestar Social (R.D. 99/2011)

UNIVERSITAT DE VALÈNCIA

Instituto de Investigación en Políticas de Bienestar Social
(POLIBIENESTAR)

"There is within each one of us a potential for goodness beyond our imagining; for giving which seeks no reward; for listening without judgment; for loving unconditionally"

Elisabeth Kübler-Ross

RESUMEN

La presente tesis constituye una investigación exhaustiva haciendo una evaluación holística de las necesidades de cuidados paliativos en pacientes mayores crónicos complejos y sus familias, identificando los retos y oportunidades para mejorar la calidad de los cuidados. La tesis compendia cuatro artículos que analizan la provisión de Cuidados Paliativos en pacientes mayores crónicos complejos con patologías no cancerígenas en España poniendo el foco en dos Comunidades Autónomas, la Comunidad Valenciana y la Comunidad Autónoma de Murcia. El cuerpo de la tesis se estructura en varios apartados que presentan el trasfondo teórico y metodológico relativo al tema escogido y los distintos estudios que conforman la tesis doctoral. En primer lugar, se expone el marco teórico, que consta de 3 apartados: 1) contexto socio-demográfico, 2) cuidados paliativos y su papel en el cuidado de los pacientes mayores crónicos complejos y 3) contexto de la tesis. Cuidados a pacientes mayores crónicos complejos y a sus cuidadores/familiares, en los que se examinan las aproximaciones teóricas al tema de estudio. A continuación, se exponen los objetivos e hipótesis que han guiado el estudio. Posteriormente se expone la sección de metodología que resume el enfoque metodológico utilizado en la tesis doctoral. En cada uno de los cuatro trabajos que componen la tesis se detalla la metodología empleada. Las técnicas empleadas han sido, la revisión de la literatura científica, los grupos de discusión y las entrevistas en profundidad. Finalmente, se presenta la discusión y conclusiones, donde se integran los hallazgos de los cuatro artículos, se reflexiona sobre las implicaciones teóricas y prácticas de la investigación y se ofrecen recomendaciones políticas derivadas de las investigaciones realizadas durante el desarrollo de la tesis doctoral.

Palabras clave: Cuidados paliativos, cuidados de larga duración, pacientes crónicos, pacientes mayores, trabajo social, investigación cualitativa, políticas públicas, política sanitaria y social.

ABSTRACT

The present thesis is a comprehensive investigation making a holistic assessment of the palliative care needs of complex chronic elderly patients and their families, identifying the challenges and opportunities for improving the quality of care. The thesis compiles four articles that analyse the provision of palliative care in complex chronic elderly patients with non-cancer pathologies in Spain with a focus on two Autonomous Communities, the Valencian Community and the Autonomous Community of Murcia. The body of the thesis is structured in several sections that present the theoretical and methodological background related to the chosen topic and the different studies that make up the doctoral thesis. Firstly, the theoretical framework is presented, which consists of 3 sections: 1) socio-demographic context, 2) palliative care and its role in the care of complex chronic elderly patients and 3) context of the thesis. Care for complex chronic elderly patients and their carers/family members, in which the theoretical approaches to the topic of study are examined. This is followed by the objectives and hypotheses that have guided the study. This is followed by the methodology section which summarises the methodological approach used in the doctoral thesis. In each of the four papers that make up the thesis, the methodology used is detailed. The techniques used were the review of the scientific literature, the discussion groups and the in-depth interviews. Finally, the discussion and conclusions are presented, integrating the findings of the four articles, reflecting on the theoretical and practical implications of the research and offering policy recommendations derived from the research carried out during the development of the doctoral thesis.

Keywords: Palliative care, long-term care, chronic patients, older patients, social work, qualitative research, public policy, health and social policy

AGRADECIMIENTOS

En primer lugar, me gustaría agradecer la financiación recibida por el Ministerio de Educación por haberme concedido una beca pre doctoral FPU (FPU17/00924) para realizar esta tesis y por haberme financiado una ayuda para realizar una estancia de investigación en el Erasmus medical Center en Rotterdam.

A mis directores de tesis, al Dr. Jorge Garcés por haberme permitido incorporarme al instituto Polibienestar, por su apoyo, su mentoria, su inmensa aportación a mi crecimiento profesional y personal, por ser un referente en este campo de estudio y haberme permitido aprender tanto de el a su lado. Al Dr. Francisco Ródenas por su inestimable apoyo durante todo el proceso, por creer tanto en mis posibilidades, por animarme a querer ser siempre mejor investigadora y por aportar tanto a mi proceso de aprendizaje. A la Dra. Ascensión Doñate por haberme enseñado tanto sobre Cuidados Paliativos y sobre investigación y por no haberse cansado nunca de mis innumerables preguntas y dudas. A mis tres maravillosos directores, este camino no habría sido tan fructífero, tan apasionante y tan enriquecedor sin todo lo que me habéis enseñado en lo profesional, pero también en lo personal, vuestra influencia ha quedado ya como una huella imborrable en mí para siempre.

Gracias a todos los pacientes, familiares y profesionales de los hospitales La Fe de Valencia y Virgen de Arrixaca de Murcia por haberme permitido acceder de una manera tan generosa a sus historias personales y únicas y por compartir esos momentos tan delicados de sus vidas. Gracias a todos y todas ellas he podido acercarme a la realidad y al día a día de los Cuidados Paliativos.

Agradecer también a todas mis compañeras y compañeros de Polibienestar por su apoyo y ayuda siempre, no puedo relatar en unas cuantas líneas cuanto he aprendido de todas y cada una de vosotras, sois referente en investigación y vuestra calidad humana es también un referente para mí. Gracias equipo.

A mi familia, mis padres, hermanos, tías, tíos y primos gracias por apoyarme y por darme siempre palabras de aliento. Durante toda mi vida mi madre y mi padre me han estado enseñando a no rendirme y a buscar siempre ser mejor persona en lo personal y en lo profesional. Mamá y papá sin vosotros ninguno de mis logros habría sido posible. A mis queridos hermanos Davinia y Jose, vuestra fuerza y coraje en todo lo que hacéis me han inspirado durante todo el desarrollo de mi tesis doctoral, gran parte de mi personalidad ha estado marcada por estos maravillosos hermanos con los que he tenido la fortuna de crecer y compartir tantos logros, gracias por no soltar nunca mi mano y por darme alas.

A mis queridas amigas, Lidia, Sandra, Lorena y Estefanía, mi familia por elección, me habéis escuchado sin descanso y me habéis dado tanto durante todo este proceso que no tengo palabras, solo deciros gracias, por tanto, gracias por todo. No habría sobrevivido sin nuestros días de conversaciones cómplices, sois unas mujeres excepcionales y las mejores compañeras de vida en lo bueno y lo malo.

A mi queridísimo amor, me has dado tanto apoyo y me has enseñado tanto que nunca podré agradecértelo bastante, eres una inspiración para mí, una de las mejores personas que se ha cruzado en mi camino y estoy en deuda eterna contigo por haber sido mi guía, mi fuerza, mi roca y mi remanso de paz. Gracias por las innumerables formas en que has moldeado mi crecimiento personal y académico y por ser el alma extraordinaria que eres. Sin ti a mi lado, este logro habría sido un sueño lejano.

A mi hija, Sofía, la luz de mi vida, para ella el mayor agradecimiento de todos. Desde que naciste he cuidado todos mis pasos, porque sé que estás viendo y aprendiendo. Espero que esos pasos marquen para ti un camino que quieras recorrer y que sea digno de admiración y respeto. No olvides nunca que si no me he rendido ha sido sobre todo gracias a ti, esos ojos curiosos y esa sonrisa eterna consiguen animar hasta el más gris de mis días. Por ti quiero ser cada día mejor mujer y mejor persona. El mundo es un lugar más bonito desde que tú estás en él, sueña a lo grande, aprende siempre y nunca te rindas hija mía.

INDEX

ABBREVIATIONS LIST

Abbreviation	**Meaning**
DCST	Domiciliary Care Support Team
EAPC	European Association of Palliative Care
EoL	End of Life
EU	European Union
HALE	Healthy Life Expectancy
HCIP	Home Care Improvement Programme
HCPs	Health Care Professionals
HCST	Hospital Care Support Teams
HST	Home Support Team
ICU	Intensive Care Unit
INE	National Statistics Institute
LE	Life Expectancy
LTC	Long Term Care
NCDs	Non comunicable diseases
NHS	National Health System
PC	Palliative Care
PCU	Palliative Care Unit
QoL	Quality of Life
SECPAL	Spanish Society for Palliative Care
PEDPAL	Spanish Society for Paediatric Palliative Care
WHO	World Health Organization

CHAPTER I

INTRODUCTION

CHAPTER I. INTRODUCTION

This document presents the doctoral thesis entitled “Holistic palliative care needs assessment in older patients with complex chronic conditions and their families: challenges and opportunities for improved quality of care” developed at the Polibienestar Research Institute, belonging to the University of Valencia, and within the doctoral programme of Design, Management and Evaluation of Public Welfare Policies. The doctoral thesis project is framed within the research line “Inequality, inclusive societies and social and individual well-being in the framework of public policies”. I, Laura Belén Llop Medina, started working on my thesis in 2018 with a FPU (Formación de Profesorado Universitario) predoctoral grant from the Spanish Ministry of Universities. The thesis has been carried out under the direction of Prof. Jorge Garcés Ferrer Professor of Social Policies, PhD in Administration and Political Sciences, PhD in Psychology, Full Professor at the Universitat de València and Prince of Asturias Distinguished Visiting Professor at Georgetown University in the period 2014-2016, the Co-Direction of Francisco Ródenas Rigla, PhD in Sociology and Associate Professor at the Universitat de València, senior researcher at Polibienenestar Research Institute and Ascensión Doñate, PhD in Social Sciences and former researcher at Polibienestar Research Institute.

My career as a pre-doctoral researcher has been inextricably linked to the Polibienestar Research Institute, where I have had the privilege of being trained as a researcher. The Polibienestar Institute is a Public Research Institute belonging to the University of Valencia (Spain), directed by Jordi Garcés, Prince of Asturias Distinguished Visiting Professor at Georgetown University (Washington DC). It specialises in research, innovation and social technology, technical advice and training in the field of public policy. His ultimate mission is to improve the Welfare and Quality of Life of society. In addition, Polibienestar has a wide network of European contacts due to its active role in European research and policy-making and develops applied interdisciplinary research in social sciences. This interdisciplinary perspective is necessary to respond to the complexity of welfare systems and has enabled Polibienestar to develop, from innovative and classical research, effective analyses and solutions to new social challenges. In addition, Polibienestar advises the Administration and private entities in the design, planning and implementation of social welfare policies and services. This excellent environment has allowed me to be trained as a researcher in a multidisciplinary team and to participate in more than 5 European research projects and a national one, which has allowed me to be part of different international working teams and to participate in scientific congresses, increasing my knowledge and experience in the field of Palliative Care (PC), inequality and social exclusion. In addition, in the framework of my doctoral thesis, I have carried out a research stay at the Department of Public Health of the Erasmus Medical Centre (Erasmus University Rotterdam, The Netherlands) with the team of Prof. Hein Raat for 3 months, for which I have applied, with the deposit of the thesis, for the PhD with International Recognition Mention.

The doctoral thesis that I present has the format of a compilation of publications in scientific journals. This format has allowed me to publish the results of my thesis and to improve them thanks to the comments of the reviewers and referees of the journals. I am the first author of all the papers included in this doctoral thesis as I have been responsible for most of the work associated with them: establishing the objectives and design; selecting the methodology; collecting, analysing and interpreting data; as well as writing them up. However, I must thank my co-authors, Jorge Garcés, Francisco Ródenas, Ascensión Doñate, Alfonso Gallego, Paula García and Yu Fu for their participation and support throughout the process.

The papers included in this thesis are linked to the InAdvance (grant agreement No 825750) and PalliaHelp (ref. PID2019-110997RB-I00) projects. The project *Patient-centred pathways of early PC, supportive ecosystems, and appraisal standard (InAdvance)* proposes a novel model of PC based on early integration and personalised pathways addressed specifically to older people with complex chronic conditions. Thus, the overall aim of InAdvance is to improve the benefit of PC by designing effective, replicable, and cost-effective early PC interventions centred on and oriented by the patients. The project aims to propose a new model of PC based on early integration and personalised pathways specifically for older people with complex chronic conditions. The project Design and validation of an index to assess PC services and needs using an interdisciplinary methodology (PalliaHelp) mobilises complementary knowledge from different scientific areas (social sciences, health sciences, bio-law/bioethics, statistics and economics) with the main objective of generating a set of indicators and an index to assess the quality of care of PC services within the National Health System (NHS). PalliaHelp aims to understand the determinants of quality of care; it is not a clinical project, but rather a project to improve service management and needs assessment.

In the midst of the development of this thesis, a global pandemic derived from COVID19 broke out, which fully affected the execution of both projects and consequently the development of the thesis. During the year 2020 it was impossible to access the samples. The professionals in both 2020 and 2021 were focused on frontline care, so collaboration with them was very complex. In despite of all this, the planned objectives have been achieved as shown in the publications that compose the doctoral thesis.

The papers, corresponding to chapter V, that compose the doctoral thesis have been published in the journals Healthcare, Nursing Open and International Journal of Environmental Research and Public Health. The journals chosen are ranked Q2 or Q1 in JCR, their choice was motivated by the fact that the content was in line with the publication objectives of the journals. The papers are listed below, including a brief description of their objective, detailed information on the impact of the journals and the PhD candidate's contribution to them.

1. **Llop-Medina, L.**, Fu, Y., Garcés-Ferrer, J., & Doñate-Martínez, A. (2022). Palliative care in older people with multimorbidities: a scoping review on the palliative care needs of patients, carers, and health professionals. *International Journal of Environmental Research and Public Health, 19*(6), e3195. https://doi.org/10.3390/ijerph19063195

The PhD candidate's contribution to this paper was focused on conceptualisation, methodology, analysis and manuscript writing.

Improving the experience of multimorbid patients receiving PC and their family's requires to find out what their experience has been in the health system and the gaps or needs they have identified in their care. The research question of this study was: "What are the experiences and views on PC of older people with multimorbidities, their family caregivers and professionals?"

This review contributes to a greater understanding of the needs of three cohorts involved in PC: older patients with non-malignant diseases, their families or caregivers, and the health professionals who care for them. The integration of the needs reported by them allowed for a more comprehensive understanding of PC needs than those that focused on a single cohort alone. In addition, this review synthesised the needs of these three groups, which are very complex, diverse and heterogeneous.

Regarding the scientific relevance of the journal, the work was published in the *International Journal of Environmental Research and Public Health* (eISSN 1660-4601) edited by MDPI since 2011 in Switzerland. Quality indicators for 2021 in JCR (latest available data): Journal Impact Factor (JIF) 4.614; JIF without Self Citations 3.995; Q1 category Public, Environmental & Occupational Health - SSCI, position 45/182. Indications of quality for the year 2022 in SJR: SJR 0.828; Q2 category Public Health, Environmental and Occupational Health; H-index 167.

2. **Llop-Medina, L.**, Ródenas-Rigla, F., Garcés-Ferrer, J., & Doñate-Martínez, A. (2022). The Experiences and Views on Palliative Care of Older People with Multimorbidities, Their Family Caregivers and Professionals in a Spanish Hospital. *Healthcare, 10*(12) e 2489. https://doi.org/10.3390/healthcare10122489.

The PhD candidate's contribution to this paper was focused on conceptualisation, methodology, formal analysis, investigation, writing—original draft preparation, writing—review and editing and funding acquisition.

The research question of this study was "What are the experiences and opinions about PC of patients/families/HCPs in the Hospitalisation Unit of the Hospital La Fe in Valencia".

This qualitative study showed multiple unmet needs of patients and their families/caregivers, including feelings of uncertainty, sense of fear, low awareness and knowledge about PC in non-malignant settings and the desire to improve physical, psychosocial and financial status. It also highlighted a continued lack of specialised psychosocial care for both patients and carers, and professionals emphasised the need for a comprehensive assessment of needs and early and effective referral pathways to PC.

Regarding the scientific relevance of the journal, the work was published in the journal Healthcare (eISSN 2227-9032) edited by MDPI since 2013 in Switzerland. Quality indicators for 2022 in JCR: Journal Impact Factor (JIF) 2.88; JIF without Self Citations 2.6; Q2 category Health Policy & Services - SSCI, position 43/87. Indications of quality for the year 2022 (last published edition) in SJR: SJR 0.550; Q2 category in Health Policy; H-index 48.

3. **Llop-Medina, L.,** Ródenas-Rigla, F., Gallego-Valadés, A., & Garcés-Ferrer, J. (2024). Factorial structure of quality of life, satisfaction with caregiving and caregiver burden in palliative care: A systematic review. *Nursing Open, 11*(1), e2067. https://doi.org/10.1002/nop2.2067

The PhD candidate's contribution to this paper was focused on conceptualisation, methodology, formal analysis, investigation, writing—original draft preparation, writing—review and editing, visualisation.

The research question of this study was "Which instruments are being used to assess the quality of PC care?". The aim of this study was to identify the main approaches and domains of PC quality assessment through different instruments. The results obtained were generally representative of the evidence supporting the factor structure of the Quality of Life Questionnaire C-30 (QLQ-C30) in the general cancer population. The factor structure of the Zarit Burden Interview remains ambiguous, although the idea of a unifactorial structure predominates. In the case of FAMCARE, most of the factor structures differ from Kristjanson's initial proposal. The categorisation of the main subjective assessment approaches could be useful for the construction of a coherent system of indicators to be used in nursing practice.

Regarding the scientific relevance of the journal, the work was published in the journal Nursing Open (eISSN 2054-1058) edited by WILEY since 2019 in England. Quality indicators for 2022 in JCR (last published edition): Journal Impact Factor (JIF) 2.3; JIF without Self Citations 2.2; Q2 category Nursing- SSCI, position 42/123. Indications of quality for the year 2022 (last published edition) in SJR: SJR 0.636; Q1 category in Nursing (miscellaneous); H-index 25.

4. **Llop-Medina, L.**, García-Muñoz, P., Ródenas-Rigla, F., & Garcés-Ferrer, J. (2023). Enhancing the Adult and Paediatric Palliative Care System: Spanish Professionals' and Family Caregivers' Suggestions for Comprehensive Improvement. *Healthcare,12*(1), e65. https://doi.org/10.3390/healthcare12010065

The PhD candidate's contribution to this paper was focused on conceptualisation, methodology, formal analysis, investigation, writing—original draft preparation, writing—review and editing.

The research question of this study was What are the elements that influence the quality of PC provision from the perspective of professionals and family caregivers? This study critically explored the shortcomings of the Spanish PC system, focusing on assessment and treatment aspects for older patients and explored paediatric patients. The recommendations that emerged include holistic care addressing social, emotional, psychological, sociofamilial and economic dimensions, supported by integrated support groups and strengthened relationships with palliative associations. This study also called for better coordination of health institutions, support from social workers and continuous monitoring of health professionals' satisfaction.

This study has initiated an exploratory process linked to paediatric patients linked to Comprehensive paediatric PC approach (PALLIAKID) project started in December 2023 and will run for 4.5 years. This project, funded by Horizon Europe (Grant N. 101137169), aims to address this situation and improve the well-being and quality of life of children and young people with PC needs, focusing on the involvement of patients, families and carers in the project. The consortium consists of 17 partners from 10 European countries, including five clinical centres in Spain, Italy, Denmark, Finland and Latvia.

Regarding the scientific relevance of the journal, the work was published in the journal Healthcare (eISSN 2227-9032) edited by MDPI since 2013 in Switzerland. Quality indicators for 2022 (latest available data) in JCR: Journal Impact Factor (JIF) 2.88; JIF without Self Citations 2.6; Q2 category Health Policy & Services - SSCI, position 43/87. Indications of quality for the year 2022 (last published edition) in SJR: SJR 0.550; Q2 category in Health Policy; H-index 48.

CHAPTER II

THEORETICAL FRAMEWORK

CHAPTER II. THEORETICAL FRAMEWORK

1. SOCIO-DEMOGRAPHIC CONTEXT

The exponential growth of the world's population in recent decades and the increase in life expectancy has led to an increase in the population of older adults, who constitute the fastest growing population group. Between 2000 and 2019, global life expectancy (LE) at birth increased from 66.8 years to 73.3 years, and healthy life expectancy (HALE) increased from 58.3 years to 63.7 years (European Commission, 2019). In 2022 life expectancy at birth in the EU was estimated at 80.6 years, reaching 83.3 years for women and 77.9 years for men (EUROSTAT, 2024a). Europe is the continent that reports the highest percentage of older adults, accounting for approximately 25% of its total population, which, according to the degrees of ageing, is expected to reach 1.4 billion older people in the world by 2030, and it is estimated that by 2050 the rest of the continents will reach a similar percentage of this population group, except for Africa (WHO, 2022).

Population ageing has mainly resulted from a long-term fall in fertility rates and an increase in life expectancy, due to several factors, such as; the reduction in infant mortality, advances in public health and medicine, greater awareness of the benefits linked to a healthy lifestyle, a shift away from heavy work towards tertiary occupations and better living conditions.

The population of the EU on 1 January 2023 was estimated at 448.8 million people. Older people (aged 65 years and over) had a 21.3 % share (an increase of 0.2 percentage points (pp) compared with the previous year and an increase of 3.0 pp compared with 10 years earlier) (EUROSTAT, 2024b).

Spain presents a similar demographic behaviour, showing an exponential increase in the proportion of older people. According to data from the National Statistics Institute (INE), on 1 January 2022, older people accounted for 19.97% of the total population. The proportion of octogenarians is 6% of the total population, and it is projected that by 2040 there could be more than 14.2 million older people, corresponding to 27.4% of the total population (Pérez-Díaz et al., 2023).

Although this increase in longevity can be seen as a success of our societies, it also poses some challenges. Some analysts suggest that population ageing may put downward pressure on the economy by reducing labour supply and leading to an increase in social costs related to age-related problems especially when older people suffer from health problems that prevent them from leading an autonomous life (Corselli-Nordblad and Strandell, 2020).

Non-communicable diseases (NCDs), also known as chronic diseases (such as stroke, heart disease, cancer, respiratory disease, diabetes, among others) are often long-lasting and result from a combination of genetic, physiological, environmental and behavioural factors and represents 70% of deaths worldwide. These diseases affect people of all age groups but are often associated with older age groups (WHO, 2017).

Despite the fact that NCDs are preventable, the number of deaths attributed to them is rising, and rising across the board. They are becoming an increasing proportion of the total number of deaths, and the trend is seen from low-income countries to the wealthiest nations. As a consequence, NCDs now account for the vast majority of deaths worldwide each year (WHO, 2020).

The global epidemic of chronic diseases is strongly linked to population ageing. Disorders with a strong age-dependent relationship will increase in prevalence in parallel with the absolute and relative (to total population size) numbers of older people (≥60 years). In high-income countries, population ageing persists, as fertility continues to fall and life expectancy increases (Martin et al., 2015).

Gender influences the provision of family care and there are inequalities in the distribution of care-related tasks. In Spain, care for the elderly is mostly provided by the family, assuming a Mediterranean model, where women are the main element of the non-professional care network (Cascella et al., 2020). Care provision in Spain is based on a cultural heritage, it is a patriarchal legacy, linked to beliefs that are held in the collective unconscious and transmitted from generation to generation, being very different for men and women (Xiong et al., 2020). Some authors have identified gender inequalities in the distribution and tasks related to family caregiving and women are generally more likely to be the ones who take on the role of caregivers (Xiong et al., 2020, Hernandez et al., 2019, Abellan et al., 2019).

Women caregivers of palliative care patients have lower levels of quality of life than men (Choy and Seo, 2019) and caregivers aged 60 years and older have lower perceptions of quality of life in dimensions such as physical health, vitality, pain, mental health, and general health compared to caregivers who are younger (Coca, 2017; Holgín et al., 2021). Gender role characteristics lead to higher levels of caregiver strain, greater morbidity and depression, and poorer quality of life in female caregivers than in male caregivers (Det Río et al., 2017).

Male patients with complex chronic illnesses tend to have a spouse who assumes responsibility for care, reducing the likelihood of needing to enter a housing institution, in contrast to women who in the same situation need external help or a housing institution, as in this case it is not the male spouse who assumes care (Bamford & Walker, 2012; Washington et al., 2015, García-Jimenez et al., 2024).

1.1. Multimorbidity and its impact on health systems

Changes in the demographic population profile have brought important consequences with a major impact not only on health systems, including increased demand for health services and care for this population, which requires quality and accessible health care, but also on other aspects of society (Andrade et al., 2018).

As illustrated in the previous section, increased longevity in many cases leads to an increase in the prevalence of chronic diseases. Chronic diseases have a significant impact on the quality of life of older people, resulting not only in a reduction in basic activities of daily living (ADLs), but also in associated psychological distress and financial worries. People living with chronic diseases are also at high risk of developing multimorbidity (Johnston et al., 2019), understood as several long-term chronic diseases that lead to increased dependency of family and caregivers due to progressive deterioration of health status and pose a significant and profound economic challenge to the healthcare system and society. Due to multimorbidity, care for this patient profile has become a challenge for healthcare systems. A key aspect of understanding the challenges around multimorbidity and health services concerns the relationship between multimorbidity and disability or reduced autonomy and the use of health and social services and their costs.

There is increasing interest and research on the relationship between the number of chronic diseases and the use and expenditure of health services. Already in early 2000, the study performed by Anderson and Horvath (2004) showed that the average per capita expenditure measured from medical claims and other records almost tripled from one chronic illness to three and doubled again from three to five or more illnesses. Ten years on, another study carried out in Canada in 2011 (CIHI, 2011) that looked specifically at older people showed a rapid increase in service use as the number of chronic conditions increased, demonstrating that the amount of services older people use is not related to age, but to the number of chronic conditions they have. More recent studies have reported similar trends: health care costs increased considerably, sometimes exponentially, with each additional chronic illness with increased access to specialist physicians, emergency department visits and hospital admissions (Bishop et al, 2022). Patient burden includes impaired quality of life, out-of-pocket expenses, medication compliance, inability to work, symptom control and high cost to caregivers. This high burden of Multiple Chronic Conditions (MCCs) is expected to continue to increase (Hajat & Stein, 2018). Moreover, studies such as Bishop et al. (2022) suggest a growing burden of multimorbidity among cohorts of older adults born more recently and should inform policies to address declining health in ageing populations.

Multimorbidity is associated with increased use of health services, including inpatient and outpatient care (Salisbury et al., 2011). People with multimorbidity have substantial additional health needs, implying a heavy burden on the use of health care. It is estimated that 70-80% of total health spending is on chronic diseases Patients with multimorbidity represent up to 75% of primary care consultations. These patients are also heavy users of hospitals, with as much as 14.6 times the risk of being hospitalised (Quinaz Romana et al., 2020). To some extent, the increased use of health services is exactly what one would expect because the need is greater in people with multiple conditions, but at least some of the increased use is due to coordination failures and complications in treatment, including adverse drug effects arising from complex prescribing regimens (Hajat & Stein, 2018; Zhang et al., 2009). Much of the increase in health service use is concentrated in the last year or two of life, which will sometimes be inappropriate if PC approaches are more indicated than aggressive 'curative' treatment (Murray et al., 2005, Zhang et al., 2022).

2. PALLIATIVE CARE AND ITS ROLE IN THE CARE OF COMPLEX CHRONIC OLDER PATIENTS

The PC concept has undergone changes and evolution in related conceptual and strategic approaches, including their use in clinical practice, in recent years. Conceptually, in 1990, the World Health Organization (WHO) adopted the definition proposed by the European Association for Palliative Care (EAPC) as the total active care of patients whose disease does not respond to curative treatment. The control of pain and other symptoms, as well as psychological, social, and spiritual problems, was considered as paramount. The WHO subsequently expanded this definition: "PC is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems. PC is the prevention and relief of suffering of any kind – physical, psychological, social, or spiritual – experienced by adults and children living with life-limiting health problems. It promotes dignity, quality of life and adjustment to progressive illnesses, using best available evidence." (WHO, 2016, p.5).

In 2018, the Parliamentary Assembly of the Council of Europe issued a resolution calling on Member States to take measures to strengthen PC services, thereby ensuring access to and provision of quality PC for both adults and children (Tziraki et al., 2020).

As mentioned before, PC has been defined by the World Health Organisation as a method of care to improve the quality of life of patients and families facing a life-threatening illness, with the aim of preventing and alleviating the suffering caused by the illness, through early identification, assessment, appropriate pain management and attention to the physical, psychosocial and spiritual consequences (Davies & Higginson, 2004). The WHO recommends approaching persons with NCCD and their caregivers as a 'unit of care', focusing on the well-being of the patient–caregiver dyad rather than just on the patient (Aoun et al., 2018).

A "family caregiver" in this sense is any person who provides any kind of physical and emotional care to an individual at home. Although family caregivers can be seen as an extension of the healthcare team, they often do not feel adequately prepared for their role, which can impact on their physical and mental well-being (Robison et al.,2009; Miller., 2009). The performance of all caregiving tasks can have an impact on family members or non-professional caregivers, who may experience psychological distress, anguish, overload, loneliness, loss of contacts and social support. The experience of illness deeply affects the physical and psychological health of family members; recognition of this has coined the term "hidden patients" (Kristjanson & Aoun., 2004). Caregiving tasks are increasingly complex, particularly in advanced disease settings, and include assistance with activities of daily living, coordination and attendance at hospital appointments, management and delivery of home health care, and assistance with decision-making (Candy et al., 2011).

PCs aim to reduce pain, considering death as a life process that should not be delayed or accelerated, but rather to provide holistic care that improves the quality of life of the terminally ill patient and their family until the time of death (WHO, 2014). PC should be adapted to the individual needs and preferences of the patient, improving and ensuring access to relevant care, providing care according to different levels of care, taking into account the possibility for the person to be cared for at home.

The development and implementation of PC has mostly developed around the area of oncology, with most PC protocols, programmes and units being more focused and directed towards cancer patients. Existing systematic reviews, like the one by Moens et al. (2014), conclude that more research is needed that directly compares PC-related problems between cancer and non-cancer patients using the same measurement tools and time points. However, the number of older patients with non-malignant diseases, such as Chronic Obstructive Pulmonary Disease (COPD), diabetes, cardiovascular and renal diseases, among others, has been increasing and outnumbering cancer patients, giving rise to the need to apply palliative therapies to these patients. There is evidence that the provision of PC for non-cancer diseases improves patients' symptom burden and quality of life, resulting in a pattern of reduced health care utilisation and avoiding unnecessary emergency department admissions (Kavalieratos et al., 2016). Other studies, such as that of Quinns et al. (2020) report that in patients dying from non-oncological diseases in Canada related to chronic organ failure (such as heart failure, cirrhosis or stroke), PC was associated with reduced rates of emergency department visits per person-year. These results suggest that increasing access to PC by sustained investment in physician training and current models of collaborative PC could improve end-of-life care, which could have important implications for health policy. Likewise, community-based specialist PC was associated with decreases in hospital costs for multiple life-limiting health conditions (Spilsbury & Rosenwax, 2017).

In most countries, PC is only provided in the last month of life, rather than in the context of living with NCDs (Arias-Casais et al., 2019), which can lead to increased cost in unnecessary tests or emergency department care that could have been avoided.

As can be seen, this situation has been aggravated by the socio-health crisis produced by COVID-19, which highlighted the great unmet needs in PC, accentuating the seriousness of these needs, which must be resolved through a new typology of services and patient care (Gómez et al., 2020; Rubio et al., 2020). PC has been highlighted as an essential part of the response to the pandemic. The pandemic has posed a unique challenge for PC services, as it has led to an increase in the number of patients in need of PC at the end of life. The risk of mortality is especially high among those with existing illnesses and multimorbidity (Etkind et al., 2020).

The COVID-19 pandemic posed a threat to essential PC services, including building connections between patients, families and healthcare teams; mitigating isolation, loneliness and fear; managing symptoms; determining priorities of care in the face of life-threatening illness; and promoting comfort, connection and dignity during the dying process.

Health care professionals around the world have faced unprecedented challenges, including adapting to the need for physical distance, supporting families who are unable to see their seriously ill loved ones, managing acute bereavement when patients die; and in some cases, working outside their usual scope of practice (Ayanian., 2020; Lam, 2020).

The pandemic also placed severe restrictions on family members, with limitations or bans on visits, to PC where the presence of a family member at the patient's bedside is essential (Mercadante et al., 2020). Patients were left alone all day with no support except from health care workers, and this resulted in many of them dying alone in an ICU. Family members who were not allowed to be with their loved ones during this critical time are at high risk of complicated bereavement. Ultimately, the pandemic increased distress around isolation at the end of life including the inability to make physical contact and say a final "goodbye" to loved ones including the lack of funerals or collective celebrations of life or bereavement (Ritchey et al., 2020).

2.1. Quality of care in palliative care

The implementation of PC and its outcomes can be monitored through quality indicators. Quality indicators are usually described with a numerator, a denominator and a performance standard. Quality indicators can indicate potential problems or good quality care (Campbell et al., 2003). These indicators can be used within this monitoring cycle to provide data on subjective and objective aspects of quality of care over time (Ostgate et al., 2010; Teno et al., 1999). In several Western countries, a number of national health care monitoring programmes based on quality indicators have been initiated (Eagar et al., 2009).

In 2009, the Council of Europe stated that "the definition and adoption of indicators of good PC that assess all dimensions of care from the patient's perspective should be encouraged". In PC, quality indicators can be important to enable us to get an indication of the quality of care being provided and subsequently improve care where necessary (Davies, & Higginson., 2004).

Most sets of quality indicators for PC contain mainly process indicators and often reflect documentation of care (Pasman et al., 2009). In this regard, there is a debate in the literature as to which type of quality indicator is most suitable for the assessment of quality of care and, in general, preference is given to process indicators (Mainz 2003; Rubin et al., 2001;). The reported advantages for this option are the following: process indicators can be used to provide feedback for quality improvement initiatives; most process indicators only require a definition of the population that is eligible to receive the process and no additional risk adjustment is needed; and most process indicators can be easily assessed with information from medical records. However, medical records may not reflect the actual care provided (Rubin et al., 2001).

Therefore, in the PC setting most of the quality indicators that have been developed relate to PC processes and outcomes, while there are few indicators that address the organisational structure of PC. However, not all PC domains are covered to the same extent; there is an under-representation of the psychosocial, spiritual and cultural domains. Finally, most indicators are limited to one setting or group of patients (De Roo et al., 2013).

Quality of care also refers to aspects such as satisfaction, quality of life, this is fundamental to know what can be improved in PC care.

For this reason, one of the studies carried out focuses in particular on the analysis of the most commonly used instruments to measure both aspects, satisfaction and quality of life. In this sense, satisfaction with care assesses the fulfilment of individual needs and expectations of patients and their families through direct or indirect questions about the quality of care provided (Aspinal et al., 2003). While involving those receiving care is essential to understand both quality of care and satisfaction with care (Stefanou et al., 2010; Vedel et al., 2014), considering also dimensions such as health care delivery, best practices and standards of care, which require input from health care providers.

Quality of life is a multifaceted concept, which has been studied mainly among patients in the fields of psycho-oncology and PC. They describe the outcome, process and structure of care needed for a given type of patient or clinical circumstance (Schuster et al., 2005). Quality indicators are explicitly defined and measurable elements that refer to outcomes, processes or structure of care (Campbell et al., 2003). The quality of life of cancer carers is a complex construct and can be measured with unidimensional and multidimensional tools. It can be affected by patient- or treatment-related factors, socio-economic status, characteristics of the caregivers themselves (e.g. gender, age) and aspects of caregiving (e.g. time spent caring for the patient). Results on these aspects vary widely depending on the samples selected, instruments and methods used (Vaupel., 2010).

3. CONTEXT OF THE THESIS. CARE FOR COMPLEX CHRONIC OLDER PATIENTS AND THEIR CARERS/FAMILY

The doctoral thesis has studied two healthcare contexts in different autonomous communities within the Spanish state; the Valencian Community, specifically the Hospital La Fe in Valencia, and the Autonomous Community of Murcia, specifically the Hospital Virgen de Arrixaca in Murcia.

3.1. Spanish decentralised health system

The General Health Act 14/1986 of 25 April 1986 establishes that the NHS is the set of health services including PC of the State Administration and the Autonomous Communities, and integrates all the health functions and benefits that are the responsibility of the public authorities for the due fulfilment of the right to health protection. In addition, the General Health Act establishes universality of coverage as one of the basic characteristics of the Spanish system by determining that public health care will be extended to the entire population.

The process of devolution of healthcare to the autonomous communities in Spain, definitively created in 2002 (Sánchez Gutiérrez et al., 2019), meant that each region could establish the measures it considered appropriate in PC care. This makes it difficult to establish a comprehensive and interdisciplinary model of care such as that proposed in the Bases for the Development of a National Palliative Care Plan in 2000.

The Law 16/2003 of 28 May 2003 on the Cohesion and Quality of the NHS included PC for the terminally ill as a specific benefit in all the Autonomous Regions, both in primary and specialised care. In 2007, the Palliative Care Strategy of the NHS was published, which defined guidelines for action and development throughout Spain, and this Strategy was updated in 2011 (Sánchez Gutiérrez et al., 2019). However, this decentralisation has currently led to inequalities in patient care, depending on the place of residence, as a result of the lack of a National Plan to support the provision of such care.

Focusing on the inequalities in the care offered by the territories, the availability of resources specialised in palliative care or the supply of long-stay centres generally stands out (Barbero & Díaz, 2007). Along the same lines, one of the indicators that is gaining importance in Spain, but also at European level, to measure the quality of PC is the place of death of the patient. Thus, more than half of the deaths in people receiving PC in Spain occur in hospitals, which is characteristic of countries with a PC model whose care is poorly integrated (Cabañero et al., 2020).

Focusing on Spain, Catalonia would be the only autonomous community whose rate of deaths in social and health care homes of people in PC is similar to that of Belgium, due to a greater supply of medium and long-stay residential centres and with a model of care focused on advanced chronicity. However, Spain's position compared to the European Union does not indicate an improvement in the integration of PC according to the data provided by the latest European rankings and atlases (Gómez-Batiste et al., 2019).

3.2. Current situation of pc in spain. The national palliative care strategy

The Palliative Care Strategy of the NHS was unanimously approved by the Interterritorial Council of the NHS on 14 March 2007, ratifying the work of consensus between institutional representatives and experts from different areas related to end-of-life care. The most obvious immediate effect since the beginning of its drafting has been a clear increase in the visibility of PC in the framework of the Spanish healthcare system. Since the approval of the Strategy, the most important observations and evidence have been analysed and the Monitoring and Evaluation Committee reached a consensus on the objectives of the Palliative Care Strategy of the National Health System 2010-2014 (Ministerio de Sanidad, Política Social e Igualdad, 2011), including modifications to some of them as well as new recommendations.

The purpose of the strategy is to improve the quality of care provided to advanced and terminally ill patients and their families, promoting a comprehensive and coordinated health system response to their needs and respecting their autonomy and values. The main objective of the strategy is to establish appropriate, viable and measurable commitments on the part of the Autonomous Regions to contribute to the homogeneity and improvement of PC in the NHS.

To this end, five strategic lines of action are proposed; Integral Care, Organisation and coordination, Autonomy of the patients, Training, Research. With regard to the first line of action (Integral Care), the Strategy aims to provide patients with advanced terminal illness and their families with comprehensive assessment and care adapted at all times to their situation, at any level of care and throughout their evolutionary process. It also aims to provide care based on the best practices and scientific evidence available. The main objective of the second line (Organisation and coordination) is to achieve an explicit regional organisational model so that patients receive PC according to their needs and at the appropriate time, adapted to the different situations and territorial delimitations. With regard to patient autonomy, it is proposed to promote the application of bioethical principles and the participation of patients in their process in accordance with the principles, values and contents of the "Patient Autonomy Act" and the legislation in force in the different Autonomous Communities. The last two lines (Training and Research) aim to promote research into PC and to establish continuous and specific training programmes for health system professionals so that they can adequately attend to the needs of patients with advanced and terminal illnesses and their families.

The main conclusions drawn from the Evaluation of the NHS Palliative Care Strategy (period 2015-2020) are shown below (Ministerio de Sanidad, 2023):

- All of the Autonomous Communities and Autonomous Cities (19) have a specific palliative care Strategy, Plan or Programme.
- The evaluation of their strategies, plans or programmes has been carried out in 11 of them.
- In addition, 11 Autonomous Communities and Autonomous Cities have carried out an evaluation of their strategies, plans or programmes and 11 Autonomous Communities and Autonomous Cities have incorporated some measure of improvement or fulfilment of objectives.
- The majority (17) have incorporated some specific measure in their strategies, plans or programmes to identify the risk of fatigue or "overload" of the main carer.
- Most of them (14) have protocoled palliative sedation. In addition, they report that it is recorded in the patients' medical records.

But other information is not recorded, such as; personal goals and wishes of the patient with palliative needs and the family, preferred care setting, the reason for sedation, drugs used, refractory symptoms, established treatments and resistance to them, pain, nutrition, mouth and skin care, sleep, respiration, etcetera. This type of data provides valuable information for health managers, planning, research and so on.

- The majority (17) of the Autonomous Communities and Autonomous Cities have organised continuous care, i.e. 24 hours a day, every day of the week, for patients with PC needs. In most cases, this is carried out telematically and generically.
- There are still 12 autonomous communities that do not have a system of support, prevention, assessment and monitoring of burnout syndrome, or psycho-emotional support for health professionals working in PC.
- Most of the Autonomous Communities have some model or plan to deal with "advance decision planning" (ADP) (15). This information will be included in the clinical history and is accessible to the different professionals who may provide care (16).
- Most of them (16) carry out initiatives to raise awareness and/or sensitise the population about PC and of these, 7 have stable structures. From which they develop training actions aimed at the population on the objectives, principles and resources in PC.
- All the Autonomous Regions have developed some initiative, action or specific training plan in PC for healthcare professionals. They promote basic and intermediate training in PC. This training is considered fundamental for improving the competencies of primary care and hospital professionals. As well as for the identification of patients with PC needs.
- With regard to research in PC, it is advisable to consider greater investment by the State R&D&I Plan in this area, as well as

greater efforts by health centres and research organisations to increase the number of national projects submitted to competitive research calls for proposals.

In Spain there are also scientific societies that contribute to the care and design of PC strategies and plans, in particular the Spanish Society for Palliative Care (SECPAL) whose aim is to promote PC in Spain and which acts as a nexus for all professionals working in this field. This organisation brings together various healthcare professionals who in their daily work attend to, care for and comfort patients who cannot be cured: oncology doctors, general practitioners and health centre doctors, anaesthetists, nurses, social workers, psychologists, religious and bioethicists. The Spanish Society for Paediatric Palliative Care (PEDPAL) also aims to provide professional support for the development of paediatric PC in Spain. This scientific society aims to bring PC to all those children and families who need it, to train professionals and to spread its values in society in order to alleviate the suffering of children diagnosed with an incurable disease. This care must be holistic and pay attention to the physical, social, psychological and spiritual components of both the sick child and his or her family. For this reason, adult and paediatric PC are multidisciplinary, as are both organisations, which aim to bring together different groups of professionals with a common goal.

3.3. How PC is implemented in Valencia and Murcia

This section will describe how the national PC system has been developed and implemented in the two Autonomous Communities in which the studies that comprise this thesis have been carried out. In both Autonomous Communities there are specific PC plans and care resources created to attend to patients and relatives who require this type of care. However, as will be shown, the development of the regional plans has not been continuous in recent years and they have not been updated. Although all the resources and teams created continue to operate in both regions. The image1 shows the location of the regions and the hospitals where the samples have been selected.

3.3.1. Valencian Community

Health care in the Valencian Community is structured into 24 health departments, which depend on the Valencian Health Agency of the Regional Ministry of Health. In each department, there is a single health department responsible for health care, both at primary care and hospital level.

The health department as a whole, as set out in DECRETO 74 /2007, de 18 de mayo, del Consell, which approves the Regulations on the structure, organisation and operation of health care in the Valencian Community and the Strategic Plan of the Valencian Health Agency, will provide all patients with comprehensive, quality care that is coordinated between the different health care services. Primary care explicitly includes in its portfolio of services the care of patients susceptible to PC.

The basic resource for the care of patients with advanced disease at the end of life is the Primary Care Team (EAP), which provides outpatient and home care to these patients in a low complexity situation. If the complexity increases, the Home Hospitalisation Unit can be used which is the Home Support Team for PC in the Valencian Community, which, after a joint assessment, decides on the therapeutic plan. Primary Care also has Mental Health Units as support teams for the assessment and intervention of both patients and relatives for psychological needs.

With respect to the resources allocated to the care of palliative patients, in the Valencian Community there are Home Care Improvement Programme (HCIP), Home Support Team (HST) and Palliative Care Unit (PCU).

The HCIP has the following basic characteristics:

- The profile of patients managed by the programme is advanced disease and at the end of life, evolved chronic patients and multi-pathological elderly.
- The pilot programme is made up of Liaison Nurses located in the Hospital area who are responsible for identifying patients in the Hospital- Home hospitalisation unit (HHU) and referring

them to the Community Management Nurses located in the Department's Health Centres for follow-up.

The HST has the following basic functions:

- Assessment and comprehensive care of complex palliative patients with advanced stage disease and their relatives, adapted to their situation and based on best practices and scientific evidence in a hospital at home regime.
- Interconsultation for in-hospital palliative therapeutic assessment and guidance.
- Telephone care.
- Coordination with primary care for the care of patients with advanced disease, acting as a home support team.
- Teaching.
- Research in palliative care.

The PCU has the following basic functions:

- Control and treatment of disabling symptoms.
- Continuous, truthful and non-traumatic information and communication.
- Emotional-psychological, social and spiritual support for the patient and family.
- Bereavement management.
- Medical and psychological care and treatment, as well as spiritual support, aimed at improving the comfort of the patient, whatever the diagnosis, when curative treatment is impossible.
- Coordination and support with/of other health and/or social care resources.
- Teaching and research.

3.3.2. Autonomous Community of Murcia

The Murcian Health System is regulated by the Law 4/1994, of 26 July, and its subsequent modifications. Within this framework, the PC model in the Autonomous Community of Murcia is aimed at ensuring, at all levels of the Murcian healthcare system, quality healthcare for the terminally ill that responds to the needs and expectations of the patient and their family.

Since 1990, the Autonomous Community of Murcia has had a healthcare system geared towards the provision of PC, both in specialised and primary care. Moreover, in the Murcian health system, the importance and contribution of the Primary Care portfolio of services which since 1992 has included care for terminal, chronic and immobilised patients at home, the collaboration and support of the Spanish Association Against Cancer, which since June 1998 has had a Palliative Medicine unit in the area of influence of the Hospital Virgen de Arrixaca, should be highlighted.

However, the evolution of the population of the Autonomous Community of Murcia and its progressive ageing, as well as the diversity of organisational models in the different Health Areas and the lack of a homogeneous development in PC led to the development of the Integrated Palliative Care Plan of the Murcia Health System in 1997, which took into account the needs of the population and introduced the necessary mechanisms for a homogeneous development and a progressive adaptation to the new needs. The general objective of the Plan was to improve the care and quality of life of terminally ill patients and their families in a comprehensive and individualised manner, guaranteeing respect for their dignity and the right to their autonomy. The Plan included in the target population those patients with a terminal illness, regardless of the pathology that originates it (terminal oncology patients and patients with chronic non-oncological illness, in advanced stage and with severe non-reversible functional limitation), with a limited life prognosis (usually less than 6 months) and their families; who present a pattern of high need and demand for care defined by the moment of the illness, and with an oscillating evolution with frequent crises of need.

The plan's service provision model takes into account the greater demand and need for early PC in non-cancer patients and the recognised needs of cancer patients. The model is based on the coordinated action of the different care resources and continuity of care. It is articulated around primary care, as the manager of patient care and regulator of referral flows to the specialised level. The most appropriate place to provide PC at any given time will be determined by the level of complexity of the patient, the availability of adequate family support and the choice of the patient and family, among other variables.

Specific services were created, specifically the Palliative Care Support Teams (PCST) whose function is based on support and training for the rest of the professionals. In this way, both the inter-consultation relationship (telephone and/or face-to-face) and occasional and/or periodic joint interventions are encouraged, proposing referral only in cases of high complexity and always at the request of the professionals.

These resources (PCST) are located in both home and hospital care, being established as the Domiciliary Care Support Team (DCST) and the Hospital Care Support Team (HCST). In addition to these two teams described, the creation of Specific PC Units in medium care hospitals was proposed, as well as the extension of DCST and HCST to complete teams with the inclusion of volunteers.

3.4. How palliative care are implemented in La Fe and Virgen de Arrixaca hospitals

The following is a description of both hospitals where the studies of this thesis were carried out. Both hospitals are referents in their respective Autonomous Communities, both at clinical and research level, having developed specific strategies in the field of PC. Their intervention teams are leaders in PC and actively participate in national and international research projects, such as those in which the thesis is embedded.

3.4.1. Valencia-La Fe Health Department

The Valencia-La Fe Health Department is one of the health provision areas belonging to the Health System of the Autonomous Community of Valencia (Spain), under the umbrella of the Valencian Health Agency (AVS).

This Health Department covers a specific geographical area located in the southern part of the city of Valencia and coordinates all the health services provided in the territory, from primary to tertiary care, with a direct coverage of 300,000 inhabitants and an area of influence of 515,000 people. The Service has a central management based at La Fe Hospital, the largest reference hospital in the region and one of the most important centres in Spain. In addition, the Health Department has extensive experience in conducting a number of pilots to validate the impact of integrated services and ICT tools for chronic patients deployed as part of its portfolio of services, and has been awarded three stars as one of the Reference Sites of the European Initiative for Active and Healthy Ageing Partnership (EIP-AHA).

The Department of Health organises its research through the La Fe Health Research Institute, whose function is to enable research and innovation activities that can subsequently contribute to the improvement of current healthcare processes and to carry out any type of evaluation and piloting within the healthcare area. More specifically, La Fe is recognised in Spain as a leading hospital in the management of various diseases, in the provision of home hospitalisation services and in the search for the integration of all levels of care.

Currently, for the care of patients with palliative needs, two case management programmes are being developed in the Valencia-La Fe Health Department: a case management programme on chronic diseases/multimorbidity; and a case management programme on EoL care needs. A patient can be cared for under the first programme, but, if necessary during the course of the disease, can be transferred to the case management programme on EoL care needs. Primary Health Care and the Hospital at Home and Telemedicine Area are the two resources on which the case management programmes pivot.

Regarding the case management plan for chronically ill patients, which cares for around 900 patients with complex conditions. This plan includes multidisciplinary teams between telemedicine and Hospital at Home Units, which coordinates, care plans, home visits, scheduled phone calls and communication with primary care in order to keep chronic patients as stable as possible. This plan is designed to anticipate any complications the patient may suffer.

The Hospital at Home and Telemedicine Area depends on the resources of the hospital level and, together with the primary health care teams, constitute a network of collaborative work between the different levels of care. When a situation of clinical instability is identified, the possibility of admission to the Hospital at Home Unit is a strong alternative of care, which allows hospital level care to be provided to the community. If a hospital admission is eventually recorded, the Hospital at Home Unit has an important role in early discharge schemes and transition to community care. In both case management programmes there is an identification and selection of patients based on the Kaiser Permanente Model, Clinical Risk Group classification and a proprietary predictive model to identify patients at risk of hospital admission during the following year. However, there are no specific tools available for the identification of patients in need of early or more advanced PC.

3.4.2. Hospital Virgen de Arrixaca

The Hospital Clínico Universitario Virgen de la Arrixaca is the reference hospital in Health Area 1 (Murcia-West) of the Murcia Health Service. In the field of palliative care there is no specific strategy or plan in the hospital. Moreover, it can be said that each health area manages the organisation of palliative care in different ways, so there is no established circuit.

As far as adult patients are concerned, there is a palliative care support team (PCST) made up of a group of professionals trained and educated in the care of patients with progressive and incurable illnesses and their families, with the aim of improving their quality of life. To this end, they work in a coordinated manner at the different levels of care and carry out their function at home and in hospital in Domiciliary Care Support Teams (DCST) and Hospital Care Support Teams (HCSP) respectively.

Within Area 1 there are the following resources for adult palliative patients:

- Those presenting non-oncological pathologies have a hospital palliative team.
- Those with oncological pathologies have the Oncology service team, which includes an advanced practice nurse with an integrated vision of the needs of the palliative oncological patient.
- For all patients, whether they are referred from oncology or from the non-oncology palliative team, there is also an outpatient primary care unit for home care in Area 1.
- There is also the support of a social worker for all adult palliative patients.
- There is also a nurse case manager who, among other functions, is in charge of establishing the referral of complex chronic patients to palliative care.

Regarding the access pathway for adult patients (both oncological and non-oncological), the request for care if the patient is already admitted is made by a referring specialist who identifies PC needs. A multidimensional assessment will be carried out between the specialist and the HCST to decide whether the patient is discharged home with follow-up by Primary Care (PC), or whether he/she goes home, but with follow-up by the DCST. In the latter case, the DCST must call the patient/family within 48 hours to assess the level of complexity of the patient's situation. In addition, the DCST will coordinate with the PC team for the follow-up of the patient/family included in the PC programme. Finally, the coding registry in SELENE is in the process of being implemented, but the codes are not definitively established in the care process for both paediatric and adult palliative patients.

CHAPTER III

OBJECTIVES AND HYPOTHESIS

CHAPTER III. OBJECTIVES AND HYPOTHESIS

The general objective of this thesis is to carry out an assessment of the PC needs of complex chronic older patients and their carers and to consider how the quality of care received by this population is measured. This objective contains the following specific objectives:

SPECIFIC OBJECTIVES

1. To identify the PC needs of older patients with multimorbidity (excluding cancer).
2. To identify the needs and preferences of family members and caregivers who assume the care of complex chronic older patients requiring PC.
3. To identify the needs of healthcare professionals working with older patients requiring PC and their carers.
4. To become familiar with the tools available in the scientific literature aimed at evaluating the quality of care received in PC settings.
5. To determine the elements that influence the quality of PC provision from the perspective of family caregivers.
6. To determine the elements that influence the quality of PC provision from the perspective of healthcare professionals.
7. To identify challenges and opportunities for improving the quality of PC care.
8. To provide suggestions for improvement for a more effective and comprehensive palliative care system.

HYPOTHESIS

H1: Patients and family members will mostly identify unmet psychosocial needs over physical needs.

H2: Healthcare professionals will identify barriers to the identification of complex chronic patients in need of palliative care.

H3: There is a wide divergence in the components used by the different tools that measure quality of care in palliative care settings.

H4: Professionals and family caregivers will indicate psychosocial and bereavement support as a fundamental element of quality in PC settings.

H5: Quality of care in PC provision will be improved due to the consideration of interdisciplinary teams and increased communication between care teams and patients.

Table 3.1 outlines the thesis hypothesis, the objectives they are aligned with as well as the publications where they are studied and verified.

Table 3.1. Correspondence between hypothesis and specific objectives

Hypothesis	Objective	Papers
H1: Patients and family members will mostly identify unmet psychosocial needs over physical needs.	1. To identify the PC needs of older patients with multimorbidity (excluding cancer).	1,2
	2. To identify the needs and preferences of family members and caregivers who assume the care of complex chronic older patients requiring PC.	1,2
H2: Professionals will identify barriers to the identification of complex chronic patients in need of palliative care.	3. To identify the needs of healthcare professionals working with older patients requiring PC and their carers.	1,2,4
H3: There is a wide divergence in the components used by the different tools that measure quality of care.	4. To become familiar with the tools available in the scientific literature aimed at evaluating the quality of care received in PC.	3
H4: Professionals and family caregivers will indicate psychosocial and bereavement support as a fundamental element of quality in PC.	5. To determine the elements that influence the quality of PC provision from the perspective of family caregivers.	2, 4
	6. To determine the elements that influence the quality of PC provision from the perspective of healthcare professionals.	2,4
H5: Quality of care in PC provision will be improved due to the consideration of interdisciplinary teams and increased communication between care teams and patients	7. To identify challenges and opportunities for improving the quality of PC care.	1,2,4
	8. To provide suggestions for improvement for a more effective and comprehensive palliative care system.	1,2,4

CHAPTER IV

METHODOLOGY

CHAPTER IV. **METHODOLOGY**

This section summarises the methodological approach used in this doctoral thesis. The methodology used in each of the four papers that compose the thesis is detailed, which imply the use pf different techniques: literature review, focus groups (FGs) and in-depth interviews.

4.1. Method

This thesis used a qualitative methodology employing a variety of methods in the research conducted to capture diverse perspectives and contextual nuances. Qualitative research draws on social science disciplines such as social work, psychology, sociology and anthropology to delve into the experiences and perspectives of individuals. Unlike quantitative methods, qualitative approaches prioritise understanding subjective realities, exploring meanings and uncovering underlying motivations. This methodology is particularly effective in generating rich, contextual data by examining language, behaviours and expressions in natural settings. Qualitative research contributes significantly to the advancement of knowledge, the development of policy and the improvement of practice in a variety of fields, including health and social work (Moser & Korstjens, 2017). By focusing on the nuanced needs and concerns of stakeholders, qualitative research equips decision-makers with essential insights to design tailored interventions and policies that effectively address complex societal problems.

While qualitative research offers deep insights, it also presents challenges such as researcher subjectivity and potential biases (Devers, 1999). To mitigate these problems, this thesis prioritised reflexivity, i.e. continuous self-awareness and critical reflection on personal beliefs and influences throughout the research process. In addition, robust strategies such as, triangulation and building rapport with interview participants and FGs were employed in the studies comprising the thesis to ensure the reliability of the data (Moser & Korstjens, 2017; Corner et al., 2019). In addition, systematic and well-established approaches such as thematic analysis, grounded theory or content analysis were adopted. For the analysis of qualitative data, ATLAS.ti software was used to manage and analyse the data more efficiently and rigorously.

Regarding ethical factors, this thesis addressed sensitive topics and vulnerable populations, which required strict ethical considerations to be followed during the qualitative studies carried out. The principles of privacy, confidentiality and informed consent were followed. Ethical approval was obtained from hospital ethics committees and the autonomy and well-being of participants was safeguarded at all stages of the research.

The different methods employed in each of the studies comprising the doctoral thesis are detailed below.

Table 4.1. Methods

Method	Paper
Scoping review	Paper 1
Qualitative FG and interviews	Paper 2
Systematic review	Paper 3
Qualitative FG and interviews	Paper 4

For **paper 1**, a systematic review methodology was used. Specifically, Arksey and O'Malley's framework was used (Arksey and O'Malley., 2005), which consists of five stages: identifying the research question; identifying relevant studies; selecting studies; plotting the data; and collating, summarising and reporting the results. To guide the conduct of the review, the Review of Systematic Reviews and Meta-Analyses for Scoping Reviews (PRISMA-ScR) checklist was used, which contains 20 essential items of information and two optional items to include when completing a scoping review. Thorough electronic searches were carried out in the Medline, Embase, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, Cochrane Library, PsycINFO, and Scopus databases covering the period January 2009 to February 2022. The protocol for the scoping review was not registered or published.

In the **paper 2**, qualitative data were collected using semi-structured interviews and focus groups with open-ended questions. Thematic analysis was used to identify, analyse and report repeated patterns (Braun and Clarke., 2006). It is a method for describing data, but also implies interpretation in the processes of choosing codes and constructing themes. Themes are actively constructed patterns (or meanings) derived from a data set that answer a research question. Independent topic guides were developed for the three target populations (patients, relatives/caregivers and healthcare professionals) that were interviewed. These topics were related to symptoms and impact of the disease, experiences of services and care provided, management of exacerbations, needs for the future (for patients and relatives/caregivers) or palliative care pathways and integration of palliative care in the management of severe illness (for healthcare professionals). All interviews and FGs were digitally recorded after a previous and signed informed consent and transcribed verbatim.

The consolidated criteria for reporting qualitative studies (COREQ) checklist was used to analyse the data which provides a systematic approach to sifting charting and sorting data using the key themes and issues. Codes were given to segment the information and the key conclusions extracted from the interviews. Codes were compared across all interviews to identify similarities and differences to be further groups into categories, synthesizing and explaining large amounts of data. Connections and relationships between codes and categories were further explored enabling the development of themes and sub-themes.

Ethics approval was granted by Ethics Committee on Research with Medicaments of Hospital La Fe in Spain (ref. 2019-013-1). For data collection, all participants who took part in the study applied the consent forms approved by the ethics committee.

For **paper 3** an analysis model consisting of three stages has been proposed: massive literature search, text mining and systematic reviews using the Quality of Life Questionnaire (QLQ) C30, Zarit Burden Interview (ZBI) and Family Satisfaction with Care at the End of Life (FAMCARE) questionnaires. The Preferred Reporting Items for Systematic Reviews

(PRISMA-P) guided the research. The review was not registered in any specific database or repository. Studies published in English in indexed academic journals focusing on the assessment of the factor structure of the tools in adult patients between 2000 and 2020 were included. Studies had to include samples composed of palliative patients. Electronic searches for eligible studies were conducted until 27/07/2022 in the Scopus, MEDLINE® and PubMed databases.

The quality assessment of paper 3 was carried out as follows: All papers reported the application of factor analysis, reporting factor structure. In addition, they report at least one measure of assessment of the analysis used in exploratory factor analysis (EFA) or principal component analysis (PCA) (Bartlett's χ2 test, Kaiser-Meyer-Olkin KMO and explained variance of the fac-tors or components), or goodness-of-fit statistics in confirmatory factor analysis (CFA) (χ2, comparative fit index (CFI), Tucker-Lewis index (TLI)/non-normed fit index (NNFI), root mean square error of approximation (RMAE) and other CFA goodness-of-fit statistics).

Finally, in the **paper 4**, three FGs were performed for identifying the perceptions of professionals and caregivers of existing deficiencies and areas for improvement in PC services, ultimately proposing recommendations to improve it. The first two FGs involved healthcare professionals, and the third was conducted with family carers of palliative patients. In addition, a semi-structured in-depth interview component was integrated into the fieldwork to further explore the families' views and active participation in decisions of care. This qualitative paradigm facilitated obtaining a deeper exploration of families' and professionals' perspectives on quality areas for improvement of the palliative care system in general, as well as understanding how the quality of care of palliative patients is measured and how this evaluation procedure can be improved. The consolidated criteria for reporting qualitative studies (COREQ) checklist was used as well as for paper 2. Ethical approval for the development of this research was obtained from the Ethics Committee on Research of Virgen Arrixaca Hospital (VAUCH) (ref. 2020-9-3). For data collection, all participants who took part in the study applied the consents approved by the ethics committee.

CHAPTER V

RESULTS- PUBLISHED PAPERS

CHAPTER V. **RESULTS- PUBLISHED PAPERS**

This section contains the papers that compose the thesis. The papers are presented in their entirety as originally published.

1. Palliative Care in Older People with Multimorbidities: A Scoping Review on the Palliative Care Needs of Patients, Carers, and Health Professionals[1]

1. Introduction

The palliative care (PC) concept has undergone changes and evolution in related conceptual and strategic approaches, including their use in clinical practice, in recent years. Conceptually, in 1990, the World Health Organization (WHO) adopted the definition proposed by the European Association for Palliative Care (EAPC) as the total active care of patients whose disease does not respond to curative treatment. The control of pain and other symptoms, as well as psychological, social, and spiritual problems, is paramount. The WHO subsequently expanded this definition, currently taking the form of: "An approach that improves the quality of life of patients and families facing life-threatening diseases, preventing and mitigating suffering through early identification, pain assessment and treatment, and other physical, psychosocial and spiritual problems" [1].

According to this definition, the delivery of PC should be guided by the improvement in patients' and their families' quality of life. Additionally, PC aims at facing needs associated with life-threatening conditions and trying to prevent and relieve suffering through several actions in the continuum of care: early and timely identification, adequate assessment and treatment of multi-domain symptomatology's. PC is applicable at the onset of the disease, alongside other curative therapies. This integration of

---

[1] **Llop-Medina, L.**, Fu, Y., Garcés-Ferrer, J., & Doñate-Martínez, A. (2022). Palliative care in older people with multimorbidities: a scoping review on the palliative care needs of patients, carers, and health professionals. *International Journal of Environmental Research and Public Health, 19*(6), e3195. https://doi.org/10.3390/ijerph19063195

PC has been developed mostly around the oncology area as most of the PC protocols, programmes and units are more focused and addressed to patients with cancer. However, the rate of older adults (60 and over) in need of PC with non-oncological diseases, such as Chronic Obstructive Pulmonary Disease (COPD), diabetes, cardiovascular disease and renal diseases [2] among others, is higher than those with cancer [3], and additionally, when they are admitted to PC units they tend to be closer to death than those patients with cancer [4]. Several systematic reviews have reported that patients with advanced cancer experience improved quality of life and symptom intensity with early PC interventions compared to those who only received cancer care alone [5,6]. There are also numerous studies that have been previously conducted on the needs of cancer patients at the end of their life, such as Bandieri [7], Haun [5], and Wang [8], however there is a lack of studies focusing on older patients with non-oncological complex chronic multipathologies, therefore, this study has focused on the needs of this profile of patients.

Chronic diseases represent around 70% of deaths worldwide [9]. The increased incidence, prevalence, and mortality of chronic diseases and multimorbidities, defined as the presence of two or more long-term health conditions [10], place a significant challenge on PC resources and a burden on health policies and practices [11]. As an increase in the rate of older people with complex chronic diseases is expected over the next 25 years, early identification of PC needs among older patients with comorbidities is becoming an important concern to health systems [12] in order to provide comprehensive care that meets the needs of both patients and family caregivers, considered by the WHO as an indivisible unit in the provision of PC. Ensuring that family caregivers' needs are appropriately assessed is one of the top quality markers for end-of-life care [13], due to them being critical to the patient's quality of life. Thus, the aim of this scoping review was to identify the PC needs of patients with multimorbidities (excluding cancer), their family caregivers and the professionals that work with these patients to obtain a global vision of the actors involved in the provision of PC. This study provides a comprehensive analysis of the needs and concerns around PC provision for non-oncological chronic conditions from a broad approach, joining perspectives of three target groups.

2. MATERIALS AND METHODS

This scoping review used the framework of Arksey and O'Malley [14], which comprises five stages: identifying the research question; identifying relevant studies; study selection; charting the data; and collating, summarizing, and reporting the results. The Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist was used to guide the conduct of this review, which contains 20 essential report- ing items and two optional items to include when completing a scoping review [15]. The protocol of this scoping review has not been registered or published.

2.1. Identifying Relevant Studies

Thorough electronic searches were carried out in the Medline, Embase, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, Cochrane Library, PsycINFO, and Scopus databases covering the period January 2009 to February 2022. A range of keywords and subject headings indicating PC needs, older people's needs, patients, families, non-formal caregivers, and health care professionals were used to maximize the retrieval of relevant studies. The specific questions addressed within this review were:

- What are the PC needs for older patients with multimorbidities?
- What are the PC needs for caregivers of older patients with multimorbidities?
- What are the needs influencing PC provision by health professionals for older patients with multimorbidities and their caregivers?

The final search strategies used in Scopus are shown below as an example:

- (((((palliative care [Title/Abstract]) AND patients [Title/Abstract]) AND needs [Ti- tle/Abstract]) OR preferences [Title/Abstract]) AND older [Title/Abstract] OR elderly [Title/Abstract]).

- ((palliative care [Tittle/Abstract]) OR palliative care unit AND health profession- als[Title/Abstract] AND perceptions [Title/Abstract]) OR needs [Title/Abstract]) NOT patients [Title/Abstract]).
- ((palliative care [Title/Abstract]) AND families [Title/Abstract] OR caregiver [Ti- tle/Abstract]) AND needs [Title/Abstract]) OR perceptions [Title/Abstract]) AND elderly [Title/Abstract]) OR aged [Title/Abstract]).

2.2. Study Selection

The records identified from the electronic searches were imported into Endnote (Reuters, 2011) to avoid duplication of the screening process. Titles and abstracts were initially screened (by L.L.-M., A.D.-M., or Y.F.) to identify potentially eligible papers, and doubts were resolved between those reviewers. The full texts of potentially eligible papers were independently screened against eligibility (see Table 1) criteria by three reviewers (L.L.-M., A.D.-M., or Y.F.). No additional manual searching was carried out.

Table 1. Inclusion and exclusion criteria

Criterion	Inclusion	Exclusion
Period	1 January 2009 until 7 February 2022	Published before 2009
Language	English	Any other languages
Type of studies	Qualitative, quantitative, and mixed method studiespublished in peer-reviewed journals	Letters, comments, conference abstracts, editorials, doctoral thesis
Type of participants	Older patients with multimorbidity (presence of two or more long-term health conditions) Caregivers of older patients with multimorbidity Health professionals in any PC healthcare setting	Cancer patients Patients who do not have multimorbidity (presence of two or more long-term health conditions) Patients under 60 years of age
Type of outcomes	Concerning Palliative care needs	Not concerning palliative care needs

The papers included were peer-reviewed studies published between 2009 and 2022, in the English language, using any research design to report the needs or concerns in PC of older patients with multimorbidity, their families or carers, and health professionals in any healthcare setting.

The papers excluded were those about PC focused on cancer, published before 2009, involving patients younger than 60 years old, covering aspects of care and treatment not related to PC, lack of availability of full text, or full text available but paper written in any language other than English.

2.3. Charting the Data

Data were extracted employing a structured data extraction form that was tested in a sample of 5 studies by three members of the research team independently (L.L.-M., A.D.-M., or Y.F.) and were double-checked by a second reviewer (L.L.-M. or A.D.-M.). Data were extracted first by identifying the target groups involved (patients, caregivers, and health professionals). Secondly, data extraction was performed in a descriptive manner according to the following variables: Age group of patients, country of the study, source of data collection, type of service, care setting, main thematic findings, and reported limitations (see Supplementary Materials, Table S1).

2.4. Collating, Summarizing and Reporting the Results

Based on the data extracted, the included studies were classified according to the WHO’s PC definition. Final topics were agreed by three members of the research team. These final topics are presented in Table 2 below.

Table 2. Final topics according to the WHO's PC definition

Patients	**Caregivers**	**Professionals**
Emotional/mental needs Physical needs Information needs Spiritual needs Other needs	Emotional/mental needs Physical needs Social needs Financial needs Other needs	PC provision Training needs

Due to the studies collected presenting a range of diverse methodologies, an exhaustive analysis of the quality of the studies was not carried out. However, the limitations of eachof the studies included, if these were reported, are listed in the extraction table.

3. RESULTS

A total of 6162 records were identified covering the time span of January 2009 to February 2022. From them, 642 records were selected for abstract review, identifying 81 final studies for full review. The process of the study selection is detailed in the PRISMA flow diagram (Figure 1).

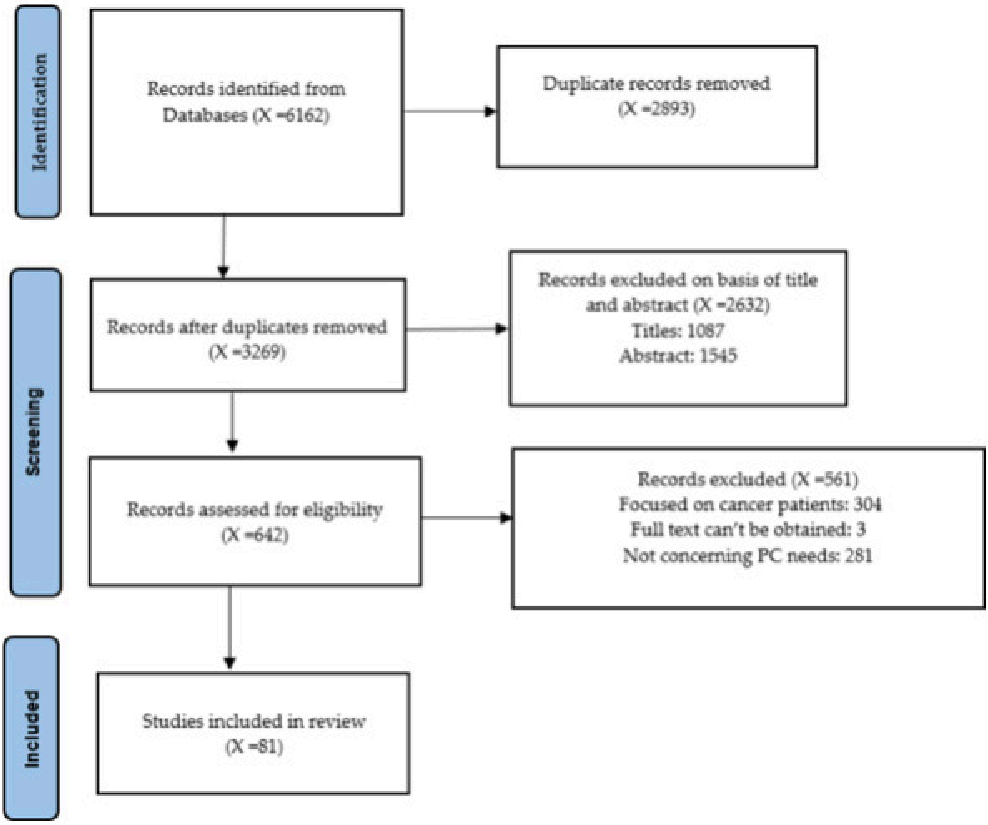

Figure 1. Study selection Prisma Flow Diagram

Although most of the papers analysed focus on a single country (51), a great deal of heterogeneity has been detected in studies addressing two or more countries. Next is detailed the distribution of studies by country. Most of the studies included were conducted in the UK [16–35], the USA [36–44], Australia [45–53], Canada [54–60], and Germany [61–66]. Some studies were performed in two or more countries: Belgium, Netherlands, UK, Germany, Hungary [67]: North America, Australia [68], UK, Ireland, USA [69], USA, UK, Australia, Canada, Belgium, Germany, Hong Kong, Japan, Malaysia, Singapore [70], USA, UK, Sweden, Netherlands, Spain, Canada, Ireland, Australia, New Zealand [71], South Africa, Kenya, South Korea, United States, Canada, UK, Belgium, Finland, Poland [72], Australia, New Zealand, UK [73], Canada, USA, UK [74]. The rest were in Belgium [75,76], Sweden [77–79], Brazil [80], China [81], Switzerland [82], the

Netherlands [83,84], Norway [85], New Zealand [86], Denmark [87] and Hong Kong [88].There were six studies with no information on the country/city where the research was performed [89–96].

Regarding the sources of data collection, the sources of data collection of all the studies analysed in the review are detailed in the following table (see Table 3).

Table 3. Sources of data collection

Sources of Data	References
Individual interviews	[18,26,27,32,44,46,48,58,59,62,63,76,77,80,82,90,92]
Focus groups	[17,18,25,48,50,51,57,61,64,72,75,78,86]
Individual interview and focus group orsimilar	[22,24,28,33,35,36,42,47,49,53,85,87]
Individual interview and questionnaire or survey	[65,81]
Survey or questionnaire	[30,34,37–39,52,56,66,69,73,83]
Reviews	[34,62,64,65,68,80,82,84]
Individual interview, focus group or similarand survey	[20,31,54,60]
Individual interview focus group or similarand survey and RTC	[21]
Individual interview, ethnographic observation	[29,41]
Non-participant observation, semi-structured interviews, focus groups and a co-design event	[19]
Individual interview, retrospective audit ofexisting hospital databases	[45]
Q -methodology (combination of qualitative and quantitative techniques)	[94]

Most of the studies (69.9%) focused on the perspective of one cohort: professionals (47.4%), relatives or caregivers (13.1%) and patients (9.4%), while the rest reported the needs of combined cohorts: patients, caregivers, and professionals (13.1%), on patients and caregivers (13.1%), and patients and professionals (3.9%).

Taking into account whether the studies can refer to several targets, some studies made reference to various targets, 31 addressed the perspective of patients, 31 addressed the perspective of caregivers and 53 analysed the perspective of professionals.

Studies included were undertaken in different health care settings: inpatient care (52.7%) [16–18,21,22,24,26,27,29–32,34,37,38,40,42–44,47–49,54,57,59,60,62,67,68,72,74,77,78,80,82,83,85,91–93] outpatient care (18.5%) [28,33,35,36,39,45,46,52,53,64,68,73,86,87], and combined inpatient and outpatient care (21.2%) [20,25,41,50,56,61,63,65,66,69–71,76,81,89,90]. In addition, five studies (6.7%) did not specify the care setting [19,23,58,75,94].

3.1. Patients' Needs

Of the studies, 31 addressed the PC needs of multimorbid older patients only or together with other cohorts.

3.1.1. Emotional/Mental Needs

Most of the needs reported were related to emotional and/or mental dimensions, such as social isolation, depression, anxiety, or feeling like a burden on families [18,28,34,39,41,69,71,91].

3.1.2. Physical Needs

Patients reported that needs at the physical level caused less concern, as they were often considered covered by health providers through therapies or treatments. However, the most commonly reported physical needs were pain, fatigue, restlessness and agitation, and limitations in activities of daily living [18,34,39].

3.1.3. Information Needs

A lack of enough information was also reported in several studies, highlighting the need for more information about PC and related resources [19,21,55,70,83,92], as well as the need for information about the progression and severity of their disease [63,70,71,89,95]. In line with information gaps, communication with health providers was also detected as an area for improvement, as patients consider it necessary to improve relationships and effective communication, for instance, to feel more supported in finding PC providers [39–41,49,71,74,89,95].

3.1.4. Spiritual Needs

Some studies revealed the need for spiritual care [33,41,45,48,71,72,96], although thesewere approached from different perspectives, with some studies mentioning the need for spiritual attention without specifying more about it [33,48,71] and others referring to more specific aspects of this concept. In this sense, patients can feel distress if their religious wishes and values are not attended to, and being able to discuss spiritual beliefs was indicated as highly important to many patients [41]. Patients felt that clinicians lacked knowledge about cultural practices, such as rituals and religious aspects considered highly sensitive and necessary in end-of-life care [45,72,96]. In some cases, spiritual care was considered to be the possibility of talking to religious leaders, or as providing a safe space, communicating with sensitivity about spirituality, listening, and counselling [72].

3.1.5. Other Needs

Other needs, such as specific cultural needs, were also mentioned, as well as clinicians' lack of cultural awareness and the potential breadth of cultural practices, rituals, and other cultural patient's needs [45].

The need for an adequate environment, with privacy and dignity, as well as the preference for receiving care in the same place and by the same clinicians in order to become comfortable with the environment and to minimize distress, especially in cases of patients with dementia, were also reported [33,48,74,83,94]. Moreover, the appointment of a key worker acting as a point of contact for the patient and family was considered relevant for continuity of care, avoiding confusion, and maintaining continuous contact [20].

3.2. Caregivers' Needs

Thirty-one of the studies addressed relatives' or informal caregivers' PC needs, together with other target groups in some cases.

3.2.1. Emotional/Mental Needs

Similarly, to patients, some of the needs pointed out in the studies by caregivers were those related to emotional and/or mental aspects, such as sleep problems, stress, confinement, physical strain, or anxiety [44,57,95]. They also desired emotional support and educational courses regarding how to handle emergency situations, e.g., falls and psychosis or medications, and more information about disease progression and what to expect in the future [35,36,56,65].

3.2.2. Physical Needs

Caregivers indicated the need for more respite services or personal outings to deal with fatigue and strain [35,57].

3.2.3. Financial Needs

Other needs related to financial concerns were also mentioned in some of the studies. Some caregivers had to leave their paid employment to provide full-time care and use their savings or accumulate debt derived from paying for care for their family member, the costs associated with long-distance travel, medications, home care, accommodation, and the rental of equipment necessary for the care of the patient's needs [36,39,44,49,58,74].

3.2.4. Social Needs

Social needs were also detected in those studies related to the impact of caring on caregivers' social life. These studies stressed the loss of and decrease in caregivers' social contacts or the experience of isolation from friends, neighbours, and the community as a result of providing full-time care [18,36,44,58]. Social assistance needs to obtain resources or benefits, such as direct financial support or social services to alleviate the burden of care, were also mentioned [36,41,58].

3.2.5. Other Needs

Some studies reported that family caregivers felt that the amount and type of information received about their patients' health were inadequate and insufficient [36,51,55,65,91,95].Some studies pointed out that caregivers consider care providers to be mainly focusedon the medical aspects of care and that they tend to exclude the psychological, emotional, practical, and spiritual domains [41,58,72]. In this line, spiritual care was reportedly lacking, due to staff members' lack of time and their lack of prioritization of this aspect of care; consequently, caregivers reported the need for spiritual care for patients and themselves and the need to have time to talk to clinicians about this [33,35,51,56,93]. Furthermore, more time and human connection with professionals, effective communication, and shared decision making were indicated as important [30,55,56,91].

Some studies reported that caregivers feel that they do not have enough information about PC services and how these can provide more comfortable care [20,29,56,68,84,91]. Regarding discussing end-of-life care preferences together with healthcare staff, some studies reported that family members would like to be more involved in medical decisions [74,93,95]. Caregivers often felt that medical staff, such as nurses or doctors, do not have enough time to listen to and discuss their relative's condition with them, becoming a source of distress to families who feel under pressure to make the right choices [33]. One study emphasized concerns about combining work with caring for their family member, highlighting the need for remote working and flexibility in working hours [84]

Lastly, other studies highlighted bereavement support as an important need for caregivers. Carers described the continued need for support in the period soon after death [33,56,84], and remarked that palliative care provision should be extended to support family carers [20,35,56,58].

3.3. Professionals' Needs

Fifty-three studies focused on professionals only, or together with other target groups, to approach PC. Two main domains were found: The needs and concerns of professionals in the provision of PC for multimorbid older patients and needs related to specific training in PC provision.

3.3.1. Needs in PC Provision

On the one hand, professionals identified barriers to providing effective PC to this group of patients. In some studies, professionals pointed out that patients with non- malignant disease were less likely to be referred to PC services due to the historical link between cancer and palliative care [24,25,66]. In other studies, professionals highlighted that patients suffering from non-cancer diseases often receive inadequate care, with poor communication between the different services that care for them, and also shared that there are fewer specific services for these patients compared to for cancer patients [61,83]. A lack of staff to provide sufficient care to patients, resulting in little time to properly address PC needs, was highlighted by some studies [48,79–81].

(a) Referral to PC

Often, multimorbid patients are referred to PC units in the terminal stages of their disease; thus, professionals consider it necessary to initiate these referrals earlier to promote continuous care [78,85], especially with older patients [61], patients with Chronic Heart Failure (CHF) and COPD [75,76], and patients with conditions other than cancer [25]. Moreover, professionals do not always know who has the responsibility to care for CCC patients in need of PC, and often the roles are not defined, which causes fear of starting conversations about palliative care with the family or the patient [26,60,66,90].

In this sense, some of the studies showed a lack of homogeneous referral criteria, protocols, or pathways to initiate PC services [31,52,67,76]. Additionally, professionals pointed out that there are barriers to referring PC patients and interspecialty dialogue, with a lack of communication between different specialists resulting in professionals only partially knowing the pathologies that can occur in patients and preventing or delaying referral to a PC itinerary [46].

Moreover, in some studies, professionals expressed that there is complexity in prescription and treatment approaches due to the impact of the complex comorbidity profiles of multimorbid patients, such as the effects of drugs in older populations (unforeseeable interactions or side effects) [61,90].

(b) Comprehensive and continuous care in PC

Professionals considered that a holistic approach to patient care is crucial, starting when curative treatment is no longer realistic, rather than focusing only on physical symptoms [16,21,76,79,88]. The necessity of going beyond the management of pain was underlined, as patients' and their relatives' non-physical needs, such as spiritual and emotional needs, were considered to need further support [16,76].

Some studies also pointed out that professionals need more time and continuity in the attention given to their patients, having time to talk calmly with patients and their families about PC decisions and needs [31,62,81,82,87]. The pressure of having less time was indicated as causing a feeling of not being able to talk with or attend to patients in a comprehensive way [62,82], and lack of continuity was pointed out as a major threat to PC attention, especially for people with severe dementia [32,79,85]. Two studies remarked on the need to take into consideration the biography of each patient, and reported that practitioners considered that they only overviewed fragments of care among older patients, which makes the provision of individualized care adapted to patients' needs difficult [52,61].

Some studies also remarked that adequate time is not available for professionals to be able to start conversations with relatives and patients about care planning and advanced directives [66,76]. Two studies stressed that professionals lack knowledge and belief in the role of advanced plans, since many changes can take place in the medium and long term [27,85]. It was also pointed out that there is a need for an objective measure to identify caregivers at risk of poor bereavement [50,53] and dedicated staff to take responsibility for bereavement care [50,57]. Furthermore, a need for formal assessments of bereavement instead of using only observations, intuitions, or informal conversations was highlighted [50].

A proactive multidisciplinary approach (combining clinical psychologists, social work- ers, and psychiatrists) and interprofessional collaboration [24,66,71,78] were described as important in PC to increase CCC patients' and their caregivers' wellbeing [52,67,73,81,86,90]. Moreover, new specialized structures for PC geriatric patients were considered necessary to be able to address the specific needs of patients with multiple needs [61].

3.3.2. Training Needs

On the contrary, several training needs were detected. Special reference was made to specialized training in PC, highlighting that professionals may feel they have a lack of skills for good communication with patients [89], the need for additional palliative and end-of-life care education [19,38,80,86], more awareness and understanding of PC, as well as further training on how to identify patients' needs and understanding of end-of-life care [66,81].

Additionally, several studies highlighted the lack of knowledge of the palliative needs of different groups of patients, such as those with COPD [87], severe dementia [18,68], disabilities [31], or complex comorbidity profiles [46]. Some studies stated the need to move toward early PC conception, as many professionals recognized that their perception of PC was associated with care during the last days of life [22,29,47]. Furthermore, one study highlighted the need for advanced training in early PC [75].

Some studies also pointed out professionals needing emotional support to prevent burnout and delineating emotional and professional boundaries [43]. One study high- lighted the need for self-care in coping with death and dealing with professional grief [31], as some professionals felt that their grief is inappropriate or that they do not have time to express it [27].

In this line also, healthcare professionals remarked on the importance of spiritual care and having the skills to address it [16,73]. However, it was pointed out that professionals felt fear of being unable to resolve spiritual problems and experienced difficulties in communication about spiritual needs due to a lack of knowledge around such issues [17,96]. Additionally, they highlighted that assessment tools for spiritual needs are not taught during the received training [17,96]. Moreover, practitioners and nurses indicated a desire for support to address patients' spiritual needs from other professionals, such as social workers, clinical/counselling psychologists, chaplains/spiritual care professionals, other alternative therapy professionals, and psychiatric professionals [81].

4. Discussion

This review contributes to a greater understanding of the needs of three cohorts involved in PC: older patients with non-malignant diseases, their family members or caregivers, and the health professionals delivering care for them. Integration of needs reported by them enabled a more comprehensive understanding of PC needs than those that focused on a single cohort only. Moreover, this review synthesized the needs for these three groups, which are very complex, diverse, and heterogeneous.

The studies included presented the support needed by patients related to their emotional/mental health, such as symptoms or experiences related to anxiety and depression. Supporting needs to address their clinical symptoms and to maintain their daily living activities was highlighted, and some studies also discussed patients' concerns about the potential burden that their families or caregivers may experience as a consequence of covering their care needs. The needs identified in caregivers mirrored those identified at the patient level, but emphasized bereavement support, need of more information and human connection with professional's involvement in decision making and financial support to care for both patients and themselves. It is worth highlighting that patients and caregivers noticed a lack of support in their psychosocial and spiritual needs, while considering their physical needs as being well-addressed.

In line with the results reported by Mathews et al. [97], where the integration of specialized palliative care with oncology patients was analysed, health professionals agreed that integrated PC services are the desired care models to facilitate integration and coordination of care using an interdisciplinary approach [74,77,78]. This study also highlighted the need to allocate more personnel, time, and training to assessing and addressing the needs of oncological patients and their families or caregivers, as identified in our review. Our review also highlighted the need for health professionals' training in palliative care across all services (primary care, ICU, residences, emergencies, home hospitalization units), especially for providing care to non-cancer patients, as well as the need for itineraries and defined responsibilities in PC and more time to attend patients holistically and discuss with family members their needs and wishes [16,35,61,76].

The follow-up of grief for caregivers was highlighted as an urgent issue, with professionals considering it neglected [47,50,53]. To substantially improve the holistic attention provided for caregivers and relatives of CCC patients, it is essential to establish mechanisms.

5. CONCLUSIONS

This review provided evidence highlighting that substantial changes are needed in health and care systems at the institutional level to provide more specialized PC environments and systematized PC processes for multimorbid older patients. It is vital to understand and address the needs of multimorbid older patients and their caregivers given that the number of these patients is growing, which may challenge current healthcare systems. Regarding clinical practice, the identification of older chronic patients in need of PC will allow healthcare professionals to plan care and pathways in advance, and to reduce unnecessary admissions to emergency departments. Therefore, a systematic assessment of needs through appropriate tools in clinical practice is necessary to enable the development of an individualized integrated PC model for patients with complex PC needs. These findings can guide policymakers in increasing investment in specialized PC services focused on multimorbid patients to support more efficient use of available resources for healthcare professionals in their routine practice. For future studies, it is recommended to take into consideration patients comorbidities, since their needs vary accordingly, as well as the particular requirements around PC of those older people with COVID-19.

Supplementary Materials: The following supporting information can be downloaded at :https://www.mdpi.com/article/10.3390/ijerph19063195/s1, Table S1: Data extraction table.

Author Contributions: Conceptualization, L.L.-M. and A.D.-M.; methodology, L.L.-M., A.D.-M. and Y.F.; analysis, L.L.-M., Y.F. and A.D.-M.; manuscript writing, L.L.-M. and A.D.-M.; critical review, Y.F. and J.G.-F. All authors have read and agreed to the published version of the manuscript.

Funding: This project received funding from the European Union's Horizon 2020 research and innovation program under grant agreement number 825750 and Grant PID2019-110997RB-I00 funded by MCIN/AEI/10.13039/501100011033.

Institutional Review Board Statement: Not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: No applicable.

Acknowledgments: The authors thank the whole InAdvance consortium for their contributions.

Conflicts of Interest: The authors declare no conflict of interest.

REFERENCES

1. WHO. WHO Definition of Palliative Care. 2007. Available online: http://www.who.int/cancer/palliative/definition/en/ (accessed on 22 December 2020).
2. Wong, M.; Ho, L.; Hui, E.; Miaskowski, Y. Burden of living with multiple concurrent symptoms in patients with end-stage renal disease. *J. Clin. Nurs.* 2020, *29*, 2589–2601.
3. Connor, S.R.; Bermedo, M.S. Global Atlas of Palliative Care at the End of Life. January 2014. Available online: http://www. thewhpca.org/resources/global-atlas-on-end-of-life-care (accessed on 30 December 2021).
4. Downar, J.; Chou, Y.C.; Ouellet, D.; La Delfa, I.; Blacker, S.; Bennett, M.; Petch, C.; Cheng, S.M. Survival duration among patients with a noncancer diagnosis admitted to a palliative care unit: A retrospective study. *J. Palliat. Med.* 2012, *15*, 661–666.
5. Haun, M.W.; Estel, S.; Rücker, G.; Friederich, H.; Villalobos, M.; Thomas, M.; Hartmann, M. Early palliative care for adults with advanced cancer. *Cochrane Database Syst. Rev.* 2017, *6*, CD011129.
6. Hui, D.; Kim, Y.J.; Park, J.C.; Zhang, Y.; Strasser, F.; Cherny, N.; Kaasa, S.; Davis, M.P.; Bruera, E. Integration of oncology and palliative care: A systematic review. *Oncologist* 2015, *20*, 77–83.
7. Bandieri, E.; Sichetti, D.; Romero, M.; Fanizza, C.; Belfiglio, M.; Buonaccorso, L.; Artioli, F.; Campione, F.; Tognoni, G.; Luppi, M. Impact of early access to a palliative/supportive care intervention on pain management in patients with cancer. *Ann. Oncol.* 2012, *23*, 2016–2020.
8. Wang, T.; Molassiotis, A.; Chung, B.P.M.; Tan, J.Y. Unmet care needs of advanced cancer patients and their informal caregivers: A systematic review. *BMC Palliat. Care* 2018, *17*, 96.
9. WHO. Noncommunicable Diseases; WHO: Geneva, Switzerland, 2017; Available online: https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases (accessed on 22 December 2020).
10. Johnston, M.; Crilly, M.; Black, C.; Prescott, G.J.; Mercer, S. Defining and measuring multimorbidity: A systematic review of systematic reviews. Eur. J. Public Health 2019, 29, 182–189.
11. Prince, M.J.; Wu, F.; Guo, Y.; Robledo, L.M.G.; O'Donnell, M.; Sullivan, R.; Yusuf, S. The burden of disease in older people and implications for health policy and practice. *Lancet* 2015, *385*, 549–562.

12. Kingston, A.; Robinson, L.; Booth, H.; Knapp, M.; Jagger, C. MODEM Project. Projections of multi-morbidity in the older population in England to 2035: Estimates from the Population Ageing and Care Simulation (PACSim) model. *Age Ageing* 2018, *47*, 374–380.
13. Saunders, C. *End of Life Care Strategy: Quality Markers and Measures for End of Life Care*; Department of Health: London, UK, 2009.
14. Arksey, H.; O'Malley, L. Scoping studies: Towards a methodological framework. *Int. J. Soc. Res. Methodol.* 2005, *8*, 19–32.
15. Tricco, A.C.; Lillie, E.; Zarin, W.; O'Brien, K.K.; Colquhoun, H.; Levac, D.; Moher, D.; Peters, M.D.; Horsley, T.; Weeks, L.; et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. *Ann. Intern. Med.* 2018, *169*, 467–473.
16. O'Brien, M.R.; Kinloch, K.; Groves, K.E.; Jack, B.A. Meeting patients' spiritual needs during end-of-life care: A qualitative study of nurses' and healthcare professionals' perceptions of spiritual care training. *J. Clin. Nurs.* 2019, *28*, 182–189.
17. Abbas, S.Q.; Dein, S. The difficulties assessing spiritual distress in palliative care patients: A qualitative study. *Ment. Health Relig. Cult.* 2011, *14*, 341–352.
18. Bajwah, S.; Higginson, I.J.; Ross, J.R.; Wells, A.U.; Birring, S.S.; Riley, J.; Koffman, J. The palliative care needs for fibrotic interstitial lung disease: A qualitative study of patients, informal caregivers and health professionals. *Palliat. Med.* 2013, *27*, 869–876.
19. Blackwell, R.W.; Lowton, K.; Robert, G.; Grudzen, C.; Grocott, P. Using Experience-based Co-design with older patients, their families and staff to improve palliative care experiences in the Emergency Department: A reflective critique on the process andoutcomes. *Int. J. Nurs. Stud.* 2017, *68*, 83–94.
20. Bone, A.E.; Morgan, M.; Maddocks, M.; Sleeman, K.E.; Wright, J.; Taherzadeh, S.; Ellis-Smith, C.; Higginson, I.J.; Evans, C.J. Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: Perspectives of older people, carers and other key stakeholders. *Age Ageing* 2016, *45*, 863–873.
21. Buckingham, S.; Kendall, M.; Ferguson, S.; MacNee, W.; Sheikh, A.; White, P.; Worth, A.; Boyd, K.; Murray, S.A.; Pinnock, H. HELPing older people with very severe chronic obstructive pulmonary disease (HELP-COPD): Mixed-method feasibility pilot randomised controlled trial of a novel intervention. *Npj Prim. Care Respir. Med.* 2015, *25*, 15020.

22. Davies, N.; Maio, L.; Vedavanam, K.; Manthorpe, J.; Vernooij-Dassen, M.; Iliffe, S.; IMPACT Research Team. Barriers to the provision of high-quality palliative care for people with dementia in England: A qualitative study of professionals' experiences. *Health Soc. Care Community* 2014, *22*, 386–394.
23. Fleming, J.; Farquhar, M.; Brayne, C.; Barclay, S.; Cambridge City over-75s Cohort (CC75C) Study Collaboration. Death and theoldest old: Attitudes and preferences for end-of-life care-qualitative research within a population-based cohort study. *PLoS ONE* 2016, *11*, e0150686.
24. Gardiner, C.; Cobb, M.; Gott, M.; Ingleton, C. Barriers to providing palliative care for older people in acute hospitals. *Age Ageing* 2011, *40*, 233–238.
25. Gott, M.; Ingleton, C.; Bennett, M.I.; Gardiner, C. Transitions to palliative care in acute hospitals in England: Qualitative study. *BMJ* 2011, *342*, d1773.
26. Handley, M.; Goodman, C.; Froggatt, K.; Mathie, E.; Gage, H.; Manthorpe, J.; Barclay, S.; Crang, C.; Iliffe, S. Living and dying: Responsibility for end-of-life care in care homes without on-site nursing provision—A prospective study. *Health Soc. Care Community* 2014, *22*, 22–29.
27. Livingston, G.; Pitfield, C.; Morris, J.; Manela, M.; Lewis-Holmes, E.; Jacobs, H. Care at the end of life for people with dementia living in a care home: A qualitative study of staff experience and attitudes. *Int. J. Geriatr. Psychiatry* 2012, *27*, 643–650.
28. Lloyd, A.; Kendall, M.; Starr, J.M.; Murray, S.A. Physical, social, psychological and existential trajectories of loss and adaptation towards the end of life for older people living with frailty: A serial interview study. *BMC Geriatr.* 2016, *16*, 176.
29. Mason, B.; Epiphaniou, E.; Nanton, V.; Donaldson, A.; Shipman, C.; Daveson, B.A.; Harding, R.; Higginson, I.; Munday, D.; Barclay, S.; et al. Coordination of care for individuals with advanced progressive conditions: A multi-site ethnographic and serial interview study. *Br. J. Gen. Pract.* 2013, *63*, e580–e588.
30. Mayland, C.R.; Mulholland, H.; Gambles, M.; Ellershaw, J.; Stewart, K. How well do we currently care for our dying patients in acute hospitals: The views of the bereaved relatives? *BMJ Support. Palliat. Care* 2017, *7*, 316–325.
31. McLaughlin, D.; Barr, O.; McIlfatrick, S.; McConkey, R. Developing a best practice model for partnership practice betweenspecialist

palliative care and intellectual disability services: A mixed methods study. *Palliat. Med.* 2014, *28*, 1213–1221.

32. Lee, R.P.; Bamford, C.; Exley, C.; Robinson, L. Expert views on the factors enabling good end of life care for people with dementia: A qualitative study. *BMC Palliat. Care* 2015, *14*, 32.
33. Poole, M.; Bamford, C.; McLellan, E.; Lee, R.P.; Exley, C.; Hughes, J.C.; Harrison-Dening, K.; Robinson, L. End-of-life care: A qualitative study comparing the views of people with dementia and family carers. *Palliat. Med.* 2018, *32*, 631–642.
34. Ryan, T.; Ingleton, C.; Gardiner, C.; Parker, C.; Gott, M.; Noble, B. Symptom burden, palliative care need and predictors of physical and psychological discomfort in two UK hospitals. *BMC Palliat. Care* 2013, *12*, 11.
35. Waldron, M.; Kernohan, W.G.; Hasson, F.; Foster, S.; Cochrane, B. What Do Social Workers Think about the Palliative Care Needs of People with Parkinson's Disease? *Br. J. Soc. Work* 2013, *43*, 81–98.
36. Boersma, I.; Jones, J.; Coughlan, C.; Carter, J.; Bekelman, D.; Miyasaki, J.; Kutner, J.; Kluger, B. Palliative care and Parkinson's disease: Caregiver perspectives. *J. Palliat. Med.* 2017, *20*, 930–938.
37. Chang, E.; Daly, J.; Johnson, A.; Harrison, K.; Easterbrook, S.; Bidewell, J.; Stewart, H.; Noel, M.; Hancock, K. Challenges for professional care of advanced dementia. *Int. J. Nurs. Pract.* 2009, *15*, 41–47.
38. Cimino, N.M.; Lockman, K.; Grant, M.; McPherson, M.L. Knowledge, Skills, and Attitudes in Caring for Older Adults with Advanced Illness among Staff Members of Long-Term Care and Assisted Living Facilities: An Educational Needs Assessment. *Am. J. Hosp. Palliat. Med.* 2016, *33*, 327–334.
39. Grudzen, C.R.; Richardson, L.D.; Morrison, M.; Cho, E.; Morrison, R.S. Palliative care needs of seriously ill, older adults presenting to the emergency department. *Acad. Emerg. Med.* 2010, *17*, 1253–1257.
40. Hall, S.; Kolliakou, A.; Petkova, H.; Froggatt, K.; Higginson, I.J. Interventions for improving palliative care for older people living in nursing care homes. *Cochrane Database Syst. Rev.* 2011, *3*, CD007132.
41. Tallman, K.; Greenwald, R.; Reidenouer, A.; Pantel, L. Living with advanced illness: Longitudinal study of patient, family, and caregiver needs. *Perm. J.* 2012, *16*, 28.
42. Kwak, J.; Ko, E.; Kramer, B.J. Facilitating advance care planning with ethnically diverse groups of frail, low-income elders in

the USA: Perspectives of care managers on challenges and recommendations. *Health Soc. Care Community* 2014, *22*, 169–177.

43. Perez, G.K.; Haime, V.; Jackson, V.; Chittenden, E.; Mehta, D.H.; Park, E.R. Promoting resiliency among palliative care clinicians: Stressors, coping strategies, and training needs. *J. Palliat. Med.* 2015, *18*, 332–337.
44. Thai, J.N.; Barnhart, C.E.; Cagle, J.; Smith, A.K. "It Just Consumes Your Life": Quality of Life for Informal Caregivers of Diverse Older Adults With Late-Life Disability. *Am. J. Hosp. Palliat. Med.* 2016, *33*, 644–650.
45. Bloomer, M.J.; Botti, M.; Runacres, F.; Poon, P.; Barnfield, J.; Hutchinson, A.M. Cultural considerations at end of life in a geriatric inpatient rehabilitation setting. *Collegian* 2019, *26*, 165–170.
46. Broom, A.; Kirby, E.; Good, P.; Wootton, J.; Adams, J. Specialists' experiences and perspectives on the timing of referral topalliative care: A qualitative study. *J. Palliat. Med.* 2012, *15*, 1248–1253.
47. Chang, E.; Bidewell, J.; Hancock, K.; Johnson, A.; Easterbrook, S. Community palliative care nurse experiences and perceptions of follow-up bereavement support visits to carers. *Int. J. Nurs. Pract.* 2012, *18*, 332–339.
48. Fleming, R.; Kelly, F.; Stillfried, G. 'I want to feel at home': Establishing what aspects of environmental design are important topeople with dementia nearing the end of life. *BMC Palliat. Care* 2015, *14*, 26.
49. Lewis, E.T.; Harrison, R.; Hanly, L.; Psirides, A.; Zammit, A.; McFarland, K.; Dawson, A.; Hillman, K.; Barr, M.; Cardona, M. End-of-life priorities of older adults with terminal illness and caregivers: A qualitative consultation. *Health Expect.* 2019, *22*, 405–414.
50. Sealey, M.; O'Connor, M.; Aoun, S.M.; Breen, L.J. Exploring barriers to assessment of bereavement risk in palliative care: Perspectives of key stakeholders. *BMC Palliat. Care* 2015, *14*, 49.
51. Sneesby, L.; Satchell, R.; Good, P.; van der Riet, P. Death and dying in Australia: Perceptions of a Sudanese community. *J. Adv. Nurs.* 2011, *67*, 2696–2702.
52. Tan, H.M.; O'Connor, M.M.; Miles, G.; Klein, B.; Schattner, P. GP and nurses' perceptions of how after hours care for peoplereceiving palliative care at home could be improved: A mixed methods study. *BMC Palliat. Care* 2009, *8*, 13.
53. Wiese, M.; Stancliffe, R.J.; Balandin, S.; Howarth, G.; Dew, A. End-of-life care and dying: Issues raised by staff supporting olderpeople

with intellectual disability in community living services. *J. Appl. Res. Intellect. Disabil.* 2012, *25*, 571–583.

54. You, J.J.; Dodek, P.; Lamontagne, F.; Downar, J.; Sinuff, T.; Jiang, X.; Day, A.G.; Heyland, D.K. What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families. *CMAJ* 2014, *186*, E679–E687.
55. Simon, J.; Porterfield, P.; Bouchal, S.R.; Heyland, D. 'Not yet'and 'Just ask': Barriers and facilitators to advance care planning—A qualitative descriptive study of the perspectives of seriously ill, older patients and their families. *BMJ Support. Palliat. Care* 2015, *5*, 54–62.
56. Gallagher, R.; Krawczyk, M. Family members' perceptions of end-of-life care across diverse locations of care. *BMC Palliat. Care* 2013, *12*, 25.
57. MacLeod, A.; Skinner, M.W.; Low, E. Supporting hospice volunteers and caregivers through community-based participatoryresearch. *Health Soc. Care Community* 2012, *20*, 190–198.
58. Maddalena, V.; O'Shea, F.; Barrett, B. An Exploration of Palliative Care Needs of People with End-Stage Renal Disease on Dialysis: Family Caregiver's Perspectives. *J. Palliat. Care* 2018, *33*, 19–25.
59. Mistry, B.; Bainbridge, D.; Bryant, D.; Toyofuku, S.T.; Seow, H. What matters most for end-of-life care? Perspectives from community-based palliative care providers and administrators. *BMJ Open* 2015, *5*, e007492.
60. Sarti, A.J.; Bourbonnais, F.F.; Landriault, A.; Sutherland, S.; Cardinal, P. An Interhospital, Interdisciplinary Needs Assessment of Palliative Care in a Community Critical Care Context. *J. Palliat. Care* 2015, *31*, 234–242.
61. Brueckner, T.; Schumacher, M.; Schneider, N. Palliative care for older people—Exploring the views of doctors and nurses from different fields in Germany. *BMC Palliat. Care* 2009, *8*, 7.
62. Geiger, K.; Schneider, N.; Bleidorn, J.; Klindtworth, K.; Jünger, S.; Müller-Mundt, G. Caring for frail older people in the last phase of life—The general practitioners' view. *BMC Palliat. Care* 2016, *15*, 52.
63. Klindtworth, K.; Oster, P.; Hager, K.; Krause, O.; Bleidorn, J.; Schneider, N. Living with and dying from advanced heart failure: Understanding the needs of older patients at the end of life. *BMC Geriatr.* 2015, *15*, 125.
64. Krug, K.; Ballhausen, R.A.; Bölter, R.; Engeser, P.; Wensing, M.; Szecsenyi, J.; Peters-Klimm, F. Challenges in supporting lay carers of patients

at the end of life: Results from focus group discussions with primary healthcare providers. *BMC Fam. Pract.* 2018, *19*,112.

65. Weber, M.; Claus, M.; Zepf, K.I.; Fischbeck, S.; Pinzon, L.C.E. Dying in Germany—Unfulfilled needs of relatives in different caresettings. *J. Pain Symptom Manag.* 2012, *44*, 542–551.

66. Ziehm, J.; Farin, E.; Schäfer, J.; Woitha, K.; Becker, G.; Köberich, S. Palliative care for patients with heart failure: Facilitators and barriers—A cross sectional survey of German health care professionals. *BMC Health Serv. Res.* 2016, *16*, 361.

67. Den Herder-van der Eerden, M.; van Wijngaarden, J.; Payne, S.; Preston, N.; Linge-Dahl, L.; Radbruch, L.; Van Beek, K.; Menten, J.; Busa, C.; Csikos, A.; et al. Integrated palliative care is about professional networking rather than standardisation of care: A qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries. *Palliat. Med.* 2018, *32*, 1091–1102.

68. Goodman, C.; Evans, C.; Wilcock, J.; Froggatt, K.; Drennan, V.; Sampson, E.; Iliffe, S. End of life care for community dwelling older people with dementia: An integrated review. *Int. J. Geriatr. Psychiatry* 2010, *25*, 329–337.

69. Higginson, I.J.; Daveson, B.A.; Morrison, R.; Deokhee, Y.; Meier, D.; Smith, M.; Ryan, K.; McQuillan, R.; Johnston, B.; Normand, C. Social and clinical determinants of preferences and their achievement at the end of life: Prospective cohort study of older adults receiving palliative care in three countries. *BMC Geriatr.* 2017, *17*, 271.

70. Ke, L.-S.; Huang, X.; Hu, W.-Y.; O'Connor, M.; Lee, S. Experiences and perspectives of older people regarding advance care planning: A meta-synthesis of qualitative studies. *Palliat. Med.* 2017, *31*, 394–405.

71. Low, J.; Pattenden, J.; Candy, B.; Beattie, J.; Jones, L. Palliative care in advanced heart failure: An international review of the perspectives of recipients and health professionals on care provision. *J. Card. Fail.* 2011, *17*, 231–252.

72. Selman, L.; Brighton, L.; Sinclair, S.; Karvinen, I.; Egan, R.; Speck, P.; Powell, R.; Deskur-Smielecka, E.; Glajchen, M.; Adler, S.; et al. Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. *Palliat. Med.* 2018, *32*, 216–230.

73. Smallwood, N.; Currow, D.; Booth, S.; Spathis, A.; Irving, L.; Philip, J. Attitudes to specialist palliative care and advance care planning in

people with COPD: A multi-national survey of palliative and respiratory medicine specialists. *BMC Palliat. Care* 2018, *17*, 115.

74. Virdun, C.; Luckett, T.; Davidson, P.; Phillips, J. Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliat. Med.* 2015, *29*,774–796.

75. Scheerens, C.; Deliens, L.; Van Belle, S.; Joos, G.; Pype, P.; Chambaere, K. "A palliative end-stage COPD patient does not exist": A qualitative study of barriers to and facilitators for early integration of palliative home care for end-stage COPD. *NPJ Prim. CareResp. Med.* 2018, *28*, 23.

76. Siouta, N.; Clement, P.; Aertgeerts, B.; Van Beek, K.; Menten, J. Professionals' perceptions and current practices of integrated palliative care in chronic heart failure and chronic obstructive pulmonary disease: A qualitative study in Belgium. *BMC Palliat.Care* 2018, *17*, 103.

77. Udo, C.; Neljesjö, M.; Strömkvist, I.; Elf, M. A qualitative study of assistant nurses' experiences of palliative care in residential care. *Nurs. Open* 2018, *5*, 527–535.

78. Wallerstedt, B.; Benzein, E.; Schildmeijer, K.; Sandgren, A. What is palliative care? Perceptions of healthcare professionals. *Scand J. Caring Sci.* 2019, *33*, 77–84.

79. Pennbrant, S.; Hjorton, C.; Nilsson, C.; Karlsson, M. "The challenge of joining all the pieces together"—Nurses' experience of palliative care for older people with advanced dementia living in residential aged care units. *J. Clin. Nurs.* 2020, *29*, 3835–3846.

80. Carvalho, G.A.F.D.L.; Menezes, R.M.P.D.; Enders, B.C.; Teixeira, G.A.; Dantas, D.N.A.; Oliveira, D.R.C.D. Meanings attributed to palliative care by health professional in the primary care context1. *Texto Contexto Enferm.* 2018, *27*, e5740016.

81. Fan, S.; Lin, I.; Hsieh, J.; Chang, C. Psychosocial care provided by physicians and nurses in palliative care: A mixed methodsstudy. *J. Pain Symptom Manag.* 2017, *53*, 216–223.

82. Lenherr, G.; Meyer-Zehnder, B.; Kressig, R.; Reiter-Theil, S. To speak, or not to speak-do clinicians speak about dying and death with geriatric patients at the end of life? *Swiss Med. Wkly.* 2012, *142*, w13563.

83. Bolt, E.; Pasman, H.; Willems, D.; Onwuteaka-Philipsen, B. Appropriate and inappropriate care in the last phase of life: An

explorative study among patients and relatives. *BMC Health Serv. Res.* 2016, *16*, 655.

84. Bijnsdorp, F.M.; Onwuteaka-Philipsen, B.D.; Boot, C.R. Combining paid work and family care for a patient at the end of life athome: Insights from a qualitative study among caregivers in the Netherlands. *BMC Palliat. Care* 2021, *2021 93*, 20.
85. Midtbust, H.; Alnes, R.; Gjengedal, E.; Lykkeslet, E. Perceived barriers and facilitators in providing palliative care for people with severe dementia: The healthcare professionals' experiences. *BMC Health Serv. Res.* 2018, *18*, 709.
86. Fryer, S.; Bellamy, G.; Morgan, T.; Gott, M. "Sometimes I've gone home feeling that my voice hasn't been heard": A focus group study exploring the views and experiences of health care assistants when caring for dying residents. *BMC Palliat. Care* 2016, *15*, 1–9.
87. Mousing, C.; Timm, H.; Lomborg, K.; Kirkevold, M. Barriers to palliative care in people with chronic obstructive pulmonary disease in home care: A qualitative study of the perspective of professional caregivers. *J. Clin. Nurs.* 2018, *27*, 650–660. [CrossRef] [PubMed]
88. Chan, H.Y.L.; Chan, C.N.C.; Man, C.W.; Chiu, A.D.W.; Liu, F.C.; Leung, E.M.F. Key Components for the Delivery of Palliative and End-of-Life Care in Care Homes in Hong Kong: A Modified Delphi Study. *Int. J. Environ. Res. Public Health* 2022, *19*, 667.
89. Barclay, S.; Momen, N.; Case-Upton, S.; Kuhn, I.; Smith, E. End-of-life care conversations with heart failure patients: A systematic literature review and narrative synthesis. *Br. J. Gen. Pract.* 2011, *61*, e49–e62.
90. De Witt Jansen, B.; Brazil, K.; Passmore, P.; Buchanan, H.; Maxwell, D.; McIlfatrick, S.J.; Morgan, S.M.; Watson, M.; Parsons, C. 'There's a Catch-22'—The complexities of pain management for people with advanced dementia nearing the end of life: A qualitative exploration of physicians' perspectives. *Palliat. Med.* 2017, *31*, 734–742.
91. Hennings, J.; Froggatt, K.; Keady, J. Approaching the end of life and dying with dementia in care homes: The accounts of family carers. *Rev. Clin. Gerontol.* 2010, *20*, 114–127.
92. Aebischer, S.; Nikolic, R.; Lazic, R.; Dropic, T.; Vogel, B.; Lab, S.; Lachat, P.; Hudelson, C.; Matis, S. Addressing the needs of terminally-ill patients in Bosnia-Herzegovina: Patients' perceptions and expectations. *BMC Palliat. Care* 2018, *17*, 123.
93. Raymond, M.; Warner, A.; Davies, N.; Iliffe, S.; Manthorpe, J.; Ahmedzhai, S. Palliative care services for people with dementia:

A synthesis of the literature reporting the views and experiences of professionals and family carers. *Dementia* 2014, *13*, 96–110.

94. Hill, S.; Mason, H.; Poole, M.; Vale, L.; Robinson, L. What is important at the end of life for people with dementia? The views of people with dementia and their carers. *Int. J. Geriatr. Psychiatry* 2016, *32*, 1037–1045.
95. Motamedi, M.; Brandenburg, C.; Bakhit, M. Concerns and potential improvements in end-of-life care from the perspectives of older patients and informal caregivers: A scoping review. *BMC Geriatr.* 2021, *21*, 729.
96. Steindal, S.A.; Nes, A.A.G.; Godskesen, T.E.; Dihle, A.; Lind, S.; Winger, A.; Klarare, A. Patients' experiences of telehealth in palliative home care: Scoping review. *J. Med. Intern. Res.* 2020, *22*, 16218.
97. Mathews, J.; Hannon, B.; Zimmermann, C. Models of Integration of Specialized Palliative Care with Oncology. *Curr. Treat. OptionsOncol.* 2021, *22*, 44.
98. Gijsberts, M.; Liefbroer, A.; Otten, R.; Olsman, E. Spiritual Care in Palliative Care: A Systematic Review of the Recent European Literature. *Med. Sci.* 2019, *7*, 25.

2. THE EXPERIENCES AND VIEWS ON PALLIATIVE CARE OF OLDER PEOPLE WITH MULTIMORBIDITIES, THEIR FAMILY CAREGIVERS AND PROFESSIONALS IN A SPANISH HOSPITAL[2]

1. INTRODUCTION

Population ageing is accelerating worldwide, increasing the incidence and prevalence of complex chronic diseases in the population over the age of 65 and, in turn, impacting health systems. Chronic diseases place a significant impact on older people's quality of life, resulting not only in reduced physical functioning but also associated psychological distress and finance concerns [1]. People living with chronic diseases are also at a high risk of developing multimorbidity, understood as several long-term chronic diseases [2], leading to an increase in reliance on family and caregivers due to the progressive decline in healthstatus. The impact of multimorbidity on functioning, quality of life and mortality risk is considerably greater than the sum of the individual effects of these diseases [3]. In addition, multimorbidity is also associated with higher rates of utilization of healthcare services and higher health costs [3]. The annual deaths due to patients with multimorbidities areprojected to increase worldwide from 38 million in 2012 to 52 million by 2030 [4].

In the case of older patients with multimorbidities, the clinical uncertainty regarding their prognosis is very high [5]. Detecting the episodes of decompensations and unmet needs of these patients and their caregivers is essential for health systems to adequately attend to this profile of patients and avoid unnecessary complications or avoidable admissions to the emergency department. The experiences of people living with multimorbidities reveal multiple areas of need [6,7]. These needs can become complex and severe for end-stage patients, but the prognosis often remains uncertain for most non-cancer life-limiting conditions [8].

---

[2] **Llop-Medina, L.**, Ródenas-Rigla, F., Garcés-Ferrer, J., & Doñate-Martínez, A. (2022). The Experiences and Views on Palliative Care of Older People with Multimorbidities, Their Family Caregivers and Professionals in a Spanish Hospital. *Healthcare, 10*(12) e 2489. https://doi.org/10.3390/healthcare10122489

It Is widely known that the provision of palliative care has typically focused on cancer patients but its extension to patients with non-malignant diseases has been reported in the literature [9], such as among older patients with multimorbidities [9,10], which can significantly improve their quality of life and reduce the costs of the medical care they currently receive. There is increasing evidence showing that the provision of palliative care to non-cancer diseases improve patients' symptoms burden and quality of life, resulting in a consistent pattern of reduced health-care use [11]. Although there is a difficulty in identifying the needs of older patients with multiple pathologies and the timing of referral to palliative care pathways due to the heterogeneity of this population and the co-occurrence of several diseases.

Solid evidence on early identification, needs assessment and mapped palliative care pathways to provide symptom management and the support to patients and their families is still lacking [12]. To improve the experience of multimorbid patients receiving palliative care and their families requires us to find out what their experience has been in the health system and the gaps or needs they have identified in their care. This qualitative study, therefore, sought to understand what constitutes successful specialist palliative care in the view of all stakeholders involved, older multimorbid patients with non-cancer diseases, their informal caregivers and the health professionals who carry out their work in the field of palliative care. The research question of this study was: "What are the experiences and views on palliative care of older people with multimorbidities, their family caregivers and professionals?".

2. MATERIALS AND METHODS

A qualitative research methodology was employed in order to explore participants' perspectives and experiences regarding palliative care. One-to-one interviews with multi- morbid older patients (aged 65 or over) and their families/carers (12 and 11, respectively), and two focus groups with health professionals (eight professionals in each focus group) who provided disease-directed services and palliative care in a

Home hospitalization unit (HHU) in La Fe Hospital (Valencia, Spain) was conducted.

This approach allowed us to understand an in-depth perspective of palliative care involvement, the current status of palliative care services and how these can be improved. Ethics approval was granted by Ethics Committee on Research with Medicaments of Hospital La Fe in Spain (ref. 2019-013-1).

2.1. Identification of Participants

The Valencia-La Fe Health Department is one of the healthcare areas belonging to the Health System of the Autonomous Community of Valencia (Spain) and is recognized in Spain as a leading hospital in the management of various diseases, in the provision of home hospitalization services and in the search for the integration of all levels of care. La Fe Health Department has a case management plan for chronically ill patients, which cares for around 900 patients with complex conditions. This plan includes multidisciplinary teams between telemedicine and Hospital at Home Units, which coordinates care plans, home visits, scheduled phone calls and communication with primary care in order to keep chronic patients as stable as possible.

Purposive sampling was used to recruit patients, who were eligible if they were 65 years or older, diagnosed with multimorbidity and able to read and speak Spanish. Patients were excluded if they were living with or receiving cancer treatment or were cognitively impaired. Families/carers were eligible if they were cognitively intact and able to read and speak Spanish. Health professionals providing direct care for palliative care patients' or managing palliative care services were targeted.

The participants were initially identified by a member of the clinical team of the HHU. Recruitment and interviews took place between November 2019 and March 2020. All of the individual interviews were conducted face-to-face at patient's home by a researcher with experience in conducting qualitative research in previous studies. In the case of health professionals, the two focus groups took place in a meeting room of La Fe Hospital inValencia and lasted one and a half and two hours, respectively.

2.2. Data Collection

Qualitative data were collected using semi-structured interviews and focus groups [13] using open-ended questions. Separate topic guides were developed for patients, families/carers and health professionals concerning disease symptoms and impact, experiences of services and care provided, management of exacerbations, needs for the future (for patients and families/carers) or palliative care pathways and integration of palliative care in the management of severe conditions (for health professionals). All of the interviews and focus groups were digitally recorded with consent and transcribed verbatim.

2.3. Data Analysis

The consolidated criteria for reporting qualitative studies (COREQ) checklist [14] was used to analyze the data which provides a systematic approach to sifting (Supplementary Table S1), charting and sorting data using the key themes and issues. Codes were given to segment the information and the key conclusions extracted from the interviews. Codeswere compared across all interviews to identify similarities and differences to be further groups into categories, synthesizing and explaining large amounts of data. Connections and relationships between codes and categories were further explored enabling the development of themes and sub-themes. Atlas.ti software was used to analyze the data [15]. Two authors contributed to coding, developing frameworks and themes. We identified four main thematic categories and fifteen sub thematic categories presented in Table 1.

Table 1. Main and sub-thematic categories

Main thematic categories	Sub-thematic categories
Management of symptoms	Health status, aggravation of symptoms, caregiver overburden.
Health service experience	Access to support, views about Home Hospitalization Unit, detection of multimorbid patients .
Views about Palliative Care	Negative connotation of palliative care term, lack of professional's training in palliative care.
Palliative Care needs	Physical needs, emotional needs, spiritual needs, social needs, economical needs, caregiver specific needs, professionals specific needs

3. RESULTS

Thirty-nine participants were interviewed (12 patients, 11 caregivers and 16 Health.

professionals). Patients were mostly male (see Table 2), with an average age of 77 years old, most of them were married but some were widowers and they were all pensioners. Five of them were in the palliative care patient program and the rest in chronic pluripathological complex case-management programme. Caregivers were mostly female (see Table 2), with an average age of 66 years old, mostly married, seven of whom are pensioners and practically all cases were in charge of the care of patient daily. 4 service managers and 12 front-line professionals from primary care and hospital settings working with older patients with multimorbidities were interviewed. Health professionals (see Table 2) were mostly female and most were nurses with specific training in Palliative Care and with direct contact with Palliative Care patients or directing Palliative Care services.

Table 2. Patients, careers and Health professional's socio-demographic characteristics

Patients socio-demographic characteristics		***(n=12)***
Age mean (SD) Min/max		77,41 (7,82) 65-89
Gender	Male (%)	8 (67%)
	Female (%)	4 (33%)
Marital status	Married/living with partner (%)	9 (75%)
	Widowed (%)	2 (17%)
Education	University degree	1 (8%)
	Secondary	2 (17%)
	Primary degree	6 (50%)
	None	3 (25%)
Employment	Retired (%)	12 (100%)
Carers' characteristics		***(n=11)***
Age mean (SD) Min/max		67 (8,54) 53-78
Relationships with patients	Spouse	9 (82%)
	Daughter	2 (18%)
Frequency of caring	Daily	10 (91%)
	Weekly	1 (9%)
Employment status	Retired	7 (64%)
	Full-time	1 (9%)
	Unemployed	1 (9%)
	Unable to work	2 (18%)

Table 2. Patients, careers and Health professional's socio-demographic characteristics. *Continuation*

Health professional's characteristics		***(n=16)***
Age mean (SD) Min/max		47,42 (10,57) 28-63
Gender	Male	4 (25%)
	Female	12(75%)
Profession/Role	Nurse	9 (56%)
	Medical doctor	5 (31%)
	Social worker	1 (6%)
	Psychologist	1 (6%)
Area of service	Front Line Area HHU	5 (31%)
	HHU doctors	3 (19%)
	Primary care	4 (25%)
	Managers/coordinators	4 (25%)
Expertise area	Chronicity, Palliative Care, Geriatrics	13 (81%)
	Primary care	2 (12%)
	Medical management	1 (7%)
Previous Training in Palliative Care	Yes	12 (75%)
	No	4 (25%)

*HHU (Home Hospitalization Unit)

3.1. Management of symptoms

Interviewees consistently reported the following symptoms by patients: breathlessness, lack of mobility, back pain, sadness, anxiety and respiratory failure. Patients (P) described the lack of mobility and fatigue as very traumatic, coinciding with caregivers (C) who faced many problems in daily care for patients due to lack of mobility of their patients. Health professionals (HP) highlighted the importance of having highly involved caregivers to keep patients' symptoms under control, as most were hospitalized at home. However, caregivers often felt overburdened and lacking information on how to deal with some of the symptoms of their relatives.

> 9P: "When I see that I don't, that I cannot do things by myself, that others have to help me to wash up, to have a shower and so on… I feel sadness when I see that I do not do things as before. I don't know how to tell you" (patient with multimorbidites, man)
>
> 9C: "I would like to have information, I mean the guidelines for example to made better movements to lift her, or to put her in bed" (caregiver, woman)

3.2. Health Service Experience

The patients and carers rated the care received at home by HHU very positively, highlighting positive aspects of this unit, such as the human quality of the professionals, the feeling of support from the healthcare team, and above all having the care of the hospital but with the patient at home. On the other hand, they highlighted the negative aspects of waiting times in Emergency Rooms (ER) and the lack of information regarding the patient's condition while waiting in this service, as well as the absence of specialists to attend to emergencies. As for primary care, patients and carers remarked that there are excessivewaiting lists.

Health professionals highlighted as fundamental to detect multimorbid patients and including them in the HHU programme which provides continuous telephone attention and home visits by physicians and nurses. The HHU identifies patients with multimorbidity who have palliative care needs and are included in the palliative management programme, then they work with the patient and family on the prevention of exacerbations, and explain how to detect an episode of decompensation, or when to notify or contact the nurse manager.

> 10C: "At hospital (ER) a different doctor visits you every time. You don't have a monitoring with a single doctor . . . This is an inconvenient because they have to revise his/her history. Each one has his/her own way to see things not all of them say the same" (caregiver, woman).

> 12C: "The number of persons, when you arrange a doctor's appointment . . . even if itis to request medications, you have to wait 5 or 6 days or a week" (caregiver, woman).

3.3. Views about Palliative Care

Patients and their families were not prepared to talk about palliative care and shied away from questions related to this topic. The use of the term palliative care has negative connotations for them, and they associated it with treatments for the last days of life and they reported not having much information about palliative care. No professionals had experienced palliative care during their training and they reported having their first contact with palliative care patients when they were already practising in their profession. There are no subjects during their training, and they remarked that their experience of palliative care depended on internal (health department) courses or training sessions.

> 9C: "What they say me now is that he is in palliative care, because maybe they need to do many medical tests, but it cannot solve anything. Since they are in charge of him he is getting better" (caregiver, woman).

> 1HP: "some course organized by the medical school years ago, to palliative care days like these, and mainly professional experience in the field" (MD specialist in Family and Community Medicine).

3.4. Palliative Care Needs

The interviews consistently reported that the main patients' needs are highest level of mobility and independence, physiotherapy, personal support at home, public fundingfor dependent patients (assistive devices and personal support at home), psychological attention, availability of health provider's time and drugs not funded by the system.

> 5P: "If I would lose mobility, my wife (current caregiver) she could not stand me up from the chair. In that case, yes, I would

> need to have a . . . a caregiver able to stand me up and so on" (patient with multimorbidities, man).
>
> 4P: "That someone comes to help me to stand up from here, to move on the bed inorder to not disturb anybody. Because I am in that bed and I have to call to my wife or tothis woman so they can turn me around in the bed" (patient with multimorbidities, man).

In terms of carers' needs, interviewees reported that families or carers of patients need some support in areas such as loss of employment and income due to the need to reduce their working hours or even leave their jobs to care for their relative. In some cases, the loss of income was due to hiring support staff to care for their relative. Similarity, they also demanded financial support to meet the costs of long-term care.

> 1C: "Regarding dependence, if we were in a situation that we cannot dispose of these resources (savings), I do not know if public subsidies would cover or to what extent a person in my situation would go crazy because it would feel helpless" (caregiver, woman).9C: "Now we also have to search privately other persons (hiring staff) that help the caregivers, because a single person cannot deal with this" (caregiver, woman).

Training to manage patients' needs—such as guidelines, information or advice on how to deal with patients' complex needs—was also highlighted by carers. Personalised care and more information from clinicians were needs highlighted by carers too.

> 7C: "We are facing a disease that even sometimes, both the patient and I we feel like a zero, I mean, blind, thus a more personalized attention, yes" (caregiver, woman).
>
> 9C: "I would like to have information, I mean the guidelines for example to made better movements to lift her, or to put her in bed" (caregiver, woman).

Carers reported the need to receive caregiving support. In some cases, caregiving involves 24 h a day and some carers expressed the need for substitute staff to allow them some respite, time and space for themselves in order to improve their own wellbeing and avoid feeling overburdened or burned out.

> 7C: “Yes, I would like to dispose of at least half an hour for myself alone to separate a bit from him, to distance myself and catch my breath, but it can’t be and, well, I adapt” (caregiver, woman).

> 7C: “I am not the first person I have told you this, being 24 h with a person around 2 consecutive years emotionally consumes you” (caregiver, woman).

The emotional overload was felt strongly and manifested in depressive symptoms, emotional fatigue, loneliness and burden. Caregivers expressed that they would like to receive emotional support to cope with these feelings.

> 10C: “I am very depressed, I am very depressed, and in fact I take one pill every day for that . . . His health status has declined and that sinks me because he does not treat me well, I mean, this is a vicious circle” (caregiver, woman).

In some cases, caregivers also expressed the need to have a physiotherapist for patients with limited mobility, and they considered that this would improve their quality of life and prevent ulcers or sores.

> 1C: “We decided to hire, privately, the services of a physiotherapist once per week. At the same time, this professional is subjected her to what he calls “passive physical exercise”, in arms and legs, which aims to alleviate the consequences of the patient’s sedentary lifestyle” (caregiver, woman).

Health professionals highlighted the lack of training in palliative care as a barrier toproviding quality care to these patients, and the professionals interviewed expressed the need for a specific training pathway in palliative care to help them gain confidence to talkopenly with patients and carers about palliative care.

> 3HP: “when I was studying the degree they don’t teach us anything about palliative care, at least they didn’t teach me anything and

> I had to go on my own. As I am a tutor of residents because I had the opportunity in the month of formation that they give us to ask for a rotation with the HHU, and it was a real discovery of what Palliative Care was" (HHU doctor).
>
> 11HP: "there was only an elective subject that was called "palliative care", althoughafter having the experience of palliative care that I have, it was really something very abstract, very focused on the traditional model of palliative care" (MD specialist in Family and Community Medicine).
>
> The ability to provide multidisciplinary care, addressing the psychosocial well-being of patients and carers was reported as limited by professionals. Time for personalised care addressing bereavement was highlighted as lacking.
>
> 4HP: "the health system is very medicalized, a lot, with a lot of nursing, but we lack physiotherapists, psychologists, social workers, that is very important for the patient and the family, little by little some have been included, but this is the future that should be sought" (HHU doctor).
>
> 10HP: "in primary care in terms of psychological, social and emotional support there is ... yes many shortcomings" (HP6 MD specialist in Family and Community Medicine).

Health professionals reported that there is a need for tools to identify older multimorbid patients in need of palliative care at an early stage and to systematise care protocols as is the case for oncology patients, so that the necessary resources can be planned for this patient profile.

> 9HP: "I believe that the cancer patient is more protected by specialized than the non-oncological patient" (nurse front line area HHU).
>
> 12HP: "We find patients at a very late stage and that is when you have to start looking for social resources, which will not arrive because they will die before, that if you had started to manage it months before because the patient could have been with more resources at home, better cared for, or you could have

> anticipated symptoms that you knew weregoing to appear and maybe the patient and the families were better informed and could detect decompensation earlier, but we treated patients in the acute processes" (social workerin HHU).

Finally, health professionals considered the scarce support and funding for patientsand also for family carers to be problematic, as this can cause the family to give up leadingto a very problematic scenario with hospitalised patients at home.

> 7HP: "The aid is usually paid later; the family has to spend it first" (nurse primary care).1HP: "You can have very good pain control, very good control of other symptoms, and have a patient who is bedridden or who cannot go out, or who cannot enjoy their quality of life because they lack other resources that you cannot give them, and that is very important" (MD specialist in Family and Community Medicine).

We will summarize the main barriers and facilitators for the integration of palliative care in Table 3.

Table 3. Perceived barriers and facilitators for Palliative care integration

	Barriers	**Facilitators**
Patients	Lack of knowledge concerning what palliative care is. Excessive waiting lists in some services. Waiting time in ER. Lack of financial resources.	Home based services. Avoid invasive treatments. Social resources and assistive devices. Physiotherapy. Availability of 24-hour medical care by telephone.
Caregivers	Lack of knowledge concerning what palliative care is. Lack of information in waiting rooms. Lack of emotional support. Lack of time with the healthcare team. Lack of financial resources	Being supported for HP. More information by healthcare team. Receiving guidelines on how to care for palliative patients. Financial support. Time and space for their wellbeing. Availability of 24-hour medical care by telephone.

Table 3. Perceived barriers and facilitators for Palliative care integration. *Continuation*

	Barriers	**Facilitators**
Health Care professionals	Lack of confidence in talking about palliative care (with patients and caregivers). Lack of training in Palliative Care. Lack of time for communicate with carers. Inexistence of early referrals to Palliative Care for this patient profile. Palliative Care usually applied to last days of life. Lack of financial support for patients.	Tools to identify earlier Palliative Care patients (older people with multimorbidities). Time to work with patients and their caregivers. Support on how to deal with sensitive issues. More and specialised resources for chronicity.

4. DISCUSSION

There is increasing evidence that the implementation of Palliative Care generates clinically significant improvements in the patient's quality of life [11]. The findings of this study suggest that there are unmet needs of older patients with multimorbidities and their families/carers for timely Palliative Care including feeling uncertain and a sense of fear, poor awareness and knowledge on Palliative Care in non-malignant settings and desire for improved physical, psychosocial and financial status, in line with previous studies such as those by Thai, Motamedi and Llop (16,17,12). Caregivers also reported a high level of frustration and anxiety in this study, not only associated with their own health conditions but also with making care decisions without adequate support.

A constant lack of specialized psychosocial care for both patients and caregivers was manifested, which generates unmet needs, which is in line with other studies [18,19]. Hashemi reported the psychosocial needs of family caregivers of cancer patients highlighting the importance of meeting the needs of family members to improve patients' quality of life. McIlfatrick underlined the need for supportive care for caregivers of people with heart failure at the end of life, including the need for emotional support, information about prognosis and advice on where and how to access the necessary support for themselves. Our study also highlights the lack of psychosocial support for older patients with multimorbidities and their caregivers.

Unmet needs for health professionals and heath care system were also identified including the lack of coherent support for patients and families, early identification, holistic needs assessment and effective referral pathways for Palliative Care input. The need expressed by professionals to have highly involved caregiver's contrasts with the testimonies of caregivers who often feel overloaded and burned by the intensity of care they must provide, often 24 hours a day, in patients with a high dependence and burden of symptoms. Responses from health professionals consistently lead to the consideration of shifting palliative care systems towards a holistic and anticipatory planning approach, this is consistent with recent studies with other patient profiles, people with dementia [20] or heart failure [21].

Understanding and addressing Palliative Care needs may support the development, implementation, mechanisms, and evaluation of the integration of Palliative Care for older people with advanced diseases, for both research and practice. While palliative care has been widely applied to cancer patients to improve their quality of life [22,23], it is currently not widely applied to patients with non-malignant diseases although there is already evidence that referring these patients to palliative care pathways decreases unnecessary hospitalisations and emergency department visits [24]. However, uncertainty about the prognosis of older multimorbid patients is a barrier to referral to palliative care, and the surprise question ("Would I be surprised if this patient died next year?") has been used [25] to try to recognise patients with non-malignant diseases who may need palliative care, although it has not proved to be an accurate predictor according to the Downar's study [26].

Additionally, the development of evidence-based tools for early identification and needs assessments with optimised clinical pathways remains a priority. Recent studies [27] have presented mathematical models that can predict frailty and mortality in older patients and support the identification of older patients in need of palliative care.

In addition, specific training in palliative care should be encouraged for all health professionals, with emphasis on the different patient profiles that may be targeted. In particular, the profile of older patients with complex chronic diseases who, although they have an uncertain prognosis due to their multiple pathologies, can clearly benefit from early referral to palliative care. Likewise, palliative care should be organised at institutional level in multidisciplinary teams that holistically address the needs of patients and their families with special attention to psychosocial well-being and including financial benefits to meet their long-term care needs

5. STRENGTHS AND LIMITATIONS

This study provided a comprehensive view of Palliative Care needs in older patients with multimorbidities. The purposive sampling allowed us to cover the different profiles of multimorbid patients attended by the HHU of the hospital where the study was carried out, as well as the professionals who work with this profile of patients, obtaining representativeness of all of them. Although the sampling was carefully done, its representativeness is limited. All study participants recruited were white Spanish which may not reflect the experiences of those from minority ethnic communities, thus future work is needed to capture their views.

Our findings suggested the need of institutional support for multimorbid older patients and identified important barriers that need to be addressed by healthcare systems facing a significant increase in these patients. Although the study was conducted before healthcare systems were severely threatened by the SARS-COV2 pandemic, the findings remain relevant to the profile of multimorbid older patients. However, post-pandemic changes should be taken into account in future studies, such as those identified by Franchini [28].

Supplementary Materials: The following supporting information can be downloaded at: www.mdpi.com/xxx/s1, SM1: COREQ checklist

Author Contributions: Conceptualization, L.L.-M., and A.D.-M.; methodology, L.L.-M., A.D.-M. and F.R-.R ; formal analysis, L.L.-M. and A.D.-M.; investigation, L.L.-M., A.D.-M. and F.R-.R; writing—original draft preparation, L.L.-M; writing—review and editing, L.L.-M., F.R-.R, and A.D-M.; project administration, J.G-F.; funding acquisition, J.G-F., F.R-.R, A.D-M., and L.L.-M All authors have read and agreed to the published version of the manuscript.

Funding: This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750, and innovation program under grant agreement number 825750 and Grant PID2019-110997RB-I00 funded by MCIN/AEI/10.13039/501100011033.

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki, and Ethics approval was granted by Ethics Committee on Research with Medicaments of Hospital La Fe in Spain (ref. 2019-013-1).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: Not applicable.

Acknowledgments: Authors thank patients, caregivers and health professionals' involvement and their contribution to this study. Authors also wish to thank Home Hospitalization Unit (La Fe) team for facilitating the recruitment.

Conflicts of Interest: The authors declare no conflict of interest.

REFERENCES

1. Maresova, P.; Javanmardi, E.; Barakovic, S.; Husic, J.B.; Tomsone, S.; Krejcar, O.; Kuca, K. Consequences of chronic diseases and other limitations associated with old age—A scoping review. *BMC Public Health* 2019, *19*, 1431.
2. Johnston, M.C.; Crilly, M.; Black, C.; Prescott, G.J.; Mercer, S.W. Defining and measuring multimorbidity: A systematic review of systematic reviews. *Eur. J. Public Health* 2019, *29*, 182–189.
3. Marengoni, A.; Angleman, S.; Melis, R.; Mangialasche, F.; Karp, A.; Garmen, A.; Meinow, B.; Fratiglioni, L. Aging With Multimorbidity: A Systematic Review of the Literature. *Ageing Res. Rev.* 2011, *10*, 430–439.
4. World Health Organization. *Global Status Report on Noncommunicable Diseases 2014*; World Health Organization: Geneva, Switzerland, 2014.
5. Pearson-Stuttard, J.; Ezzati, M.; Gregg, E.W. Multimorbidity—A defining challenge for health systems. *Lancet Public Health* 2019, *4*, e599–e600.
6. Hopman, P.; Schellevis, F.G.; Rijken, M. Health-related needs of people with multiple chronic diseases: Differences and underlying factors. *Qual. Life Res.* 2016, *25*, 651–660.
7. Portz, J.D.; Kutner, J.S.; Blatchford, P.J.; Ritchie, C.S. High Symptom Burden and Low Functional Status in the Setting ofMultimorbidity. *J. Am. Geriatr. Soc.* 2017, *65*, 2285–2289.
8. Etkind, S.N.; Koffman, J. Approaches to managing uncertainty in people with life-limiting conditions: Role of communication and palliative care. *Postgrad. Med. J.* 2016, *92*, 412–417.
9. Field, D.; Addington-Hall, J. Extending specialist palliative care to all? *Soc. Sci. Med.* 1999, *48*, 1271–1280.
10. de Nooijer, K.; Pivodic, L.; Van Den Noortgate, N.; Pype, P.; Evans, C.; Van den Block, L. Timely short-term specialized palliative care service intervention for older people with frailty and their family carers in primary care: Development and modelling of the frailty+ intervention using theory of change. *Palliat. Med.* 2021, *35*, 1961–1974.
11. Kavalieratos, D.; Corbelli, J.; Zhang, D.I.; Dionne-Odom, J.N.; Ernecoff, N.C.; Hanmer, J.; Hoydich, Z.P.; Ikejiani, D.Z.; Klein-Fedyshin, M.; Zimmermann, C.; et al. Association between palliative care and patient and caregiver outcomes: A systematic review and meta-analysis. *JAMA* 2016, *316*, 2104–2114.

12. Llop-Medina, L.; Fu, Y.; Garcés-Ferrer, J.; Doñate-Martínez, A. Palliative Care in Older People with Multimorbidities: A Scoping Review on the Palliative Care Needs of Patients, Carers, and Health Professionals. *Int. J. Environ. Res. Public Health* 2022, *19*, 3195–3208.

13. Gysels, M.; Shipman, C.; Higginson, I.J. Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Med. Ethics* 2008, 9, 7.

14. Tong, A.; Sainsbury, P.; Craig, J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Int. J. Qual. Health Care* 2007, *19*, 349–357.

15. Friese, S. *Qualitative Data Analysis with ATLAS. Ti*, 3rd ed.; Sage: London, UK, 2019.

16. Thai, J.N.; Barnhart, C.E.; Cagle, J.; Smith, A.K. It Just Consumes Your Life": Quality of Life for Informal Caregivers of Diverse Older Adults With Late-Life Disability. *Am. J. Hosp. Palliat. Med.* 2016, *33*, 644–650.

17. Motamedi, M.; Brandenburg, C.; Bakhit, M.; Michaleff, Z.A.; Albarqouni, L.; Clark, J.; Ooi, M.; Bahudin, D.; Chróinín, D.N.; Cardona, M. Concerns and potential improvements in end-of-life care from the perspectives of older patients and informal caregivers: A scoping review. *BMC Geriatr.* 2021, *21*, 729.

18. Amblàs-Novellas, J.; Murray, S.A.; Oller, R.; Torné, A.; Martori, J.C.; Moine, S.; Latorre-Vallbona, N.; Espaulella, J.; Santaeugènia, S.J.; Gómez-Batiste, X. Frailty degree and illness trajectories in older people towards the end-of-life: A prospective observational study. *BMJ Open* 2021, *11*, e042645.

19. Hashemi, M.; Irajpour, A.; Taleghani, F. Cuidadores que necesitan atención: Las necesidades insatisfechas de los cuidadores familiares de pacientes con cáncer al final de su vida. *Support Care Cancer* 2018, 26, 759–766.

20. McIlfatrick, S.; Doherty, L.C.; Murphy, M.; Dixon, L.; Donnelly, P.; McDonald, K.; Fitzsimons, D. 'The importance of planning for the future': Burden and unmet needs of caregivers' in advanced heart failure: A mixed methods study. *Palliat. Med.* 2018, *32*, 881–890.

21. Van Rickstal, R.; Vleminck, A.D.; Engelborghs, S.; Versijpt, J.; Van den Block, L. A qualitative study with people with young-onset dementia and their family caregivers on advance care planning: A holistic, flexible, and relational approach is recommended. *Palliat. Med.* 2022, 36, 964–975.

22. Bonares, M.J.; Mah, K.; MacIver, J.; Hurlburt, L.; Kaya, E.; Rodin, G.; Ross, H.; Zimmermann, C.; Wentlandt, K. Referral Practices of Cardiologists to Specialist Palliative Care in Canada. *CJC Open* 2021, *3*, 460–469.

23. Temel, J.S.; Greer, J.A.; Muzikansky, A.; Gallagher, E.R.; Admane, S.; Jackson, V.A.; Dahlin, C.M.; Blinderman, C.D.; Jacobsen, J.; Pirl, W.F.; et al. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. *N. Engl. J. Med.* 2010, *363*, 733–742.

24. Kassianos, A.P.; Ioannou, M.; Koutsantoni, M.; Charalambous, H. The impact of specialized palliative care on cancer patients' health-related quality of life: A systematic review and meta-analysis. *Support. Care Cancer* 2018, *26*, 61–79.

25. Kingston, A.E.; Kirkland, J.; Hadjimichalis, A. Palliative care in non-malignant disease. *Medicine* 2020, *48*, 37–42.

26. Moss, A.H.; Ganjoo, J.; Sharma, S.; Gansor, J.; Senft, S.; Weaner, B.; Dalton, C.; MacKay, K.; Pellegrino, B.; Anantharaman, P.; et al. Utility of the "surprise" question to identify dialysis patients with high mortality. *Clin. J. Am. Soc. Nephrol.* 2008, *3*, 1379–1384.

27. Downar, J.; Goldman, R.; Pinto, R.; Englesakis, M.; Adhikari, N.K. The "surprise question" for predicting death in seriously ill patients: A systematic review and meta-analysis. *Can. Med. Assoc. J.* 2017, *189*, E484–E493. [CrossRef]

28. Gómez-Batiste, X.; Turrillas, P.; Tebé, C.; Calsina-Berna, A.; Amblàs-Novellas, J. NECPAL tool prognostication in advanced chronic illness: A rapid review and expert consensus. *BMJ Support. Palliat. Care* 2022, *12*, e10–e20. [CrossRef]

29. Blanes-Selva, V.; Doñate-Martínez, A.; Linklater, G.; García-Gómez, J.M. Complementary frailty and mortality prediction modelson older patients as a tool for assessing palliative care needs. *Health Inform. J.* 2022, *28*, 14604582221092592. [CrossRef]

30. Franchini, L.; Varani, S.; Ostan, R.; Bocchi, I.; Pannuti, R.; Biasco, G.; Bruera, E. Home palliative care professionals perception ofchallenges during the Covid-19 outbreak: A qualitative study. *Palliat. Med.* 2021, *35*, 862–874.

3. FACTORIAL STRUCTURE OF QUALITY OF LIFE, SATISFACTION WITH CAREGIVING AND CAREGIVER BURDEN IN PALLIATIVE CARE: A SYSTEMATIC REVIEW[3]

1. INTRODUCTION

Due to the increasing incidence, prevalence and mortality of chronic diseases, identifying the needs and assessing the quality of palliative care are becoming a challenge for healthcare systems. Palliative care (PC) patients often experience a range of debilitating physical symptoms combined with high levels of psychosocial distress. In 2018, The Lancet Commission on PC stated that 35.5 million people experienced severe health-related suffering due to life-threatening and life-limiting conditions (Centeno et al., 2015; Woitha et al., 2016) and according to the WHO, alleviating severe health-related suffering, whether physical, psychological, social or spiritual, is a global ethical responsibility (WHO, 2014).

The European Association for Palliative Care (EAPC) recommends two specialist PC services per 100,000 inhabitants (one home care team and one hospital team); according to the European Atlas of PC (2019), PC provision remains uneven with most services available in Western Europe. Austria and Ireland stand out (2.2 and 1.9 services per 100,000 inhabitants, respectively), and Spain has 0.6 per 100,000 (Arias-Casais et al., 2019). Most European countries have adapted their general health laws and have included PC as a mandatory provision, as a patient's right. PC is included in the portfolio of services of the NHS in Spain, but it lacks an adequate set of evaluation indicators that could help medical and nursing services in clinical practice. This study is relevant in this field as it provides an analysis of three fundamental instruments commonly used in nursing practice to assess quality of life, satisfaction with care and care-giver burden. A comprehensive overview of the variability of the factor structure of the main dimensions of palliative care across cultures, settings and patients is of utmost relevance when adapting

---

[3] **Llop-Medina, L.**, Ródenas-Rigla, F., Gallego-Valadés, A., & Garcés-Ferrer, J. (2024). Factorial structure of quality of life, satisfaction with caregiving and caregiver burden in palliative care: A systematic review. *Nursing Open, 11*(1), e2067. https://doi.org/10.1002/nop2.2067

care protocols from a patient-centred perspective. The main aim of this study is to collect, analyse and systematise the available evidence on the factor structure of the QLQ-C30, FAMCARE and ZBI tools in the palliative care population and to observe their cross-cultural differences.

2. Background

As Aspinal et al. (2003) state, assessing the quality of healthcare is essential, but finding reliable methods to assess the quality of palliative care provision is particularly difficult. The reasons lie in the less direct measurability of the health impact of palliative care as it is oriented towards patients at the end of life. One of the most commonly used approaches to address this task is the measurement of satisfaction with palliative care, however, as acknowledged by the authors (Aspinal et al., 2003), this is a dynamic concept subject to great variability between settings and groups. As a consequence of this less direct measurability, an alternative approach has been to measure the quality of life of palliative patients.

According to the WHO definition (WHO, 2011), the primary goal of palliative care is to optimise the quality of life (QoL) of patients suffering from an incurable illness by controlling physical symptoms and addressing the patient's psychological, social and spiritual needs. Although there is no universally accepted definition of QoL and it is influenced by many factors, the concept is usually understood as a general sense of well-being, defined by the WHO as individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, standards and concerns, including six categories, physical health, independence, psychological well-being, social relationships, environmental characteristics and spiritual concerns (Ahmedzai et al., 2004).

Quality of life is usually independent of satisfaction with care, although there are some associations between them. Aboshaiqah et al. (2016) show that emotional function of palliative cancer patients was more strongly associated with overall satisfaction with care than physical function or global health status. Tierney et al. (1998) or Morishita and

Kamibeppu (2014) obtain analogous results, the latter in the case of informal caregivers. However, the analytical question of the direction of causality between the two elements remains inconclusive, as the assessment of self-perceived satisfaction may depend on personal situation and personality traits.

The third dimension to consider in the conceptual framework would be the burden of the informal caregiver. Palliative patients do not only require care from health services but also from their family and relatives. Traditionally, different measures have been used to assess quality of life by assessing the impact of the illness and clinical treatment on the daily lives of patients but also of family caregivers who are a key part of palliative care provision, as according to the literature they spend a large amount of time caring for palliative patients, whether they are in hospital or at home (Funk et al., 2010). According to the literature, the task of caring for a seriously ill per-son at the end of life can have a major impact on the caregiver's life, impacting their psychosocial, physical and emotional well-being (Yeandle et al., 2017). Strategies such as a partnership approach to support cancer patients and their families/caregivers as they navigate the complex cancer care system can improve PC satisfaction, quality of life and caregiver burden (Palos & Hare, 2011).

The use of tools to measure quality of life and patient and caregiver satisfaction in palliative care is key to improving the delivery of palliative care and can help to improve nursing practice. There is substantial evidence on the factor structure and cross-cultural validity of several tools applicable to populations with different chronic or life-threatening conditions. In particular, evidence has been found on the most commonly used tools for assessing quality of life and satisfaction with care.

The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) has been translated into more than 54 languages and is widely used to measure cancer-specific quality of life (QoL) (Aaronson et al., 1993). The Zarit Burden Interview (ZBI) has demonstrated high reliability and good validity for measuring family caregiver burden related to caring for older people with dementia but also in palliative care settings, it is the most widely used measure to detect caregiver overload (Bachner & O'Rourke, 2007).

The Family Satisfaction with Care at the End of Life (FAMCARE) is a widely used scale to measure satisfaction with caregiving and has been applied internationally to assess satisfaction with palliative care (Hwang et al., 2023; Kristjanson, 1986). However, a systematic and comprehensive review of the factor structure of the most relevant tools addressing the main dimensions of quality assessment in palliative care has not been reported. Due to the absence of literature reviewing the structure of tools that can examine the quality dimensions of palliative care, this review was conducted with the aim of collecting, analysing and systematising the available evidence on the factor structure of the QLQ-C30, FAMCARE and ZBI tools in the palliative care population and observing their cross-cultural differences. In this way, the main approaches and domains of pallia-tive care quality assessment were identified through three question-naires used for this purpose. This study presented could be useful to design new evaluation tools based on the instruments analysed or to propose new versions of the instruments considered.

3. METHODS

3.1. Search and eligibility criteria

The main aim of the study was to collect, analyse and systematise the available evidence on the factor structure of the QLQ-C30, FAMCARE and ZBI tools in the palliative care population and to observe their cross-cultural differences. In this way, the main approaches and domains of palliative care quality assessment were identified through three questionnaires used for this purpose. To this end, the following research questions were developed: Are there differences in the factor structure of the three tools considered? If so, to what factors is this variability due? Are they due to cross-cultural factors? Three systematic reviews were con ducted, one for each tool QLQ-C30, FAMCARE and ZBI, following the PRISMA 2020 statement (Page et al., 2021). The PRISMA 2020 checklist is available for consultation in Appendix S1. A protocol for this systematic review was developed before the research began; however, this review was not registered in any specific database or repository. We included all studies published in English in indexed academic journals, focused on assessing the factor structure of the tools in adult patients from 2000 to 2020. Studies were required to include samples composed of palliative patients or, alternatively, advanced-stage cancer patients.

The quality assessment of the included studies was carried out as follows: All papers reported the application of factor analysis, informing of the factor structure; in addition, they report at least one measure of analysis assessment used in exploratory factor analysis (EFA) or principal component analysis (PCA) (Bartlett's χ2 test, Kaiser–Meyer–Olkin KMO and explained variance of fac-tors or components), or goodness-of-fit statistics in confirmatory factor analysis (CFA) (χ2, comparative fit index (CFI), Tucker–Lewis index (TLI)/non-normed fit index (NNFI), root mean square error of approximation (RMSEA) and other CFA goodness-of-fit statistics). Electronic searches for eligible studies were conducted by date 27/07/2022 within the Scopus, MEDLINE® and PubMed databases. The search terms used and the number of documents obtained are specified in Table 1.

Table 1. Search terms

Database	Search terms	Results (n)	Questionnaire
Scopus	TITLE(qlq AND c30) AND TITLE-ABS-KEY((factor AND structure) OR (factor AND analysis)) AND (LIMIT-TO(LANGUAGE, "English"))	73	QLQ C30
Scopus	TITLE(zarit AND burden AND interview) AND TITLE-ABS-KEY((factor AND analysis) OR (factor AND structure)) AND (LIMIT-TO(LANGUAGE , "English"))	40	Zarit
Scopus	TITLE(famcare) AND TITLE-ABS-KEY((factor AND analysis) OR (factor AND structure)) AND (LIMIT-TO(LANGUAGE, "English"))	15	FAMCARE

Table 1. Search terms. *Continuation.*

PubMed	("qlq c30"[Title] AND ("factor analysis"[Title/Abstract] OR "factor structure"[Title/Abstract])) AND (english[Filter])	24	QLQ C30
Database	**Search terms**	**Results (n)**	**Questionnaire**
PubMed	("zarit"[Title] AND ("factor analysis"[Title/Abstract] OR "factor structure"[Title/Abstract])) AND (english[Filter])	34	Zarit
PubMed	("famcare"[Title] AND ("factor analysis"[Title/Abstract] OR "factor structure"[Title/Abstract])) AND (english[Filter])	11	FAMCARE
MEDLINE®	((TI=(QLQ C30) AND TS=((factor analysis) OR (factor structure))) AND (LA==("ENGLISH")))	59	QLQ C30
MEDLINE®	((TI=(Zarit) AND TS=((factor analysis) OR (factor structure))) AND (LA==("ENGLISH")))	43	Zarit
MEDLINE®	((TI=(famcare) AND TS=((factor analysis) OR (factor structure))) AND (LA==("ENGLISH")))	14	FAMCARE

3.2. Data collection process

Two researchers (L-LLM, A-GV) independently screened titles and abstracts of all papers retrieved. In case of disagreement, consensus on which papers to screen full-text was reached by discussion. If necessary, the third researcher (F-RR) was consulted to make the final decision. Next, two researchers (L-LLM, A-GV) independently screened full-text papers for inclusion. Again, in case of disagreement, consensus was reached on inclusion or exclusion by discussion and if necessary, the third researcher (F-RR) was consulted. In the process, a standardised data extraction form was developed to extract the characteristics of each study included. The standardised form was pilot tested by researchers using five randomly selected studies. The quality of the included studies was verified by reviewing the methodology used in each study and checking the established criteria. The study variables included: population, setting, tool, version, techniques, factorial structure and goodness of fit. Reviewers worked independently to extract study details. A third reviewer reviewed data extraction and resolved conflicts.

3.3. Data analysis

The outcomes of interest consisted mainly of the factors obtained from different factor analysis techniques implemented and the interpretation made by the authors. In studies where two or more analyses were conducted, separated by sub-samples, number of items or factor structure, only those analyses that obtained the best goodness-of-fit statistics were selected. The Open Source R pack-age has been used to design the PRISMA flow diagrams of the systematic reviews linked to each tool (Haddaway et al., 2022).

4. RESULTS

The searches in scientific databases allowed 313 records to be identified and exported to RefWorks, of which 178 duplicate re-cords and 3 for not being a research paper were removed. During the screening phase, 132 records were peer reviewed based on the title and abstract and 75 records were excluded as they did not meet the inclusion criteria. Subsequently, 57 papers were selected for full-text reading, with 41 papers being excluded for various reasons (not including samples with palliative patients, or cancer patients, at an advanced stage and/or not implementing factor analysis). Finally, 16 papers were included in our study (Table 2). In order to facilitate the reading and interpretation of the findings, the results are presented according to the three tools analysed. A specific flow diagram has been included for each of them (Figure 1).

Table 2. Study characteristics

Research	Population	Setting	Version	Techniques	Factorial structure	Goodness of fit
Chaumier et al., 2020	N = 176; patients with cancer	Outpatient clinic and Chemotherapy Day Hospitals of Oncology, Pneumology and Gastroenterology Department of the University Hospital of Tours, France	French FAMCARE-Patient-16 items	CFA	One-factor structure	CFI = 0.93; RMSEA = 0.07
Kühnel et al., 2020	N = 84 informal caregivers of patients in inpatient and outpatient palliative care settings	Department for Palliative Medicine at Munich University Hospital	German ZBI-7	CFA	One-factor structure	χ^2/df = 1.84; CFI = 0.938; TLI = 0.907; standardised RMR = 0.0643; RMSEA = 0.100; factor loadings > 0.4
Ooraikul et al., 2020	N = 66; caregivers of patients with cancer (n = 62), heart diseases (n = 2) and chronic renal disease (n = 2)	Inpatient wards at Maharaj Nakorn Chiang Mai Hospital, Faculty of Medicine, Chiang Mai University, Thailand	Thai FAMCARE-2	PCA	Four-factor structure: 1) management of physical symptoms and comfort, 2) patient care and sharing information, 3) symptoms and side effects, and 4) family and patient support	KMO = 0.88
Teresi et al., 2020	N = 1,834; caregivers of patients with Alzheimer (n = 317, Hispanics) and cancer (n = 1,517, non-Hispanics)	Mount Sinai Medical Center and Columbia University Medical Center	FAMCARE Short-form	PCA & CFA	One-factor structure	Explained Variance of Component 1 = 77.9%; CFI = 0.991; TLI = 0.988; RMSEA = 0.101 [1]

Table 2. Study characteristics. *Continuation*

Research	**Population**	**Setting**	**Version**	**Techniques**	**Factorial structure**	**Goodness of fit**
Viada et al., 2020	N = 1,107 patients with advanced lung cancer [2]	Settings from 19 hospitals or health centres in Cuba, conducted between 2002 and 2017. Hermanos Ameijeiras" Hospital; Center for Surgical Medical Research (CIMEQ); National Institute of Oncology and Radiobiology (INOR); Pneumological Hospital (Charity-Legal); Institute of Military Medicine "Luis Díaz Soto"; "Calixto García" Hospital; "Salvador Allende" Hospital; "October 10" Hospital; "Celestino Hernández" Hospital (Villa Clara); "Saturnino Lora" Hospital (Santiago de Cuba); "V. I. Lenin" Provincial Hospital (Holguin); "Maria Curie" Cancer Hospital (Camagüey); "José Ramón López Tabranes" Hospital (Matanzas); "Gustavo Aldereguía Lima" Hospital (Cienfuegos); "Celia Sánchez" Hospital (Granma); "Ernesto Che Guevara" Hospital (Las Tunas); "III Congress" Hospital; Oncology Unit (Pinar del Río); "Camilo Cienfuegos" Provincial Hospital (Sancti Spiritus).	QLQ-C30 [3]	CFA	One-factor structure	CFI = 0.98; RMSEA = 0.055

Table 2. Study characteristics. *Continuation*

Research	**Population**	**Setting**	**Version**	**Techniques**	**Factorial structure**	**Goodness of fit**
D'Angelo et al., 2017	N = 185; caregivers of patients with cancer (n = 145)	Palliative Care Units at Antea Centre and Madonna dell'Uliveto, Italy	Italian FAMCARE-2	CFA	One-factor structure	$\chi^2 = 833.42$ ($p < .001$); CFI = 0.91; RMSEA = 0.05; SRMR = 0.04. Factor score determinacy was 0.98
Parpa et al., 2017	N = 100; patients with cancer	Palliative Care Unit, University of Athens, Greece	Greek FAMCARE-Patient-13	PCA & CFA [4]	Two-factor structure: 1) Information/interaction with the health-care professionals, and 2) Availability of care	Explained Variance of: Component 1 = 32.1%, Component 2 = 15%
Chattat et al., 2016	N = 132; caregivers of patients with cancer	Istituto Scientifico Romagnolo per lo Studio e la Cura dei Tumori (IRST) IRCCS (Oncology Ward and Outpatient Clinics in Meldola and Forlì) and the community-based hospice in Forlimpopoli, Italy	Italian FAMCARE	PCA	Four-factor structure: 1) giving information, 2) physical care of the patient, 3) availability of care, and 4) pain management	Bartlett's $\chi^2 = 1{,}424.7$ ($p < .001$); KMO = 0.91; Explained Variance of: Component 1 = 25.3%, Component 2 = 13%, Component 3 = 12.6%, Component 4 = 12.2%

Table 2. Study characteristics. *Continuation*

Research	Population	Setting	Version	Techniques	Factorial structure	Goodness of fit
Costa et al., 2015	N = 1,906 cancer patients (n = 124 oesophagus/ stomach) [5]	Seventeen data sets obtained from a variety of sources were pooled: nine were obtained from the EORTC (The European Organisation for Research and Treatment of Cancer); the other eight data sets were obtained from individual researchers or clinical trial groups. Countries represented were Australia, Canada, France, Germany, Italy, New Zealand, Norway, Spain, Sweden, Taiwan, Turkey, the UK and the USA	QLQ-C30 [6]	CFA	Nine-factor structure	χ^2 p = 0.0038; CFI = 0.995; RMSEA = 0.047
Teresi et al., 2014	N = 1,983; caregivers of patients with cancer	Six hospitals in the Eastern and Midwestern United States	FAMCARE	PCA & CFA	One-factor structure [7]	Explained Variance of Component 1 = 84.4%; CFI = 0.965; TLI = 0.961; RMSEA = 0.095 [8]
Aoun et al., 2010	N = 497; caregivers of patients with cancer (80%), end-stage organ failure (cardiac, respiratory, renal and hepatic) and neurodegenerative diseases [9]	29 palliative care services across Australia (participating in the Australian Palliative Care Outcomes Collaboration)	FAMCARE-2	PAF	Four-factor structure: 1) management of physical symptoms and comfort, 2) provision of information, 3) family support and 4) patient psychological care	KMO = 0.932; Cumulative Explained Variance of Factors = 66%

Table 2. Study characteristics. *Continuation*

Research	**Population**	**Setting**	**Version**	**Techniques**	**Factorial structure**	**Goodness of fit**
Rodriguez et al., 2010	N = 51; caregivers of patients receiving long-term care in Veterans Affairs facilities	Geriatric palliative care unit (GPCU) and two traditional nursing home care units (NHCUs) at an urban Veterans Affairs medical center in the Northeastern United States	FAMCARE	PCA	Four-factor structure: 1) quality of care, 2) family, 3) pain and 4) avaliability	Cumulative Explained Variance of Factors = 70.2%
Lo et al., 2009a	N = 315; patients with cancer	24 outpatient oncology clinics at Princess Margaret Hospital, Toronto ,Canada	FAMCARE-Patient-13 [10]	CFA	One-factor structure	CFI = 0.95; NNFI = 0.94; RMSEA = 0.076
Lo et al., 2009b	N = 145; patients with cancer	Oncology Palliative Care Clinic (OPCC) at Princess Margaret Hospital, Toronto, Canada	FAMCARE-Patient-16	PAF [11]	One-factor structure	Explained Variance of Factor 1 = 80%
Ringdal et al., 2003	N = 181; caregivers of patients with cancer	Palliative Medicine Unit (PMU), University Hospital of Trondheim, Norway.	FAMCARE	PCA	Three-factor structure: 1) general care, 2) information, and 3) physical care [12]	Cumulative Explained Variance of Components = 68.5%

Table 2. Study characteristics. *Continuation*

Research	**Population**	**Setting**	**Version**	**Techniques**	**Factorial structure**	**Goodness of fit**
Mystakidou et al., 2001	N = 120 cancer patients	Outpatient clinic of a palliative care unit in Athens, Hellas	Hellenic QLQ-C30	PCA	Six-factor structure (not labelled)	Bartlett's χ^2 = 358.9 ($p < 0.001$); KMO = 0.71; Cumulative explained variance of factors = 76.85%

---

[1] Goodness of fit statistics for caregivers of cancer patients (n = 1,517); results from PCA consisted on two principal components although CFA was driven specifying a one-factor model

[2] CFA was implemented in a test set (n=775)

[3] 28 core items

[4] CFA used only to reject the one-factor structure

[5] Results are only shown for patients with oesophageal/stomach cancer (97.6% of whom have late cancer).

[6] Only the multiple-item domains were included in the measurement model (24 items)

[7] Authors support the unidimensionality of the scale, despite the comparison with bi-factor models

[8] Goodness of fit statistics for total sample (N = 1,983)

[9] n not specified

[10] After deleting three items corresponding to an initial version of 16

[11] PAF was carried out on a 17-item version; item 1 loaded poorly and was dropped to produce a 16-item scale

[12] However, authors support the unidimensionality of the scale, due to the large differences in eigenvalues

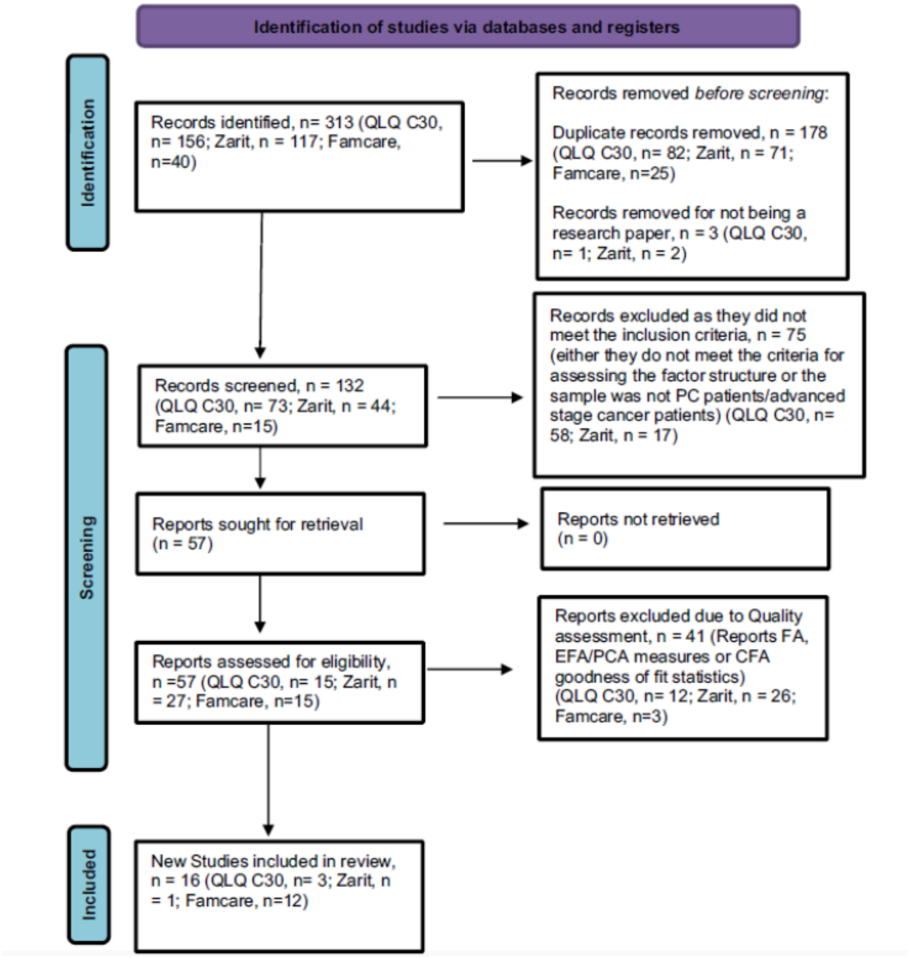

Figure 1. Prisma Flow diagram

4.1. QLQ C30

Three studies met the criteria for inclusion. The study by Mystakidou et al. (2001) on a sample of Hellenic terminally ill cancer patients receiving palliative care reports a six-factor solution from PCA (Bartlett's $\chi2=358.9$, $p<0.001$; KMO=0.71; cumulative explained variance of factors=76.85%). Based on CFA, Viada et al. (2020) provide evidence supporting the unidimensionality of the 28 core items in a Cuban population of patients with advanced non-small cell lung cancer (CFI=0.98; RMSEA=0.055). However, the authors point to a possible lack of generalisability of the results to other cancer patient populations due to the multicentric composition of the sample. Both results contrast with those provided by the multigroup study by Costa et al. (2015) in the subsample of patients with late oesophageal/stomach cancer. A nine-factor structure can be interpreted from the CFA ($\chi2$ p=0.0038; CFI=0.995; RMSEA=0.047), composed of the multi-item scales of the questionnaire.

4.2. Zarit

Only one study met the criteria for inclusion. Kühnel et al. (2020) provide evidence in favour of the use in palliative care of the 7-item ZBI version (Gort et al., 2005) suggested by Higginson et al. (2010), for the one-factor measurement of caregiver burden. The analysis developed by the authors shows the structural validity of the tool from CFA ($\chi2$/df=1.84; CFI=0.938; TLI=0.907; standardised RMR=0.0643; RMSEA=0.100; factor loadings >0.4).

4.3. FAMCARE

In total, 12 studies that met the above characteristics were included. All studies administered FAMCARE family questionnaires, but the versions varied among the original FAMCARE questionnaire (n=5), FAMCARE-Patient (n=4), and FAMCARE-2 (n=3). Several studies administered or validated shortened versions of the questionnaires (n=5).

Most studies included caregivers or patients, either inpatients or outpatients, with cancer (n=11). At least two studies also included caregivers of patients with other pathologies. Only one study included caregivers of patients receiving long-term care in Veterans Affairs facilities.

The most frequent analysis technique was PCA (n=7), followed by CFA (n=6) and PAF (n=2). In several cases (n=3), PCA was ac-companied by CFA to assess the goodness of fit of the resulting model. Only in one case was it used to reject the alternative model (Parpa et al., 2017). Generally, the results support the idea of unidimensionality of the scale, although there are some nuances to be made.

The study by Chattat et al. (2016) reports a four-factor structure (1. giving information, 2. physical care of the patients, 3. availability of care and 4. pain management) of the Italian FAMCARE, based on PCA (Bartlett's $\chi 2 = 1424.7$, $p < 0.001$; KMO=0.91; explained variance of: factor I=25.3%, factor II=13%, factor III=12.6% and factor IV=12.2%). These results contrast with those obtained in other studies implementing factor analysis methods. Specifically, they op-pose those previously obtained by Teresi et al. (2014), who support the one-factor structure of the scale from PCA (explained variance of factor=84.4%) and CFA (CFI=0.965; TLI=0.961; RMSEA=0.095), despite the comparison with bi-factor models. Analogous results (Explained Variance of Component 1=74.2%; CFI=0.988; TLI=0.984; RMSEA=0.101) are obtained by Teresi et al. (2020) in a sample of 1517 non-Hispanic white caregivers of cancer patients, using a short-form FAMCARE.

In a similar line, Rodriguez et al. (2010) report a four-factor structure (1. quality of care, 2. family, 3. pain and 4. availability) of the 20-item FAMCARE, from PCA (cumulative explained variance of factors=70.2%), in patients receiving long-term care in Veterans Affairs facilities. However, as the factor analysis yields one very strong factor with an eigenvalue of 9.42 and three weak factors with eigenvalues of 1.99, 1.43 and 1.21 – the authors state that the scale has a one-factor structure. Quite similar results were previously obtained by Ringdal et al. (2003) from PCA (cumulative explained variance of factors=68.5%), showing the existence of three factors (1. general care, 2. information and 3. physical care) with eigenvalue >1. As in the previous study, the wide gap between the eigenvalue of the first factor (10.95) and that of the second (1.52) drives the authors to interpret the Norwegian FAMCARE as a one-factor scale.

A four-factor structure (1. management of physical symptoms and comfort, 2. patient care and sharing information, 3. symptoms and side effects and 4. family and patient support) is obtained by Oraikul et al. (2020) in the validation of the Thai FAMCARE-2 Scale, based on PCA (KMO=0.88). These results are similar to those obtained by Aoun et al. (2010) from PAF (KMO=0.932; cumulative explained variance of factors=66%), although the item loadings onto the sub-scales differ.

Factors are labelled as: 1. management of physical symptoms and comfort, 2. provision of information, 3. family support and 4. patient psychological care. In contrast to these findings, D'Angelo et al. (2017) provide evidence supporting the one-factor structure of the Italian FAMCARE-2 based on CFA results ($\chi2=833.42$; $p<0.001$; CFI=0.91; RMSEA=0.05; SRMR=0.04).

In the first study assessing the psychometric properties of a patient-oriented version of FAMCARE (FAMCARE-P16), Lo, Burman, Rodin, et al. (2009) obtained results from PAF suggesting the presence of a single dominant factor (explained variance of factor=80%). A second study by Lo, Burman, Hales, et al. (2009) strengthens the evidence in favour of a one-factor structure of the tool based on CFA (CFI=0.95; NNFI=0.94; RMSEA=0.076), although excluding some items from the analysis (FAMCARE-P13). In this line, Chaumier et al. (2020) support the idea of a one-factor structure of the French patient-oriented version of FAMCARE (FFP-16) based on CFA (CFI=0.93; RMSEA=0.07). These results are in contrast, however, to those previously obtained by Parpa et al. (2017), who reject the one-factor structure of the Greek FAMCARE-P13 ($\chi2=219.67$; df=65; $p<0.0005$; $\chi2/df=3.38$; RMSEA=0.155; GFI=0.735; AGFI=0.628; NFI=0.520; CFI=0.592), although they do not report analogous results with the two-factor structure obtained from PCA (explained variance of: factor I=32.1%; factor II=15%). They labelled factor I as Information/interaction with the healthcare professionals (8 items), while factor II is labelled as Availability of care (5 items).

5. Discussion

The variability in the latent dimensionality of the questionnaires analysed could be due to: (i) the characteristics of the sample, (ii) the population studied, (iii) cross-cultural variability, (iv) the design of the questionnaire and (v) the analysis techniques employed. For example, cultural differences between countries may influence definitions and descriptions of pain (Free, 2002), pain sensitivity (Al-Harthy et al., 2016), pain empathy or the relationship between fear avoidance of chronic pain and pain intensity (Kroska, 2016).

The results obtained are generally representative of the evidence behind the factor structure of QLQ-C30 in the general cancer population. Most studies show unidimensional and nine-factor solutions, although it is unknown whether or not this pattern is in-dependent of other confounding variables. In Sommer et al. (2020), violations of scalar invariance concerning sex were detected in items within both the physical functioning and emotional functioning scales. The authors also identified scalar invariance violations for items in the physical, emotional and cognitive functioning scales. For Viada et al. (2020), the potential for measurement invariance of the core QLQ-C30 among various cancer populations presents as a hypothesis meriting further exploration. This argument is partially supported by evidence provided by Costa et al. (2015) in a widely heterogeneous study on the invariance of QLQ-C30 measurement across primary cancer sites based on multigroup CFA. The authors provide provisional evidence that the measurement properties of the QLQ-C30 are, for the most part, invariant across primary cancer sites, although the measurement models are composed of nine multiple-item domains and do not support the unidimensionality of the tool.

The studies included are too few to unequivocally support a conclusion in the palliative care setting. Although from a comprehensive approach, the results provided by the literature may suggest that the conceptual distinction between the global notion of quality of Life and the different domains is a theoretical rather than a statistical issue. Thus, it is clear that the concept of quality of life constitutes a global and multidimensional standard, but there are clear differences between the various domains. A clear example is provided in the introductory section: emotional function correlates moderately with overall satisfaction with care, but not other domains. The QLQ-C30 does not take into consideration the spiritual or religious dimension, and this may be a limitation, particularly in other cultural contexts.

Evidence on the factor structure of the ZBI in populations receiving palliative care or with advanced cancer is very limited. The studies conducted employ reduced versions (ZBI-7 and ZBI-6) and lead to the idea of a unifactorial structure, which conceptually relates to caregiver burden in general. The study included in our analysis shows a unifactorial solution and this contrasts, however, with most of the evidence in other population groups.

The factor structure of the Zarit Burden Interview remains ambiguous. Various researchers have proposed distinct models, with the two-factor model (Bachner & Ayalon, 2010; Branger et al., 2016) addressing personal strain and role strain being the most commonly referenced. Hébert et al. (2000) support this model, offering widely cited information on the reliability and validity of the Zarit Burden Inventory. However, there are studies reporting a four-factor structure (Cheah et al., 2012; James et al., 2021), "personal strain" and "role strain" systematically present the highest self-evaluations.

The unifactorial solution of the only available study could be due to the fact that palliative care, due to its intensity, may lead the care-giver to interpret the burden from a more holistic viewpoint than in other cases. However, we do not rule out that this is due to a methodological rather than a theoretical issue associated with the drastic cutback of items by the authors. For this reason, it would be advisable to conduct further studies applying the full scale to the palliative care population to test whether the introduction of a greater diversity of items has any effect on the factor structure of the tool. It should also be noted that, as is the case with quality of life, it is quite likely that the subjective tolerance of the burden of care and how it is interpreted is highly variable across cultures.

In the case of FAMCARE, most of the factor structures differ from the initial proposal of Kristjanson (1993). It should be taken into consideration that while the method employed by the author was based on cluster analysis, subsequent research has employed factor analysis techniques. Additional sources of variation may come from shortening or adapting the tool for assessment from the patient's perspective, or a combination of both, as in the case of Chaumier et al. (2020), among others. Most authors, however, attribute these variations to cultural specificities. Parpa et al. (2017), on the other hand, attribute the disagreement of their model with the original structure to the suggestion that patients discriminate their satisfaction concerning their relationship with healthcare professionals. Alternatively, D'Angelo et al. (2017) explain the one dimensionality of their factor solution as an indicator that caregivers tend to make a global judgement about the care received and conceive the different aspects of care within an overall cognitive framework.

5.1. Limitations

Not all of the tools analysed in this study have a tradition of implementation in the palliative care context. For example, while FAMCARE has been extensively validated, ZBI has hardly been used, despite its potential usefulness in measuring caregiver burden in palliative care. This is an implicit limitation to the availability of evidence.

Questionnaires focused on assessing knowledge and attitudes of formal caregivers in palliative care exist, but have not been systematically identified as these are not the predominant assessment approaches. Furthermore, these are domains that may be closely correlated with satisfaction with care, if it is theoretically assumed that specific knowledge of the topic and a good attitude result in higher satisfaction from both patients and relatives.

Finally, it has not been possible to perform a meta-analysis to systematically assess the latent structure of the tools analysed.

Firstly, as mentioned above, due to the disparity in the availability of evidence. Secondly, as a consequence of the wide heterogeneity in the way results are reported. In some studies, reporting omitted the inclusion of certain common statistical tests or goodness-of-fit statistics, which makes direct comparability difficult. Many reports also fail to include the inter-item correlation/covariance matrix, which is a key element for performing meta-analysis (Norton et al., 2013; Strunk et al., 2021). The creation of a standardised protocol for re-porting results in such studies would be a major step forward.

6. CONCLUSIONS

This study constitutes a comprehensive synthesis of the best available evidence on the factor structure of three widely used tools (QLQ-C30, ZBI and FAMCARE) for assessing dimensions with practical relevance and utility in palliative care for nursing practice. The study has allowed us to highlight the most frequent factor structures, and to compare the variability between different studies. The sources of variability have been examined in light of the available empirical evidence, but to date, there is a lack of theoretical background to systematically identify the relevant drivers of variability in the structural validity of the tools. It is argued that one of the most likely sources of variability in the factor structure of questionnaires is cultural context. As in other anthropological phenomena, culture exerts a significant influence on the way in which behaviour, perception or meanings are constructed. However, it is not known exactly how this cross-cultural variation influences variation in the factor structure of questionnaires. An integration of qualitative and quantitative perspectives in research would be necessary to address this task.

Author contributions: Conceptualisation, L.L.-M., F.R.-R. and A.G.-V.; methodology, L.L.-M., A.G.-V. and F.R.-R.; formal analysis, L.L.-M. and A.G.-V.; investigation, L.L.-M., A.G.-V. and F.R.-R.; writing–original draft preparation, L.L.-M., A.G.-V. and F.R.-R.; writing–review and editing, L.L.-M., A.G.-V. and F.R.-R.; visualisation, L.L.-M., A.G.-V. and F.R.-R.; supervision, F.R.-R. and J.G.-F.; project administration, F.R.-R. and J.G.-F.; funding acquisition, F.R.-R. and J.G.-F. All authors have read and agreed to the published version of the manuscript.

Acknowledgements: The authors would like to thank the researchers at the Polibienestar Research Institute for their critical review of the text of the manuscript.

Funding information: This research was funded by MCIN/AEI/10.13039/501100011033 Grant PID2019-110997RB-I00 and the European Union’s Horizon 2020 research and innovation programme under grant agreement No 825750.

Conflict of interest statement: The authors declare no conflicts of interest.

Data avail ability statement: Data sharing not applicable - no new data generated, or the article describes entirely theoretical research.

Ethics statement: Not applicable.

REFERENCES

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., Filiberti, A., Flechtner, H., Fleishman, S. B., & de Haes, J. C. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: A quality of life instrument for use in inter-national clinical trials in oncology. Journal of the National Cancer Institute, 5, 365–376. https:// doi. org/ 10. 1093/j nci/ 85.5. 365

Aboshaiqah, A., Al-Saedi, T. S. B., Abu-Al-Ruyhaylah, M. M. M., Aloufi, A. A., Alharbi, M. O., Alharbi, S. S., Al-Saedi, A. S., & Al-Erwi, A. F.(2016). Quality of life and satisfaction with care among palliative cancer patients in Saudi Arabia. Palliative & Supportive Care, 14(6), 621–627. https:// doi. org/ 10. 1017/ S1478 95151 6000432

Ahmedzai, S. H., Costa, A., Blengini, C., Bosch, A., Sanz-Ortiz, J., Ventafridda, V., & Verhagen, S. C. (2004). A new international framework for palliative care. European Journal of Cancer, 40, 2192–2200. https:// doi. org/ 10. 1016/j. ejca. 2004. 06. 009

Al-Harthy, M., Ohrbach, R., Michelotti, A., & List, T. (2016). The effect of culture on pain sensitivity. Journal of Oral Rehabilitation, 43(2), 81–88. https:// doi. org/ 10. 1111/ joor. 12346

Aoun, S., Bird, S., Kristjanson, L. J., & Currow, D. (2010). Reliability testing of the FAMCARE-2 scale: Measuring family carer satisfaction with palliative care. Palliative Medicine, 24(7), 674–681. https:// doi. org/ 10. 1177/ 02692 16310 373166

Arias-Casais, N., Garralda, E., Rhee, J. Y., de Lima, L., Pons, J. J., Clark, D., Hasselaar, J., Ling, J., Mosoiu, D., & Centeno, C. (2019). EAPC Atlas of palliative care in Europe 2019. EAPC Press. Retrieved July 15, 2022, from http:// hdl.handle.net/ 10171/56787 and https:// www. researchgate. net/ publication/ 33339 0123_ EAPC_ Atlas_ of_ PalliativeCarein_ Europe_ 2019

Aspinal, F., Addington-Hall, J., Hughes, R., & Higginson, I. J. (2003). Using satisfaction to measure the quality of palliative care: A review of the literature. Journal of Advanced Nursing, 42(4), 324–339. https:// doi. org/ 10. 1046/j. 1365- 2648. 2003. 02624. X

Bachner, Y. G., & Ayalon, L. (2010). Initial examination of the psychometric properties of the short Hebrew version of the Zarit Burden Interview. Aging & Mental Health, 14(6), 725–730. https:// doi. org/ 10. 1080/ 13607 86100 3601841

Bachner, Y. G., & O'Rourke, N. (2007). Reliability generalization of responses by care providers to the Zarit Burden Interview. Aging and Mental Health, 11, 678–685. https:// doi. org/ 10. 1080/ 13607 86070 1529965

Branger, C., O'Connell, M. E., & Morgan, D. G. (2016). Factor analysis of the 12-item Zarit Burden Interview in caregivers of persons di-agnosed with dementia. Journal of Applied Gerontology, 35(5), 489507. https:// doi. org/ 10. 1177/ 07334 64813 5202

Centeno, C., Lynch, T., Garralda, E., Carrasco, J. M., Guillen-Grima, F., & Clark, D. (2015). Coverage and development of specialist pallia-tive care services across the World Health Organization European Region (2005–2012): Results from a European Association for Palliative Care Task Force survey of 53 countries. Palliative Medicine, 30, 351–362.

Chattat, R., Ottoboni, G., Zeneli, A., Berardi, M. A., Cossu, V., & Maltoni, M. (2016). The Italian version of the FAMCARE scale: A validation study. Support Care Cancer, 24, 3821–3830. https:// doi. org/ 10. 1007/ s0052 0- 016- 3187- 1

Chaumier, F., Flament, T., Lecomte, T., Vegas, H., Stacoffe, M., Pichon, E., Narciso, B., Caulet, M., Barbe, C., Jaillais, A., Carmier, D., By, M. A., Bourdon, M., & Hardouin, J. B. (2020). Cross-cultural adap-tation and psychometric validation of the French version of the FAMCARE-patient (FFP-16) questionnaire for outpatients with advanced-stage cancer. Journal of Pain and Symptom Management, 60(1), 94–100.e1. https:// doi. org/ 10. 1016/j. jpain symman. 2020. 02. 007

Cheah, W., Han, H., Chong, M., Anthony, P., & Lim, W. (2012). Multidimensionality of the Zarit Burden Interview across the se-verity spectrum of cognitive impairment: An Asian perspective. International Psychogeriatrics, 24(11), 1846–1854. https:// doi. org/ 10. 1017/ S1041 61021 200110X

Costa, D. S. J., Aaronson, N. K., Fayers, P. M., Pallant, J. F., Velikova, G., & King, M. T. (2015). Testing the measurement invariance of the EORTC QLQ-C30 across primary cancer sites using multi-group confirmatory factor analysis. Quality of Life Research, 24, 125–133. https:// doi. org/ 10. 1007/ s1113 6- 014- 0799- 0

D'Angelo, D., Punziano, A. C., Mastroianni, C., Marzi, A., Latina, R., Ghezzi, V., Piredda, M., & De Marinis, M. G. (2017). Translation and testing of the Italian version of FAMCARE-2: Measuring fam-ily caregivers' satisfaction with palliative care. Journal of Family Nursing, 23(2), 252–272. https:// doi. org/ 10. 1177/ 10748 40717 697538

Free, M. M. (2002). Cross-cultural conceptions of pain and pain control. Proceedings (Baylor University Medical Center), 15(2), 143–145. https:// doi. org/ 10. 1080/ 08998 280. 2002. 11927832

Funk, L., Stajduhar, K., Toye, C., Aoun, S., Grande, G. E., & Todd, C. J. (2010). Part 2: Home-based family caregiving at the end of life: A comprehensive review of published qualitative research (1998-2008). Palliative Medicine, 24(6), 594–607. https:// doi. org/ 10. 1177/ 02692 16310 3714

Gort, A. M., March, J., Gómez, X., de Miguel, M., Mazarico, S., & Ballesté, J. (2005). Short Zarit scale in palliative care. Medicina Clínica, 124(17), 651–653. https:// doi. org/ 10. 1157/ 13074742

Haddaway, N. R., Page, M. J., Pritchard, C. C., & McGuinness, L. A. (2022). PRISMA2020: An R package and Shiny app for producing PRISMA 2020-compliant flow diagrams, with interactivity for optimised digital transparency and open synthesis. Campbell Systematic Reviews, 18(2), e1230. https:// doi. org/ 10. 1002/ cl2. 1230

Hébert, R., Bravo, G., & Préville, M. (2000). Reliability, validity and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. Canadian Journal on Aging / La Revue Canadienne Du Vieillissement, 19(4), 494–507. https:// doi. org/ 10. 1017/ S0714 98080 0012484

Higginson, I. J., Gao, W., Jackson, D., Murray, J., & Harding, R. (2010). Short-form Zarit Caregiver Burden Interviews were valid in advanced conditions. Journal of Clinical Epidemiology, 63(5), 535–542. https:// doi.org/ 10. 1016/j.jclinepi. 2009. 06. 014

Hwang, S. S., Chang, V. T., Alejandro, Y., Osenenko, P., Davis, C., Cogswell, J., & Kasimis, B. (2023). Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center. Palliative & Supportive Care, 1, 319–329. https:// doi. org/ 10. 1017/ s1478 95150 3030475

James, K., Chin-Bailey, C., Holder-Nevins, D., Thompson, C., Donaldson-Davis, K., & Eldemire-Shearer, D. (2021). Zarit burden interview among caregivers of community-dwelling older adults in a caribbean setting (Jamaica): Reliability and factor structure. Health & Social Care in the Community, 29(5), e79–e88. https:// doi. org/ 10. 1111/ hsc. 13244

Kristjanson, L. J. (1986). Indicators of quality of palliative care from a family perspective. Journal of Palliative Care, 1, 8–17. https:// doi. org/ 10. 1177/ 08258 59785 00100203

Kristjanson, L. J. (1993). Validity and reliability testing of the FAMCARE scale: Measuring family satisfaction with advanced cancer care. Social Science & Medicine, 36(5), 693–701. https:// doi. org/ 10. 1016/ 0277-9536(93) 90066 – D

Kroska, E. B. (2016). A meta-analysis of fear-avoidance and pain intensity: The paradox of chronic pain. Scandinavian Journal of Pain, 13(1), 43–58. https:// doi. org/ 10. 1016/j. sjpain. 2016. 06. 011

Kühnel, M. B., Ramsenthaler, C., Bausewein, C., Fegg, M., & Hodiamont, F. (2020). Validation of two short versions of the Zarit Burden Interview in the palliative care setting: A questionnaire to assess the burden of informal caregivers. Support Care Cancer, 28(11), 5185–5193. https:// doi. org/ 10. 1007/ s0052 0- 019- 05288 – w

Lo, C., Burman, D., Hales, S., Swami, N., Rodin, G., & Zimmermann, C. (2009). The FAMCARE-patient scale: Measuring satisfaction with care of outpatients with advanced cancer. European Journal of Cancer, 45(18), 3182–3188. https:// doi. org/ 10. 1016/j. ejca. 2009. 09. 003

Lo, C., Burman, D., Rodin, G., & Zimmermann, C. (2009). Measuring patient satisfaction in oncology palliative care: Psychometric properties of the FAMCARE-patient scale. Quality of Life Research, 18(6), 747–752. https:// doi. org/ 10. 1007/ s1113 6- 009- 9494- y

Morishita, M., & Kamibeppu, K. (2014). Quality of life and satisfaction with care among family caregivers of patients with recurrent or metastasized digestive cancer requiring palliative care. Supportive Care in Cancer, 22(10), 2687–2696. https:// doi. org/ 10. 1007/ s0052 0- 014- 2259- 3

Mystakidou, K., Tsilika, E., Parpa, E., Kalaidopoulou, O., Smyrniotis, V., & Vlahos, L. (2001). The EORTC core quality of life questionnaire (QLQ-C30, version 3.0) in terminally ill cancer patients under palliative care: Validity and reliability in a Hellenic sample. International Journal of Cancer, 94, 135–139. https:// doi. org/ 10. 1002/i jc. 1439

Norton, S., Cosco, T., Doyle, F., Done, J., & Sacker, A. (2013). The hospital anxiety and depression scale: A meta confirmatory factor analysis. Journal of Psychosomatic Research, 74(1), 74–81. https:// doi. org/ 10. 1016/j.jpsychores. 2012. 10. 010

Ooraikul, L., Wirojratana, V., Phuackchantuck, R., Chompukeaw, P., & Khaisuwan, C. (2020). Reliability and validity testing of the FAMCARE-2 scale: Thai translation. Asia-Pacific Journal of Oncology Nursing, 7(3), 280–286. https:// doi. org/ 10. 4103/ apjon. apjon_5_ 20

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for re-porting systematic reviews.

Systematic Reviews, 10(1), 1–11. https:// doi. org/ 10. 1186/ s1364 3-021- 01626 – 4

Palos, G. R., & Hare, M. (2011). Patients, family caregivers, and patient navigators: A partnership approach. Cancer, 117(S15), 3590–3600. https:// doi. org/ 10. 1002/ cncr. 26263

Parpa, E., Galanopoulou, N., Tsilika, E., Galanos, A., & Mystakidou, K. (2017). Psychometric properties of the patients' satisfaction instrument FAMCARE-P13 in a palliative care unit. The American Journal of Hospice & Palliative Care, 34(7), 597–602. https:// doi. org/ 10. 1177/ 10499 09116 645511

Ringdal, G. I., Jordhøy, M. S., & Kaasa, S. (2003). Measuring quality of palliative care: Psychometric properties of the FAMCARE scale. Quality of Life Research, 12(2), 167–176. https:// doi. org/ 10. 1023/A: 10222 36430131

Rodriguez, K. L., Bayliss, N. K., Jaffe, E., Zickmund, S., & Sevick, M. A. (2010). Factor analysis and internal consistency evaluation of the FAMCARE scale for use in the long-term care setting. Palliative & Supportive Care, 8(2), 169–176. https://doi.org/ 10. 1017/ S1478 95150 9990927

Sommer, K., Cottone, F., Aaronson, N. K., Fayers, P., Fazi, P., Rosti, G., Angelucci, E., Gaidano, G., Venditti, A., Voso, M. T., Baccarani, M., Vignetti, M., & Efficace, F. (2020). Consistency matters: Measurement invariance of the EORTC QLQ-C30 questionnaire in patients with hematologic malignancies. Quality of Life Research, 29, 815–823. https:// doi.org/ 10. 1007/ s1113 6- 019- 02369 – 5

Strunk, K. K., Lester, W. S., Lane, F. C., Hoover, P. D., & Betties, J. S. (2021). Testing the mastery-avoidance construct in achievement goal theory: A meta-analytic confirmatory factor analysis (MA-CFA) of two achievement goals scales. Educational Psychologist, 41(4), 383–400. https://doi.org/ 10. 1080/ 01443 410. 2020. 1824268

Teresi, J. A., Ocepek-Welikson, K., Ramirez, M., Kleinman, M., Ornstein, K., Siu, A., & Luchsinger, J. (2020). Evaluation of measurement equiva-lence of the family satisfaction with the end-of-life care (FAMCARE): Tests of differential item functioning between Hispanic and non-His-panic white caregivers. Palliative & Supportive Care, 18(5), 544–556. https:// doi.org/ 10. 1017/ S1478 95152 0000152

Teresi, J. A., Ornstein, K., Ocepek-Welikson, K., Ramirez, M., & Siu, A. (2014). Performance of the family satisfaction with the end-of-life care (FAMCARE) measure in an ethnically diverse cohort: Psychometric analyses using item response theory. Support Care Cancer, 22(2), 399–408. https:// doi. org/ 10. 1007/ s0052 0- 013- 1988- z

Tierney, R. M., Horton, S. M., Hannan, T. J., & Tierney, W. M. (1998) Relationships between symptom relief, quality of life, and satisfaction with hospice care. Palliative Medicine, 12(5), 333–344. https://doi.org/ 10. 1191/ 02692 16986 70933919

Viada, C., Bouza, C., Fors, M., Frías, A., Alvarez, M., García, L., Wilkinson, B., Rodríguez, C., Crombet, T., & Ballesteros, J. (2020). Underlying dimensions of the EORTC QLQ-C30 in a Cuban population of patients with advanced non-small cell lung cancer. Quality of Life Research, 29, 3441–3448. https:// doi.org/ 10. 1007/ s1113 6- 020- 02584 – 5

Woitha, K., Garralda, E., Martin-Moreno, J. M., Clark, D., & Centeno, C. (2016). Ranking of palliative care development in the countries of the European Union. Journal of Pain and Symptom Management, 52(3), 370–377. https://doi.org/ 10. 1016/j.jpainsymman. 2016. 03. 008

World Health Organization. (2011). WHO definition of palliative care. Retrieved July 17, 2022, from https:// www. who.int/cancer/palliative/ definition/en/

Yeandle, S., Chou, Y.-C., Fine, M., Larkin, M., & Milne, A. (2017). Care and caring: Interdisciplinary perspectives on a societal issue of global significance. International Journal of Care and Caring, 1(1), 3–25. https:// doi.org/ 10. 1332/ 23978 8217X 14866 27817 1183

Supporting information: Additional supporting information can be found online in the Supporting Information section at the end of this article.

4. ENHANCING THE ADULT AND PAEDIATRIC PALLIATIVE CARE SYSTEM: SPANISH PROFESSIONALS' AND FAMILY CAREGIVERS' SUGGESTIONS FOR COMPREHENSIVE IMPROVEMENT[4]

1. INTRODUCTION

Palliative care, as defined by the World Health Organisation [1], aims to enhance the quality of life and alleviate suffering for patients with life-threatening illnesses and their families. This approach involves early detection, appropriate symptom management [2,3] and comprehensive care that addresses physical, emotional, social, spiritual, and psychological needs through the collaboration of an interdisciplinary team [4,5].

However, palliative care faces challenges in practice. Both families and patients are constrained by the capacities of the health care system, resulting in long waits due to long standby lists, compounded by a shortage of professionals and insufficient resources in palliative care [6,7]. This situation generates a greater burden for family caregivers, who lack the training and information necessary to provide this care [6], and professional care is limited to the terminal phase of the disease [3,5,8]. In short, this reality harms the physical, social, and psychological well-being of both patients and family caregivers.

Limited access to palliative care, stemming from resource scarcity and its subsequent effects on the timeliness and quality of assistance, results in underutilised palliative care units [9–11]. The consequence of this underutilisation is an augmented fatality rate. Studies [11,12] have highlighted the significantly shortened duration from the initial palliative consultation to the time of death for adult palliative patients due to this issue. These studies remark on the effect on surgical palliative patients; other researchers have found similar results in other adult palliative patients [13]. In the case of paediatric palliative patients, a study centred on Spain disclosed an alarming rate of mortality of children and adoles-cents diagnosed with life-threatening illnesses [9]. This underscores the critical

---

[4] **Llop-Medina, L.**, García-Muñoz, P., Ródenas-Rigla, F., & Garcés-Ferrer, J. (2023). Enhancing the Adult and Paediatric Palliative Care System: Spanish Professionals' and Family Caregivers' Suggestions for Comprehensive Improvement. *Healthcare, 12* (1), e65. https://doi.org/10.3390/healthcare12010065

impact of restricted access to palliative care services, particularly in the paediatric demographic, emphasising the urgency for comprehensive improvements in palliative care accessibility and delivery.

Considering this challenging scenario, it becomes imperative to take decisive actions to address the needs of both adult and paediatric patients requiring palliative care. This necessitates attention from the moment of diagnosis and patient assessment through the treatment of their needs, extending beyond the purely physical aspects.

In this paper, our focus is directed towards the region of Murcia, Spain, which boasts a population of 462,979 inhabitants [14], making it the seventh most populated municipality in Spain. With shared competencies in health matters with the government, this region is served by the Virgen de la Arrixaca University Clinical Hospital in Murcia (VAUCH), the largest hospital complex in the Murcia public health system. VAUCH has a comprehensive history of delivering palliative care, bereavement support, and end-of-life care, and it has actively engaged in researching the effectiveness of these services [15]. To address these challenges, the main objective of this research is to analyse the elements that influence the quality of palliative care provision from the perspective of professionals and family caregivers, considering the use of certain scales by professionals and the perceptions of deficiencies and proposals for improvement by both stakeholders. This analysis aims not only to point out the deficiencies but also to provide enhancement suggestions for a more effective and comprehensive palliative care system.

2. Materials and Methods

This research employs a qualitative methodological design with the overarching aim of comprehensively studying the perspectives of family members of patients in palliative care and healthcare professionals regarding the palliative care system. The focus is on identifying their perceptions of existing deficiencies and areas for improvement, ultimately proposing recommendations in the treatment and evaluation areas.

Three focus groups were designed for this purpose. The first two involved healthcare professionals, and the third was conducted with family carers of palliative care patients. In addition, a semi-structured in-depth interview component was integrated into the fieldwork to further explore the nuanced views and active participation of families.

All the fieldwork for this study was carried out at VAUCH. The dedicated healthcare team at VAUCH played a crucial role in assisting with the research, and this paper presents findings that emerged from the collaborative efforts with their team, leveraging their extensive experience and expertise in these specialised areas.

This qualitative paradigm facilitated a profound exploration of perspectives on the quality improvement of the palliative system in general, as well as understanding how they measure the quality of palliative patients and how we can improve the way they assess it.

Ethical approval for the development of this research has been obtained from the Ethics Committee on Research of VAUCH (ref. 2020-9-3).

2.1. Identification of Participants

Three focus groups and a semi-structured in-depth interview were designed to study the perspectives of quality care on palliative care services. Two of the three focus groups were designed to attend the professional standpoint: doctors, hospital managers, nurses, and paediatricians from the region of Murcia. Each focus group was composed of 4 persons. The third focus group, with three participants, was focused on the viewpoint of families caring for palliative care patients.

The selection of techniques in this research employed a purposive sampling approach, a deliberate choice driven by the sensitive nature of the study and the inherent challenges in accessing the stakeholders involved busy healthcare practitioners and family caregivers of palliative patients. The intricacies of this research field not only justify the specific number of participants but also account for the deliberate lack of variability in our sample, as outlined in Table 1. The sampling method as the size of our sample is also justified by previous studies in the health field [16,17], as well as by the principle that the transferability and dependability of the data are influenced by the comprehensive description of all possible contextual factors impacting the inquiry [18]. A sample that is fully contextualised helps prevent unwarranted generalisation. To accomplish the best description of the context of this research, we have followed the COREQ guideline [19] and we apport 32 criteria of our research in the Supplementary Materials (Table S1).

Table 1. Sociodemographic characteristics of participants (focus groups and interviews)

Healthcare Professionals (HP) n = 9		**Family Caregivers (FC) n = 4**	
Gender		Gender	
Woman	5 (55.56%)	Woman	3 (75%)
Man	4 (44.46%)	Man	1 (25%)
Average age	47 years old	Average age	54 years old
Professional profile		Professional profile	
Health manager ** (HM)	4 (44.44%)	Education	1 (25%)
Nursing (N)	3 (33.33%)	Law	1 (25%)
Medicine (M)	2 (22.22%)	Housekeeper	1 (25%)
Specialisation		Retiree	1 (25%)
Adults palliative care *	3 (33.33%)	Familiar relationship with the patient	
Paediatric palliative care	3 (33.33%)	Parenthood	3 (75%)
Chronic	1 (11.11%)	Other	1 (25%)
Internist	1 (11.11%)	Palliative unit of their familiar	
Primary care physician	1 (11.11%)	Adult	3 (75%)
Average experience in the area		Paediatrician	1 (25%)
Adults palliative care *	14 years	Pathology of their familiar	
Paediatric palliative care	14 years	Alzheimer	1 (25%)
Chronic	9 years	Multiple morbidities	1 (25%)
Internist	20 years	Oncological	2 (50%)
Primary care physician	22 years		
Training courses in palliative care			
Yes	8 (88.88%)		
No	1 (11.11%)		

* Healthcare participants can work in different units at the same time. ** All of them have a medical profile.

The inclusion of a semi-structured in-depth interview served a dual purpose: to augment the richness of qualitative data and, more critically, to adhere to a standard of scientific rigour by enhancing the symbolic representation within the research framework. This approach ensures a nuanced and comprehensive exploration of the perspectives of the participants, contributing to the depth and validity of the study's findings.

The enrolment of the participants in the research was facilitated by health workers of VAUCH between October and November of 2021.

To identify the participants in the verbatim, the following coding has been established: HP (health professionals) and FC (family caregivers). FC1 to FC3 corresponds to focus group participants, and FC4 corresponds to the case study of the only family member with a patient in a paediatric palliative care unit. Within the group of professionals, we distinguish HM (Health managers), M (medicine profile) and N (nursing profile).

2.2. Data Collection

The research design encompassed three focus groups conducted at Murcia's University due to its well-equipped facilities and proximity to VAUCH. Each focus group had a duration ranging between 60 and 90 min. Meanwhile, the semi-structured in-depth interview had a duration of around an hour.

Before the commencement of the focus groups and the in-depth interview, a comprehensive set of open-ended questions, categorised by relevant topics, was meticulously designed for each technique. Both family caregivers and healthcare professionals were invited to share their perspectives about the deficiencies of the palliative care system, as well as to provide insights and recommendations for its improvement. In addition, healthcare professionals were specifically asked about academic and professional evaluation indicators in palliative care, delving into aspects such as their application within the hospital setting and eliciting their opinions on the sensitivity and appropriateness of these indicators in capturing the diverse dimensions of palliative care. This meticulous approach ensured a thorough exploration of the perspectives of both groups, enriching the qualitative data and contributing to a comprehensive understanding of the palliative care landscape.

All focus groups were conducted with meticulous attention to ethical standards, obtaining informed consent from participants before proceeding. The sessions were digitally recorded to ensure accurate capture of discussions and subsequently transcribed. The intent behind this comprehensive documentation was to facilitate in-depth data analysis, a task entrusted to an experienced researcher well-versed in the subject matter and adept in qualitative research methodology. This methodological rigour was employed to derive meaningful insights from the rich tapestry of perspectives and experiences shared during the focus groups, contributing to the robustness of the research findings.

2.3. Data Analysis

Following the implementation of research techniques, a rigorous analysis of the qualitative data ensued. Two members of the research team, well-versed in the subject matter and guided by perspectives of value-based care [19] and patient and family-centred [20] approaches, undertook the codification of the qualitative data, and undertook the codification of the data. In a posterior phase, the researchers discussed the codes, arriving at an interpretative agreement of focus groups and the interview transcripts by exploring the connections and associations between codes and categories. The result was the emergence of overarching themes and sub-themes, as illustrated in Table 2. This thematic analysis was driven by the interpretative objective of the study and the inherent limitations within the sample.

Table 2. Main and sub-themes

Main Thematic Categories	Sub-Thematic Categories
Palliative care indicators	Usage; adequacy; proposals
Improvements in adults' palliative care system	Timing constraints; health personal increase; support of social workers and social services; establishment of commissions; health professional satisfaction; health professional overburden; institutional coordination; support groups; bereavement support
Improvements in paediatric palliative care system	Health personal increase; empathy; lack of professional training in palliative care; continuity of the care team; caregiver overburden; lack of emotional, spiritual, and psychological support; economic support; 24-h paediatrician care; direct communication among health professionals; units for complex patients, transitional units, and professionals

To enhance the efficiency of this intricate coding process, we leveraged the capabilities of Atlas.ti software version 9.

To allow a structured and focused exploration of the research objectives, the research team elaborated a discussion group and interview script. Two proficient members of the research team conducted the focus groups and participated in the codification and discussion process to ensure a robust and reliable analysis. The inclusion of the Consolidated Criteria for Reporting Qualitative Studies (COREQ) 32 checklist was used to demonstrate a commitment to transparency as well as ensure the most systematic approach possible to data analysis, considering the evident bias given the insufficient heterogeneity and size of the sample and the own characteristics of VAUCH [21] (Supplementary Table S1).

2.4. Trustworthiness

The methodological rigour of this paper is underscored by a comprehensive research methodology incorporating ethical considerations. Before the start of the fieldwork, this research was designed with the support and collaboration of the VAUCH team and with the approval of its ethics committee. The committee played a central role in guiding and approving the ethical premises, emphasising the protection of participants' rights and confidentiality, and considering the sensible object of study.

The collaboration with professionals of VAUCH was fundamental during the recruitment phase to access a very sensible sample of familiars and busy professionals.

3. RESULTS

In this research, we explored recommendations for enhancing the palliative care system by focusing on the evaluation of the assistance of palliative patients (adults and paediatrics). Through initial three focus groups and an in-depth interview with healthcare professionals and family caregivers, we gained insights into proposals for improving the quality of the care palliative system.

3.1. Palliative Care Scales

To delve into the recommendations for improving the palliative care system, it is essential to focus on how healthcare professionals evaluate their palliative patients. The focus groups with healthcare professionals shed light on various evaluation indicators, offering contextual information on their usage, the appropriateness of their dimensions and the adequacy of their application in assessing palliative care patients. Among the main scales utilised and known by the clinical team at VAUCH, they were asked about some scales: Karnofsky, ECOG, Edmonton, Gijón, and FAMCARE. Notably, healthcare professionals at VAUCH emphasised that while they employ some of the mentioned scales, the Karnofsky and ECOG are the primary choices. Among these, ECOG is favoured from a feasibility point-of-view: this scale is brief, so it is easier to apply due to the unit time-attention constraints. As one professional explained, "We tend to write ECOG rather than Karnofsky because the assessment is much longer, so we use ECOG, which is shorter" (HP, M5).

However, it is acknowledged that despite the usage of these scales for palliative patient evaluation, they may not be the most suitable for this patient population. The ranges of the scales are viewed as somewhat general and may either overlook the specific challenges faced by the palliative patient or focus solely on a particular palliative group, the ones that are in an outpatient phase.

> "ECOG is not very suitable because it is too broad a scale, it is much better to use the Karnofsky or the PTS because the sections of ECOG correspond to two or three sections
>
> of the Karnofsky, so it is too broad and not very specific for palliative issues. . . so I think ECOG should not be used in palliative issues because it is too general. . ." (HM, M7).
>
> ". . .perhaps Karnofsky is more for palliative patients who are still in an ambulatory phase. . .the Karnofsky scale is used in the usual oncological patient. . .[. . .]" (HM, M8).

This insensitivity to attending to the particularities that palliative patients are facing is not exclusive to Karnofsky or ECOG; it affects widely used scales such as Edmonton and Gijón ones. The lack of sensitivity to address the specific challenges faced by palliative patients is not confined to scales like Karnofsky or ECOG; it extends to other widely utilised measures such as Edmonton and Gijón. This insensitivity is attributed to the omission of palliative symptoms such as insomnia, delirium, or asthenia from the evaluation, as well as the certain dimensions (e.g., socio-familiar or economic aspects) in assessing the sick; or the trickiness of estimating some of their dimensions.

> "I think that in general, the Edmonton scale is complete, but. . . there may be situations where it doesn't fit or there may be some symptoms that are not included. . ." (HM, M7).
>
> "[about Edmonton scale] There are some symptoms that are also frequent and that are not there. . . here he does not talk about delirium or insomnia. . . I do miss the nocturnal delirium quite a lot. I also miss the symptom of asthenia which is also very prevalent and very disabling" (HM, M8).
>
> "Yes, at home we have the Gijón scale in the computerized history, but I don't like it, I don't think it identifies socio-familial or economic

> needs. . . it is a bit cumbersome in some items. . . I don't think it is the most appropriate, no, nor do I know which other scale could replace it. . . the social, socio-familial, and economic dimension is very broad and very important, perhaps here the social workers would provide us with much more" (HM, M7).
>
> "As for the socio-family scale of Gijón, it is not specific to palliative care, and I think it's good that you don't reflect it" (HM, M8).

Finally, healthcare professionals express mixed views on the appropriateness of using the FAMCARE scale in assessing satisfaction with palliative care. While some suggest its utilisation as a valuable tool for evaluating care satisfaction and initiating improvement cycles, others argue against its current application. One notable critique is the absence of an item assessing whether patients and their families have received empathetic assistance from healthcare professionals. This oversight, according to dissenting voices, represents a crucial dimension in palliative care that directly influences overall satisfaction. The recommendation to add an item related to the provision of empathetic care underscores the importance of capturing the emotional and relational aspects of the patient-caregiver-professional dynamic. This nuanced perspective from healthcare professionals highlights the ongoing dialogue and refinement needed in the selection and application of evaluation tools like the FAMCARE scale in the complex landscape of palliative care.

Above the mixed opinion, healthcare professionals lean towards the FAMCARE scale, which is potentially the most effective evaluation indicator for palliative care patients, particularly with suggested modifications. This viewpoint emphasises the importance of tailoring evaluation tools to the unique needs and nuances of palliative care, acknowledging that a one-size-fits-all approach may not be suitable. The proposed modifications likely aim to enhance the scale's sensitivity to the specific challenges and dimensions relevant to palliative care, emphasising the holistic nature of patient and family needs. This professional perspective signals a recognition of the FAMCARE scale's potential to capture a more comprehensive understanding of the palliative care experience, making it a valuable candidate for refining the assessment process in this critical healthcare domain (Table 3).

Table 3. Main evaluation indicators of the condition of palliative care patients

Scale Name	Dimensions	Range	Perceptions of HCUVA Professionals	Use Reason
Kanofsky	Autonomy in the daily task development	0 (autonomous) to 100 (died) [22]	Time-consuming Just palliative patients in an outpatient phase targeted	Brevity
ECOG	Autonomy in the daily task development	0 (autonomous) to 4 (died) [23]	Excessively broad Non-palliative patients targeted	Brevity
Edmonton	physical and psychological alterations related to fragility	0 (non-vulnerability) to 17 (maximum vulnerability) [24]	Extremely long Time-consuming No disease stages covered Lack of significant symptoms (sleeplessness)	Includes interesting symptoms variables: fatigue, nausea, depression, anxiety, loss of appetite, etc.
Gijón	Socio-familiar and economic situation	0 (absence of social problem) to 25 (social problem) [25]	Non-palliative patients targeted	Includes socio-familiar support aspects
FAMCARE	Communication between family/ patient and healthcare professional Support: familiar, economic, social, spiritual, and psychological Physical symptoms treatment Availability of care and assistance Family/patient participation in decision-making	20 (unsatisfied) to 100 (totally satisfied) [26]	Palliative patients targeted Lack of empathic professional assistance dimension Suggestions for its incorporation with modifications	Palliative sensitivity

Note: Scale could vary depending on the version of the indicator application.

3.2. Advancing Palliative Care for Adults: Some Improvement Suggestions

In the context of advancing care for adults, several improvement suggestions emerged from the insights gathered from the focus groups that included professionals and families affected by palliative care. These insights contribute to the policy debates regarding healthcare system enhancements, specifically for adult palliative and their families' lives. The recommendations presented below correspond to the results obtained from the three discussion groups.

3.2.1. Lack of Resources and the Need to Increase the Headcount of Workers and Dimensions in Palliative Care Units

Professionals voiced some common demands for improving the working conditions of healthcare providers. They emphasised the constrained time and available resources they dispose of to attend to their patients, often resulting in the prioritising of certain tasks over others. More particularly, their time tends to be focused on addressing the physical symptoms reported by patients, which can lead to the neglect of patients' psychological needs and comprehensive evaluation.

> ". . .I think that tackling everything. . .it gives me a shock. . .but if you put a scale and we start little by little and the system helps us with another team of doctors and nurses. . .but right now we work. . .in a state of hierarchical prioritization. . ." (HP, N1).

> "I would prioritize the physical, what the symptoms are and that the symptoms are controlled and then the social, I mean, if a patient is in pain, has physical suffering, I think that would be the first thing to prioritize" (HP, N6).

The specific demand or suggestion arising from this discussion is crystal clear: an increase in the workforce would directly impact patient care overall given the complex and demanding need of palliative care patients. Professionals call for not only more healthcare staff but also the addition of social workers who could help in the evaluation tasks.

Families also demand the help of social workers and highlight the lack of economic and socio-familiar support within palliative care.

> ". . .There has to be someone else on top to follow up. . . I don't care who it is, but there is also a lack of follow-up, I have no complaints about palliative care, but financially, well, one must deal with the family" (HM, M7).

> ". . .Not only if he has support, but also where he lives, with whom he lives. . .how this patient is social, is the dimension that needs to be assessed with the social workers. . .[. . .]" (HP, M4).

The psychological, socio-familiar, and economic dimension is totally forgotten because of the lack of resources and workforces. Addressing these resource shortages by increasing the staff workforce and economic support systems would lead to a holistic improvement in palliative care.

3.2.2. Social and Resources Support: From Support Family and Patients' Groups to National Committees

Healthcare professionals and family members involved consistently emphasise the crucial role of addressing social aspects within the care framework. Recognising that palliative care extends beyond the purely medical domain, there is a shared acknowledgement of the impact that social support can have on patients and their families. To address this, there is a strong consensus among families on the necessity of establishing support groups within palliative care units or fostering collaborations with external associations linked to hospitals. These support groups are envisioned as multifaceted resources, serving not only as a source of emotional and psychological solace during the challenging journey of illness but also as invaluable repositories of information. The exchange of experiences and insights within these groups is seen as a means of empowerment, allowing individuals to navigate the complexities of palliative care more effectively. By integrating such social support mechanisms, healthcare professionals and family members envision a more holistic and compassionate palliative care approach that attends not only to the physical aspects of illness but also to the broader dimensions of human experience and connection.

> “. . .And as a possibility for you to make contact, to give you another resource, as. . . «There is this association, this other one». . . because sometimes it is good that others tell you about their experience or even inform you about where you are going to go. . . I wish someone had told me about this. . .” (FC 1).

> “. . .Imagine that through the palliative team, you could have access to being told «look, I am going to put you in contact with this association that also works in your issue», or «I am going to give you the name of the person who is working with relatives who are in a similar situation» and you decide whether to contact them” (FC 1).

The burden of palliative care extends beyond the families and patients directly affected, with healthcare professionals shouldering a significant weight in the process. It is imperative to recognise and address the needs of these professionals who play a pivotal role in delivering compassionate and comprehensive care. Healthcare professionals openly expressed the challenges they face, highlighting the stress and anxiety inherent in their work. Managing the emotional aspects of caring for patients with life-threatening illnesses adds a layer of complexity to their responsibilities. The emotional toll of witnessing the struggles and suffering of patients, coupled with the intense demands of the caregiving environment, underscores the importance of supporting healthcare professionals in their crucial roles. Addressing their well-being and providing resources for emotional resilience is not just a matter of professional development but is intrinsic to sustaining a healthcare system that can deliver high-quality, empathetic palliative care. Recognising and mitigating the burden on healthcare professionals contributes not only to their well-being but also ensures the continued delivery of effective and compassionate palliative care for patients and their families.

> “. . . there is no professional quality of life. . . In internal medicine, we used a questionnaire that measures the risk biopsychosocial and did not pass eh because for a very specific circumstance and there was measured the level of stress and we came out a stress level of ninety, an exaggerated thing, but usually do not pass any questionnaire. . .” (HP, N1).

> ” The level of anxiety is very high and close to depression is not far away.” “We do what we can, we try to take care of ourselves. . . it’s indeed very complicated, very complicated” (HP, N9).

> The healthcare team claimed that before the COVID-19 pandemic, they were followed up by a questionnaire on professional satisfaction to keep in mind that the professional should be considered and taken care of. Retaking these questionnaires could be a good proposition.

> “Covid came, and all got jammed. . . I take it for granted. Of course, you have stress, anxiety, and depression, of course, you do, but, but we don’t measure it, I think it should be measured. . . and we should have more resources to be able to do everything and do it well, and not doing this is not doing things well” (HM, M8).

Following this idea, some of the medical team also proposed the creation of committees in the national care system to make an adequate follow-up on the satisfaction and state of health of the professionals. Some ideas, above the creation of these units, could be to retake the questionnaires and control support sessions—as it was used before the COVID pandemic—and commit to acquiring necessary resources in palliative care units.

> “. . .There are things that are already measured and that are known from SECPAL—the Spanish Palliative Care Society—which has already mapped out the necessary resources. . .it is already known that there should be one home care team for every hundred thousand patients, right now. . . we are far short of meeting this target, far short because, at the beginning of the creation of the comprehensive plan, of the regional palliative care plan, it was done equitably to the number of health cards and how many support teams were needed. That was fourteen years ago. . . and the population has logically increased, so now there is a huge disparity between areas. Some areas have grown more and right now the resources are insufficient in all of them. . .” (HM, M3).

The common theme across these discussions is the central role of a comprehensive support system, not only for patients and their families but also for healthcare professionals. Such support should encompass psychological, emotional, socio-familiar, administrative, and economic aspects. The burden of care is, in professionals' words, the main reason why a patient is hospitalised in a final situation and not before. "There is an indissoluble union among patient, family and professional caregiver" (HM, M8).

3.2.3. Upgrading in the Professional Procedures

Improvements in the realm of the palliative care system should also extend to the way healthcare professionals operate within the system. The effectiveness and quality of healthcare and palliative care system are intrinsically linked to the knowledge, skills, and practices of healthcare providers. Among the initiatives to enhance healthcare standards stand the coordination between healthcare institutions and social services. This lack of coordination has left family members feeling abandoned. They highlight the importance of better cooperation between these entities:

> "A bit of abandonment of the system, of the transition. . .the transition when you are referred to palliative care, which is also a very complicated decision for them, even their family doctor, in a way, when he found out that we wanted this, he gave up a bit, as if he didn't agree. . .and it was as if he didn't want to know anything about the palliative care area, right? so of course. . .the coordination of the system is for me what failed the most" (FC 1).

Another critical aspect of professional procedures is the registration and systematisation of grief in clinical reports. While some professionals currently provide post-death support to families and believe this task is an essential part of palliative unit care work, this information is not systematically registered, leading to an under-documented account of this crucial aspect within the system. The bereavement of grief is a profound experience for families, and acknowledging and recording this process systematically is crucial for understanding the impact of palliative care.

Therefore, early engagement and better coordination with social services, along with the creation of grief care reports, are essential steps to upgrade the palliative care system, positively impacting patients and their families.

3.3. A Family Caregiver Experience in Paediatrics Palliative Care System: A Field to Explore

While many improvement suggestions are relevant to palliative care in general, it is crucial to recognise that palliative paediatrics has unique characteristics and specific needs due to the young age of the patients with life-limiting conditions. The insights into improvements in the paediatric palliative care unit were obtained thanks to the participation of the family's focus groups and the in-depth interview. Focusing on a specific case is not intended for generalisation but rather to provide a rich and illustrative example of a paediatric palliative care system. This approach appreciates the significant information garnered from the individual case while also acknowledging the need for future efforts and advancements in this field.

3.3.1. Same Problems but Different Intensities

Families in paediatric palliative face similar issues to those in adult palliative care but with distinct intensities. Resource scarcity and lack of available healthcare personnel generate difficulties for families who require constant care. The absence of paediatricians on weekends in the region of Murcia adds to the challenges. This situation has led pae diatricians to share their personal contact information with families to provide urgent assistance.

> ". . .Because the problem that Murcia had at that time was that it only had three teams to be able to attend. I think there are fifty or so families in a region where you have families ninety kilometres away like Yecla or any other place. Sometimes they didn't have the time to get there or to be on the phone to be able to assist you. So, the Murcia team. . .they gave their telephones. . ."
>
> To address this problem, they propose implementing rotating paediatrician teams and ensuring 24 h access to paediatric specialists (FC 4).

> “. . . They said that the best system was to rotate all of them at the same time so that they could cover the weekends. . .” (FC 4).

> “What does it take to have a 24-h on-call service? That is the essence. . .a team that is there, on duty, in the afternoons, evenings and weekends you need five teams for that to be effective. . .but if you only have one. . .that’s what happens in Murcia. . .” (FC 4).

The coordination issues are also extended to paediatric palliative care, with families reporting greatly suffering from the absence of communication channels between paediatricians, specialists, and other essential units of the healthcare system. For example, they inform that 112 (emergency call number in Spain) does not have the expedient for kids in palliative care, so if an emergency enters the system, families are not attended to correctly, leaving them in dire situations.

> “. . . If we call [to 112 number] it is because our palliative care team cannot come and because we need them to be attended directly by the doctor or directly taken to the hospital. . .we are in a very serious situation. A mobile unit or ICU unit must come, a normal ambulance cannot come. . .”.

> “Doctors speak directly with the specialists. . . in an admission, for example, there is direct communication. . . if there are any doubts or such. . . palliative or home doctors speak with the specialists to modify the treatment for everything [not to paediatricians]” (FC 4).

Another key to paediatric palliatives is emphatic support. Childhood diseases often involve complex medical conditions in a very early moment of life. Children in palliative care not only require excellent medical attention but also need emotional and psychological support, including attention to their families who navigate the challenging journey along-side them. This level of specialised care requires a team whose empathy and experience extend far beyond traditional healthcare.

> “. . .In summer, substitutes came in, but people who did not have much experience came. . . we had nurses who came from nursing homes who had not even been in a hospital, and they trembled when they had to do anything” (FC 4).

However, support means beyond the professionalism, experience, and human treatment of the professionals. It also means focusing on the special caregiver burden that families in paediatric palliative face. Having a kid in paediatric palliative units means giving up work and consequently reducing their family's financial income. This overburdening of the caregiver can lead even to the development of diseases by neglecting their health (e.g., not attending a mammography appointment).

> "If I have to go two nights without sleep, three nights without sleep, until [she names her daughter] comes out of that risk zone. . . of course you get overloaded" (FC 4).

> ". . .I had to give up law. . . I had three contracted lawyers, a huge office and I have to give it all up, it is impossible to make it compatible. You can't. . ." (FC 4).

> ". . .one of the partners does not work, sometimes even both, but normally one is working and the other is in caring. You can't go to the doctor, you can't go to buy medicine sometimes, that is if you have. . . if you have not an extended family or friends around you. . ." (FC 4).

> ". . .I am self-employed. The issue with so many requirements for a child to enter palliative care. . . the family has no resources. It is difficult to get direct help. There are fifty families and maybe twenty of those fifty need it. . . direct help to that family. The problem of getting food to the house or paying for electricity and water must be not a worry" (FC 4).

Support for these families must encompass psychological, emotional, socio-familiar, administrative, and economic aspects too. This support needs to be not only provided but also delivered promptly and directly.

> "Because this is not going there, ask for aid and have it. . . aid that is going to reach you after eight months or when your child has already died" (FC 4).

3.3.2. Particular Challenges in Paediatric Palliative Care

In paediatric palliative care, there are unique challenges beyond those faced by adults. Families expressed the need for continuity in the composition of their care teams due to the close bonds that form between families and their medical teams. Changes in the care team can disrupt the trust and require unnecessary effort to start by becoming familiar with the needs of the family and the patient's situation.

> ". . .In November of that year, they said that they were removing everyone, and new people were coming in without any training, without having been in palliative care, and without knowing the families and the children here. During this time, you create a bond with the paediatricians and that is very important because not all families know how to communicate in the same way. Not all families for example speak fluent Spanish like us, or the children don't. They can't express everything. Each family has a specific need. . ." (FC 4).

Regarding changes in the configuration of the medical team, it is essential to handle these transitions with sensitivity and minimal disruption. The lives of both patients and families are already greatly shaken by the illness challenges they are facing, so dramatic adjustment can exacerbate the difficulties they encounter.

There is also a common demand for addressing the substantial gap that exists between paediatric palliative care units and adult palliative care units; as well as between home care palliative care units and hospital-based units. Families advocate for the establishment of transitional units.

> "My daughter is now eighteen years old. We are still in paediatrics because she is still an oncological child and is a complex child and well, we still have a few days to go to adults. The same thing happens with children who are in palliative care and are old enough to go to adult palliative care. We need a transition team, a team between paediatrics and adults" (FC 4).

> "That child goes to home care and the truth is that the home care service has nothing to do with paediatrics'. . . if there was a transition team. . . that family with that child. . . It would make everything much easier for the family as well" (FC 4).

Another specific care involving the units' requirements is about expanding "complex units". These units are created for children with rare and life-threatening illnesses. These facilities should not be considered exceptions, as their contribution to both the families and patients is profoundly significant. Complex units offer a unique and invaluable solution, providing concentrated attention and specialised treatment within a single care facility, thereby eliminating the need for constant transfers and consultations with various specialists. Is a more individualised treatment that functions, in the eyes of family caregivers, as a "protective bubble" (FC 4).

4. DISCUSSION

The predominant research in this field tends to be qualitative studies, primarily due to the challenges associated with accessing representative samples and the complexities involved in studying the needs of patients and families facing life-threatening illnesses.

Nevertheless, we aim to complement this prevailing trend by incorporating quantitative studies into this discussion. This approach seeks to strengthen the robustness of the results obtained in our study, challenging the notion that our stakeholders are solely the ones experiencing dissatisfaction and serving as the primary motivation for their participation.

Professionals in the VAUCH team acknowledged the prioritization of physical symptoms over psychological aspects due to time constraints, workforce shortages, and inadequate institutional support, as well as the deficiencies in their training, as reported in another study within VAUCH [27]. Families not only in this research but also in previous studies conducted in VAUCH, especially in the field of neonatal care grieving [14], echoed this sentiment, feeling abandoned within a treatment approach lacking in social and emotional dimensions. This is a clear error due to the implication fact that has been shown: the alleviation of anxiety and resolution of depression, as well as the provision of verbal and nonverbal support, positively influences the quality of dying of palliative patients [28]. Moreover, research also indicates a notable reduction in the burden on family caregivers when these emotional and psychological dimensions are adequately addressed [29].

As a result, families expressed in our research some changes in the support they received as well as some specific demands such as the enhancement of the association role in the healthcare system. Social support is remarked as fundamental in quantitative studies [30,31]. A review of community-based palliative care (CBPC) programmes [32] found that programmes based on social networks and efficient coordination between community, home-based care programmes, and primary health care could improve patients' life quality as well as caregiver burden. This approach could be one of the responses to address some of the deficiencies we detected, such as the scarcity of workforce (of healthcare professionals but also social workers) and inadequate resources for a more comprehensive treatment. Previous studies [31,32] have reported the positive impact of social support in reducing hospitalisations. The provision of social support to families and patients serves as a buffer against stressors, enhances coping mechanisms and provides essential assistance in patient care. This approach results in a notable reduction in caregiver burden, leading to an improvement in overall patient treatment. Importantly, this positive impact extends to a decrease in the frequency of hospitalisations and the duration of hospital stays that could have an impact of over 2% on a country's GDP [32]. Therefore, when evaluating the feasibility of the recommendations proposed in this research, it is crucial to recognise that financial investment not only aligns with enhancing the quality of palliative care for patients but also contributes to the satisfaction and dignity of professionals' work conditions while simultaneously health improvements, in turn, result in cost savings for healthcare institutions and the broader healthcare system.

A way to ensure a comprehensive treatment of palliative patients is also providing good quality indicators or scales to evaluate these patients and their needs. In our study, we recollect the distinctive indicators the VAUCH team used and known to evaluate palliative patients, arriving at the final idea that changes should be made in this procedure, too. Specifically, we propose the adoption of the FAMCARE scale with adjustments, emphasis-ing some dimensions, such as the measurement of empathic professional assistance. This modification aligns with findings from studies on the most crucial elements valued by palliative patients and their families [28]. These elements include effective communication and shared decision-making, expert care, respectful and compassionate treatment, and trust and confidence in clinicians. Integrating these considerations, along with insights gleaned from our data (p., e.g., attention to social, psychological, administrative, and economic dimensions) underscores the inadequacy of current scales like Kanorsky, ECOG, Edmonton, or Gijón in addressing the holistic needs of palliative patients. Thus, adopting modified indicators is imperative for accurately capturing and addressing the multifaceted requirements of palliative care recipients. Despite presenting FAMCARE as a promising avenue for enhancing the holistic evaluation of palliative patients, the commitment requires sufficient time from health professionals. Therefore, to ensure the improvement of palliative care for patients and their families, enhancements in work conditions and the availability of resources must be made.

Other aspects of attending are the paediatric palliative needs and the improvements that can be made. As we observed, paediatric palliative patients deal with other intensities of palliative care issues because of the patients' early age. Previous studies on paediatric palliative care units have studied their critical issues and the way to improve them. Among the findings, they remarked the coordination issues between paediatrics and other professionals such as social workers or the rest of the medical team [33,34], the lack of emotional support (during and after de illness [34–36], the need of maintaining continuity in the medical team, the constant of attention by paediatrics (24-h attention) due to the special bond and trust created with families [34] and the difficulties related to the transition from paediatric palliative to adult palliative [36], which can suggest the idea of the establishment of transition units.

Finally, there is a need for further research on quantitative studies of the long-term benefits of interventions and a focus on socio-economic aspects. It is also crucial to assess the feasibility of the suggestions and changes in palliative care policies to meet the demands of paediatric palliative care. Above all, some insurgencies should be transferred to hospitals to emphasise the exploration of new applications of the FAMCARE scale and understanding of the associated costs. Further research should attend to these gaps. Additionally, there is a call for incorporating the bereavement and grief aspects into clinical reports.

5. CONCLUSIONS

This research has highlighted several aspects of VAUCH's palliative care system, pointing out the shortage of healthcare staff and resources to comprehensively assess and address the needs of palliative patients and their families. It also pointed to the need to establish the use of improved indicators to measure the quality of care and assistance and identified problem areas in palliative care services, as well as proposals for improvement.

Several suggestions have been put forth by healthcare professionals and families affected by a system that has often left them feeling abandoned. These recommendations span from providing holistic caregiving attention to the psychological, emotional, socio-familial, administrative, and economic aspects of care to expanding the creation of complex units and establishing new ones or strengthening the connection with palliative care associations. All these recommendations should be thoroughly examined in the context of paediatric palliative care due to their unique challenges and characteristics. Further-more, it is essential to incorporate some of the families' petitions, such as maintaining continuity in the medical teams or establishing transitional units. Addressing these areas of improvement is crucial to providing more comprehensive, patient-centred, and empathetic palliative care for both adults and children.

Our research has gone beyond merely identifying the problems within the palliative care system; it has provided valuable insights that have become points for better health policies and the necessity to implement modifications for a more comprehensive evaluation of palliative patients. Furthermore, the findings from this study should be applied to other hospitals to discern common issues and determine the most effective suggestions, considering the varying resources available in each case.

6. Strengths and Limitations

The study shows some deficiencies in the palliative care systems and contributes to the policy field with some suggestions and ideas for implementation that can be made in the palliative care system. These suggestions have been conveyed to hospital policymakers and policymakers of the regional healthcare system. This proactive dissemination aims to foster meaningful dialogue and collaborative efforts toward addressing and implementing positive changes in the palliative care landscape.

However, it is important to acknowledge certain biases inherent in the research methodology, particularly related to purposive sampling. While this sampling strategy facilitated access to challenging stakeholder's healthcare professionals grappling with time constraints and families navigating difficult moments it comes with limitations in terms of representativeness. The sampling process, managed by the clinical team of HCUVA, may have inadvertently led to the inclusion of highly engaged or dissatisfied participants, influencing the generalizability of the findings. Moreover, the specific context of the hospital introduces an additional layer of potential bias. The unique operational and resource aspects of HCUVA may affect the transferability of our findings to various healthcare settings, underscoring the importance of exercising caution when interpreting and applying the study's outcomes in diverse contexts.

Another notable bias pertains to the homogeneity of the sociodemographic characteristics of the sample, consisting entirely of white Spanish participants. This limited representation raises concerns about the applicability of the findings to individuals from minority ethnic communities. Additionally, the predominantly female composition of the sample (10 out of 12 participants) may not fully capture the experiences of male participants or the unique challenges faced by family caregivers of paediatric patients, as only one such caregiver participated, which also reflects the feminisation of care.

To strengthen the robustness of the study's findings, future research endeavours should focus on increasing the sample size, ensuring greater sociodemographic heterogeneity among participants, and exploring palliative care units in diverse demographic settings within the country as well as attending more paediatric family caregivers. This approach would enhance the comprehensiveness and generalisability of the research findings, contributing to a more nuanced understanding of palliative care challenges and potential solutions.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/healthcare12010065/s1 Table S1: Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist.

Author Contributions: Conceptualization, L.L.-M. and F.R.-R.; methodology, L.L.-M. and F.R.-R.; formal analysis, P.G.-M. and L.L.-M., investigation, L.L.-M. and F.R.-R.; resources, F.R.-R.; writing—original draft preparation, P.G.-M. and L.L.-M.; writing—review and editing, P.G.-M., L.L.-M., F.R.-R. and J.G.-F.; supervision, F.R.-R. and J.G.-F.; funding acquisition, F.R.-R. All authors have read and agreed to the published version of the manuscript.

Funding: This project has received funding from MCIN/AEI/10.13039/501100011033, grant PID2019-110997RB-I00.

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki, and Ethics approval was granted by Ethics Committee on Research with Medicaments of VAUCH (ref. 2020-9-3).

Informed Consent Statement: Written informed consent was obtained from all subjects involved in the study.

Data Availability Statement: Data are contained within the article.

Acknowledgments: Authors extend their gratitude to the participation and valuable contributions of family caregivers and health professionals to this research endeavour. Furthermore, the authors express their appreciation to the VAUCH team for the support and their role in streamlining the recruitment process.

Conflicts of Interest: The authors declare no conflict of interest.

REFERENCES

1. Organización Mundial de la Salud. Cuidados Paliativos. 2020. Available online: https://www.who.int/es/news-room/fact-sheets/detail/palliative-care (accessed on 10 November 2023).
2. Davies, E.; Higginson, I.J. Better Palliative Care for Older People; World Health Organization, Regional Office for Europe: Geneva, Switzerland, 2004. Available online: https://pesquisa.bvsalud.org/portal/resource/en/lis-10864 (accessed on 10 November 2023).
3. Pinilla, J.M.G.; Díez-Villanueva, P.; Freire, R.B.; Formiga, F.; Marcos, M.C.; Bonanad, C.; Leiro, M.G.C.; García, J.R.; Molina, B.D.; Grau, C.E. Documento de consenso y recomendaciones sobre cuidados paliativos en insuficiencia cardiaca de las Secciones de nsuficiencia Cardiaca y Cardiología Geriátrica de la Sociedad Española de Cardiología. Rev. Española Cardiol. 2020, 73, 69–77.
4. Formiga, F.; Balaguerma, O.F. Terminal heart failure: Continuous care is essential from the onset. Rev. Esp. Geriatr. Gerontol. 2019, 54, 2–4.
5. Rial Carrillo, I.; Martínez-Santos, A.E.; Rodríguez-González, R. Características del empleo de la vía subcutánea para la administración de medicamentos en pacientes en cuidados paliativos. Index Enfermería 2020, 29, 37–41.
6. Barbero, J.; Díaz, L. Diez cuestiones inquietantes en cuidados paliativos. In Anales del Sistema Sanitario de Navarra; Gobierno de Navarra, Departamento de Salud: Pamplona, Spain, 2007; Volume 30, pp. 71–86.
7. Boceta-Osuna, J.; Peiró-Peirón, A.; Cevas-Chopitea, F.J.; Vidal-Castro, L.M.; Acedo-Gutiérrez, M.S.; Mayoral-Rojals, V.; SED Bioethics Working Group (BioSED). Problemas éticos en el manejo del dolor. Estudio cualitativo mediante entrevista de reflexión abierta. Rev. Soc. Española Dolor (SED) 2020, 27, 89–96.

8. Martínez-Sellés, M.; Vidán, M.T.; López-Palop, R.; Rexach, L.; Sánchez, E.; Datino, T.; Cornide, M.; Carrillo, P.; Ribera, J.M.; Díaz-Castro, Ó.; et al. Cardiopatía terminal en el anciano. Rev. Española Cardiol. 2009, 62, 409–421.
9. Cantero, M.J.P.; Asencio, J.M.M.; Marchena, L.N.; González, M.D.R.V.; Echàniz, J.S.; Ortega, L.R.; Alba, R.M. Final de la vida en pacientes bajo el cuidado de equipos de cuidados paliativos pediátricos. Estudio observacional multicéntrico. An. Pediatría 2022, 96, 394–401.
10. Mitchell, S.; Morris, A.; Bennett, K.; Sajid, L.; Dale, J. Specialist paediatric palliative care services: What are the benefits? Arch. Dis. Child. 2017, 102, 923–929.
11. Kwong, M.; Curtis, E.E.; Mell, M.W. Underutilization of Palliative Care for Patients with Advanced Peripheral Arterial Disease. Ann. Vasc. Surg. 2021, 76, 211–217.
12. Scally, C.P.; Robinson, K.; Blumenthaler, A.N.; Bruera, E.; Badgwell, B.D. Identifying Core Principles of Palliative Care Consultation in Surgical Patients and Potential Knowledge Gaps for Surgeons. J. Am. Coll. Surg. 2020, 231, 179–185.
13. Olmsted, C.L.; Johnson, A.M.; Kaboli, P.; Cullen, J.; Vaughan-Sarrazin, M.S. Use of palliative care and hospice among surgical and medical specialties in the Veterans Health Administration. JAMA Surg. 2014, 149, 1169–1175.
14. INE. Encuesta de Población Activa (EPA). Primer Trimestre 2014; Instituto Nacional de Estadística: Madrid, Spain, 2014.
15. Plaza Fornieles, M.; García-Marcos Barbero, P.; Galera Miñarro, A.M.; Barbieri, G.; Bellavia, N.; Bermúdez Cortés M del, M.; Navarro Mingorance, Á. Eficacia del Equipo de Cuidados Paliativos Pediátricos de Murcia según la experiencia de los padres. An. Pediatría 2020, 93, 4–15.
16. Campbell, S.; Greenwood, M.; Prior, S.; Shearer, T.; Walkem, K.; Young, S.; Bywaters, D.; Walker, K. Purposive sampling: Complex or simple? Research case examples. J. Res. Nurs. 2020, 25, 652–661.
17. Devik, S.A.; Lersveen, G.L. Specialist and Primary Physicians' Experiences and Perspectives of Collaboration While Caring for Palliative Patients—A Qualitative Study. Healthcare 2023, 11, 2188.
18. Guba, E.G. ERIC/ECTJ Annual Review Paper: Criteria for Assessing the Trustworthiness of Naturalistic Inquiries. Educ. Commun. Technol. 1981, 29, 75–91.

19. Porter, M.E. What Is Value in Health Care? N. Engl. J. Med. 2010, 363, 2477–2481.
20. Seniwati, T.; Rustina, Y.; Nurhaeni, N.; Wanda, D. Patient and family-centered care for children: A concept analysis. Belitung Nurs. 2023, 9, 17–24.
21. Tong, A.; Sainsbury, P.; Craig, J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. Int. J. Qual. Health Care 2007, 19, 349–357.
22. Mor, V.; Laliberte, L.; Morris, J.; Wiemann, M. The Karnofsky performance status scale: An examination of its reliability and validity in a research setting. Cancer 1984, 53, 2002–2007.
23. Roila, F.; Lupattelli, M.; Sassi, M.; Basurto, C.; Bracarda, S.; Picciafuoco, M.; Boschetti, E.; Milella, G.; Ballatori, E.; Tonato, M.; et al. Intra and interobserver variability in cancer patients' performance status assessed according to Karnofsky and ECOG scales. Ann. Oncol. 1991, 2, 437–439.
24. Chang, V.T.; Hwang, S.S.; Feuerman, M. Validation of the Edmonton Symptom Assessment Scale. Cancer 2000, 88, 2164–2171.
25. Alarcón, A.T.; González, J.I. La Escala Socio-Familiar de Gijón: Instrumento útil en el hospital general. Rev. Española Geriatría Gerontol. 1998, 33, 179.
26. Kristjanson, L.J. Validity and reliability testing of the FAMCARE Scale: Measuring family satisfaction with advanced cancer care. Soc. Sci. Med. 1993, 36, 693–701.
27. Hiciano Guillermo, A.I.; Jover Aguilar, M.; Martínez-Alarcón, L. Nivel de conocimientos en cuidados paliativos de las enfermeras; un estudio descriptivo en el Área de Salud VII de la Región de Murcia. Med. Paliativa 2020, 27, 79–87.
28. Cheng, S.; Dy, S.; Hu, W.; Chen, C.; Chiu, T. Factors affecting the improvement of quality of dying of terminally ill patients with cancer through palliative care: A ten-year experience. J. Palliat. Med. 2012, 15, 854–862.
29. Ate¸s, G.; Ebenau, A.F.; Busa, C.; Csikos, Á.; Hasselaar, J.; Jaspers, B.; Menten, J.; Payne, S.; Van Beek, K.; Varey, S.; et al. "Never at ease"—Family carers within integrated palliative care: A multinational, mixed method study. BMC Palliat. Care 2018, 17, 39.
30. Bradley, N.; Lloyd-Williams, M.; Dowrick, C. Effectiveness of palliative care interventions offering social support to people with life-limiting illness. A systematic review. Eur. J. Cancer Care 2018, 27, e12837.

31. Vernon, E.; Courtney, M.; Kowalczyk, M. Measuring effectiveness in community-based palliative care programs: A systematic review. Soc. Sci. Med. 2022, 296, 114731.
32. French, E.B.; McCauley, J.; Aragon, M.; Bakx, P.; Chalkley, M.; Chen, S.H.; Christensen, B.J.; Chuang, H.; Côté-Sergent, A.; De Nardi, M.; et al. End-of-Life Medical Spending In Last Twelve Months of Life Is Lower Than Previously Reported. Health Aff. 2017, 36, 1211–1217.
33. Bosquet-del Moral, L.; Campos-Calderón, C.; Hueso-Montoro, C.; Pérez-Marfil, N.; Hernández-Molinero, Á.; Arcos-Ocón, L.; Cruz-Quintana, F. Vivencias y experiencias de duelo en madres tras un proceso de enfermedad oncológica de sus hijos. Med. Paliativa 2010, 19, 64–72.
34. Tagarro García, A.; Ruza Tarrió, F. Percepción subjetiva de los padres sobre los cuidados al final de la vida en una UCIP y cómo mejorarlos. An. Pediatría 2008, 69, 119–123.
35. Casanueva-Mateos, L.; Ruiz-López, P.; Ignacio Sánchez-Díaz, J.; Ramos-Casado, V.; Belda-Holfheinz, S.; Llorente-de la Fuente, A.; Mar-Molinero, F. Cuidados al final de la vida en la unidad de cuidados intensivos pediátricos. Empleo de técnicas de investigación cualitativa para el análisis del afrontamiento de la muerte y situaciones críticas. Rev. Calid. Asist. 2007, 22, 36–43.
36. Fuentes, L.; Bernadá, M.; Fuentes, L.; Bernadá, M. Transición de la atención sanitaria de adolescentes con enfermedades que amenazan o limitan sus vidas desde equipos de cuidados paliativos pediátricos a equipos de adultos. Arch. Pediatría Urug. 2021, 92, e404.

CHAPTER VI

DISCUSSION AND CONCLUSIONS

CHAPTER VI. DISCUSSION AND CONCLUSIONS

The starting point for this thesis is basically determined by two phenomena that Western countries have been experiencing for decades: the first is demographic change and the consequent ageing of the population, and the second is the increase in the prevalence of chronic diseases. Both are having an impact on the use of care resources by different population groups and on the health and social systems that are important pillars of the welfare state. The population is living longer and longer and the percentage of older (or very old) people is progressively increasing.

This situation, characterised by demographic changes and an increase in chronic diseases, has significant implications for health care provision, in particular for older people facing chronic diseases. As the population of Western countries ages and the prevalence of chronic diseases increases, the demand for specialised care resources, including PC services, intensifies. With people living longer and an increasing proportion reaching old age, there is a critical need to address the unique care requirements of this demographic, ensuring that PC interventions are tailored to support their complex health and social needs within the health and social systems of the welfare state. Efforts to improve PC for the chronically ill older people must be aligned with the evolving dynamics of population demographics and health challenges to provide effective, compassionate and sustainable care solutions.

The use of different qualitative methodologies has enabled an understanding of the subjective realities of patients, their families and professionals working in PC, exploring the meanings of discourses in the particularly sensitive environment of end-of-life care (Steinhauser et al, 2009; Lim et al, 2017). This methodology is particularly effective in generating rich and contextual data through the examination of language in diverse fields such as health and social work. By focusing on the nuanced needs and concerns of stakeholders, qualitative research provides decision-makers with essential insights to design tailored interventions and policies that effectively address complex social problems, such as those studied in this doctoral thesis.

However, while qualitative research offers deep insights, it also has weaknesses, such as researcher subjectivity and potential biases. To mitigate these problems, the thesis prioritised reflexivity, that is, continuous self-awareness and critical reflection on personal beliefs and influences throughout the research process while minimising bias. Furthermore, robust strategies such as triangulation and building rapport with interview and focus group participants were employed in the studies comprising the thesis to ensure the reliability of the data, and systematic and well-established approaches such as thematic analysis, grounded theory or content analysis were adopted.

As a strength, in order to try to understand the complex and multifaceted needs of complex chronic older patients, this doctoral thesis took into account all the actors involved in the provision of PC: patients, their carers and health and management staff working in the provision of this care (doctors, nurses, workers, social workers, psychologists, managers). This provides robustness to the results that can guide policy makers to improve PC delivery systems in a holistic way.

Regarding ethical factors, as previously mentioned, this thesis addressed sensitive issues and vulnerable populations, which required strict ethical considerations to be followed during the qualitative studies conducted. To this end, the principles of privacy, confidentiality and informed consent were followed. Ethical approval was obtained from hospital ethics committees and the autonomy and well-being of participants was safeguarded at all stages of the research.

Moreover, a bias observed in the FGs and patient interviews in the studies conducted is related to the homogeneity of the sample's sociodemographic characteristics, which was composed entirely of white Spanish participants. This limited representation raises doubts about the applicability of the results to individuals from minority ethnic communities. Furthermore, the predominantly female composition of the sample of caregivers may not fully reflect the experiences of male participants but it also reflects the feminisation of caregiving.

Future research should focus on increasing the sample size, ensuring greater socio-demographic heterogeneity among participants and exploring palliative care units in diverse demographic settings across the country – including rural settings too –, as well as reaching out to more family caregivers of paediatric patients. This approach would improve the comprehensiveness and generalisability of the research results.

Regarding the instruments analysed to assess the quality of care, it has not been possible to perform a meta-analysis to systematically assess the latent structure of the tools analysed; this would be a step for future studies.

The main conclusions reached after comparing the results obtained in the four studies that compose this thesis are presented below, analysing the hypotheses proposed, establishing whether or not they have been confirmed and the level of achievement of the objectives associated with them.

Hypothesis 1

Patients and family members will mostly identify unmet psychosocial needs over physical needs.

Patients and carers reported a lack of support for their psychosocial needs, while they felt that their physical needs were well met. However, in the studies conducted, patients and relatives highlighted that spiritual needs are neglected even though they are fundamental. Therefore, although this hypothesis has been confirmed, as shown in papers 1 and 2, spiritual needs should have been taken into account in formulating the hypothesis.

With regard to **specific objective 1,** emotional/mental and social health was highlighted by patients as the most pressing need. Symptoms or experiences associated to anxiety and depression related to the disease process have been the most highlighted need by patients in papers 1 and 2 which form part of this doctoral thesis. In reference to **specific objective 2,** the needs identified by the interviewed carers mirrored those identified at the patient level (psychosocial support). Additionally, carers emphasised bereavement support, the need for more information and human connection with professional involvement in decision making and financial support to care for both patients and themselves. Notably, patients and carers noted a lack of support for their psychosocial and spiritual needs, while they felt that their physical needs were well met. Therefore, the results obtained have allowed both objectives to be achieved.

Hypothesis 2

Healthcare professionals will identify barriers to the identification of complex chronic patients in need of PC.

Papers 1, 2 and 4 provide strong support for hypothesis 2. Healthcare professionals identified several barriers to the identification of complex chronic patients with palliative needs. Firstly, they reported the absence and/or lack of knowledge of tools to help identify this patient profile. The second barrier they identified was the scarce of coordination between services to detect these patients who are often treated by different specialists without interconnection between professionals. Consequently, the results confirm hypothesis 2.

Regarding **specific objective 3**, both in the literature review (paper 1) and in the interviews and FG (paper 2 and 4), the lack of standardised screening tools to detect complex chronic older patients in need of PC was identified as a barrier. Standardised tools are needed for the early detection of complex chronic older patients with palliative needs, some of which currently exist but are not known to clinicians and are not used in their daily practice.

It is estimated that at least 75% of patients would benefit from access to PC during their end-of-life (Etkind et al., 2017). However, uncertainty about prognosis is cited as a common barrier to referral to PC, particularly for patients with non-malignant diseases. (Murray et al., 2015). For this early detection of palliative patients, the InAdvance project proposed a set of Machine Learning tools capable of making predictions about mortality and frailty of older patients, oncology and non-oncology, so that healthcare professionals can benefit from quantitative approaches on data-driven evidence when deciding on advance care planning. Three different but complementary models were created: (a) a 1-year mortality classifier that functions as a binary predictor; (b) a survival regression model aimed at obtaining a prediction in days from admission to death; and (c) a 1-year frailty classifier to predict the health status, as assessed by the Frailty Index, of a patient 1 year after admission. In their study, Blanes et al. (2022) considered that the combination of mortality and frailty criteria, functioning as complementary sources of information, can positively impact on the detection of needs to initiate PC conversations.

In paper 1 and 4, the lack of coordination between professionals was highlighted as a barrier for professionals, hindering the identification of complex chronic patients with palliative needs. Due to fragmented care and poor communication between the different specialists, professionals only see a partial picture of the pathologies affecting older patients, making it very difficult to identify them.

Hypothesis 3

There is a wide divergence in the components used by the different tools that measure quality of care.

The three instruments analysed in paper 3 to measure quality of care in PC, namely QLQ-C30, ZBI, and FAMCARE, show variability in the dimensions they include, linked to the characteristics of the sample, the population studied, cross-cultural variability, the design of the questionnaire and the analysis techniques employed. This variability may lead to differences in the assessment of quality of care, which would have an impact on the responses to improve this quality. Especially in the case of FAMCARE, most of the factor structures differ from Kristjanson's initial proposal. Hypothesis 3 has therefore been confirmed.

The systematic review carried out in paper 3 has allowed us to analyse three of the most commonly used instruments for evaluating the quality of care received (**specific objective 4**). Specifically, quality of life, overload and satisfaction with care. The use of tools to measure quality of life, overload and patient and caregiver satisfaction in palliative care is key to improving the delivery of PC. The QLQ-C30 is widely used to measure quality of life mostly in cancer patients. ZBI has demonstrated high reliability and good validity for measuring family caregiver burden related to the care of elderly people with dementia, but also in palliative care settings. FAMCARE is a widely used scale to measure satisfaction with care and has been applied internationally to assess satisfaction with palliative care. Specific objective 4 has been satisfactorily achieved.

Hypothesis 4

Professionals and family caregivers will indicate psychosocial and bereavement support as a fundamental element of quality in PC.

This hypothesis has been confirmed by papers 2 and 4. Both papers highlighted the need for health professionals and family caregivers to include bereavement support and psychosocial care as a necessary element of quality palliative care. Bereavement follow-up of caregivers was highlighted also as an urgent issue, as professionals consider it to be neglected. Professionals and family members also highlighted that there was a lack of time for personalised care to address bereavement as one of the key issues in bereavement care as highlighted in some recent studies in the literature (Boven et al., 2022). In addition, the lack of care for family members in a bereavement process can lead to complicated or persistent, prolonged and intense bereavement that makes it impossible for family members to continue with their normal activities (Mason et al., 2020). Social workers and other clinicians should be in contact with family members to identify family caregivers at higher risk of complicated bereavement and refer them or implement early intervention to lessen its impact.

Specific objectives 5 and 6 are addressed in papers 2 and 4. Regarding specific objectives 5, carers recommended as essential elements to increase the quality of PC care to provide holistic care - paying attention to the psychological, emotional, socio-familial, administrative and economic aspects of care - and to expand the creation of complex units and establish new ones or strengthen the connection with palliative care associations. As reported in other studies in the current literature (Bijnsdorp et al., 2021; Hudson et al., 2018) bereavement support for family carers is a key aspect of quality palliative care and this was also identified as a key aspect in studies 2 and 4.

The aspects mentioned in the previous paragraph, bereavement support for relatives and holistic care, were also highlighted by professionals as key elements of quality palliative care (**specific objective 6**). The need for specific training in palliative care was highlighted by professionals in all services (primary care, ICU, nursing homes, emergency, home hospitalisation units), especially to provide care to non-cancer patients. This training would help them gain confidence to talk openly with patients and carers about palliative care. Professionals also highlighted the need for specific pathways for complex chronic older patients and more time to attend these patients in a holistic way and to discuss with them and their relatives their needs and wishes regarding care pathways. Specific objectives 5 and 6 have therefore been achieved.

Hypothesis 5

The quality of PC care will be improved through consideration of interdisciplinary teams and increased communication between care teams and patients.

Hypothesis 5 has been largely confirmed by papers 2 and 4, which highlighted the need to implement interdisciplinary teams in PC units and stressed the need to expand and improve communication between PC teams and patients and their families.

With regard to **specific objective 7**, fragmentation and discontinuity of PC was identified as a challenge to provide effective PC. This fragmentation and discontinuity in care results in the provision of limited, discontinuous, intermittent, sporadic and disorganised care when it comes to responding to the needs of complex chronic older patients who express dissatisfaction with the care they receive. Fragmentation of care is associated with negative health and social care outcomes such as unnecessary care interventions (hospital readmissions, emergency room visits), risk of complications (disability, pressure ulcers), increased care costs (unnecessary interventions, unnecessary medical tests), burnout and family overload (Snow et al., 2020; Joo., 2023). Older people experience more than one end-of-life condition, leading to a complex need for care and support; this demands a multidisciplinary approach that responds to physical, emotional, spiritual and social needs.

With reference to **specific objective 8**, to improve the effectiveness and comprehensiveness of the palliative care system, it is imperative to implement strategic improvements focused on the management of complex chronic diseases among older patients. These improvements should streamline management processes, ensuring more effective and targeted actions that optimise patient outcomes. Among the improvements identified by papers 2 and 4 the following were highlighted: it would be necessary that social services and health resources are coordinated and integrated taking into consideration a more holistic view of the patient.

The triad (patient-family-professional) requires constant communication; communication between patients and carers and professionals facilitates the work of the professional, as they have access to all the information necessary to design an itinerary centred on the patient's needs. The participation of patients and relatives in decision-making is very crucial for them to feel involved in the decision-making process of the health care pathway in which they are immersed.

Previous studies such as those carried out by Vernon et al. (2022) and French et al. (2017) have reported the positive impact of social support in reducing hospitalisations. The provision of social support to families and patients serves as a buffer against stressors, improves coping mechanisms and provides essential assistance in patient care. This approach results in a significant reduction in caregiver burden, leading to an improvement in overall patient management. This positive impact extends to a decrease in the frequency of hospitalisations and the length of hospital stays that could have an impact of more than 2% on a country's GDP (French et al., 2017).

Primary care and Home Care Services can play a key role in fostering a change in the culture of care by introducing improvements in the management, care and referral of older and/or chronically ill patients. For many patients, palliative care can be optimally provided through existing general and primary health services, which are appropriate to their needs and wishes and those of their family, and which fit into their own socio-cultural environment. Home-based palliative care, as outlined in the literature, can contribute to reduce hospitalisation costs (Gonzalez-Jaramillo et al., 2021), improve health promotion (Leclerc-Loiselle et al., 2024) and improve continuity of care (Morey et al., 2021).

The results obtained in studies 2 and 4, as mentioned in the previous paragraphs, show that objectives 7 and 8 have been achieved.

CHAPTER VII

POLICY RECOMMENDATIONS

CHAPTER VII. POLICY RECOMMENDATIONS

In September 2022, the European Commission presented the European Care Strategy (European Commission, 2022) to ensure high quality, affordable and accessible care services across the European Union and to improve the situation of both care recipients and carers, professional or informal. Although the Council's recommendations adopted were warmly welcomed by representatives of older people on access to affordable and high quality long-term care, the recommendations did not specifically mention palliative care. In this doctoral thesis, taking into account this shortcoming, some recommendations are made that would allow progress to be made in improving PC for older people with complex chronic pathologies.

The policy recommendations proposed below are based on the extraction of results from the development of this doctoral thesis, in which information has been collected from healthcare professionals involved in PC (direct care, managers), PC patients and relatives or carers of PC patients. The recommendations made here have been reiterated by all the agents (professionals, patients and relatives) who have participated in the qualitative studies (interviews and FGs) and have also been repeated in the international literature analysed in this doctoral thesis.

Policy makers should take into account the situation of poor palliative care provision in Spain and the critical consequences it has on the health and well-being of vulnerable older patients and their families, as well as on the health and performance of health professionals. These recommendations are intended to serve as suggestions for policy makers to provide solutions based on a holistic and human rights approach to complex chronic elderly patients. In designing any palliative care strategy, policy makers need to consider the gender perspective and analyse the possible differences that may exist in the provision of palliative care, based on the premise that the majority of care provision relies on women.

- **Development of a common PC strategy for the whole Spanish Healthcare System to ensure early access to PC for complex chronic older patients.**

  A multi-level rethink of health policies, health education and community support systems is needed to address the problems of the older population with chronic non-communicable diseases. In terms of early PC provision, easy and well-organised accessibility to PC for patients suffering from chronic non-oncological diseases would be one of the proposals for improvement to be implemented. Often chronic patients and their families suffer from erroneous referral processes because they are not identified as palliative patients, lack of resources and overloaded primary care end up referring patients to other services such as emergency departments, unnecessary admissions and invasive tests. Late implementation of PC may also entail costs. Some patients may have received many health interventions (referrals to specialists or emergency episodes) before starting the PC programme, often at a late stage of the disease progression, which have added little value to the quality of life of patients who arrive already very impaired and have also resulted in inefficient expenditure for health systems, as, in the process of end-of-life care, there arrives a point at which the person no longer benefits from the PC programme.

  Another factor to be taken into account is geographical disparities, as the provision of palliative care is distributed differently in the different regions of the Spanish territory. Specialised PC units do not exist in all territories and sometimes even within the same autonomous community, depending on which hospital the patients are assigned, they may or may not have a PC unit. This leads to disparities and inequality in access to the care that this patient profile needs. Within this geographical disparity, it is worth noting that there are rural areas where PCs do not reach. In these cases, it could be relevant to implement technologies that help the telemonitoring or education/support of patients at home, which could increase the safety of patients and their families, their empowerment and self-efficacy. Without intending this as a solution for access to palliative care for people living in rural areas, the InAdvance project has implemented some of these solutions to try to improve the monitoring and quality of life of these patients.

In this respect, consideration should also be given to the development of local/regional/national guidelines adapted to the specific needs and characteristics of the target population with respect to cultural particularities and religious beliefs.

- **Increase in the training of professionals (refresher and continuous training).** Professionals interviewed during the development of the doctoral thesis reported a lack of formal training in PC and self-reported gaps in their own skills and confidence with regard to the provision of palliative care. In many cases training in PC depends on the motivation of professionals who are already actively working in PC services to be trained in specialised courses that are sometimes offered by the services in which they work, but in other cases must be sought outside. Continuous and specialised training is necessary for professional development in PC units. End of life is not included in the curricula as a basic and solid ethical training in all healthcare degrees. It is worth developing more specific education in this field through postgraduate degrees and healthcare specialisations. Technologies can act as tools to support the training and development of professionals. Virtual reality (VR) has been applied from teaching anatomy to various surgical practices, enhancing the skills of medical students in an effective and safe way. In the InAdvance project, VR has been used as a complementary tool in the training of healthcare professionals targeting the enhancement of communication skills and empathy.

- **Improving holistic care by including psychosocial care and involving patients and families in decision-making.** Policy makers should focus on ensuring the monitoring of psychological status and social needs within the PC care process. Psychological support should be ensured for patients and also for their relatives with a special focus on those in the role of being the primary caregiver. Likewise, the provision of social support and social resources that are very necessary in this patient profile must be guaranteed, such as technical and financial assistance, respite services for caregivers, or community support networks. Furthermore, decisions must be adapted to the specific needs and characteristics of the target population with respect to cultural particularities and spiritual or existential needs. Involvement of patients in decision-making and the design of their own pathway should be sought, respecting their choices, limits and level of care they wish to receive or decline, as older people have the legal right to make their own decisions with full autonomy. Policy makers should be aware that holistic, patient-centred care should be designed around the patient's values, needs and preferences by allocating adequate time to explore these needs with the individual and their families.

- **Establish evaluation frameworks that allow for comparison and measurement.** Policy makers should have national indicators, set minimum targets and quality standards, and invest in auditing and improving the quality of PC services around the Spanish territory. Initiatives such as the PC ATLAS have opened up the possibility for comparisons but there is a need to develop more extensive and complex evaluation systems that cover not only available resources but also take into account aspects such as the evaluation of quality of care, including satisfaction with care and quality of life.

- **Empowering older people and their families promoting their participation in decision making.** The promotion of the active participation of patients and their families in the decision-making process in the care plan should be sought, facilitating communication between professionals and patients and families. This should be done by initiating early conversations about the present and future care plan, as well as discussing advance directives and possible present or future treatments. In addition, families and patients should be provided with access to information and psychological and social support to make informed decisions and have access to mental health and bereavement services if needed.

CHAPTER VIII

REFERENCES

CHAPTER VIII. **REFERENCES**

Aoun, S. M., Breen, L. J., White, I., Rumbold, B., & Kellehear, A. (2018). What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach. Palliative medicine, 32(8), 1378-1388. https://doi.org/10.1177/0269216318774995

Arias-Casais N, Garralda E, Rhee JY, Lima L de, Pons JJ, Clark D, Hasselaar J, Ling J, Mosoiu D, Centeno C. (2019). EAPC Atlas of Palliative Care in Europe 2019. EAPC. Available online: http://hdl.handle.net/10171/56787 (accesed at 22 july 2022)

Arksey, H.; O'Malley, L. (2005) Scoping studies: Towards a methodological framework. Int. J. Soc. Res. Methodol, 8, 19–32.

Aspinal, F., Addington‐Hall, J., Hughes, R., & Higginson, I. J. (2003). Using satisfaction to measure the quality of palliative care: a review of the literature. Journal of advanced nursing, 42(4), 324-339. https://doi.org/10.1046/j.1365-2648.2003.02624.x

Ayanian, J. Z. (2020). Mental health needs of health care workers providing frontline COVID-19 care. In Jama health forum, 1(4), e200397-e200397. https://doi.org/10.1001/jamahealthforum.2020.0397

Bamford, S. M., & Walker, T. (2012). Women and dementia–not forgotten. Maturitas, 73 (2), 121-126.

Barbero, J., & Díaz, L. (2007). Diez cuestiones inquietantes en cuidados paliativos. In Anales del Sistema Sanitario de Navarra (Vol. 30, pp. 71-86). Gobierno de Navarra. Departamento de Salud.

Bijnsdorp, F. M., Onwuteaka-Philipsen, B. D., Boot, C. R., van der Beek, A. J., Klop, H. T., & Pasman, H. R. W. (2021). Combining paid work and family care for a patient at the end of life at home: insights from a qualitative study among caregivers in the Netherlands. BMC Palliative Care, 20(1), 93. https://doi.org/10.1186/s12904-021-00780-9

Bishop, N. J., Haas, S. A., & Quiñones, A. R. (2022). Cohort trends in the burden of multiple chronic conditions among aging US adults. The Journals of Gerontology: Series B, 77(10), 1867-1879. https://doi.org/10.1093/geronb/gbac070

Blanes-Selva V, Doñate-Martínez A, Linklater G, García-Gómez JM. Complementary frailty and mortality prediction models on older patients as a tool for assessing palliative care needs. Health Informatics Journal. 2022;28(2). https://doi.org/10.1177/14604582221092592

Boven, C., Dillen, L., Van den Block, L., Piers, R., Van Den Noortgate, N., & Van Humbeeck, L. (2022). In-hospital bereavement services as an act of care and a challenge: an integrative review. Journal of Pain and Symptom Management, 63(3), e295-e316. https://doi.org/10.1016/j.jpainsymman.2021.10.008

Cabañero-Martínez, M. J., Nolasco, A., Melchor, I., Fernández-Alcántara, M., & Cabrero-García, J. (2020, April). Lugar de fallecimiento de las personas con enfermedades susceptibles de cuidados paliativos en las diferentes comunidades autónomas de España. In Anales del Sistema sanitario de Navarra (Vol. 43, No. 1, pp. 69-80). Gobierno de Navarra. Departamento de Salud. https://dx.doi.org/10.23938/assn.0856

Campbell, S. M., Braspenning, J. A., Hutchinson, A., & Marshall, M. (2002). Research methods used in developing and applying quality indicators in primary care. Quality and Safety in Health Care, 11(4), 358-364. https://doi.org/10.1136/qhc.11.4.358

Candy, B., Jones, L., Drake, R., Leurent, B., & King, M. (2011). Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database of Systematic Reviews, (6). https://doi.org/10.1002/14651858.CD007617.pub2

Choi, S., y Seo, J. (2019, April). Analysis of caregiver burden in palliative care: An integrated review. In Nursing forum (Vol. 54, No. 2, pp. 280-290).

CIHI (2011). Seniors and the Health Care System: What Is the Impact of Multiple Chronic Conditions? Ottawa: Canadian Institute for Health Information. Available online: https://secure.cihi.ca/free_products/air-chronic_disease_aib_en.pdf (accesed on 5 February 2022)

Coca, S. M. (2017). Calidad de vida en los cuidadores familiares de pacientes con enfermedad terminal, bajo un programa de cuidados paliativos domiciliarios. Revista de Salud Pública, 21(3), 22-34.

Corner, E. J., Murray, E. J., & Brett, S. J. (2019). Qualitative, grounded theory exploration of patients' experience of early mobilisation, rehabilitation and recovery after critical illness. BMJ open, 9(2), e026348. https://doi.org/10.1136/bmjopen-2018-026348

Corselli-Nordblad, L., and Strandell, H. (ed.) (2020). Ageing Europe – looking at the lives of older people in the EU 2020 edition. EUROSTAT. https://doi.org/10.2785/628105

Davies, E., & Higginson, I. J. (2004). The solid facts: palliative care.

Davies, E., y Higginson, I. J. (2004). Better palliative care for older people. World Health Organization. Regional Office for Europe.

De Roo, M. L., Leemans, K., Claessen, S. J., Cohen, J., Pasman, H. R. W., Deliens, L. (2013). Quality indicators for palliative care: update of a systematic review. Journal of pain and symptom management, 46(4), 556-572. https://doi.org/10.1016/j.jpainsymman.2012.09.013

Devers, K. J. (1999). How will we know" good" qualitative research when we see it? Beginning the dialogue in health services research. Health services research, 34(5 Pt 2), 1153.

Eagar, K., Watters, P., Currow, D. C., Aoun, S. M., & Yates, P. (2010). The Australian Palliative Care Outcomes Collaboration (PCOC)–measuring the quality and outcomes of palliative care on a routine basis. Australian Health Review, 34(2), 186-192. Available online: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101684.pdf (accessed on 9 November 2020).

Etkind, S. N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I. J., & Murtagh, F. E. M. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC medicine, 15, 1-10. https://doi.org/10.1186/s12916-017-0860-2

Etkind, S. N., Bone, A. E., Lovell, N., Cripps, R. L., Harding, R., Higginson, I. J., & Sleeman, K. E. (2020). The role and response of palliative care and hospice services in epidemics and pandemics: a rapid review to inform practice during the COVID-19 pandemic. Journal of pain and symptom management, 60(1), e31-e40. https://doi.org/10.1016/j.jpainsymman.2020.03.029

EUROPE, C. O. (2003). Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care.

European Commission (2019). Report "Ageing Europe". Available online: https://ec.europa.eu/eurostat/documents/3217494/10166544/KS-02-19%E2%80%91681-EN-N.pdf/c701972f-6b4e-b432-57d2-91898ca94893 (accessed on 4 May 2022)

European Commission. (2022, September 7). A European Care Strategy. Available online: https://ec.europa.eu/commission/presscorner/detail/en/ip_22_5169 (accessed on 05 December 2023)

EUROSTAT (2024a). Mortality and life expectancy statistics - European Commission. Available online: https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Mortality_and_life_expectancy_statistics (accessed on 29 march 2024)

EUROSTAT (2024b). Population structure and ageing - European Commission. Available online: https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Population_structure_and_ageing#The_share_of_elderly_people_continues_to_increase (accessed on 29 march 2024)

French, E. B., McCauley, J., Aragon, M., Bakx, P., Chalkley, M., Chen, S. H., ... & Kelly, E. (2017). End-of-life medical spending in last twelve months of life is lower than previously reported. Health Affairs, 36(7), 1211-1217. https://doi.org/10.1377/hlthaff.2017.0174

Gómez-Batiste, X., Amblàs, J., Costa, X., Lasmarías, C., Santaeugènia, S., Sanchez, P., ... & Ela, S. (2019). Development of palliative care: Past, present, and future. Textbook of palliative care, 1-12. https://doi.org/10.1007/978-3-319-31738-0_2-1

Gómez-Batiste, X., Santos, J. P. L., Tuca, A., Beas, E., Montoliu, R., Mateos, R. G., ... y Novellas, J. A. (2020). Organización paliativa durante la pandemia de la COVID-19 y propuestas para la adaptación de los servicios y programas de cuidados paliativos y de atención psicosocial ante la posibilidad de reactivación de la pandemia y época pos-COVID-19. Medicina paliativa, 27(3), 242-254.

Gonzalez-Jaramillo,V.,Fuhrer,V.,Gonzalez-Jaramillo,N.,Kopp-Heim,D.,Eychmüller, S., & Maessen, M. (2021). Impact of home-based palliative care on health care costs and hospital use: a systematic review. Palliative & Supportive Care, 19(4), 474-487. https://doi.org/10.1017/S1478951520001315

Hajat, C., & Stein, E. (2018). The global burden of multiple chronic conditions: A narrative review. Preventive Medicine Reports, 12, 284–293. https://doi.org/10.1016/j.pmedr.2018.10.008

Holgín, E. A., Arias-Rojas, M., y Moreno, S. C. (2021). Calidad de vida de cuidadores familiares de personas con cáncer que reciben atención de cuidados paliativos. Revista da Escola de Enfermagem da USP, 55.

Hudson, P., Hall, C., Boughey, A., & Roulston, A. (2018). Bereavement support standards and bereavement care pathway for quality palliative care. Palliative & supportive care, 16(4), 375-387. https://doi.org/10.1017/S1478951517000451

INE (2018). Encuesta de Población Activa. Personas ocupadas, cuidado de personas dependientes (niños o adultos enfermos, incapacitados o mayores). Madrid: Instituto Nacional de Estadística.

Johnston, M. C., Crilly, M., Black, C., Prescott, G. J., & Mercer, S. W. (2019). Defining and measuring multimorbidity: a systematic review of systematic reviews. European journal of public health, 29(1), 182-189.

Joo, J. Y. (2023). Fragmented care and chronic illness patient outcomes: A systematic review. Nursing open, 10(6), 3460-3473. https://doi.org/10.1002/nop2.1607

Kavalieratos, D., Corbelli, J., Zhang, D. I., Dionne-Odom, J. N., Ernecoff, N. C., Hanmer, J., ... & Schenker, Y. (2016). Association between palliative care and patient and caregiver outcomes: a systematic review and meta-analysis. Jama, 316(20), 2104-2114. https://doi.org/10.1001/jama.2016.16840

Kristjanson, L. J., & Aoun, S. (2004). Palliative care for families: remembering the hidden patients. The Canadian Journal of Psychiatry, 49(6), 359-365. https://doi.org/10.1177/070674370404900604

Lam, S. C. (2020). Understanding and Addressing Sources of Anxiety Among Health Care Professionals During the COVID-19 Pandemic: Association Between Insufficient PPE and Depressive Symptoms. JAMA - Journal of the American Medical Association, 323(21), 2133-2134. https://doi.org/10.1001/jama.2020.5893

Leclerc-Loiselle, J., Gendron, S., & Daneault, S. (2024). Nursing activities for health promotion in palliative home care: an integrative review. Palliative Care and Social Practice, 18. https://doi.org/10.1177/26323524241235191

Lim, C. T., Tadmor, A., Fujisawa, D., MacDonald, J. J., Gallagher, E. R., Eusebio, J., & Park, E. R. (2017). Qualitative research in palliative care: applications to clinical trials work. Journal of palliative medicine, 20(8), 857-861. https://doi.org/10.1089/jpm.2017.0061

Mainz, J. (2003). Defining and classifying clinical indicators for quality improvement. International journal for quality in health care, 15(6), 523-530. https://doi.org/10.1093/intqhc/mzg081

Mason, T. M., Tofthagen, C. S., & Buck, H. G. (2020). Complicated grief: risk factors, protective factors, and interventions. Journal of social work in end-of-life & palliative care, 16(2), 151-174. https://doi.org/10.1080/15524256.2020.1745726

Mercadante, S., Adile, C., Ferrera, P., Giuliana, F., Terruso, L., & Piccione, T. (2020). Palliative care in the time of COVID-19. Journal of pain and symptom management, 60(2), e79-e80. https://doi.org/10.1016/j.jpainsymman.2020.04.025

Ministerio de Sanidad (2023). Informe de evaluación de la Estrategia de Cuidados Paliativos del Sistema Nacional de Salud Periodo 2015-2020. Centro de Publicaciones del Ministerio de Sanidad. Available online: https://www.sanidad.gob.es/areas/calidadAsistencial/estrategias/cuidadosPaliativos/docs/Informe_estrategia_paliativos._Accesible.pdf (Accessed on 3 October 2022)

Ministerio de Sanidad, Política Social e Igualdad (2011). Estrategia en Cuidados Paliativos del Sistema Nacional de Salud. Actualización 2010-2014. Centro de Publicaciones del Ministerio de Sanidad, Política Social e Igualdad. Available online:https://www.sanidad.gob.es/areas/calidadAsistencial/estrategias/cuidadosPaliativos/docs/cuidadospaliativos.pdf (Accessed on 13 June 2022)

Moens, K., Higginson, I. J., Harding, R., Brearley, S., Caraceni, A., Cohen, J., Costantini, M., Deliens, L., Francké, A. L., Kaasa, S., Linden, K., Meeussen, K., Miccinesi, G., Onwuteaka-Philipsen, B. D., Pardon, K., Pasman, R., Pautex, S., Payne, S., & Van Den Block, L. (2014). Are there differences in the prevalence of Palliative Care-Related problems in people living with Advanced Cancer and eight Non-Cancer conditions? A Systematic review. Journal of Pain and Symptom Management, 48(4), 660–677. https://doi.org/10.1016/j.jpainsymman.2013.11.009

Morey, T., Scott, M., Saunders, S., Varenbut, J., Howard, M., Tanuseputro, P., & Isenberg, S. (2021). Transitioning from hospital to palliative care at home: patient and caregiver perceptions of continuity of care. Journal of pain and symptom management, 62(2), 233-241. https://doi.org/10.1016/j.jpainsymman.2020.12.019

Moser, A., & Korstjens, I. (2017). Series: Practical guidance to qualitative research. Part 1: Introduction. European Journal of General Practice, 23(1), 271-273. https://doi.org/10.1080/13814788.2017.1375093

Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. European journal of general practice, 24(1), 9-18. https://doi.org/10.1080/13814788.2017.1375091

Murray, S. A., Firth, A., Schneider, N., Van den Eynden, B., Gomez-Batiste, X., Brogaard, T., & Moine, S. (2015). Promoting palliative care in the community: production of the primary palliative care toolkit by the European Association of Palliative Care Taskforce in primary palliative care. Palliative medicine, 29(2), 101-111. https://doi.org/10.1177/0269216314545006

Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. BMJ. British Medical Journal (Clinical Research Ed.), 330(7498), 1007–1011. https://doi.org/10.1136/bmj.330.7498.1007

Organización Mundial de la Salud, A. M. (2014). Fortalecimiento de los cuidados paliativos como parte del tratamiento integral a lo largo de la vida (No. WHA67. 19).

Ostgathe, C., & Voltz, R. (2010). Quality indicators in end-of-life care. Current opinion in supportive and palliative care, 4(3), 170-173. https://doi.org/10.1097/SPC.0b013e32833add10

Pasman, H. R. W., Brandt, H. E., Deliens, L., & Francke, A. L. (2009). Quality indicators for palliative care: a systematic review. Journal of pain and symptom management, 38(1), 145-156. https://doi.org/10.1016/j.jpainsymman.2008.07.008

Pérez, J., Ramiro, D., Aceituno, P., Escudero, J., Bueno, C., Castillo, A., de las Obras-Loscertales, J., Fernández, I., Villuendas, B. (2023). "Un perfil de las personas mayores en España, 2023 Indicadores estadísticos básicos". Madrid, Informes Envejecimiento en red nº 30, 40p. Available online: https://envejecimientoenred.csic.es/wp-content/uploads/2023/10/enred-indicadoresbasicos2023.pdf (Accessed on 3 October 2023)

Prince, M. J., Wu, F., Guo, Y., Robledo, L. M. G., O'Donnell, M., Sullivan, R., & Yusuf, S. (2015). The burden of disease in older people and implications for health policy and practice. The lancet, 385(9967), 549-562. https://doi.org/10.1016/S0140-6736(14)61347-7

Quinaz, G., Kislaya, I., Cunha Gonçalves, S., Salvador, M. R., Nunes, B., & Matias Dias, C. (2020). Healthcare use in patients with multimorbidity. European Journal of Public Health, 30(1), 16-22. https://doi.org/10.1093/eurpub/ckz118

Quinn, K. L., Stukel, T., Stall, N. M., Huang, A., Isenberg, S., Tanuseputro, P., ... & Bell, C. M. (2020). Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness: population based matched cohort study. bmj, 370. https://doi.org/10.1136/bmj.m2257

Ritchey, K. C., Foy, A., McArdel, E., & Gruenewald, D. A. (2020). Reinventing palliative care delivery in the era of COVID-19: how telemedicine can support end of life care. American Journal of Hospice and Palliative Medicine®, 37(11), 992-997. https://doi.org/10.1177/1049909120948235

Robison, J., Fortinsky, R., Kleppinger, A., Shugrue, N., & Porter, M. (2009). A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 64(6), 788-798. https://doi.org/10.1093/geronb/gbp015

Rohleder, N., Marin, T. J., Ma, R., & Miller, G. E. (2009). Biologic cost of caring for a cancer patient: dysregulation of pro-and anti-inflammatory signaling pathways. J Clin Oncol, 27(18), 2909-2915. https://doi.org/10.1200/JCO.2008.18.7435

Rubin, H. R., Pronovost, P., & Diette, G. B. (2001). The advantages and disadvantages of process-based measures of health care quality. International Journal for Quality in Health Care, 13(6), 469-474. https://doi.org/10.1093/intqhc/13.6.469

Rubio, O., Estella, Á., Cabré, L. J. M., Saralegui-Reta, I., Martín, M., Zapata, L., Esquerda, M., Ferrer, R., Castellanos, Á., Trenado, J., & Amblàs-Novellas, J. (2020). Recomendaciones éticas para la toma de decisiones difíciles en las unidades de cuidados intensivos ante la situación excepcional de crisis por la pandemia por COVID-19: revisión rápida y consenso de expertos. Medicina Intensiva (Madrid. Ed. Impresa), 44(7), 439–445. https://doi.org/10.1016/j.medin.2020.04.006

Salisbury, C., Johnson, L., Purdy, S., Valderas, J. M., & Montgomery, A. (2011). Epidemiology and impact of multimorbidity in primary care: a retrospective cohort study. British Journal of General Practice, 61(582), e12–e21. https://doi.org/10.3399/bjgp11x548929

Sánchez, M. E., Rubiales, Á. S., Simó, R. M., & Flores, L. A. (2019). Estrategias regionales de cuidados paliativos en España: estudio descriptivo. Medicina Paliativa,26(2),104-112.https://doi.org/10.20986/medpal.2019.1046/2019

Schuster, M. A., McGlynn, E. A., & Brook, R. H. (1998). How good is the quality of health care in the United States?. The Milbank Quarterly, 76(4), 517-563. https://doi.org/10.1111/1468-0009.00105

Servicio Murciano de Salud (2007). Plan Integral de Cuidados Paliativos en el Servicio Murciano de Salud 2006-2009. Consejería de Sanidad de la Región de Murcia. Available online: https://www.murciasalud.es/recursos/ficheros/97914-PLAN_CUIDADOS_PALIATIVOS-2009_nueva_edicion.pdf (Accessed on 21 December 2022)

Snow, K., Galaviz, K., & Turbow, S. (2020). Patient outcomes following interhospital care fragmentation: a systematic review. Journal of general internal medicine, 35, 1550-1558. https://doi.org/10.1007/s11606-019-05366-z

Spilsbury, K., & Rosenwax, L. (2017). Community-based specialist palliative care is associated with reduced hospital costs for people with non-cancer conditions during the last year of life. BMC palliative care, 16, 1-12. https://doi.org/10.1186/s12904-017-0256-2

Stefanou, N., & Faircloth, S. (2010). Exploring the concept of quality care for the person who is dying. British journal of community nursing, 15(12), 588-593. https://doi.org/10.12968/bjcn.2010.15.12.588

Steinhauser, K. E., & Barroso, J. (2009). Using qualitative methods to explore key questions in palliative care. Journal of Palliative Medicine, 12(8), 725-730. https://doi.org/10.1089/jpm.2009.9580

Tziraki, C., Grimes, C., Ventura, F., O'Caoimh, R., Santana, S., Zavagli, V., ... & Illario, M. (2020). Rethinking palliative care in a public health context: addressing the needs of persons with non-communicable chronic diseases. Primary health care research & development, 21, e32. https://doi.org/10.1017/S1463423620000328

Vaupel, J. W. (2010). Biodemography of human ageing. Nature, 464(7288), 536-542. https://doi.org/10.1038/nature08984

Vedel, I., Ghadi, V., Lapointe, L., Routelous, C., Aegerter, P., & Guirimand, F. (2014). Patients', family caregivers', and professionals' perspectives on quality of palliative care: a qualitative study. Palliative Medicine, 28(9), 1128-1138. https://doi.org/10.1177/0269216314532154

Vernon, E., Hughes, M. C., & Kowalczyk, M. (2022). Measuring effectiveness in community-based palliative care programs: a systematic review. Social Science & Medicine, 296, 114731. https://doi.org/10.1016/j.socscimed.2022.114731

Wasti, S. P., Simkhada, P., Van Teijlingen, E., Sathian, B., & Banerjee, I. (2022). The growing importance of Mixed-Methods research in health. Nepal Journal of Epidemiology, 12(1), 1175–1178. https://doi.org/10.3126/nje.v12i1.43633

WHO (2016). Planning and Implementing Palliative Care Services: A Guide for Programme Managers. Geneva: World Health Organization, 2016. Available online: https://iris.who.int/bitstream/handle/10665/250584/9789241565417-eng.pdf?sequence=1 (accesed on 18 February 2022)

WHO (2017). Noncommunicable Diseases. Available online: https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases (accessed on 22 December 2020)

WHO (-2020)-. World health statistics 2020: monitoring health for the SDGs, sustainable development goals. Available online: https://apps.who.int/iris/handle/10665/332070. Licencia: CC BY-NC-SA 3.0 IGO (accessed on 7 June 2021)

World Health Organization: WHO. (2022, October 1). Ageing and health. https://www.who.int/news-room/fact-sheets/detail/ageing-and-health

Zhang, M., Holman, C. D. J., Price, S. D., Sanfilippo, F. M., Preen, D. B., & Bulsara, M. (2009). Comorbidity and repeat admission to hospital for adverse drug reactions in older adults: retrospective cohort study. BMJ. British Medical Journal, 338(jan07 3), a2752. https://doi.org/10.1136/bmj.a2752

Zhang, Y., Gupta, A., Nicholson, S., & Li, J. (2022). Elevated end-of-life spending: A new measure of potentially wasteful health care spending at the end of life. Health Services Research, 58(1), 186–194. https://doi.org/10.1111/1475-6773.14093

ANNEX I

DATA EXTRACTION TABLE.
PAPER 1

S1: Data Extraction table

	Study	Target	Source of data collection	Age group of patients	Main thematic findings	Reported limitations
16	O'Brien et al 2019	Professionals	Individual interview	-	Participants emphasized the importance of identifying what matters to the individual, what is fundamental to them and what their priorities are at this stage of their lives. The need to be aware of religious beliefs and how these can affect end-of-life care and preconceptions about spirituality and religion was detected, as many consider them to be the same thing. Importance of recognizing that the environment, within which patients find themselves at the end of their lives, may be adding to their spiritual distress. The value of allowing patients time to think was stressed. Post course, there was realization that an essential aspect of providing holistic care was to ensure that participants addressed more than just the patient's physical well-being.	The study was retrospective with only one data collection time point; this must be considered as a potential limitation.
17	Abbas & Dein 2010	Professionals	Focus group or similar	-	Lack of knowledge about what spiritual needs mean. Lack of training in spiritual needs assessment tools. Difficulty detecting and treating spiritual needs or pain. Tendency to consider spiritual needs as something related to religion and is considered something that belongs to the private sphere	The small sample size and the fact that this was a single site study mean that the findings cannot be generalized.
18	Bajwah et al 2013	Patients, Relatives or informal caregivers, Professionals	Individual interview	57-81	Scope of physical and psychosocial needs. Professionals find a lack of skills and training to manage some symptoms. All three groups had an impact on their social activities. Patients and caregivers reveal significant changes in their social relationships causing isolation and loneliness. The effects of the disease on caregivers are often not identified by professionals	Number of subjects interviewed is small All subjects had a TLCO less than 40% indicating severe, if not terminal, disease. There can be marked heterogeneity in progression within the disease population.

* In all the studies both genders are represented.

						All patients and informal caregivers were recruited from specialist ILD centers in the United Kingdom.
19	Blackwell et al. 2017	Patients, Relatives or informal caregivers, Professionals	Non-participant observation, semi-structured interviews, focus groups and a co-design event	Only 'older patients' is mentioned	Patients and family members require more information and personalized attention. Professionals manifest a lack of training and experience in PC and on how to identify the needs of the patient. Lack of resources in the Emergency Department to provide palliative care.	Informal fact-finding exercise via email, this approach prevented probing questions and deep exploration
20	Bone et al 2016	Patients, Relatives or informal caregivers, Professionals	Individual interview, focus group or similar, questionnaire/s or survey	Elderly with frailty and hospital attendance	More information for decision-making or symptom management and bereavement support. Ensure older people are informed about to avoid anticipate plans and directives. Involve relatives in discussions about plan of care Identify carer's needs. Fast and easy access to specialist palliative care advice. Key worker assigned to patient for continuity of care.	Selection bias. The consensus survey was conducted in a single round
21	Buckingham et al 2015	Patients, Relatives or informal caregivers, Professionals	Individual interview, questionnaire/s or survey, RCT	Mean age 72.2	People highlighted the benefits derived from discussion about spiritual or psychological needs. Patients desired more information provision about resources. Professionals had a strong sense that existing services did not address the complex and long-term support needs of people with severe COPD. The uncertain prognosis meant that palliative care services were not adequate for these patients, as they are linked to the last months of life.	The findings of this unicentric study may not be representative of other contexts.
22	Davis et al 2014	Professionals	Individual interview, focus group or similar	-	Palliative care of patients with dementia was described as chaotic and disorganized, cancer patients receive specialized care while patients with dementia do not. The need for some element of systematization without too much rigidity was recognized. Palliative care for people with dementia was	Small sample (not all job roles involved in palliative care for people with dementia were included).

					described as fragmented and disconnected while a holistic model of care was desired. Need of training in PC	
23	Fleming et al 2016	Patients, Relatives or informal caregivers	Focus group or similar	95-101 years	Patients expressed their desire not to prolong life with invasive treatments and to consult family members about patients' wishes. The main concerns of patients and family members regarding the end of life were to feel comfortable and stay at home avoiding hospital admissions and respecting the patient's wishes.	The lack of response potentially limits the validity of the research. An additional limitation was the study's inability to explore how older people's opinions might change over time, particularly as they approached death.
24	Gardiner et al 2011	Professionals	Individual interview, focus group or similar	-	Participants identified several barriers to the provision of palliative care for older people, such as; the role of the health professional is poorly defined in terms of providing palliative care, lack of psychosocial support available, patients with non-malignant diseases were less likely to be referred to PC services, partly due to the historical link between cancer and palliative care, lack of staff causing lack of time in care, sometimes doctors are too interventionist.	Not reported
25	Gott et al. 2011	Professionals	Focus group or similar	-	Time and resources to appropriately time transitions to palliative care was detected as a need Improve communication between clinicians and patients about palliative care approaches. Particular difficulties in communicating with patients with conditions other than cancer who were particularly likely to undergo a late transition to a palliative care approach. Patients typically left hospital with a poor understanding of their diagnosis and prognosis. Patients' preferences for place of death, and in particular dying at home, could not always be met for a range of reasons	Participants reported on their practice and that of their colleagues, therefore this was not directly observed. As all data collection was carried out in England, findings may not be generalizable to other countries.
26	Handley et al. 2013	Professionals	Individual interview	-	Lack of clarity about roles and responsibilities in providing end-of-life care. Recognising deterioration was not easy and was a more	This study is limited in studying six care homes and associated primary care

					nuanced process than was openly discussed between primary healthcare and care home staff. Need of collaboration between care homes and primary healthcare staff and the need to discuss how residents and family members can be involved over time. There is a need for a pattern of working between health and care staff that can encourage review and discussion between multiple participants over sustained periods of time.	services in areas that may not be representative.
27	Livingstone et al 2012	Professionals	Individual interview	-	In general, staff felt uncomfortable discussing death-related issues with residents or family members. Some staff members felt that their role was to preserve life for as long as possible, sending people to the hospital, even against the wishes expressed by the family. They sometimes felt that they had no emotional support and that their pain was inappropriate or there was no time to express it. They also expressed a lack of knowledge in advanced plans or that perhaps these could be invalidated by residents' families.	The interviews were all conducted in a single nursing home in a large city, suggesting that the problems encountered may be different than elsewhere.
28	Lloyd et al 2016	Patients, Relatives or informal caregivers, Professionals	Individual interview, focus group or similar	Over the age of 75	Social and community support was identified as a source of well-being, the prominent fears were the loss of mobility and independence and being a burden for family members and caregivers. Refusal to speak openly about death was also detected.	Sample not include frail older people who may lack an informal carer or who have dementia.
29	Manson et al 2013	Patients, Relatives or informal caregivers, Professionals	Individual interview, ethnographic observation	-	Patients, caregivers and professionals identified problems related to communication difficulties, lack of information and collaboration in care transitions. Difficulties were detected in identifying patients in need of palliative care and were often identified when they were already in the last days of life. The professionals considered that they had only a partial understanding of the patients' long-term circumstances. In many cases, patients and professionals considered palliative	The variety of data sources occasionally caused difficult decisions about which areas to prioritize.

					care as care for situations where death is imminent. Caregivers reported that communication was inconsistent and had little information about the patient.	
30	Mayland et al. 2017	Relatives or informal caregivers	Questionnaire/s or survey	-	Participants expressed unmet information needs as they would have benefit in knowing more about what to expect as their family member was dying. Nurses and doctors had not enough time to listen and discuss with family member's the patient's condition. Relatives perceived that they were not involved in decision-making.	Not reported
31	McLaughlin et al 2014	Professionals	Individual interview, questionnaire/s or survey	-	Communication needs were identified between specialized palliative care services and disability care services, as well as end-of-life care training for people with intellectual disabilities, as services are often not adapted for people with disabilities. Likewise, in the intellectual disability services, continuous training needs were highlighted on how to manage physical symptoms and pain, end-of-life care and grief. Other learning needs were self-care in coping with death and professional grief. The need for better coordination and continuity of care was also highlighted.	Not reported
32	Lee et al 2015	Professionals	Individual interview	-	The professionals highlighted as important issues for the end-of-life care of people with dementia: knowing the person with dementia, interpreting non-verbal communication, listening to and respecting family caregivers and ensuring personal and physical comfort. They identified the following necessary interventions: ensuring continuity of care, listening to and respecting family caregivers in terms of leveraging existing knowledge of family members and providing post-bereavement support and managing the transition to shared care with staff. They identified barriers in elder care, such as; low salaries of care staff, high staff turnover and inadequate	Approach to the sampling of national and local experts was pragmatic and purposive and based on team meetings, snowball sampling and the identification of experts through searching.

					numbers of qualified staff. The need for specific palliative care for elderly patients was suggested and it was recognized that clinical and palliative experience has an important role to play in end-of-life care for people with dementia.	
33	Poole et al. 2012	Patients, Relatives or informal caregivers	Individual interview, focus group or similar	-	In general, both patients and caregivers emphasised the importance of remaining in their preferred place of care and ensuring comfort and minimising distress. Being comfortable and pain-free. Importance of psychosocial elements such as emotional comfort, compassion and spirituality. well-trained staff, skilled in the delivery of individualized and person-centred care as well as they should have additional or specialist training Patients desire for family to be with them at the end of life Caregivers want to explicitly discussed wishes and preferences with their familiar (source of distress to families who felt under pressure to make the right choices) Organizational barriers to coordinating good end-of-life care: navigating complex systems to access continuing healthcare funding, pressure from service providers to move their relative into institutional care and coordinating care providers from different services. Some carers described the continued need for support in the co-ordination of care in the period soon after death	People with dementia were recruited from the community, and from one area of England, rather than through healthcare services. Therefore, the views of people with dementia living in residential care or people with dementia without family carers and regional variation were not captured.
34	Ryan et al. 2013	Patients	Questionnaire/s or survey	Mean age 70.85 years	Patients with PC need were more likely to identify higher levels of physical burden, including: weakness; tiredness; shortness of breath; restlessness and agitation. Also they reported being bothered by a number of psychological burdens, including: anxiety; low mood; poor concentration and confusion.	Non-English speakers and those people who were unable to consent and did not have a close relative or friend who was available were excluded from the study. Small sample size used in the regression analysis

35	Waldron et al 2013	Relatives or informal caregivers	Individual interview, focus group or similar	-	Both participant groups stressed the need for the specialist knowledge of drugs in a palliative care setting, access to good nursing care and holistic support from social and health care professionals in terms of psychological, spiritual and emotional needs. palliative care needs of carers: palliative care provision should be extended to support family carers. Practical help, information, emotional support, referral to appropriate agencies that might be of benefit and respite opportunities Having contact with a PDNS from an early stage and access to bereavement care were regarded as valuable. Support groups: Provision of care to people with non-malignant and malignant conditions NHS-based participants: Scarcity of resources and funding in the current economic climate with heavy caseloads Lack of knowledge and recognition among Primary Care Trusts' staff that clients with PD might need palliative care. Lack of PD experience and training: The difficulty in defining the palliative care stage in clients with Parkinson's disease Participants identified more resources, more knowledge, more understanding of PD, more information regarding advice and awareness.	Not reported
36	Boersma et al 2017	Relatives or informal caregivers	Individual interview, focus group or similar	-	Need of individual attention and support, of boundaries in their role as an informal caregiver and the importance of maintaining their own social lives and involvement in hobbies despite the illness. Educational needs and helpful resources about disease progression, medications and their side effects, to respond to emergency situation sand useful resources.	Small sample size and thus may have missed issues important to many caregivers.

					Cognitive dysfunction was challenging and negatively impacted their lives. Financial concerns.	
37	Chang et al 2012	Professionals	Questionnaire/s or survey	-	Need of support for home visits in grief (for nurses) Importance of extending the bereavement care to recently deceased families and carers of their former palliative clients. A common misunderstanding that palliative care is only for the final phase of life. Difficulty addressing spiritual and cultural issues with patients and with the resident's family.	A higher response rate and sample size are desirable to increase the generalizability of results that is also limited by the inclusion of only one metropolitan health service administrative area.
38	Cimino et al. 2014	Professionals	Questionnaire/s or survey	-	Main learning needs and preferences were understanding topics such as principles of palliative care, pain assessment, pain management, and non-pain symptom management	Sample limitation (more than two-thirds of respondents were nurses or social workers)
39	Grudzen et al. 2010	Patients, Relatives or informal caregivers	Questionnaire/s or survey	65 years or over	A majority of patients exceeded cut-offs for financial need (help with insurance coverage, caregivers working to pay for medical costs caregivers missing work to provide care, or using savings or incurring debt to pay for medical expenses) Need of access to care (patients need help finding providers and/or clinics that could provide care for their particular illness). Patients needed help with household chores and had significant limitations in activities of daily living. Caregivers reported sleep problems, confinement, physical strain, and emotional or family problems related to caring for a loved one. Patients also manifest needs related to physical health, pain, fatigue, anxiety, and/or shortness of breath.	Patient sampling was not representative of all seriously ill, older adults.
40	Hall et al. 2011	Patients	Review	average age from 80.0 to 87.9 years	Often older people in resident care home are not referred to specialist hospice or palliative care services, their symptoms are poorly managed, they are frequently hospitalized unnecessarily, advance care planning and communication is	Heterogeneity of the three included studies that made it difficult to combine and compare their results, and the small

					often inadequate, and their families are dissatisfied with their care. Need of increase relationships between care homes and specialist palliative care services who can provide specialist support for residents with complex needs. Training to improve the care of residents. Development of multidisciplinary teams.	number of studies together with their risk of bias.
41	Karen Tallman et al 2012	Patients, Relatives or informal caregivers	Individual interview, longitudinal video-ethnographic Study	from 46 to 89	Patient, Family, and Caregiver Needs: Five major need themes central to the patient, family, and caregiver experience were identified: 1) sensitive, effective communication about advanced illness; 2) timely access to coordinated medical care; 3) respect for and honoring care decisions; 4) psychological, social, and spiritual needs; and 5) caregiver support.	
42	Kwak et al 2013	Professionals	Individual interview, focus group or similar	-	Professionals recognized that death and dying are taboo discussion topics. Participants' recommendations were to develop trust with elders over time; cultivate cultural knowledge and sensitivity to respect value orientations; promote designating a healthcare proxy; recognize and educate families and community leaders as critical partners in advance care planning and provide practical support as needed throughout the illness experience.	The views reported are based on a select sample of Care Managers team members working with frail, low-income elders in the Family Care programme, so the results may not be generalizable.
43	Perez et al. 2015	Professionals	Individual interview	-	Challenges associated to their work environment were detected, such as time pressures, unpredictable schedules and competing role demands. Also they detect challenges in addressing patients' mutable needs, managing family dynamics, and meeting patient and family demands and expectations. They found challenges in delineating emotional and professional boundaries. Need of training in mind-body skills, such as yoga, meditation, and education to combat the effects of stress and cognitive strategies to avoid negative thinking was detected.	This study represents the perspectives of clinicians from only one medical institution in Boston, findings are limited in generalizability and may not reflect the opinions of clinicians beyond this sample.

44	Thai et al 2015	Relatives or informal caregivers	Individual interview	65+	The caregivers who experienced a decline in their QoL identified the following reasons: they had less time for self (social and financial domains), their health declined (physical domain), and the emotional impact of the patient's illness took a toll on them (emotional domain).	Due to the small sample size, correlations cannot be established between the circumstances of care and how they affect quality of life
45	Bloomer et al 2018	Patients, Professionals	Individual interview, retrospective audit of existing hospital databases	over 65	Patients' and families' cultural needs before and after death were not always accommodated (influence by organizational constraints and inadequate communication) Clinicians typically lacked cultural awareness and the potential breadth of cultural practices, rituals, and other needs considered essential to the provision of culturally sensitive EoL care. Clinicians identified a need for further education to improve understanding of how to address cultural needs for older people and their families at the EoL.	The retrospective audit is limited by the quality of the evidence. The study was conducted in one setting in Melbourne, Australia, findings may not be transferable across other settings or patient groups.
46	Broom et al. 2012	Professionals	Individual interview	-	Timely referral was beneficial to prepare patient and FGCs for the end of life, limit unnecessary treatment, and streamline care focused on quality of life. Some medical specialists lacked the knowledge, experience, or inclination to give due consideration to referral to palliative care understanding these derivations as a failure of curative treatment and causing a lower quality of life of the patient. The presence of palliative care clinicians was viewed as a significant facilitator of timely referral.	Not reported
47	Chang et al 2009	Professionals	Individual interview, focus group or similar	-	Difficulties evaluating people with advanced dementia because they are not verbally communicative which makes it difficult to manage pain, dysphagia, behavioral symptoms Emotional difficulties derived from connecting with patients. Lack of knowledge about palliative care and common misunderstanding that palliative care is only for the end-of-life	Small sample and random sampling may be a limitation

					phase.	
48	Fleming et al 2015	Patients, Relatives or informal caregivers, Professionals	Focus group or similar	-	Ensure a quiet and familiar environment favoring privacy for dementia patients and their families. Promote participation and contact with family members. Pay attention to spirituality. A key area of concern for practitioners was the lack of staff to provide sufficient care to their patients.	The views expressed in the focus groups may not be generalizable to the wider population of people with dementia, their family or professional careers as the sample is small and no steps were taken to attempt to make it representative.
49	Lewis et al 2019	Patients, Relatives or informal caregivers	Individual interview, focus group or similar	60 and over	Participants agreed that a good quality of life was the most important consideration in EOL care. They converged on the notion that a good quality of life is when an individual has control and can meet their own personal standards and expectations. For patients, attending appointments for care at the EOL could be challenging, with the difficulty of multiple visits to services that were not localized, compounded by poor mobility and the associated costs of transport. Discussions about the EOL were identified as limited, lacking, too late and emotionally challenging, leading to a lack of sufficient understanding of each patient's wishes. Caregiver participants described the impact of their loved one's life-limiting illness as putting their life on hold to care for another, making financial, career and personal compromises in order to do this. Participants desire competent and caring health professionals to assure patient dignity and quality EOL care to patients and caregivers.	The majority of participants were females and caregivers and only Three FG were conducted.
50	Sealey et al. 2015	Professionals	Focus group or similar	-	There is no clear delineation as to which service is responsible for grief care. As patients move through the system and between various services, there is a chance that they and their caregivers will get lost between services, caregivers don't know where to turn when they need help or information.	The findings may not transfer to other locations with different palliative care service models although research shows that similar challenges to bereavement care exist in other developed countries

					Referral and timely interventions would reduce the risk of complex grief and PTSD. The professionals found it very challenging to evaluate the grief after the death of the patient, since there is usually no contact with relatives. A problem for the services was the amount of time that grief support could be offered to people, in addition in the services there are no staff dedicated to grief, this absence causes inconsistency in contact and follow-up. Bereavement former caregivers could be difficult to contact after the patient's death, if they did not respond to the call the follow-up was stopped. It was suggested that a measure be constructed that could be adapted for use in palliative care, prior to the patient's death, in order to assess the caregiver's risk of grief.	
51	Sneesby et al 2011	Relatives or informal caregivers	Focus group or similar	-	Communication issues including disclosure and consent (death and dying are taboo subjects they are rarely discussed). Attitudes towards medical treatment: tend to discontinue medication once symptoms have passed. Herbal remedies will often be used in conjunction with conventional medicine. Spiritual and religious issues: The main religions of Sudan are Christianity and Islam. The participants found great strength in their religious beliefs and considered it as an important need.	Not reported
52	Tan et al 2009	Professionals	Questionnaire/s or survey	-	Barriers such as poor communication and limited availability of afterhours services were identified. Some GPs indicated that they did not use the elements of the EPC because of the paperwork involved. it was also highlighted that it would be useful to have more information about what PC services are available in your area and what they can provide. Additional resources such as increased	The response rate was very low, particularly in the case of GPs

					access to PA consultants and PA nurses, out-of-hours patient data, and palliative care guidelines were suggested.	
53	Wiese et al 2012	Professionals	Individual interview, focus group or similar	-	Importance of providing care at the end of life in the place chosen by patients and relatives, in general they considered that the ideal place was the home but recognized that this is not always possible, sometimes they felt guilt when making the decision to transfer the patient to the hospital. They also expressed the importance of communication with external health services. They recognized the importance of paying attention in the post-death period and attending to the grieving process of family members.	The perspective obtained was only from the staff
54	You et al 2014	Patients, Relatives or informal caregivers	Individual interview, focus group or similar, Questionnaire/s or survey	Mean age 81.2 years	Patients and family members identified the same 5 elements as being the most important to address: preferences for care in the event of life-threatening illness, values, prognosis, fears or concerns, and questions about goals of care, these elements are infrequently discussed and that the concordance between preferred and prescribed care objectives is low.	The sample is not representative of populations that do not speak English or French as a first language and that may have different values related to end-of-life care
55	Simon et al 2013	Patients and caregivers	Individual interview	Mean age 80 years	Some patients and family members were reluctant to talk about advance directive processes, for fear of talking about the end of life. Others expressed a desire to plan the life-support treatments they wanted and which they didn't want in the future. Patients and family members manifested continuous contact with doctors as the most important thing and the absence of communication as a problem. They also identified the need for information on PCA in general and its benefits or difficulties. To start conversations about end-of-life care, patients felt that conversations should be initiated by their doctors but with those who are known and reliable to them.	The major limitation is the use of a semi qualitative tool (questionnaire). The sampling strategy also limited participants linguistically

56	Gallagher et al. 2013	Relatives or informal caregivers	Questionnaire/s or survey	-	Bereaved relatives felt that the patient/resident had an unmet need for personal care and emotional support and that their own emotional needs were not addressed adequately. Lack of focusing on the goals of the patient and family, and provider's lack of insight into what a family can be expected to know about the dying process. Need for families to be supported after the death of a patient or resident.	The sample size is too small to make causal arguments. Participants stated that their perceptions were affected by events before the 48-hour time period and admitted that this shaped their responses. Participants wanted to provide differential scores between nurses, doctors and support staff but the survey does not allow this.
57	MacLeod et al 2011	Relatives or informal caregivers	Focus group or similar	-	Caregivers reported unmet needs related to communication, emotional support and education. They found it difficult to navigate the health system and expressed problems dealing with fatigue and strain. The need for resources such as telephone support, respite services and referral mechanisms were noted as very important for family members.	Not reported
58	Maddalena et al 2018	Relatives or informal caregivers	Individual interview	-	Major themes identified included challenges navigating the health system, caregiver burden, perceptions of palliative care, symptom management, and decision-making. Caregiver burdens are significant including physical, emotional, social, and economic dimensions. Some caregivers had to leave their paid employment to provide full-time care to their loved one. There is a need to recognize and improve support for family caregivers and increase collaboration with nephrology and palliative care services from commencement of dialysis until death and into bereavement. Care providers focusing primarily on the medical aspects of care and excluding the psychological, emotional, practical, and spiritual domains	Not reported

59	Mistry et al 2015	Professionals	Individual interview	-	It emerged as a crucial issue in EoL, addressing the non-physical needs of the patient including a holistic perspective of care attending to the psychosocial and spiritual needs of the patient and caregivers. They stressed the importance of communication and cohesion between health teams to provide coordinated care and respect the wishes of the patient and family by giving them the option to decide and participate in medical and EoL care decisions. To provide quality EoL care it is necessary that the family and the patient participate in the decision making and are informed of the options available to them.	Provider perspectives captured may not be representative of those in other countries
60	Sarti et al 2015	Professionals	Individual interview, focus group or similar, questionnaire/s or survey	-	A lack of expertise, and a lack of interest in gaining expertise, in palliative/end of life care (PC in the ICU) was detected. Gaps in PC: not seen as part of practice; lack of interest; lack of general expertise in PC. Gaps in conducting EOL discussions and determining goals of care: when to have EOL discussions; they are not always initiated; Where to have EOL discussions: emergency department, ICU or family physician's office; who should have EOL discussions: roles and responsibilities are poorly understood; lack of comfort Resource gaps: lack of physician availability; lack of PC services	The provision of palliative care in critical care was assessed at a single community hospital and the study did not specifically obtain qualitative data from patients and families
61	Brueckner et al. 2009	Professionals	Focus group or similar	-	Move forward to an holistic approach to patient care (multidisciplinarity and cooperation) due to practitioners overviewed fragments of older patient care only. Lack of specialist geriatric medicine in the outpatient sector in Germany. Palliative care physicians get involved in the care of older palliative patients relatively late and the palliative care nurses	Not reported

					consider that general practitioners would also need palliative medicine and geriatric expertise. Need of training in pain therapy and symptom control Great Risk of unforeseeable interactions and side effects of drugs in elderly population. Lack of financial resources and staff in PC.	
62	Geiger et al 2016	Professionals	Individual interview	-	The care of frail older patients represents a particular challenge for the GPs and is influenced by a variety of considerations, particularly the complexity and fragility of the overall situation, the expectations of patients and their families, the high organizational effort, and the prevailing contextual and individual circumstances. The time and the effort required for these patients are generally high. Physical examinations and consultations take much longer than with younger patients, and home visits and terminal care for frail older patients are highly time-consuming. never having sufficient time to provide the amount of care necessary within the practice routine (time and sufficient calm for discussions with patients and their families about their needs and questions at the end of life) Regarding the collaboration with specialists, timely and sufficient communication exchange is vital, but often missing.	Not reported
63	Klindtworth 2015	Patients	Individual interview	≥70 years	Patients' identified functional constraints and changing conditions that lead to problems in activities of daily living as their main concerns. Often patients with heart failure do not have enough information about the condition and their prognosis in particular regarding the problems they will face at the end of life. In general, patients wanted to increase interaction with professionals and discuss aspects of the medical care they will receive.	Patients were only recruited in an inpatient setting at two geriatric hospitals and not in general practice or other outpatient settings, the tendency towards socially desirable statements must be considered as a limitation of this study.

64	Krug et al 2018	Professionals	Focus group or similar	-	Professionals detected challenges in communicating with patients, caregivers and within the professional network. There are difficulties in interpreting the needs of patients who cannot communicate verbally. Sometimes the professionals' own opinion of "appropriate" death influenced care decisions. They expressed the need to have a close relationship with caregivers but also problems with the overly demanding attitudes of some caregivers. In the professional network they stressed that structures are missing, not all services are available in all areas, they also detected lack of communication between professionals.	Due to the mixture of GPs and medical assistants in the focus group discussions, statements might be influenced by a possible social status gradient.
65	Weber et al. 2012	Relatives or informal caregivers	Individual interview, questionnaire/s or survey	-	Need of information. Caregivers wanted to be informed about the actual medical condition by the responsible physician Professionals' lack of time was strongly associated with the unfulfilled needs for emotional support, many relatives also lacked this type of care when physicians seemed to have enough time. Emotional support. More than half of the respondents wanted the physicians to provide emotional support.	Questions regarding the relatives' needs and experiences were not tested for their psychometric properties in advance, thus partly limiting the quality of the data. Selection and recall bias.
66	Ziehm et al. 2016	Professionals	Questionnaire/s or survey	-	Interprofessional communication and communication with the patients and their relatives was seen as important for PC. Type and scope of life-sustaining measures should be discussed with the patient. PC should be aimed to care for the patient at home and emphasize that PC should be patient-centered. PC should always include all people affected by the disease of the patient, i.e. relatives and health care professionals. Cooperation of all healthcare professionals and medical disciplines are essential for PC of patients with CHF	Low response rate in the questionnaires, more than half of the participants were men, the generalization of the results is not indicated.

					Education for all healthcare professionals and collective education throughout all medical disciplines should be offered. Healthcare professionals do not possess sufficient knowledge about the content and the possibilities of PC. Death is still a taboo subject No sufficient financial conditions for PC. Time to initiate PC (In general, most participants thought that PC of CHF patients should be initiated earlier than it is actually practiced)	
67	Herder-van der Eerden et al 2018	Professionals	Focus group or similar	-	Need for a proactive approach to multidisciplinary palliative care including an anticipated holistic assessment of the patient's current and future needs and desires, as well as multidisciplinary collaboration among all professionals involved in patient care. Need for standardized criteria, protocols, or pathways, particularly for patients suffering from diseases other than cancer (COPD, heart failure, and other chronic non-malignant diseases). In these cases, referrals to PC often occur too late. Problems with funding and availability of trained personnel.	Due to the complex international context, it was difficult to fully achieve an iterative process of simultaneous data collection and analysis, that would be considered as a limitation.
68	Goodman et al. 2010	Patients, Relatives or informal caregivers, Professionals	Review	65 years and older	Have structured time to communication, addressing issues of resident comfort, avoidance of tube feeding and care in a specialist unit. Health professionals are not skilled at recognizing the end stages of dementia. Families need assistance to process difficult and painful emotions, to understand the disease trajectory, to appreciate that some decisions might impede a natural death and to grasp the available comfort and palliative care options.	The absence of a shared understanding of how end of life is recognized may have resulted in some documents being excluded from the review

69	Higginson et al 2017	Patients	Questionnaire/s or survey	65 years and older	Patients stressed that they would like to make decisions about the care they will receive, preferred to receive the treatments and face the last period of life at home and if not possible in the hospital within a palliative unit. In some cases, extending their life would be more important than its quality Home was consistently the most preferred place to dead and hospital the least preferred place, with no differences between countries adjusting for age, gender. Non cancer was associated with a preference for in-patient hospice and palliative care however this usually being little available	People with cognitive impairment were excluded this makes the results not generalizable to all older people.
70	Ke et al. 2017	Patients	Review	Older people	Older people's perspectives and experiences of Advanced Care Planning were varied and often conflicted; cultural differences amplify variances among older people. Participants remarked that it was necessary to have time to talk about EoL care, they wanted to have a private and quiet environment to discuss their concerns and make decisions. Feeling they had little information about end-of-life care and often didn't understand terminology, many of them expected healthcare professionals to start conversations about advance care planning. They also expressed concerns about the fear of being a burden to their relatives.	The review included only articles in English and the search was conducted in four databases, some relevant studies could be excluded. The age of the participants in the included articles was from 50 years to more than 90 years.
71	Low et al. 2011	Patients	Review	Mean ages from 67 to 92 years across all studies	Patients identified a good patient-professional and interprofessional communication as an important need. They desire an appointment of a designated health professional who would assume responsibility for patient assessment and care coordination. They also stressed the need for recognition of their physical, psychosocial and spiritual needs that go beyond those related to their state of heart failure.	Lack of descriptive data makes it difficult to compare experiences across different countries and health care systems.

72	Selman et al 2018	Patients, Relatives or informal caregivers	Focus group or similar	Patients median age 62 years,	Five themes were identified: patients' and caregivers' spiritual concerns, understanding of spirituality and its role in illness, views and experiences of spiritual care, preferences regarding spiritual care, and research priorities. Patients and caregivers reported a lack of that spiritual care and perceived insufficient staff time as a barrier to the provision of good spiritual care. Human connection was perceived as a prerequisite to providing effective spiritual care They also emphasize seeing spiritual care as an integral part of care and the staff should avoid categorizing or stereotyping. Patients wanted conversations about spirituality and spiritual needs to be initiated with sensitivity, they also wanted information about the availability of spiritual care and self-care practices, and to improve public discussion about death and dying.	A limitation of this study is that did not conducted back translation to check the validity of the translations.
73	Smallwood et al 2018	Professionals	Questionnaire/s or survey	-	doctors recommended referring people with advanced COPD to specialist palliative care, mainly for access to: psychosocial and spiritual care (105, 59.3%), carer support (104, 58.5%), and end-of-life care (94, 53.1%). Themes highlighted in open responses included: inadequate, fragmented models of care, with limited collaboration or support from palliative care services.	The response rate in this study, whilst similar to other online surveys of physicians was low, thus limiting the generalizability of our findings.
74	Virdun et al. 2015	Patients, Relatives or informal caregivers	Review	-	Effective communication and shared decision-making was highlighted as of great importance to both patients and families. For the patients the most important thing was; honest communication, the ability to prepare for the end of life, ensure someone's availability to listen and be aware of what to expect from their physical condition. In relation to shared decision-making, patients specifically noted the importance of appropriate testing and treatment, not receiving life support	A single author examined the titles and abstracts and undertook data extraction for included studies. Only descriptive data were reported and therefore should be seen as informative rather than definitive. Additionally, the focus on purely quantitative data allows discrete categorical data. The sample involved in this review is biased towards Western

					when there was little hope of recovery, and having the opportunity to nominate their preferred decision maker. Families stated the importance of feeling supported in decision-making and having a sense of control over their loved one's care. Both patients and families noted the importance of comprehensive care, specifically in relation to effective discharge and family planning to ensure that the patient died in the desired location. Patients noted that the preservation of dignity was extremely important. Ensuring that one is not a physical or emotional burden was classified as very important by patients. Two major American studies pointed to the importance of financial issues in relation to end-of-life care.	developed world culture, White adults, predominantly older patients and female family caregivers (adult children or spouses).
75	Scheerens et al 2018	Professionals	Focus group or similar	-	Needs were related to the unpredictability of COPD, a lack of disease insight and resistance towards care of the patient, lack of cooperation and experience with palliative home care (PHC) for professional caregivers, lack of education about early integrated PHC, insufficient continuity of care from hospital to home, and lack of communication about PHC between professional caregivers and with end-stage COPD patients.	Not all participants met the predefined inclusion criteria for the study. Lack of knowledge of other professional caregivers involved in the care of patients with end-stage COPD (pulmonologists and physiotherapists
76	Siouta et al 2018	Professionals	Individual interview	-	Provision of a holistic approach is crucial for the care of patients with CHF and COPD. Most mentioned that PC should start when the curative treatment is no longer realistic. PC is implemented frequently at the end of life but that it should be ideally initiated earlier in the disease trajectory for the benefit of the patients. Lack of time as a potential barrier for not assessing the goals (wishes of the patients) more regularly in reality. Advance care planning (ACP) is central/mandatory to	This study opted for a total population purposeful sampling, but only a fraction of the population agreed to participate.

					CHF/COPD patients. PC team is not involved in the treatment of a patient with CHF/COPD or is involved much too late in the terminal phase of life. Many participants would welcome a protocol or a guideline on how to deal with the last hours of life of patient. Word “palliative” is a bad word that results in undesirable confrontation with both patients and their families (supportive care)	
77	Udo et al 2018	Professionals	Individual interview	Old patients	The participants reported that incidents with a positive impact on palliative care situations included successful cooperation with both the patient's family members and colleagues. Presence and provision of psychosocial support was reported as important factor to providing appropriate attention. The care environment as an important factor in palliative care: Participants noted that positive incidents involved the discovery of how different environmental factors, such as a painting or photography, could awaken the dying person's memories and thus initiate a deeper dialogue. A noisy environment and a lack of peace and quiet contributed to the unease and worry of the dying person.	Participants were intentionally selected and were a homogeneous group; all of them were women born in a Scandinavian country. Data are limited to two municipalities in central Sweden
78	Wallerstedt et al 2018	Professionals	Focus group or similar	-	Challenge to communicate transitions: Participants’ perceptions of palliative care were also connected to how and when the transition to palliative care was communicated. Need of interprofessional collaboration: Interprofessional collaboration was described as important in palliative care to increase the ill person's well-being and to make the death as easy as possible. The participants noted that the care delivered to the ill person should be characterized by preserving dignity, which is facilitated if everybody is working	The use of multiple moderators in the study may have jeopardized the reliability of the results. The few numbers of participating physicians.

					in the same direction. However, it was said that this collaboration in palliative care could be improved using proactive, diverse professional knowledge earlier in the process.	
79	Pennbrant et al 2020 Sweden	Professionals	Individual interview	only 'older patients' is mentioned	Need for specialized palliative care for older people with dementia. Specialized knowledge, experience and skills when working so close to death are needed. Difficulties in meeting the needs of an elderly patient with dementia triggered feelings of stress and inadequacy due to his lack of specialized knowledge. Need for teamwork to provide holistic care (doctors, nurses, occupational therapists, physical therapists and nursing assistants). Need for time to know the patient's needs, determine itineraries and evaluate symptoms. Need for communication and continuous contact with patients' families.	Small number of nurses included in this study reduces its transferability to other healthcare settings
80	Carvalho et al 2018	Professionals	Individual interview	-	Discoordination of the health care network, lack of resources for the provision of safe care, absence of professional training and influences of culture and the hospital-care centered model in palliative care in primary health care.	The study was conducted in only one Danish municipality, albeit large, which may limit the scope of the findings. Empirical data from three specific professional groups analyzed as a single group can be considered a limitation.
81	Sheng-Yu et al 2017	Professionals	Individual interview, questionnaire/s or survey	-	Excessive workload without enough time and lack of support and teamwork from psychosocial care professionals Lack of standardized ways to provide psychosocial care. Interference from patients' physical condition, e.g., symptoms, too tired, delirium. Lack of consensus in medical team, e.g., ways to provide psychosocial care.	Sampling of participants for the quantitative survey was conducted via the Internet; therefore, they may not be representative of the entire population.

					Lack of skills or abilities in PC. Lack of suitable indices to ensure effectiveness Worries about saying something wrong that hurts patients and families Need of tools to assess the psychosocial status and needs of patients and their families and training in communication skills, truth-telling and psychosocial care. Support needs from psychosocial care professionals (social worker, clinical/counselling psychologist, chaplains/spiritual care professionals, other alternative therapy professionals, psychiatric physicians)	
82	Lenherr et al 2012	Professionals	Individual interview	-	Interviewees expressed a considerable willingness to talk about death and care with patients nearing the end of life, but expressed some obstacles to address it such as lack of time and/or privacy to address these issues; some cited personal reasons that prevented them from talking about death such as feeling confronted with their own mortality; they also mentioned resistance, aversion and refusal on the part of patients to discuss these issues with them; and the barrier that represents the cognitive state of some patients to be able to address the issue of care at the end of life.	The sample size is too small to make any general conclusions. Another limitation is the fact that the data were only collected in geriatric hospitals.
83	Bolt et al 2016	Patients, Relatives or informal caregivers, Professionals	Questionnaire/s or survey	23-88	The cases of appropriate care were diverse, but all involved care in (one or more of) five dimensions; supportive care, treatment decisions, location, the role of the patient's wish and communication. Concern about situations of overtreatment and lack communication with professionals. Desire to be involved in treatment decisions	Selection bias, participants were not randomly sampled. Recall bias might also have led to some distortion. Use of retrospective data.

84	Bijnsdorp et al 2021	Caregivers	Individual interview	only 'older patients' is mentioned	Worries about combining work and care. Understanding from supervisors and colleagues at work, having autonomy at work, flexibility in working hours and being able to work remotely. Having short lines of communication with healthcare professionals would help family caregivers to make decisions effectively and plan ahead. Combination of work and care as burdensome. Communication with healthcare professionals Shortage in professional healthcare for the care recipient (e.g. long waiting lists). Problems included bureaucracy, lots of paperwork, unclear application procedures and files that went missing, which made it hard for caregivers to arrange the care that was needed. Frustration in relation to illness progression. Support in Grieving process	This study doesn't include male caregivers. The results of this study are from a single stakeholder perspective.
85	Midtbust et al. 2018	Professionals	Individual interview, focus group or similar	-	Lack of continuity was identified as a major threat to the palliative care of people with severe dementia in long-term care facilities. Time pressure and the scarcity of resources was pointed as a barrier to provide appropriate attention. Advanced care planning was highlighted as a facilitator for providing palliative care. Extensive use of temporary staff among nurses and doctors and the relocation between the sheltered and long-term wards threaten the continuity in planning and providing palliative care. Palliative care for residents with severe dementia demands knowledge and precise observations. Security and calmness is necessary for residents with	Recruitment may have been influenced by the preferences of the management; they may have chosen informants that they thought were suitable, and other potential informants who might have added important information may have been excluded.

					dementia, but this can be difficult to provide in a ward where staff must run back and forth constantly	
86	Fryer et al 2016	Professionals	Focus group or similar	-	Need for professionals (healthcare assistants) to receive greater support to address the emotional and practical aspects. A preference for education delivered through peer support was identified. Professionals working in residential care for elderly patients do not have time to process grief when patients die, as one patient is replaced by another immediately.	Due to the cohort of women, the study cannot include the experiences of male HCAs.
87	Mousing et al 2017	Patients, Professionals	Individual interview, focus group or similar	Old patients	Nonawareness of PC needs in patients with COPD and vague understanding of PC. Organizational barriers to a PC approach and lack of time and continuity in attention. Difficulties to initiate difficult conversations with patients. The thought that PC was offered to patients with cancer and that initiatives primarily concerned pain management.	Empirical data from three specific professional groups has been analyzed as one group may be considered a study limitation.
88	Chan et al 2022	Professionals	Review, survey (Delphi)		Including trained volunteers in care delivery. Exploring the spiritual, religious, and existential concerns of residents and family members. Promoting person-centred and holistic care. Maintaining residents' dignity, privacy, and autonomy. Including nutritional screening in the initial assessment. Formulate and regularly review nutrition and hydration care plan. Managing the prescription of controlled drugs according to the local laws.	Study focused on the Hong Kong context, non-generalizable results. The response rate for the Delphi survey is relatively low and could not achieve Sumsion's standard
89	Barclay et al. 2011	Patients, Professionals	Review	60 and over	Lack of understanding of heart failure by patients. Professionals worry about not being able to provide an accurate prognosis and feel they lack the skills needed for good communication with patients. Patients fear discussing EoL care as it generates anxiety and loss of hope.	The smaller number of quantitative studies were given a lower weight of evidence, being retrospective or limited data being available from routine sources such as medical records.

					Professionals time pressures are seen by patients and clinicians as limiting the potential for conversations. Both patients and clinicians wait for the other to open up EOLC conversations which makes it difficult to start these conversations.	
90	De Witt Jansen et al. 2017	Professionals	Individual interview	-	Difficulty diagnosing due to the presence of neuropsychiatric symptoms (patients with dementia) that can result in inappropriate treatments. The profiles of patients with complex comorbidity and neurodegenerative diseases present difficulties in the prescription of drugs and treatments. Drug prescribing and symptom control is a challenge for the profile of patients with advanced dementia as there is no possibility of engaging in a discussion with patients. Care for patients with dementia requires the involvement of families and health professionals in all disciplines. Training needs through workshops to provide optimal care to this profile of patients was pointed as a need for professionals.	The sampling approach may have resulted in a biased sample of physicians with interest or previous experience in participating in research, who felt comfortable talking about professional challenges.
91	Hennings et al. 2010	Relatives or informal caregivers	Review	-	Family carers felt that they lacked knowledge of the dying process, they wanted communication, information and support in their decision-making, but they perceived professionals as lacking preparation and education for their role in guiding and supporting them in their decision making. Caregivers wanted to participate in the decision-making process and wanted continuous contact and communication with professionals, especially in EoL processes.	Not reported
92	Perone et al 2018	Patients	Individual interview	The sample contains more than 50% of	Patients expressed the following needs; lack of autonomy in daily activities, depression and loneliness, especially people with less mobility who perceived social isolation, dissatisfaction with pain control and symptom management,	Possibility of selection bias of participants

				patients over 65	were concerned about being a burden on families, sometimes felt that they had been treated without dignity and highlighted the lack of information. They also noted the lack of access to paid caregivers, home care, physical therapy, wheelchairs or diapers.	
93	Raymond et al 2012	Patients, Relatives or informal caregivers, Professionals	Review	only 'older patients' is mentioned	The importance of keeping the person with dementia in a stable care environment was highlighted by avoiding repeated moves from one family member's home to another's, and then to a residence. Family carers expressed frustration that they were not prepared for the end-stages of the dementia. Advanced planning for end of life was pointed as a need. Health professionals manifest a Lack of awareness of the person with dementia's. wishes among options and preferences should be discussed with the person and their carers while the person with dementia is able. Importance of religion for some people with dementia and for some carers who drew emotional strength from religious faith when witnessing the terminal stages.	This search was confined to electronic databases and focused on papers in peer-reviewed journals.
94	Hill et al. 2016	Patients, Relatives or Informal caregivers	Q-methodology (combination of qualitative and quantitative techniques)	Mean age 72.88 years	There are multiple perspectives of good EoL care for people with dementia; and thus, a 'one-size-fits-all' approach to planning is not appropriate to accommodate individual needs. Compassionate care is essential and incorporates respect for the person with dementia as an individual. Family members should have some involvement in medical decisions about the person with dementia together with health care staff. Comfort and safety of the person with dementia at the end of their life is crucial, for instance, receiving care in the same location to favor familiarity with surroundings, people and facilities and, thus, minimize distress.	The sample of participants with dementia was relatively small, findings may not be generalizable.

95	Montamedi et al 2021	Patients and caregivers	Review	Older patients (+60)	Effective communication between clinicians and patients/ caregivers. Accessible and frequent communication. Communication that involves the whole family and multidisciplinary team. Clear, comprehensive, and consistent information about the patients' condition, diagnosis, treatment, and prognosis. Healthcare that values patient preferences and shared decision-making. Discuss and respect patient's preferences for EOL care. Models of care that support care at home for as long as possible. Healthcare services that meet patient expectations: Staff well trained in managing specific conditions and complex issues. Support for family/caregivers in dealing with EOL challenges (emotional support, services for caregivers, information on how to manage symptoms)	Searches were only conducted in one database, Medline. Potential for exclusion of some countries if studies were not published in English language, selection bias amongst participants.
96	Steindal et al 2020	Patients and professionals	Review	65 years or over	The articles do not provide a clear definition of spiritual needs. The need to feel connected to others, such as family and other important people, was highlighted. Muslim patients report a large number of religious needs, such as praying, reading religious texts, and attending religious services. Patients interviewed in the studies report a high number of unmet spiritual needs and a lack of spiritual attention. The articles describe a lack of knowledge, competence, and training to address spiritual (professional) needs. More training, guidance, and training is needed to activate spiritual care in health care.	There may be terms that we have not been able to identify and include in our search strategy. Only included studies in English, Nordic, Spanish, and Portuguese.

ANNEX II

CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE STUDIES (COREQ): 32-ITEM CHECKLIST. PAPER 2

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist.

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Laura Llop-Medina (LLL)/Ascensión Doñate-Martinez (ADM)
2.	Credentials	PhD candidate/PhD
3.	Occupation	Researchers at the University of Valencia.
4.	Gender	The researchers were female.
5.	Experience and training	The researchers were trained in qualitative research techniques and had worked on similar studies in the past.
Relationship with participants		
6.	Relationship established	No relationship was established between the participants and the researcher prior to the start of the study.
7.	Participant knowledge of the interviewer	Participants were provided with an information sheet with the purpose of the study and the researcher's credentials.
8.	Interviewer characteristics	Interviewer name, professional affiliation and education were provided.
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	Thematic framework analysis, an inherently comparative form of thematic analysis that employs an organised structure of inductively and deductively derived themes (i.e. a framework) to conduct a cross-sectional analysis through a combination of description and abstraction of data.
Participant selection		
10.	Sampling	Participants were purposively selected meeting the criteria of age (older patients) with a diagnosis of complex chronic patients, excluding cancer, and cared for in the home hospitalisation unit of

No	Item	Guide questions/description
		La Fe hospital. The caregivers had to be caring for a complex chronically ill older patient cared by the home hospitalisation unit of La Fe hospital. The professionals had to be providing direct care to palliative care/chronic patients or managing palliative care services.
11.	Method of approach	Participants were initially identified by a member of the hospital's clinical team, who arranged the interview with the researcher by telephone.
12.	Sample size	20 participants were interviewed (12 patients, 11 caregivers) and 16 health professionals participated in the Focus Groups.
13.	Non-participation	10 patients refused to participate due to their delicate health status or the worsening of some of their symptoms, which in some cases led to hospital admission. 3 medical professionals refused to participate due to scheduling problems.
Setting		
14.	Setting of data collection	All the individual interviews were conducted face to face at patient’s home. In the case of health professionals, the focus groups took place in a meeting room of La Fe Hospital in Valencia.
15.	Presence of non-participants	There was no one else present besides the participants and researchers.
16.	Description of sample	See Results section.
Data collection		
17.	Interview guide	Interview scripts were provided by the authors, and a pilot test was conducted with a patient and a caregiver to ensure that the questions were understandable.
18.	Repeat interviews	No.
19.	Audio/visual recording	Data were collected via voice recorder after receiving explicit consent from participants.
20.	Field notes	Field notes were taken during the interviews to assist the researchers in the interpretation of the data collected.
21.	Duration	Focus groups: average duration 95 minutes. Interviews: average duration 40 minutes.
22.	Data saturation	Data saturation was discussed and agreed between the research authors of the manuscript.

No	Item	Guide questions/description
23.	Transcripts returned	Transcripts were not provided but the results were discussed with the participants.
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	The data were coded by two of the authors of the manuscript (LLL and ADM)
25.	Description of the coding tree	See table 1
26.	Derivation of themes	Themes were identified as derived from data.
27.	Software	Atlas.Ti software was used to manage the data.
28.	Participant checking	The results were discussed with the participants.
Reporting		
29.	Quotations presented	Quotes from participants were presented to illustrate the main findings. Each quote was identified with the number and profile of each participant, e.g. HP11 (MD specialist in Family and Community Medicine)
30.	Data and findings consistent	The manuscript presents consistency between the data collected and the results described.
31.	Clarity of major themes	The four main themes were presented in the findings in sections
32.	Clarity of minor themes	The 15 sub thematic themes were presented in the section of results.

ANNEX III

PRISMA 2020 CHECKLIST. PAPER

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	2
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	3
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	3-4
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	3-4
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	3
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	3-4
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	4
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	4-5
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	N/A
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	N/A
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	3-4
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	N/A
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	N/A
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	5
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	5
Study characteristics	17	Cite each included study and present its characteristics.	8
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	N/A
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 1 8-12
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	N/A
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	13-14
	23b	Discuss any limitations of the evidence included in the review.	15
	23c	Discuss any limitations of the review processes used.	15
	23d	Discuss implications of the results for practice, policy, and future research.	N/A
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	N/A
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	16
Competing interests	26	Declare any competing interests of review authors.	16
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	16

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

ANNEX IV

CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE STUDIES (COREQ): 32-ITEM CHECKLIST. PAPER 4

healthcare

MDPI

Table S1. Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist.

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Laura Llop-Medina (LLL)/ Francisco Ródenas-Rigla(FRR)
2.	Credentials	PhD candidate/PhD
3.	Occupation	Researchers at the University of Valencia.
4.	Gender	Female and male.
5.	Experience and training	The researchers were trained in qualitative research techniques and had worked on similar studies in the past.
Relationship with participants		
6.	Relationship established	No relationship was established between the participants and the researcher prior to the start of the study.
7.	Participant knowledge of the interviewer	Participants were provided with an information sheet with the purpose of the study and the researcher's credentials.
8.	Interviewer characteristics	Interviewer name, professional affiliation and education were provided.
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	Thematic framework analysis, an inherently comparative form of thematic analysis that employs an organised structure of inductively and deductively derived themes (i.e. a framework) to conduct a cross-sectional analysis through a combination of description and abstraction of data.
Participant selection		
10.	Sampling	Participants were purposively selected meeting thesecriteria: a) Professionals: experienced palliative care manager or professionals b) Family caregivers with current or deseased patients cared for in PCUs

No	Item	Guide questions/description
		Hospital Clínico Universitario Virgen de la Arrixaca. The caregivers chronically ill older patient cared by the home hospitalisation unit of La Fe hospital. The professionals had to be providing direct care to palliative care/chronic patients or managing palliative care services.
11.	Method of approach	Participants were initially identified by members of the hospital's clinical team whitin research team. They arranged the focus group with families by telephone, and by mail with professionals.
12.	Sample size	13 participants: 9 healthcare professionals and 3 family caregivers (focus group.) One more family caregiver participated in a in-depth interview
13.	Non-participation	5 family care givers refused to participate due to the recent death of the patient. 3 professionals refused because of workload.
Setting		
14.	Setting of data collection	All the individual interviews were conducted face to face at University of Murcia.
15.	Presence of non-participants	There was no one else present besides the participants and researchers.
16.	Description of sample	See Results section.
Data collection		
17.	Interview guide	Interview scripts were provided by the authors, and a pilot test was conducted with a patient and a caregiver to ensure that the questions were understandable.
18.	Repeat interviews	No.
19.	Audio/visual recording	Data were collected via voice recorder after receiving explicit consent from participants.
20.	Field notes	Field notes were taken during the interviews to assist the researchers in the interpretation of the data collected.
21.	Duration	Focus groups: average duration 95 minutes. Interviews: average duration 40 minutes.
22.	Data saturation	Data saturation was discussed and agreed between the research authors of the manuscript.

No	Item	Guide questions/description
23.	Transcripts returned	Transcripts were not provided but the results were discussed with the participants.
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	The data were coded by two of the authors of the manuscript (LLL and PGM)
25.	Description of the coding tree	See table 2
26.	Derivation of themes	Themes were identified as derived from data.
27.	Software	Atlas.Ti software was used to manage the data.
28.	Participant checking	The results were discussed with the participants.
Reporting		
29.	Quotations presented	Quotes from participants were presented to illustrate the main findings. Each quote was identified with the number and profile of each participant. HP (health professionals) and FC (family caregivers). Within the group of proffesionals we distinguised: M (medicine) and N (nursing)
30.	Data and findings consistent	The manuscript presents consistency between the data collected and the results described.
31.	Clarity of major themes	The three main themes were presented in the findings in sections
32.	Clarity of minor themes	The 22 sub thematic themes were presented in the section of results.


ALEXANDER PP VI VALENTINVS FERDINANDVS DEI GRA REX ARAGONVM