TESI DOCTORAL

An Integrated Palliative Care System in Osona

Meritxell Mondejar Pont

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DOCTORAL THESIS

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Thesis Directors: Anna Ramon Aribau i Xavier Gómez Batiste
Doctoral Program: Integral Care and Health Services

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“I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel”.

— Maya Angelou

“He après que la gent oblidarà el que heu dit, la gent s’oblidarà del que heu fet, però la gent no s’oblidarà mai de com els heu fet sentir”.

— Maya Angelou

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Summary

The ageing population of the 21st century faces chronic diseases, frailty, cancer, life-threatening conditions, multimorbidity and a longer life span. Palliative care (PC) has been traditionally the answer to these patients, evolving today into integrated palliative care (IPC). IPC, as suggested by the literature, could help health care systems to offer a better response to the terminally ill and patients with chronic conditions, as well as being more cost-effective. There is currently an increased interest in integrated palliative care systems (IPCS), and thus further research on IPCS is needed to improve IPC services provided to PC patients and their families. The purpose of this case study is to describe the Osona Palliative Care System (OPCS) in Catalonia, Spain and to identify the elements that it includes and lacks an IPCS when compared with the IPCS definition and essential elements found in the literature.

This research first explored the meaning of IPC by identifying its constitutive elements. It then carried out an analysis of a concrete case, the OPCS, which provided data for a description of the system and services offered to the chronically ill and patients with a limited life prognosis. This case study on the OPCS first sought to find and identify the essential elements that IPCS should have, and then enquired about the level of integration, needs and ethical dilemmas of the health care system in this region.

Methodology

This research followed a qualitative methodology with a constructivist approach, using a case study method technique to thoroughly understand and describe the OPCS studied. In order to respond to the main research question, the study was divided into two phases, using several research techniques. Phase I aimed to find a description of the OPCS, and a document review was performed and questionnaires were completed by professionals in the OPCS. Phase II aimed to identify the integrative elements of the OPCS an interview was conducted with the case study participants. The research method design used previous theoretical propositions found in the literature to develop the design, data collection and analysis. The study followed a single embedded case study design, using deductive content analysis.

Results

The results from phase I described the OPCS organisation, services and professionals from a structural view. Phase II identified the essential integrative elements of an IPCS, by comparing the study results to the essential elements found in the literature. This combination resulted in the creation of the IPCS Elements Theory and Practice Blended Model.

Additionally, the study found the integrative elements that the OPCS includes and has as facilitators from the structural and service care level view: having motivated multidisciplinary teams, leadership and a specific PC system that is cost-efficient. Some elements that hindered the proper functioning of the OPCS were then pointed out, which were also mentioned as excluded or needing some changes. These elements were: the need to improve collaboration, continuity of care, problems with early patient identification and the lack of specific funding, professionals and services. Finally, the study identified the most common ethical dilemmas encountered by providers in the OPCS. The most repeated, among others described, were: threat to patient autonomy, decisions about discontinuing or continuing non-beneficial treatment and poverty.

Conclusions

The main conclusion for this research is that the main elements described in the literature, the theoretical view of an IPCS, were also found in the results from this study, which confirms their essentiality. The research also found that the OPCS includes most of the integrative elements described in the literature for an IPCS. Nevertheless, some of the elements need changes and improvements to provide better care to the PC patient.

The most important recommendations for practice from this research are as follows: improve continuity of care, provide specialised PC training, train providers in multicultural competence, increase early patient identification, improve the shared information system, ensure patient-centred care and increase the number of professionals and PC services. A recommendation for further research is the need for more studies on successful implementations of IPCS to better understand the processes and elements needed.

Resum

L'envellida població del segle XXI pateix malalties cròniques, fragilitat, càncer, malalties que poden ser mortals, multimorbiditat i té també una vida més llarga. Les cures pal·liatives (CP) han estat tradicionalment la resposta a aquestes afeccions i han evolucionat al que avui en dia anomenem cures pal·liatives integrades (CPI). Les CPI, tal i com suggereix la bibliografia revisada, podrien ajudar el sistema assistencial a oferir una millor opció a malalts terminals i a pacients amb malalties cròniques a més de ser el sistema més rendible. Tot i que actualment hi ha un gran interès en els sistemes integrats de cures pal·liativa (SICP) encara cal més investigació per a millorar els serveis prestats als pacients de CP i les seves famílies. L'objectiu d'aquest estudi de cas és descriure el sistema de cures pal·liatives d'Osona (SCPO) a Catalunya, Espanya i identificar els elements que inclou i els que li falten com a SICP en relació als elements essencials que es troben a la bibliografia revisada.

Aquesta investigació ha explorat primer el significat de les cures pal·liatives integrades (CPI) identificant els seus elements constitutius. A continuació, s'ha fet una anàlisi del cas concret del sistema de cures pal·liatives d'Osona (SCPO), a partir del qual es descriu el sistema i els serveis oferts als malalts crònics i als pacients amb un pronòstic de vida limitat. Aquest estudi de cas sobre el SCPO ha permès identificar els elements essencials que hauria de tenir el sistema integrat de cures pal·liatives (SICP). De la mateixa manera, ha cercat el nivell d'integració i les necessitats del SCPO així com els dilemes ètics del sistema d'atenció sanitària d'Osona.

Metodologia

Aquesta investigació ha seguit una metodologia qualitativa amb un enfoc constructivista fent servir una tècnica de metodologia d'estudis de cas per comprendre i descriure exhaustivament el SCPO. Per donar resposta a la qüestió principal de l'estudi, s'han executat dues fases d'estudi mitjançant diverses tècniques de recerca. En la fase I que tenia com a objectiu trobar una descripció del SCPO i es va realitzar una revisió de documents complementada amb els resultats d'uns qüestionaris adreçats a professionals del SCPO. La fase II tenia l'objectiu d'identificar els elements considerats integradors del SCPO i es van realitzar entrevistes amb els participants de l'estudi de cas. El disseny metodològic de la investigació es va basar en proposicions teòriques anteriors trobades a la bibliografia revisada per a la recollida de dades i l’anàlisi posterior. L'estudi va seguir un disseny metodològic d’un estudi de cas *embedded* (incrustat) mitjançant l’anàlisi de contingut deductiu.

Resultats

Els resultats de la fase I d'estudi descriuen l'organització, els serveis i els professionals del SCPO des d'una perspectiva estructural. La fase II va identificar els elements integradors essencials per a un SICP, comparant els resultats de l’estudi amb els elements essencials trobats en la documentació revisada. Aquests resultats va donar lloc a la creació del model combinat, *blended* dels elements teòrics i pràctics per un SICP.

L'estudi també va trobar els elements integradors que inclou el SCPO i que té com a facilitadors d’aquest tipus de sistema des de un punt de vista més estructural i des del punt de vist dels serveis assistencials, com ara: un equip multidisciplinari motivat, lideratge i un sistema de CP específic i rendible. De la mateixa manera va trobar els elements que són obstacles pel bon funcionament del SCPO i també els mateixos es van esmentar com a exclosos o que necessitaven millores. Aquests elements són: millorar la col·laboració, la continuïtat de l’atenció, problemes d’identificació de pacients en els primers estadis de la malaltia i la manca de finançament específic, de professionals i de serveis. Finalment, l'estudi va identificar els dilemes ètics més comuns que s’han trobat els professionals del SCPO. Els més repetits, d’entre els mencionats són: amenaça a l’autonomia del pacient, la presa de decisió sobre seguir o no amb tractaments no beneficiosos i la pobresa.

Conclusions

Les principals conclusions d'aquesta investigació són que els principals elements descrits a la bibliografia revisada sobre la visió teòrica d'un SICP es van trobar també en els resultats d'aquest estudi, confirmant el fet de que són essencials. També es va trobar que el SCPO inclou la majoria d'elements integradors per a un SICP indicats en la documentació revisada. Tot i això, alguns dels elements necessiten canvis i millores per a una millor atenció al pacient de CP.

Les recomanacions més importants d’aquesta investigació per a posar en pràctica són: millorar l’assistència continuada, proporcionar formació especialitzada en CP, formar treballadors en competències de multiculturalitat, identificació precoç del pacient, millorar el sistema d'informació compartida, assegurar l'atenció centrada en el pacient, i augmentar el nombre de professionals i dels serveis per a les CP. Les recomanacions per a investigacions futures són la necessitat de que hi hagi més estudis sobre bones pràctiques en SICP per entendre millor els processos i els elements necessaris.

Glossary

ABS	Primary Care Area
BVD	Dependency Evaluation scale
CHF	Congestive Heart Failure
CKD	Chronic Kidney Disease
COPD	Chronic Obstructive Pulmonary Disease
COVID	Coronavirus SARS-CoV-2
CVA	Cerebral Vascular Accident
EAIA	Ambulatory Integral Evaluation Team
EAP	Primary Care Team
EBA	Associative Base Primary Care Entity
GMA	Adjusted Morbidity Groups
GP	General Population
HC3	Shared Medical Record
HIV	Human Immunodeficiency Virus
IC	Integrated Care
Intermediate	Intermediate, convalescent, rehabilitation care
IPC	Integrated Palliative Care
IPCS	Integrated Palliative Care Systems
INSALUD	Government’s Public Health Organisation
LAPAD	Dependency Law
LOSC	Health Law of Catalonia
MACA	Advanced Chronic Disease Patient
NECPAL	Palliative Needs Tool
OPCS	Osona Palliative Care System
PADES	Home Care Support Team
PC	Palliative Care
PCS	Palliative Care Systems
PCC	Chronic Complex Patient
PDA	Advance Care Directive
PIAISS	Interaction Health and Social Care Plan
PIIC	Shared Individualised Intervention Plan

PPAC	Chronicity Prevention and Care Programme
PT	Patient
SISO	Integrated Health System in Osona
SWOT	Strength Weaknesses Opportunities and Threats questionnaire
UCP	Palliative Care Units in hospitals
UFISS	Interdisciplinary Functional Unit in Convalescent Care
UK	United Kingdom
WHO	World Health Organisation

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CHAPTER 1

INTRODUCTION

1. INTRODUCTION

Population ageing in developed countries is associated with the increased prevalence of patients with multiple chronic diseases that will eventually cause their death (Ela et al., 2014). Due to increasing life span and this new ageing population, it is important to consider how effectively health care systems are responding to their needs, including in the area of palliative care (PC) services for older patients (Ewert et al., 2016; Lyngsø et al., 2014; Garralda et al., 2016).

Following the World Health Organisation (WHO) palliative care (PC) is a type of care that aims to improve the quality of life of patients with life-threatening diseases by reducing their suffering, and providing them with early care and treatment of any symptom associated with their disease process (World Health Organization, 2018). Historically, PC was dedicated to cancer patients (Gómez-Batiste et al., 2012a) and described as the care for those with a life-threatening disease (Siouta et al., 2016). With an ageing population, palliative care systems (PCS) have a new challenge that is not limited to oncological or life-threatening diseases (Den Herder-Van Der Eerden et al., 2017).

Nowadays, the population eligible for PC includes patients with multimorbidity (Kamal et al., 2013) as well as those in need of this kind of care due to frailty or very old age (Kallen et al., 2012) or disabling conditions (Engel et al., 2016). Gómez-Batiste and Connor (2017) advocate determining PC services according to individual patient needs rather than by specific diagnostic codes. They describe the palliative target patient as having a “palliative cluster” of symptoms with a chronic and/or advanced and/or progressive and/or life-threatening disease or condition and with multidimensional needs.

The main challenge now facing health care systems is to provide integrated care (IC) for patients with increasingly complex chronic conditions (Singer et al., 2011). IC has been defined as the combination of multiple services at different levels of care aiming to improve the quality of health services (Lyngsø et al., 2014), and also as care that provides connection and cooperation between funding sources, organisations, services and clinical levels aiming to offer system efficiency and quality care (Kodner & Spreeuwenberg, 2002).

To find out if the combination of these two concepts, PC and IC, into integrated palliative care (IPC) is the best approach to the chronically ill and patients with a limited life prognosis, more research is required. As Ewert et al. (2016) stated, IPC supports professionals, caregivers and patients involved in PC, while improving the quality of care for patients.

1.1. Need for Research

My professional practice as an oncology nurse and personal experience as a caregiver for a family member facing an incurable disease, made evident the need for a new form of PC that could better support PC patients and families. Currently, there is an increased interest in integrated palliative care systems (IPCS), which could be a cost-effective and optimal approach to provide care for the terminally ill and patients with chronic conditions (Bainbridge et al., 2011). The hypothesis of this research is that there is no agreement on the definition of IPC nor on its essential elements since there are several studies stating the need to find a common definition for IPC, identify its constitutive elements (Van Der Eerden et al., 2014) and identify successful IPC implementation models (Tan et al., 2016). Consequently, IPC implementation is different across settings and the analysis of its implementation and comparison is complicated.

Consequently further research on IPC is needed to improve integrated palliative care services for patients and their families (Garralda et al., 2016). Considering my personal experience, existing theory and studies reviewed, there is a need to further explore the definition of IPC, its operationalisation, application and evaluation.

1.2. Study Purpose and Research Questions

The present research aims to further explore the meaning of IPC by identifying its constitutive elements. After examining more deeply in the operative meaning of the term, an analysis of a concrete case will be carried out, followed first by a description of the Osona Palliative Care System (OPCS) and then an analysis of the system and services offered to the chronically ill and patients with a limited life prognosis. This case study research on the OPCS first sought to identify what the essential elements of IPCS should be. Then, the OPCS case study inquired about the level of integration of the health system within this region.

The purpose of this case study is to describe the OPCS in Catalonia (Spain) and to identify those elements it includes and those it lacks as an IPCS when compared with the IPCS definition and essential elements found in the literature.

1.2.1. Research Goals and Questions

The goals and central questions for this research were:

1. Description of the OPCS: How is the palliative care system serving the chronically ill and palliative patients in the Osona region of Catalonia, Spain?
2. Identification of the essential integrative elements of an IPCS: What are the essential elements of an IPCS?
3. Identification of the integrative elements that the OPCS includes, excludes and those that are needed: What elements does the OPCS include, exclude and lack as an IPCS?
4. Description of the ethical dilemmas encountered by providers in OPCS: What ethical problems does the professional in the OPCS encounter?

1.3. Methodological Research Design

The OPCS has a long tradition of collaborative and integrative care practices (Blay Pueyo, 2017). It is thus probable that the OPCS is already implementing IPC to some level. Therefore, research that studies this system thoroughly could provide us with some insights into its degree of IPC implementation. In order to respond to the goals and questions for this research into the OPCS, a qualitative methodology involving a case study was used. This methodological approach enabled the acquisition of a thorough understanding of the case studied and a comparison of it to the theoretical proposition found in the literature. In the defining and design phase the literature was reviewed to find the definition of the term IPC and the essential elements of ICPS, and a framework to evaluate an IPCS was also identified. These theoretical propositions guided the preparation and data collecting phase, the study design, and analysis of the multiple units of analysis within the embedded single case studied. Finally, the results were compared with the theoretical propositions, and the case report was written (see Figure 1).

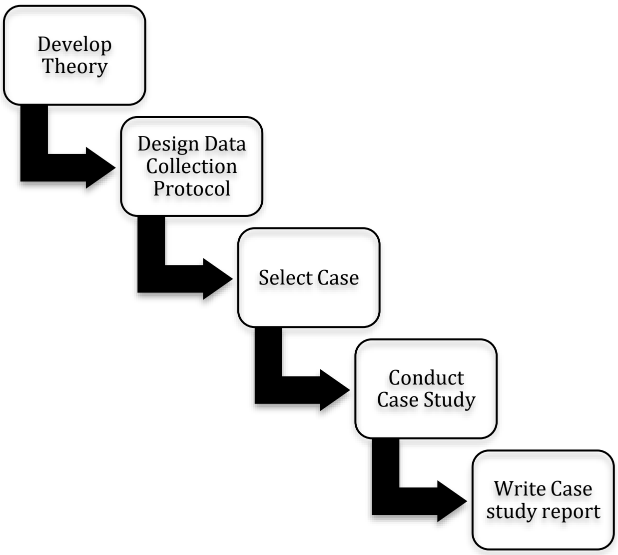


Figure 1. *Case Study Procedure. Source: Yin, 2014*

1.4. Thesis Layout

This thesis is organised into six chapters, which describe the study process from the conceptual framework review to the case study of a specific PCS in the Osona region, with its data collection and analysis and the report of the findings (see Figure 2.OPCS Thesis Layout).

Chapter 1, the introduction, presents the main queries of the study, such as the increasingly ageing population and the new challenge for health care systems to respond to this reality with IPC. These are the motivations and justification for starting this study. It then introduces the purpose, main research questions and methodology strategy. Chapter 2, the conceptual framework, presents an in-depth description of the key concepts and themes subjects in this research, such as the situation of the growing elderly population, how the system approaches their needs with IPCS, a definition for IPC and it essential elements, and how PC has been in Spain, Catalonia and the Osona region. This conceptual framework helped guide the research design and posterior data analysis and results. Chapter 3, the methodology chapter, describes the study's purpose, research questions and goals. It describes the methodological approach, research strategy and case study method in more detail, as well as the study methodological design, data collection and analysis strategies and research feasibility and ethical considerations. Chapter 4 presents the results from the documents review, the questionnaires and the interviews. The results were divided into two phases: Phase I described the structure, services and professionals of the OPCS; and Phase II identified the essential integrative elements of an ideal IPCS. It then identified he integrative elements that were included, excluded and needed by the OPCS, as well as the providers' ethical concerns. Chapter 5 presents the discussion for the different research questions and study phases, followed by a general discussion on the overall findings on the OPCS by providing an overall description of the system and an understanding of the elements included, excluded and needed. It also describes the ethical dilemmas most commonly experienced by the providers in this system. Chapter 6, the conclusions chapter, summarises the study findings and discusses the implications for the OPCS and for future researcher in IPC, as well as the study limitations.

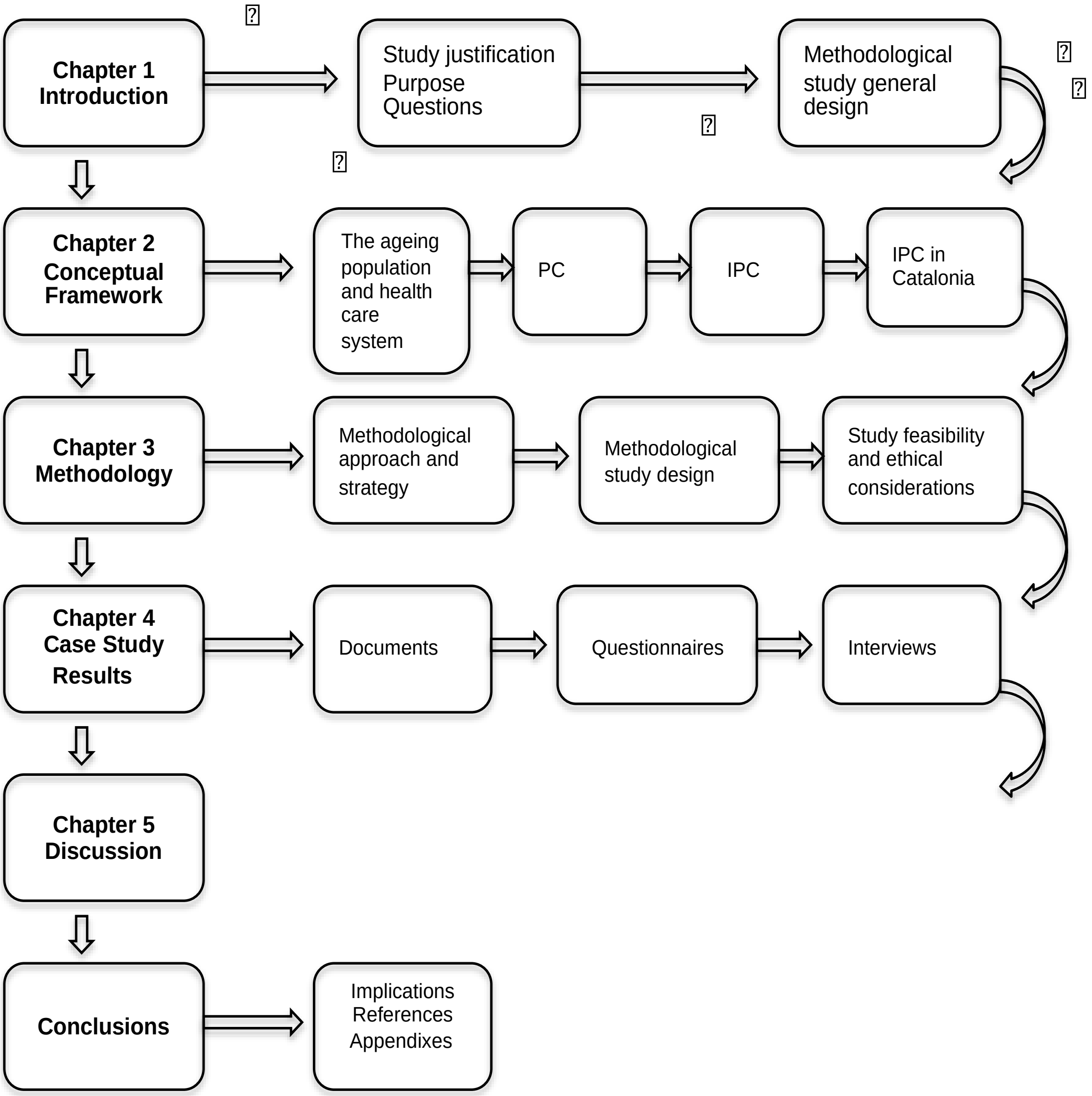


Figure 2. *OPCS Thesis Layout*

CHAPTER 2

CONCEPTUAL FRAMEWORK

2. CONCEPTUAL FRAMEWORK

This conceptual framework begins by describing the new reality of the ageing population in the 21st century, since this population has increased in the last few decades and there is a need to explore how the health care system is responding to their needs. Traditionally, PC has cared for this ageing population, and in this study we will analyse the history of PC as well as the main characteristics of its patients and the ethical dilemmas faced by the professionals. In addition, in theory we have identified new responses to the PC patient such as IPC. This study reviews the concept of IPC in the literature and explores IPC implementation in the Catalan region of Osona, its policies, health care plans, system structure and services.

2.1. The Ageing Population and Health Care Systems

2.1.1. The Ageing Population

Western countries are experiencing a rapid increase of ageing individuals. As the WHO indicates, the population over 60 years old will double from 2015 to 2050 to become 22% of the overall population (World Health Organisation, 2014). Nowadays, older people live longer lives, but they may also suffer from multiple chronic diseases that will eventually cause their death (Gómez-Batiste et al., 2014a). Health care systems have to confront the increased demand for services from this older population and the cost impact that comes from responding to their needs (Bainbridge et al., 2010).

It is a fact that the world population is living longer. In 2017, life expectancy increased to 73 years of age, and for 2040 it is projected to probably increase to 77.4 years. This is a big change when compared to a life expectancy of 48 years for males and 53 years for females in 1950. On the other hand, the proportion of people dying at 75 years and older increased from 12% in 1950 to 39% in 2017. Nonetheless, while life expectancy has increased to 73 years, a healthy prospect is only expected until 63 years of age (Institute for Health Metrics and Evaluation, 2018). Therefore, this ageing population currently lives about ten years more than years ago, but during these years they might suffer several diseases and disabilities.

An older age population often experience multiple chronic diseases. The leading causes of death and disability in the world in 2017 were ischemic heart disease, low back pain, stroke, lung cancer and chronic obstructive pulmonary disease (COPD) (Institute for Health Metrics and Evaluation, 2018), most of them caused by abnormal blood glucose, pain, blood and heart conditions and risk factors related to chronic conditions. Deaths related to common diseases have dropped but non-communicable diseases have increased the death toll. The prospect of death from chronic and non-communicable conditions worldwide is projected to be 69% in 2030 (Siouta et al., 2016). Globally, life expectancy is higher for females than males, but females also suffer more disability and poor health in old age (Institute for Health Metrics and Evaluation, 2018). Hearing loss, cataracts, refractive errors, back and neck pain, osteoarthritis, COPD, diabetes, depression and dementia are common conditions experienced by the older population (World Health Organisation, 2014). The increase of long term conditions in the older population also involves a higher prevalence of multimorbidity (Boeckxstaens et al., 2011). The older population also suffers from what has been called geriatric syndromes - such as frailty, urinary incontinence, falls, delirium and pressure ulcers among others - which are not associated with a specific disease, but they are the result of the later state in life. These complex health conditions are also contributors to the death of this ageing population (World Health Organisation, 2014).

This growing chronically ill population causes an extensive use of the existing services and an increase cost for health systems. Patients with chronic diseases need more medical care, and this puts pressure on the existing health services in a system (Ramanayake et al., 2016). As indicated by Smith (2014), 25% of health care expenditure in the United States is associated with the last year of life, and 20% of hospital beds in the United Kingdom (UK) are occupied by end-of-life patients (Smith et al., 2014) This new situation leaves health care systems with an increase cost to care for the older age patients (Bainbridge et al., 2010). In order to respond to this increase cost and service demand, more practical and cost-efficient strategies are needed (Bull et al., 2012) that are at the same time high quality services and that are beneficial to end-of-life care (Tan et al., 2016).

2.1.2. The Characteristics of Palliative Care Patients

People living longer lives also face more chronic conditions. The older population frequently experience multimorbidity, as they also develop complex states that are not related to a specific disease but that are due to the advanced stage on their life (Bone et al., 2016).

A chronic disease is one that affects activities of daily living and/or requires continuous medical care that last a year or longer (National Center for Chronic Disease Prevention and Health, 2018). These chronic diseases usually last a long time and progress slowly, and they are responsible for almost 70% of the death toll in the world (World Health Organisation, 2018). The most frequent chronic diseases experienced by this advanced age population are cardiovascular disease, malignant neoplasms, chronic respiratory diseases, musculoskeletal diseases and neurological and mental disorders (Prince et al., 2015). However, as indicated, the most common condition in advanced age is multimorbidity (Rizzuto et al., 2017).

Multimorbidity is when an individual has numerous chronic conditions, appearing mostly as the individual ages. In the Barnett et al. (2012) study in Scotland, patients at 50 years suffered mostly from one disease, but at 65 years and above they were already experiencing multimorbidity. Patients with a multimorbidity state have two or more chronic conditions, and they may die earlier and will be hospitalised more often and for longer periods of time compared to those with one condition (Smith et al., 2012). Patients suffering from multimorbidity also experience increasing difficulty in managing their complex multiple illnesses (Roland & Paddison, 2013).

Complexity in health care terms is a multidimensional incidence of medical conditions, ageing, frailty, cultural, contextual, socio-economic and systemic factors interacting at the same time (Kuipers et al., 2011). The complexity of a patient is not just seen in terms of the medical conditions, but also how the multiple social and environmental factors impact their health. This complexity is the results of many different aspects, such as the patients' living arrangements, their social relationships, health accessibility, housing and mental health and immigration status - all these aspects will have an effect on their health (Manning & Gagnon, 2017). Consequently, the complex patient is described as the patient that usually has multiple chronic conditions, is cared for by multiple providers, takes many medications, is hospitalised frequently and has limitations in activities of daily living due to a physical, mental or psychosocial difficulty (Berry-Millett & Bodenheimer, 2009). In addition, if the patient is in the end-of-life phase, complexity for this patient will include the specific needs of the dying patient and their families. These needs will include physical, psychological and psychiatric, social, spiritual, religious, existential and cultural aspects (National Consensus Project for Quality Palliative Care, 2018).

Complexity care is the level of difficulty in managing a patient and the need to apply an individualised care plan due to their illness, multiple conditions and the use of health care resources (Termcat. Generalitat de Catalunya, 2013). The complex patient brings uncertainty into the clinical practice and difficulty in the decision-making and problem-solving processes. This can ultimately affect the quality of care and the outcomes for patients and the health care system (Amblàs-Novellas, 2016).

2.1.3. The Healthcare System Response to the Ageing and Palliative Care Population

How do health care systems better serve the ageing, chronically ill, multimorbid and complex patient? An integrated health care response must address the ageing population's needs (World Health Organisation, 2016).

IC becomes the main challenge for health care services as they need to attend to the ageing chronically ill (Singer et al., 2011), complex and multimorbid patients (Lyngsø et al., 2014) that are increasing in age and number (Kinley et al., 2013). The European Union and the WHO have supported care integration in recent years. These institutions urge the world health care systems to reorient their mission to offer IC that better serves the ageing chronically ill population (Blay Pueyo, 2017). Internationally, many frameworks and chronic care models have been developed and implemented, with the aim of organising care for older people. The models and frameworks aiming to integrate care have many aspects in common and some differences resulting from the characteristics specificities of their contexts (Carvalho et al., 2017).

IC is defined as the combination of multiple services at different levels of care aiming to improve the quality of health services (Lyngsø et al., 2014) and to achieve system efficiency (Kodner & Spreeuwenberg, 2002). This efficiency is obtained by offering coordinated and cost-effective services (Bainbridge et al., 2016). IC should be implemented in all levels of care: in the high level (policy or sector levels), middle levels (organisations, professionals) and in the lower levels (intervention and clinical level) (World Health Organisation, 2016).

An integrated health care system will require a transformation from a traditional structure. Services should be centred on people's needs, not on the intrinsic service's needs; care should be focused on optimising patients' physical and psychosocial capacities rather than just aiming to manage a disease or condition; and the health system should ensure timely access to care when needed (Araujo de Carvalho et al., 2017). The model of IC aims to achieve three objectives: better patient experience, better health results and cost-effective service (Ham et al., 2011). The IC model ensures better health outcomes for the older chronic patient than traditional systems, and thus provides the health system with a better investment result (Araujo de Carvalho et al., 2017).

Finally, it is important to consider that the ageing population is consistently increasing over time, and although they have a higher survival rate, they live with multiple, complex health-threatening conditions. Who will provide them with IC within the health care system? As

(Ramanayake et al., 2016) stated, the requirement for PC services will increase now and in the future in order to respond to the growing ageing population with multiple chronic conditions. Therefore, this larger group of ageing individuals will have a greater need for PC services at the end of their lives (Davies et al., 2014). PC should be part of the continuum of services provided by integrative care services (World Health Organisation, 2016), and it should be introduced in parallel with other disease-treating therapies to promote quality of life to individuals with progressive diseases (Gómez-Batiste et al., 2017b).

2.2. Palliative Care

2.2.1. The Historical Evolution of Palliative Care

Palliative and hospice are two common words used when thinking of death and the dying process. The origin of the word palliative comes from *pallium* in Latin, meaning to cover, to protect from symptoms or suffering. Hospice in Latin, *hospitium*, at first referred to the warm feeling that a guest felt. Later this term would denominate the place where it took place (Rio & Palma, 2007). The concept and understanding of death have changed through history. In the early Middle Ages, death was known as domestic death and was seen as a biological continuum. At the deathbed, a ritual was performed where all the family members were present, and the dying person, knowing his fate, prepared for the event spiritually and socially. Later, people's concern regarding the death process, the funeral processes and also the process of identifying the deceased people once they had been buried grew, and death became known as the death of oneself. It was not until the 19th century, that mourning and cemetery rituals started, and death became known as the death of the other. After World War One and its large death toll, death became a social taboo and became known as prohibited death. It was not until the 20th century that medicine started to try to find the causes and treatments for illnesses, instead of just treating the symptomatology in which the integral vision of the patient is lost, and the systematic application of treatments is applied. Then, in the 1970s, a movement to provide support for the dying was initiated in England (Rio & Palma, 2007), and the concept of death and the death process came to be understood as in the current times.

The history of hospices started in the fourth century when the first centres named hospices or hospitals were founded by Christian charities. Later, in the Middle Ages, in the context of the crusades and pilgrimage routes, hospices appeared in order to provide those in need with medical care, shelter and food. During the 18th and 19th centuries, hospices changed from places that cared for travellers and pilgrims to health care centres (Gómez-Batiste & Connor, 2017). In France in 1842, Mme Jeanne Garnier founded the Calvary or hospices for the dying. In 1879, in Dublin, and later in 1905, in London, Our Lady's Hospice and the Saint Joseph's Hospice were founded, respectively, by the Charity Irish Sisters (Rio & Palma, 2007). St. Christopher's Hospice, founded in London by Cicely Saunders in 1967, is considered the first modern hospice. The goal of this centre was to provide full care for terminally ill patients and their families with the goal not of lengthening their lives, but of improving their quality of life and serve their needs. In the United States, a couple of years later, in 1969, E. Kubler-Ross published her book On Death and Dying, in which she researched and explained the five stages that dying patients go through: denial, anger, bargaining, depression and acceptance. At this point, the discussion about better care for terminal patients started in the United States, and the American hospices were included in the Medicare health care system in the 1980s (Gómez-Batiste et al., 2014a).

From 1970 to 1980, PC spread to many countries in North America, Australia and Europe. In 1990, the WHO identified PC as an important public health topic, after which countries throughout the world started developing PC programmes. In recent years, the palliative approach concept has developed as the mortality and prevalence of people with chronic conditions has grown increasingly, and they are in need of this kind of care (Gómez-Batiste & Connor, 2017).

The terms hospice and palliative have been used interchangeably over time. Balfour Mount in Canada called care for the dying palliative care, while in England, in 1987, palliative medicine was the term used for a subspecialty in medicine. In the 1980s, the WHO incorporated the term PC in a programme for patients with cancer. Currently, the term hospice is still used in the United States and England to denominate the services offered to the patient at the end of life (Rio & Palma, 2007).

2.2.2. Palliative Care in the Twenty-First Century

The PC concept has changed over time. Historically, PC was dedicated to cancer patients (Gómez-Batiste et al., 2012a) and described as the care for those with a life-threatening disease (Siouta et al., 2016). With an ageing population, PCS have a new challenge that is not limited to oncological or life-threatening diseases (Den Herder-Van Der Eerden et al., 2017). As defined by the World Health Organization (2018):

> Palliative care 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, whether physical, psychosocial or spiritual (para.1).

There has been a change in how and when PC is initiated. In the past, sudden death was frequent, and PC was part of the terminal phase when no curative treatments were effective any more. Nowadays, PC is also part of the supportive phase when patients are suffering the effects of chronic conditions that will lead to death. Murray et al. (2005) described three different trajectories for progressive chronic illnesses, as Figure 3 indicates:

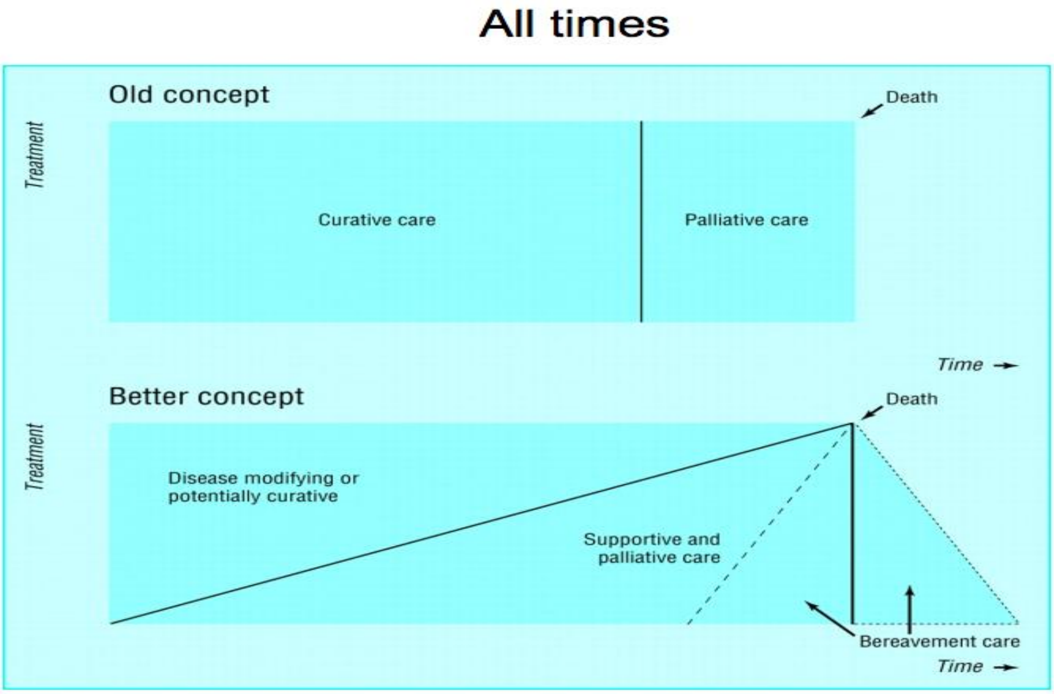


Figure 3. *Illness Trajectory and PC. Source: Murray et al. (2005)*

1. Cancer trajectory, progressive and clearly terminal.
2. Organ Failure trajectory, progressive decline, acute deteriorating crisis, more unpredicted death.
3. Frailty and dementia trajectory characterised by a long gradual decline.

PC should respond to patients in all three trajectories from early on in the trajectory with a chronic or terminal disease (Murray et al., 2005). This PC approach should be applied in combination with disease treatment therapies to patients suffering from one or multiple conditions that are life threatening. However when curative treatments are not useful to the patient PC should focus mostly on their quality of life (Gómez-Batiste & Connor, 2017).

In 2005 the WHO developed the report on preventing chronic diseases (World Health Organization, 2005), guiding heath care systems in developed countries to reorient their response to the growing number of patients with chronic conditions and complex situations in need of palliative care (Amblàs-Novellas, 2016). It is important to consider that as there is a larger number of patients needing PC services, a greater number of professionals, programmes and resources are involved in PC services.

PC has changed over time. In the past, it was dedicated to cancer patients and terminal diseases, a fragmented institutionalised care initiated late in the disease process. In the present, PC needs to respond to a larger number of patients with chronic and complex conditions, a PC that is patient-centred, that detects the patient earlier, and that takes place in all settings where the patient receives care (see Table 1), causing the involvement of more professionals and resources from the healthcare system. The new reality for PC has required a shift into a care that is more integrated (Gómez-Batiste & Connor, 2017) to better respond to the chronically ill patient.

	Past	Present
Concepts	Terminal Disease	Advanced progressive chronic disease
	Prognosis of weeks, months	Limited life prognosis
	Mortality	Prevalence
Models of Care	Curative or palliative	Shared, combined care
	Prognosis criteria for intervention	Complexity severity as criteria for intervention
	Late patient identification in specialist services	Early patient identification in all settings
	Passive patients' role	Patient-centred care
	Fragmented care	Integrated care
	Institutionalised approach	Community approach
	Service approach	Population approach

Table 1. *Conceptual Transitions in PC in the 21st century. Source: Gómez-Batiste and Connor (2017)*

2.2.3. Palliative Care Patient Needs

The PC patient, as explained by Gómez-Batiste and Connor (2017), should be identified according to the individual patient's needs rather than by a specific diagnosed disease. These authors describe the palliative target patient as having a "palliative cluster" of symptoms with a chronic and/or advanced and/or progressive and/or life-threatening disease or condition with multidimensional needs. The population eligible for PC now includes patients with multimorbidity (Kamal et al., 2013) as well as those in need of this kind of care due to frailty or very old age (Kallen et al., 2012) or disabling conditions (Engel et al., 2016).

PC, as stated before, should not just aim to treat diseases or multiple conditions that patients endure in an advance stage, it should care for all the patients' needs and all conditions and situations that affect their wellbeing. According to the Clinical Practice Guidelines for Quality Palliative Care (2018), PC should address:

- Psychological and psychiatric aspects, by giving emotional care and addressing psychological distress experienced by patients and their families.
- Social and environmental factors such as resources, social support, relationships and the care environment that affect their quality of life.
- Spiritual, religious and existential aspects such as screening for spiritual needs and distress, assessing spiritual background, beliefs, values and rituals that are preferred by patients and families.
- Cultural aspects by assessing for preferred language and communication style and assessing literacy, health care practices, customs, beliefs, values of patient and families.

2.2.4. Ethical Dilemmas Encountered by Palliative Care Professionals

Medicine now is able to prolong life and the dying process, which leads to ethical and technical challenges in the care of patients and their families. This is true in a cross-cultural context where the literature indicates that the problems are very much the same. This study examines international studies to see how ethical issues in Spain compared to those experienced in PC by other countries and systems such as the US, Mexico, Spain and Taiwan. PC professionals encounter ethical dilemmas, for which they might feel unprepared (Cheon et al., 2015). Ethical dilemmas do not just concern the professionals, however. They can also affect patients' achievement of a quality, easeful and meaningful process of dying (Chiu et al., 2000).

An ethical dilemma is a situation in which an individual needs to decide between two options that are both morally unacceptable (Philosophyterms, 2018). PC professionals face dilemmas frequently, but their attitudes and actions toward them vary, since there is no one ethically right model that can be followed. Usually one option is chosen, over the other, by supporting the selection with some personal values (Guevara-López et al., 2015).

The Universal Declaration of Human rights, 1948, recognises the worth and dignity of human persons and therefore human freedom (United Nations, 1948). In 1978 in the United States, the Belmont Report, established 3 ethical principles to assist in solving the ethical problems that frame the conduct of research with human participants (US Department of Health and Human Services, 1979).

- The beneficence principle, is an obligation to act in the best interest of the patient. One rule formulated as complementary of the beneficence principle is the do not harm. The non-maleficence or no harm, in a medical context, is the balance between the benefits and the risk, where the benefits should always outweigh the risks.

- The autonomy principle, the patient has the freedom and the right to decide on their own wellbeing.

- The justice principle, to promote equality and avoid inequality in the health sector.

Similarly, the right to freely decide was acknowledged in Spain in 1986 in the General Health Law. Later, in 2002, this Health law was further developed to strengthen the patient's right to autonomy. These are summarised by Sangüesa Cabezudo (2012) as the following:

- Respect for the dignity, autonomy and privacy of all people.
- All health intervention requires agreement by the patient.
- The patient is free to choose among the clinical options after receiving the needed information.
- The patient has the right to refuse treatment except in cases determined by the law.
- Patients have the duty to inform clinicians about their health and physical state.
- Professionals are obliged to provide people with service, clinical information, and documentation.
- Professionals with access to health records are obliged to keep the information confidential.

Advanced care planning is defined as the plan for medical care to be applied in the future (Ko et al., 2011). Advanced care directives are important because they support patient autonomy. In the US, advanced care directives were installed as documents which expressed the patients' wishes and choices to protect the patients' rights (Huang et al., 2018). In Catalonia, Spain, the *Pla de decisions anticipades* (PDA), (advanced care directive) is a similar document that collects in writing the preferences, convictions and values of patients going through treatment for a disease (Delgado et al., 2016). These advanced care directives might help healthcare professionals in solving some of the ethical dilemmas by knowing the patient's preferences when they are unable to decide. Chiu et al. (2000) indicated that more education and communication between professionals, patients and families are essential to help resolve these ethical dilemmas. As indicated by Arce García (2006), another way to solve many of these ethical dilemmas is by having good clinical training in palliative care, as well as knowledge of the ethical principles and legal context. Other authors have suggested that professionals encountering ethical dilemmas should consult ethics committees or examine them in team meetings and discuss them with all the professionals involved, including clergy (Cheon et al., 2015).

2.2.4.1. Common Ethical dilemmas in Palliative care

In the literature reviewed, several studies described different ethical dilemmas encountered by providers while caring for the PC and hospice care patient. It is important to note that the studies described the same ethical dilemmas encountered by professionals across countries, although there were slight variations reflecting cultural differences. The ethical dilemmas most shared by the studies reviewed were: palliative sedation, discontinuation of life prolonging therapies, use of opioids, communication of diagnosis and truth telling, communication difficulties, provision of futile or nonbeneficial treatment, threat to patients' autonomy, euthanasia.

Palliative sedation, is a well-defined process and ethically and legally accepted medical procedure, recommended for terminal and end-of-life processes when there is uncontrollable suffering and no therapeutic possibilities, and death is promptly expected (López & de la Lama, 2020). Palliative sedation might accelerate death as a result of sedative and analgesic treatments (Bátiz & Loncán, 2006), but professionals nonetheless believe it should be offered to patients suffering intensely (Guevara-López et al., 2015; Ko et al., 2011).

Discontinuation of life prolonging therapies. The most common life prolonging therapies in PC are artificial nutrition, hydration and blood transfusion (Guevara-López et al., 2015; Huang et al., 2018; Kinzbrunner, 1995). As explained by some studies, this dilemma relates to withholding or withdrawing these types of life-sustaining treatments or therapies when these treatments would be more hurtful or burdensome than helpful (Cheon et al., 2015; Ko et al., 2011).

Use of opioids involves the management of symptoms, and the ethical dilemma here is similarly concerned with the underuse of opioids and appropriate limits on their use (Cheon et al., 2015; Guevara-López et al., 2015). With regards to overmedication, some providers might be hesitant to use morphine as it could inhibit breathing (Kinzbrunner, 1995). Although, as indicated by Ko et al. (2011), the provision of adequate pain medication to relieve symptoms is needed since pain treatment is a moral obligation and human right.

Communication of diagnosis and truth telling is another difficulty confronted by providers. It is difficult to communicate a patient's diagnosis and treatment to them and their families (Huang et al., 2018; Kinzbrunner, 1995). Although the norm is changing with regards to providing patients with this information, it is still very common to tell families first, who often request or demand that the patient not be told (Guevara-López et al., 2015). This is increasingly an ethical dilemma for PC professionals.

Communication difficulty when there is intergroup conflict. This is an ethical concern for healthcare providers when there is intergroup conflict between patients and family, patients and family and professionals, and between professionals (Guevara-López et al., 2015); Cheon et al., 2015; Chiu et al., 2000;). The stakes of poor communication are high because it impacts treatment plans and the goals of care.

Provision of futile or nonbeneficial treatment is the provision of medical treatment, sometimes due to families request, when treatments might no longer be indicated for the patient's cure (Bátiz & Loncán, 2006). These treatments could include providing aggressive treatment while the patient is in the end-of-life process (Cheon et al., 2015), the administration of antibiotics (Guevara-López et al., 2015) or the use of corticosteroids (Huang et al., 2018).

Threat to patients' autonomy is another ethical problem. This occurs when the patient's right to choose what they think their best option is, and to reject or interrupt treatment is ignored by the family or health care team (Cheon et al., 2015; Guevara-López et al., 2015). As indicated by these authors, it is important to assess the patient's capacity to make decisions. If decision-making capacity is lacking, a living will or previously appointed surrogate decision-maker would be needed to assured the patient's autonomy (Bátiz & Loncán, 2006; Ko et al., 2011).

Euthanasia requested by some patients is another ethical dilemma encountered by professionals (Guevara-López et al., 2015; Huang et al., 2018) and is defined as the intentional ending of the patient's life performed by a physician (Ko et al., 2011).

2.3. Integrated Palliative Care: A New Approach to Palliative Care

As described above, the population eligible for PC nowadays includes patients with multimorbidity, frailty, disabling conditions and old age. The main challenge now for health care systems is to provide IC to patients with increasingly complex chronic conditions and PC needs (Singer et al., 2011). IPC, which combines these two concepts, "integrated care" and "palliative care", now becomes the new approach for working with this multimorbid population within PC. IPC changes care from being just for the terminally ill, to also being for the chronically ill and for patients with a limited life prognosis.

A European Union research project, Patient-centred palliative care pathways in advanced cancer and chronic disease (INSUP-C), (Larkin et al.,2016), defines IPC as follows:

> It involves bringing together administrative, organizational, clinical and service aspects in order to realize continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers paid and unpaid (p. 8).

Previous definitions in the literature suggested a need for a specific definition for IPC that incorporates concepts such as comprehensive and continuous care (Pesut et al., 2013), the participation of a multidisciplinary health team (Bergenholtz et al., 2016), control of symptoms (Partridge et al., 2014) and relief of suffering (Gómez-Batiste et al., 2014a). Some authors, such as Bruera and Hui (2011), have called for a clearer conceptualisation of the term "IPC" in order to establish standards for services. Others have also asked to find a universal definition for IPC Siouta et al. (2016), and pointed to the need to identify the constitutive elements of IPCS (Van der Eerden et al., 2014).

2.3.1. Integrated Palliative Care Definition

Some researchers have tried to find a unified definition for IPC and identify the elements that facilitate or hinder its implementation (Mondejar-Pont et al., 2019) (see Appendix K for published article abstract). These authors explain that after reviewing studies on this topic, when defining IPC the main purpose stated by studies was to provide patients with an early PC intervention. The second most often-mentioned purpose was to be centred on patient needs. Others indicated that IPC aims to ensure a continuum of care, improve quality of life and reduce suffering. Finally, some studies referred to providing patients with efficient and quality care.

Regarding the target population, they found that most studies included patients with chronic conditions related to cardiovascular, respiratory, dementia, renal, (HIV) Human Immunodeficiency Virus, diabetes, and cerebrovascular diseases. Cancer was also indicated by many studies as the motivation for IPC services. Other conditions mentioned as contributing to patient eligibility for PC care were multimorbidity, frailty, very old age, and life-threatening diseases.

In addition, they explained how most authors agreed on the features it must have, for example that a multidisciplinary or interdisciplinary team should provide IPC, that case management should be implemented, and that IPC should be offered as a pathway, network or model of care. Finally, most authors concluded that this care should be offered in the inpatient setting, although most also indicated the importance of offering outpatient, community and home care.

As a conclusion, this study developed the following definition for IPC:

> IPC is coordinated and collaborative care across the different health organisations, levels of care and palliative care providers. The purpose of IPC is to provide early, patient-centred PC interventions, ensuring a continuum of care, improved quality of life and reduced suffering, as well as efficient, quality care. IPC targets the population with conditions such as chronic disease, cancer, multimorbidity, frailty, older age and life-threatening disease. This care is in the form of a pathway, network or model of care, and is provided by a multidisciplinary/interdisciplinary team applying case management in the inpatient, outpatient, community and homecare settings (Mondejar-Pont et al., 2019, p. 8).

According to Mondejar-Pont et al. (2019), PC and IPC have some aspects in common and some important differences. PC and IPC include the concepts of comprehensive and continuous care provided by a multidisciplinary team to patients with a chronic condition or life-threatening illness, such as cancer. This approach to care aims for the early identification of patients and families who can benefit from these services and provides patient-centred care focused on quality of life and the relief of suffering.

A key difference between the definitions is that the IPC specifies that collaborative care should include all organisations, levels of care and providers of PC services. The PC definitions simply reference the PC provider, while IPC takes a broader, more inclusive perspective. As the authors state, this difference could help to ensure that all potential IPC agents become involved, in all organisations and at all levels of care, and that the goal of continuity throughout PC services in a health care system can be attained. Furthermore, in this study the IPC definition makes clear that this type of care should be provided in multiple settings, including inpatient and outpatient facilities, home care and community settings. As some authors have explained, IPC care effectiveness improves (Johnston et al., 2016), and continuum of care is ensured if services are implemented through hospital, clinic, home and community settings (Rabow et al., 2015). Abel and Kellehear (2018) concluded that effective

PC will result from medical health care that cooperates with a strong group of community partnerships.

Mondejar-Pont et al.(2019) indicated that although the PC and IPC definitions concur that patients with life-threatening and oncological diseases are the target population, IPC also includes patients with multimorbidity, frailty and older age in need of this kind of care. According to Gómez-Batiste and Connor (2017), PC services should be offered to patients with a cluster of symptoms indicating the need for such care, rather than limiting PC to very specific diagnoses. According to Mondejar-Pont et al. (2019), a shift in perspective, from a disease-oriented model to a needs-based, patient-centred model of care is required to implement an IPC model and provide services to patients with a larger range of chronic diseases, conditions and comorbidities.

In summary, IPC teams specifically aim to ensure continuity of care in all settings where the patient receives services and the family receives support for their role in caring for the patient. These services can be initiated not just as a response to a critical situation during a hospital admission, but also as a planned service initiated by outpatient or community caregivers. In other words, IPC services are offered holistically throughout the progression of a disease or condition (Mondejar-Pont et al., 2019).

2.3.2. Integrated Palliative Care System Essential Elements Description

Mondejar-Pont et al. (2019) found a total of twelve IPCS-facilitating elements most frequently noted. Figure 4 below illustrated the main elements in a circle of IPCS elements.

Figure 4. *Circle of IPCS Elements. Source: Mondejar-Pont et al. (2019)*

The list and description of the items is as follows:

- Multidisciplinary teams, as explained by Siouta et al. (2016), include professionals from different specialties and disciplines such a doctors, specialists, nurses, psychologists, chaplains, physiotherapists and nutritionists. Interdisciplinary teams organised from inpatient to primary care (Kaye et al., 2015) and within organisations (Gilbert et al., 2012), with a common goal of meeting the patients' needs (Kuzmarov & Ferrante, 2011). Case management provides comprehensive care for the physical, functional, pharmacological, social, emotional and financial needs (Boeckxstaens et al., 2011) that will interact with patients throughout transitions (Kamal et al., 2013).

- Coordination meaning collaboration of services and organisations (Boeckxstaens et al., 2011) between primary and secondary services (Fernando et al., 2014), home services (Kaye et al., 2015) from different specialties (Siouta et al., 2016) and across professionals (Lyngsø et al., 2014).

- Early Intervention of IPC with patients with advanced chronic conditions (Gómez-Batiste et al., 2016) in need of this care (Evans et al., 2015). The identification of these patients should be early on their disease process (Bone et al., 2016; Davison, 2011; Fernando et al., 2014) by performing early geriatric evaluations (Wilhelmson et al., 2011) and by applying it right at the beginning of diagnosis (Davison, 2011).

- Patient-centred means that IPC is focused on fulfilling the needs and preferences of patients, their families and caregivers (Lyngsø et al., 2014).

- Continuity of care is provided between all agents involved in the IPC services (Garralda et al., 2016) and all the health care settings (Von Roenn et al., 2013). The continuity process occurs when there is sharing of patients' documentation electronically, and with electronic, phone and in-person communication between the team members (Kaye et al., 2015).

- Training and education are necessary for IPC providers so that they offer services with confidence (Freeman et al., 2016) and develop their competence (Rabow et al., 2015).

- A standard implementation model should be applied in IPC direct services and health practices (Bainbridge et al., 2011; Bull et al., 2012; Gilbert et al., 2012). A standard model is a key element for effective care delivery (Bainbridge et al., 2016) and is developed by all stakeholders (Kar et al., 2015).

- Supportive Policies and leadership specifically for IPC are necessary, and they need to be established at the national (Freeman et al., 2016; Stjernsward, et al., 2013) and regional level (DeMiglio & Williams, 2013).

- A shared information system facilitates patient information collection, reporting and availability of care providers (Bull et al., 2012). It also ensures effective IPC care delivery (Bainbridge et al., 2016).

- A standard screening tool helps providers to identify the IPC patient and determine prognosis (Gómez-Batiste et al., 2016). It screens for symptoms and assesses the patient (Von Roenn et al., 2013) and generates service referrals (Rabow et al., 2015).

- Funding for IPC is essential at the country and regional level (DeMiglio & Williams, 2013; Gómez-Batiste et al., 2012b), and deficient funding is an inhibitor for IPC and its proper functioning (Bainbridge et al., 2016). Resources being human and social (Morita et al., 2013) are essential for the effectiveness of an IPCS.

- Cost-efficiency can be the result of the implementation of an IPCS, since it decreases emergency visits and inappropriate admissions, reduces time in hospitalisation stays and reduces infection acquisition and delirium/confusion development from hospitalisations (Lee & Titchener, 2016). It also reduces the cost of care in general for the IPC patient (Johnstone et al., 2012; Partridge et al., 2014; Rabow et al., 2015).

2.3.3. Integrated Palliative Care System Faciliating and Hindering Elements

Mondejar-Pont et al. (2019) examined many studies in order to find the elements that facilitate and hinder IPCS. The facilitating elements were depicted in Figure 4, and described in the previous section 2.3.2. Then, the same study described the most frequently mentioned elements that hinder an IPCS. These elements are listed here in the order of frequency with which they were mentioned.

The first most frequently mentioned element was the lack of coordination and collaboration between health professionals and different levels of care. The next most common hindering element was the lack of funding, as well as the lack of resources and shortage of PC providers. Third, the absence of a timely referral process for patients in need of PC services is a barrier to IPCS success. Fragmentation of services and care was the fourth hindering element. Fifth, a lack of PC training and education for providers and the absence of a standard implementation model. Sixth, an unclear structure and model for an IPCS could be challenging obstacles to IPCS implementation. Seventh, the need for a standard screening tool to evaluate a patient’s PC needs. Eighth, the lack of policies and legislation promoting IPCS as an element impeding IPCS success. Ninth, an unstructured system for information sharing between those providing services. And tenth, the purpose of care was cited as a deterring element for an IPCS since care with a disease-centred model should be changed to become more patient-oriented (Mondejar-Pont et al., 2019).

2.3.4. Integrated Palliative Care System: Interrelationships of the Essential Elements

It is important to note that many of the IPCS elements that were found to be facilitators if present were also considered impediments if absent in a system. Mondejar-Pont et al. (2019) explained that this correlation could indicate that these elements are the most relevant – possibly essential – in an IPCS: coordination, early patient identification, patient-centred, continuity of care, providers’ education and training, standard implementation model and screening tool, shared information technology system, and supportive policies and funding.

The same authors also defended that most of the elements found in the circle of IPCS are similarly interrelated. The presence of a facilitating element usually enables another facilitating element, while a missing or malfunctioning element becomes a barrier to IPCS implementation and usually impedes or affects the efficiency of other elements. For example, the coordination/collaboration element guarantees that patients will receive the care they need (Evans et al., 2015). Therefore, coordination ensures patient-centred care, another key element. It is logical to suppose that coordination and collaboration would provide continuity of care between care levels, settings and providers. In contrast, lack of coordination causes patients to experience suboptimal care, unnecessary suffering and preventable hospital admissions (Bainbridge et al., 2011). Therefore, lack of coordination between providers and care settings causes care to become fragmented, less than optimal and less cost-efficient.

Regarding training and education of PC providers, it is clear that PC-trained professionals are better able to relieve a patient's suffering and thus may provide more patient-centred care (Kaye et al., 2015). A logical corollary, then, is that providers lacking PC training may not be as successful at meeting patients' PC needs, and therefore the care will be less patient-centred. In addition, political support was identified as an important element to ensure successful IPCS implementation (Bainbridge et al., 2011; Kar et al., 2015), while a lack of policy support becomes a barrier. Supportive PC policies could help to set standardised implementation models, with the standard IPC screening tool indicated as a need by many studies.

Finally, the absence of funding and resources causes lack of specialised PC providers (Sleeman et al., 2015), lack of coordination and fragmented care (Kaye et al., 2015), while adequate funding and resources may ensure that PC providers are better trained and that patients receive better care (Mondejar-Pont et al., 2019).

2.3.5. Integrated Palliative Care at a Country and Service Level

Another way to look at integration of PC services is to analyse it by country. Mondejar-Pont et al. (2019) explained how Connor and Sepulveda Bermedo (2014) evaluated the integration of PC into health care systems and reported that optimal PC integration in a country has three essential elements: a comprehensive offering of PC services by various professionals and entities; a national PC association and recognised educational centres that specialise in PC; and informed awareness of PC in public health policies, the health community and the general society. These authors explain how it becomes clear that the elements of advanced country-level integration of PC into the health care agenda has similarities with the essential elements of IPC at the service level. At a country level, IPC requires a comprehensive offering of PC services by multiple providers and organisations, and further involves coordination among centres and providers at the service level that can ensure continuity and truly integrated care. Furthermore, recognised educational organisations at a country level are needed to ensure that care providers can be trained and specialised in PC and in coordination among providers at the service level. In addition, a national PC association with a commitment to IPC could set standards, guidelines and implementation models at the service level. Finally, IPC should be considered in the development of public health policies that influence funding and institutional support for relevant programmes, services and regulations.

Mondejar-Pont et al. (2019) also highlighted the barriers to IPC implementation at a country level: an absence of educational organisations, well-defined PC policies that address integration of care, or organised programmes to deliver this kind of care (Connor & Sepulveda Bermedo, 2014). Mondejar-Pont et al. (2019) relate both country and service level and indicated that the lack of specialised PC educational programmes at the country level directly hinders the availability of well-trained professionals to promote IPC implementation at the service level. Likewise, IPC can have only limited success in the absence of supportive policies, standard implementation models, funding and other resources. Even with good intentions, poorly organised or underdeveloped IPC programmes at a higher level will result in fragmented and uncoordinated care at the service level, clearly a barrier for IPC. In contrast, the presence of the essential elements of IPC at the service level may reflect a country's integration of PC into their health system (Mondejar-Pont et al., 2019).

2.4. Integrated Palliative Care in Catalonia and in Osona

This thesis aims to analyse the specific case of Osona and therefore a brief explanation of context is required.

2.4.1. Territorial organisation in Spain, Catalonia and Osona

Spain, located in the southwest part of Europe, has a population of 46,937,060 inhabitants (Fernández, 2019). Spain is organised into seventeen *comunidades autónomas* (territorial regions). These regions have their own government and parliament as well as their own *Estatuto de Autonomía* (its main regulation), and together with the central government they supervise and finance their local governments. The *comunidades autónomas* have competencies in organising their own education, health, social services and other economic areas such as road infrastructures, environmental protection, culture, sport and leisure, and economic development. The *comunidades autónomas* are further divided into fifty provinces and 8,078 municipalities (Glocal, 2019). Catalonia is the second largest *comunidad autónoma*, and it has a population of 7,619,494 (Fernández, 2019). The Catalonian region is administratively divided into 41 *comarques* (territorial division between a municipality and a province) that hold competencies regarding urbanism and organisation, health and social services, sports, education and public health and environment (Glocal, 2019). Osona is a *comarca* situated in the central region of Catalonia, with fifty municipalities and, in 2020, 163,530 inhabitants (Generalitat de Catalunya. Idescat, 2020).

2.4.2. The Historical Evolution of Palliative Care in Catalonia and Spain

PC started in Spain in the 1980s. At this time medical experts visited institutions dedicated to the terminally ill in the United Kingdom and Italy that were already implementing PC initiatives (Gómez-Batiste et al., 2014a). It was then that the first palliative initiatives started in Spain. In 1992, the *Sociedad Española de Cuidados Paliativos* (SECPAL) (The Spanish Society for Palliative Care) was founded, and in 1993 the Spanish Ministry of Health published a guide for PC according to SECPAL. In 1994, the journal *Medicina Paliativa* was published, becoming the first Spanish journal dedicated to this topic. In 2000, Spain developed a National Plan for Palliative Care, and in 2007 the country formed the Estrategia en *Cuidados Paliativos del Sistema Nacional de Salud* (Strategy for Palliative Care in the National Health System) aiming to standardise PC in the country (Gómez-Batiste et al., 2014a). The first PC units in Spain were opened in 1986. Since then the number of programmes has increased at a rate of around ten programmes per year, covering terminally ill patients with diverse services, centres and activities. All of this indicates that palliative medicine has been developing to an optimal level in Spain (Centeno et al., 2000).

Nowadays, the Spanish health care system is a public structure that provides universal access to all residents. The *Instituto Nacional de la Salud* (INSALUD) (the government's public health organisation) provides health care to ten of the seventeen *comunidades autónomas* in the country. In the other seven *comunidades autónomas*, health care functions were transferred to the region, operated under the INSALUD framework, with Catalonia being one of them (Centeno et al., 2000). PC has been implemented in acute and intermediate/convalescent hospitals, nursing homes and in homecare services offered by the health care system. Spain is undergoing a process in which its population is ageing and increasing in number rapidly. These ageing patients, sometimes with multi-morbidity conditions require multiple health and social services and PC could improve their quality of life (Gómez-Batiste et al., 2014a).

2.4.3. Integrated Palliative Care Development and Regulations in the Catalan Health System

The current Catalan health care model emerged in 1990, under the ordinance 15/1990, *de 9 de juliol, d'ordenació sanitària de Catalunya* (LOSC) (health law of Catalonia) in order to create a health system that would integrate all the health care resources in one network. As Amil et al. (2016) explain, this region has a new challenge regarding the increasingly ageing population compared to other European countries. It is predicted that in 2050, 30% of the population will be over 65 years old and 12% over 80. Consequently there will be a huge increase of people with chronic conditions (Amil et al., 2016). There are several models of PC across *comunidades autónomas* in Spain, one of them developed in Catalonia. Health care functions have been transferred to Catalonia under the country's directives. The Catalonian health system is divided into seven health regions according to a geographical and socioeconomic distribution. These regions are further organised into health sectors that have the *àrees bàsiques de salut* (ABS) (Basic areas of health), which provide the population with primary care (Generalitat de Catalunya. Departament de Salut, 2017a).

In the last decade, some important documents and plans have been developed in the Catalan health system that reflect its goal to establish integrated care, as shown in Figure 5 below. These plans explicitly describe how PC needs to be offered to patients with chronic conditions, patients with complex clinical conditions situations, as well as patients with a life-threatening illness in an integrated manner.

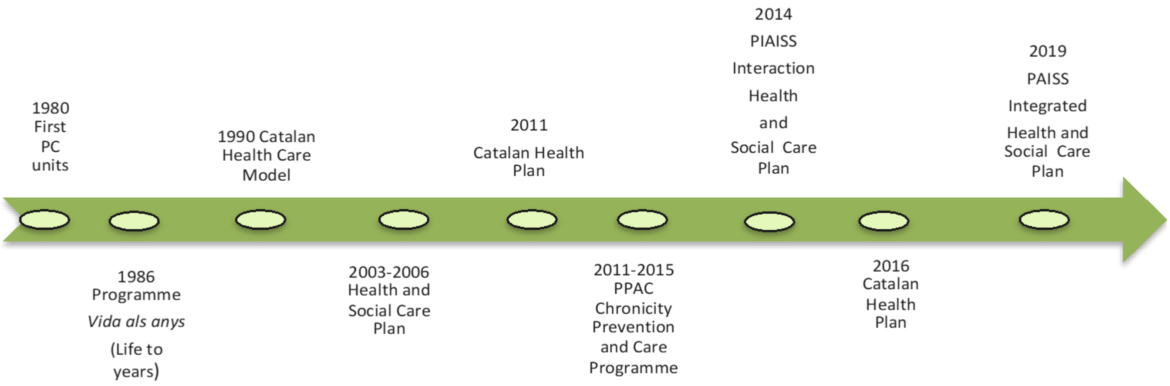


Figure 5. *Timeline of Catalonia Health Care Regulations and PC Development*

In the 1980s in Catalonia the first PC units were instituted. Catalonia developed the programme *Vida als anys* (Life to years) in 1986, a project designed to improve access, coverage and quality of health services for patients with multiple conditions, terminal and older patients in need of care. In 1990, the Catalonia Palliative Care Project was developed by the World Health Organisation (Gómez-Batiste et al., 2016). This project was the first formal PC programme developed in a public comprehensive health system, aiming to provide specialised PC services, the needed drugs and medications and also professional training (Gómez-Batiste et al., 2016). Later, the *Pla Director Sociosanitari* (Health and Social Principal Plan) for 2003-2006 was developed to systematically evaluate the health care system in general, but also to evaluate specifically the PC system. It is also in this year that a directory of PC resources in Catalonia was created (Gómez-Batiste et al., 2009).

Then in 2011, the new *Pla de Salut* (Health Plan) for Catalonia for 2011-2015 and the *Programa de prevenció i atenció a la cronicitat* (PPAC) (Chronicity prevention and care programme) emerged in order to respond to the needs of patients with chronic conditions (Generalitat de Catalunya. Departament de Salut, 2012a). One of the aims of the PPAC is to provide integrated and coordinated care. The different goals established by this plan are as follows (Generalitat de Catalunya. Departament de Salut, 2012b):

- to implement integrated clinical processes.
- to support health protection/promotion programmes and chronic disease prevention programmes.
- to promote patient and family self-care.
- to develop alternative care options to hospitalisations.
- to offer programmes that proactively identify patients with chronic conditions, and merge medication plans and treatments.

In addition, the 2011-2015 Catalan *Pla de salut* (Health plan) stated the need to create the *Pla d'intervenció individualitzat compartit* (PIIC) (shared individualised intervention plan) for patients with chronic conditions. The goal of this plan is to share within the medical team important information about the patient that is accessible to any care provider making health decisions about the patient. The PIIC should be developed by the primary clinical professionals and it should be shared in the *Historia clínica compartida de Catalunya* (HC3) (shared medical records of Catalonia) (Generalitat de Catalunya. Departament de Salut, 2012a).

In 2014, the *Pla interdepartamental d'interacció i atenció social i sanitària* PIAISS) (Interaction health and social care plan) had the goal of transforming the health and social care model to ensure integrated and patient-centred care that will respond especially to the complex patients' health and social needs (Generalitat de Catalunya, 2016b).

The latest version of the Health plan 2016-2020 sets specific goals to respond in an integrated and patient-centred manner, especially for patients with chronic conditions and complex clinical needs. It describes the following goals related to the complex chronic patient (Generalitat de Catalunya, 2016b):

- To develop and implement an integrative model that is patient-centred.
- To develop and implement an integrative health and social and care model.
- To extend and improve regional treaties on complex patient services and integrative health and social care.
- To review the strategies already in place for PC.

This health plan seems to merge the goals for IPC already stated in the previously mentioned health plan from 2011. This plan developed a specific strategy for chronic and integrated care that is patient-centred and directed at patients with chronic conditions and complex clinical situations, placing attention on the interaction between social care and health services. As a result, the PIAISS is reviewed under this plan proposing that the different members of the health and social care team work as a network, in a horizontal coordinated manner, in order to promote a trustful working approach among them (Generalitat de Catalunya, 2016b).

The *Pla director sociosanitari* (health and social care plan) was developed in 2017-2019 to improve the health of patients in need of care due to their age and PC needs, or because they have Alzheimer's or other neurodegenerative diseases (Generalitat de Catalunya. Departament de Salut, 2017b).

In 2019, the PAISS *Pla d'atenció integrada social I sanitària* (Integrated health and social care plan) was developed in order to reinforce integrated care between health and social services through their proper coordination and shared cared provision (DIXIT Generalitat de Catalunya, 2019)

2.4.4. Palliative Care Patient Identification in the Catalan System

In accordance with the PPAC, a complex patient is defined and differentiated into two main types of patients: the *pacient crònic complex* (PCC) (complex chronic patient) and the *pacient* *amb malaltia crònica avançada* (MACA) (patient with advanced chronic disease) (Generalitat de Catalunya. Departament de Salut, 2012b), as shown in see Figure 6.

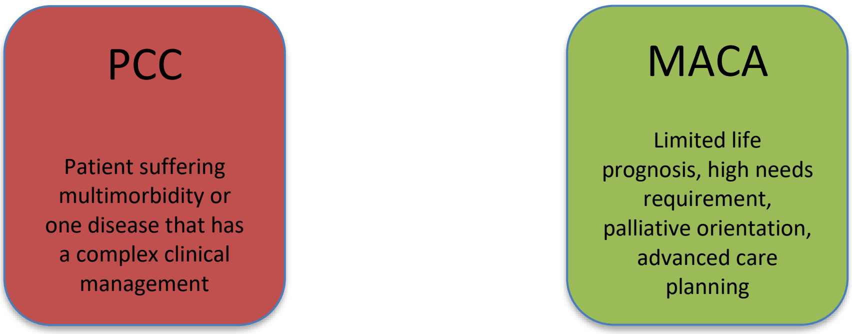


Figure 6. *Complex Patient Types. Source: Santaeugènia Gonzalez (2017)*

PCC patients with a complex clinical situations, suffer multimorbidity, or an acute disease, and their condition will probably evolve progressively with many symptoms requiring continuous follow up, high usage of health services and medications, and the need for a multidisciplinary approach due to their clinical and individual complexity. They will probably also experience functional or cognitive loss, or adverse psychosocial situations. The PCC patient has a prevalence of 4% in the total population (Generalitat de Catalunya, 2017d).

The MACA patient suffers one or more chronic condition and a combination of a clinical profile equivalent to the PCC, progressive and evolving disease, acute clinical presentation when compared to other patients with similar diseases and limited life expectancy of no longer than 12 months. These patients need case management, end-of-life planning decisions and mostly PC. MACA patients usually have a prevalence of 1.3-1.5% in the general population (Generalitat de Catalunya, 2017d; Gómez-Batiste et al., 2014b) or as indicated in a later study of 1% (Blay et al., 2019).

Since the 2011-2015 Health Plan and the development of the PPAC (2011-2014), patients' complexity has been the guideline to identify patients in need of PC services in the Catalan context. In the health care area, complexity is consequently understood to involve several dimensions, such as patients' clinical contextual complexity and the health care system's own complexity. In order to care for the chronically ill patient, it is essential to know what the individual's multidimensional complexity is. The patient's complexity is explained by their physical, psycho-emotional, social-family, spiritual, ethical and end-of-life needs (Amblàs-Novellas, 2016). The Catalan model suggests three steps to identify the complex patient (Blay Pueyo, 2017):

> -Step 1. Patient's complex specific needs (morbidity, crisis profile, progression, hospital admissions, emergency admission, multiple medication, fragility, geriatric symptoms).
>
> -Step 2. Professional's criteria about complexity in managing the patient (morbidity, multiple professionals involved, personal, social and systemic components).
>
> -Step 3. Patients will be better cared for if identified as a complex patient (improvement in the triple aim: better patient care, more care efficiency and better care experience).

The complex patient will then appear in a risk list of patients, because they either suffer from a multimorbidity situation or the illness is acute and they will benefit from integrated PC intervention (Amblàs-Novellas, 2016). Since complexity is associated with the patients' multimorbidity and their risk factors, it is necessary to have a system that will stratify patients according to their medical needs and therefore facilitate their identification.

In Catalonia there are *Grups de Morbiditat Ajustada* (GMA) (Adjusted Morbidity Groups) have been used to stratify the population, classifying patients into different categories according to their morbidity and risk (such as being admitted to the hospital, dying, visiting the emergency room or receiving primary care services). This system establishes algorithms that will show a patient's risk and level of acuteness, as illustrated in Figure 7. This predictive model aids the health care system to organise their health interventions according to the population's needs, as well as helping to identify complex cases (Blay Pueyo, 2017). The GMA determines the patients' multimorbidity and then classifies them into risk groups. The population's complexity is calculated according to two dimensions: their chronic pathologies (seven morbidity groups); and their complexity level (five levels of complexity based on the visits to primary care, the emergency room, and pharmacy expense) (Monterde et al., 2016).

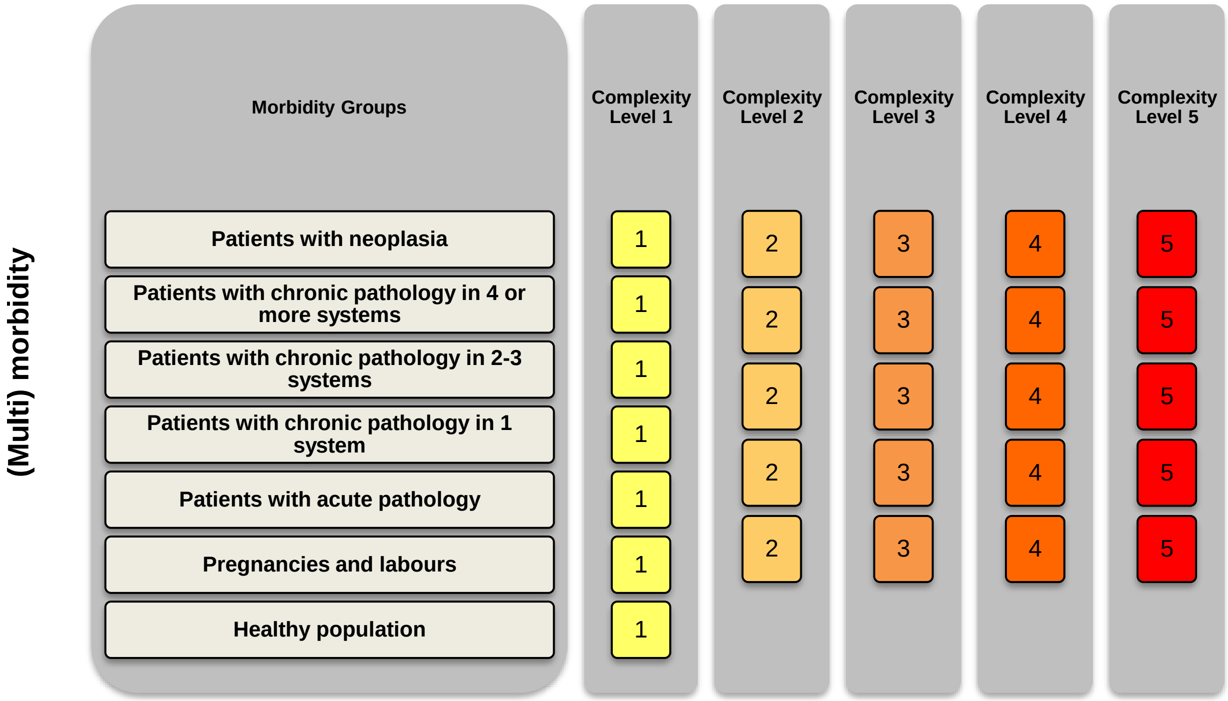


Figure 7. *GMA Architecture. Source: Monterde et al. (2016)*

This GMA then assigns patients a risk state. These states are divided into GMA 1- low risk; GMA 2- moderate risk; GMA 3- high risk and GMA 4- very high risk. The GMA indicator appears in the patient's digital HC3 record, showing the health professionals their complexity level (Monterde et al., 2016).

In addition, the PCC and MACA patients are identified with the palliative needs screening tool (NECPAL), created by the Qualy-ICoCCOMS observatory. The NECPAL screening tool is used by doctors and nurses in this region for the early identification of patients in need of PC, those suffering from advanced chronic conditions and terminal conditions (Gómez-Batiste et al., 2012b). If a patient is identified by this tool, considered a NECPAL positive, it means that they have a limited life prognosis and will need IPC that should include the following (Gómez-Batiste, 2017a):

1. A multidimensional evaluation that is patient-centred.
2. An exploration of the patient's and family's values, preferences and concerns.
3. A review of the disease and condition.
4. A review of the treatment plan.
5. An identification of the main care giver and support provision.
6. An identification of the team that is in charge to take care of the patient.

7. An elaboration of an integrative multidimensional therapy plan.
8. An integrative care plan: organisation of care in all services, definition of the specific role of PC services.
9. A sharing and recording process of the patient's relevant medical history records with all the professionals involved.
10. A results evaluation and revision.

In order for healthcare providers to offer IPC to the chronically ill patient, the PIIC is used. The PIIC, stored in the patients' medical history, ensures that the important information about the PC patient is shared among the whole professional team concerned. In addition, the PDA, was also created by the health professionals in order to respond to the patients' care preferences and wishes at the end of life (Delgado et al., 2016).

The complex patient is also usually identified by the social services as a dependent person. A dependent person is one that, due to ageing, disease or physical, sensorial or intellectual disability, lacks autonomy and needs permanent care and support from another person (Generalitat de Catalunya, 2019b). The dependent patient is identified with the *Barem de valoració a la dependència* (BVD) (Dependency evaluation scale), which establishes the dependency level of the person according to their health status, their context and their lack of autonomy in performing activities of daily living. As indicated by Blasco (2017), many of the MACA patients have medical complexity and high levels of dependency. Social services provide the dependent person with the support and services needed according to their dependency level and needs (Fundació Antiga Casa Manlleu, 2017).

2.4.5. Palliative Care Patients in the Catalan Social Services System

Social services in Catalonia include the resources, services, activities, programmes and equipment to serve the social needs of the Catalan population. It includes private and public services administered by the Catalan government, and together they constitute the social services network in Catalonia within the Work, Social and Family Services Department of the Catalan government (Generalitat de Catalunya, 2019b).

In our society, with an increasing older population group, there has been a change in the constitution of the family unit. Nowadays, families are smaller and women are working outside the home. The older people would mostly want to continue at home through this period in life, therefore, public services need to provide them with the support they need (Viñas Segalés, 2016).

In Osona, the *Consorci d'Osona de Serveis Socials* (Social Services Osona Consortium) oversees the social services of the area. This entity provides the region with a variety of services, and it is in charge of promoting the autonomy and services for dependents, following the law 39/2006, *de 14 de desembre, de promoció de l'autonomia personal i atenció a les persones en situació de dependència* (a dependency law called LAPAD). It was created in 2006 with the aim of promoting the autonomy and services of people in dependency situations (Consell Comarcal d'Osona, 2017). As previously explained, a dependent person lacks autonomy and cannot independently perform activities of daily living due to ageing, disease or disability (Generalitat de Catalunya, 2019b). Such dependent people need support and services in the context where they live. According to Viñas Segalés (2016), the profile of the dependent adult receiving home care is 75.4 % women, with an average age of 77, receiving services for about 3 years. Social services in Osona organise services to promote their autonomy, providing them with services and invigorating them. A social worker is in charge to decide what services an adult in this situation needs through the evaluation of their dependence level and needs. These services are organised into home or community services. Usually the dependent adult is mostly at home, and different services are offered to them from social services such as tele-assistance, *Servei d'Atenció a Domicili* (SAD) (home care services), community activities, occupational therapy (OT) and equipment and support products (Consell Comarcal d'Osona, 2017).

2.4.6. Palliative Care Patients and the Ethical Context in Catalonia

In the 1980s and 90s, there was a movement in Spain that campaigned for patients' rights, recognising patients' autonomy. This movement changed the status of patients from initially having no legal standing to later possessing rights. In 2000, the first law in Spain to protect human rights and dignity in relationship to biological and medicine aspects, the *Coveni d'Oviedo* (Oviedo Agreement), was passed. This law was essential for recognising patients' autonomy regarding healthcare decisions. The specific application (or version – perhaps better) of this law in Catalonia is the law 21/2000, which states that patients have a right to have their health information, autonomy and clinical documentation. The Spanish government later developed the law 41/2002, in which the basics regarding patients' autonomy, rights, and obligations for information and clinical documentation were established for the whole country (Generalitat de Catalunya, 2016b).

In Catalonia, in 2006, the right to die with dignity, together with the right to receive PC and to specify in advance medical care wishes and preferences, was established (Generalitat de Catalunya, 2016a). The Catalan Health Plan from 2011 to 2015 was developed and specifically guides interventions to chronic patients and those with palliative needs. This health plan includes and promotes the PDA, advanced care directive, a form to establish the patient's decision-making autonomy (Generalitat de Catalunya, 2016a). The PDA should be a document that is the product of a reflexive process between the patient, their family and the healthcare providers. This document should express in writing the patient's wishes and preferences for health and social care, especially in situations where the patient is receiving PC or is at the end of life with a prognosis of less than a year. The PDA document is located in the patient's personal medical record, and it is shared by all the team members (Generalitat de Catalunya, 2019a).

2.4.7. The Integrated Palliative Care System in Osona

Osona has a large network of health and social services. It is a mixed urban-rural region with a population of 160,898, 18.3% of whom are older than 64 (CatSalut. Servei Català de la Salut, 2019). This region has a population density of 125 habitants/km2, making it a densely populated area compared to other regions in Catalonia. Osona doesn't have a balanced population distribution. It has two big cities, Vic and Manlleu, with a 41% concentration of the region's total population, and the rest resides in towns or villages with a lower population density of about 77 habitants/km 2. Financially, this region has an industrial tradition specialised in agricultural and food production focus. It also has a well-developed industrial metal-mechanic sector and an emergent sector in social services, real estate, innovations and entrepreneurship in information technology, health and education (Nogueron et al., 2017).

Osona, along with Anoia, Bages, Solsonès and Berguedà, belongs to the *Regió sanitària Catalunya central* (Central Catalan Health Region) within the seven-part territorial division in the Catalan health services structure. This divided structure aims to decentralise the public health system and to make services closer and more accessible to the population they serve (Generalitat de Catalunya. Departament de Salut, 2017a).

PC in this region started in the 1980s, when a homecare volunteer programme for terminal patients was started. This programme provided positive outcomes regarding symptom control, less hospitalisation and patient satisfaction (Gómez-Batiste et al., 2009). The Hospital de la Santa Creu in Vic was then founded, becoming one of the first PC units in Catalonia (Gómez-Batiste et al., 2014a). Since then, the integrative view of care for patients in this region has been a distinctive trait. As Gómez-Batiste et al. (2016) stated, Osona's PCS is a comprehensive and coordinated service system for the elderly, and for patients with PC needs and chronic diseases. The PC system in this region has been implemented in a comprehensive and systematic manner, making it an integrated health care system (Gómez-Batiste et al., 2012a). Osona's territorial coordination with a high identification index of PCC, chronic patients, and MACA advanced chronic patients and the effective management of the chronically ill, has been a model for good practices in integrative care (Blay Pueyo, 2017).

2.5. Conceptual Framework Considerations

The ageing population of the 21st century presents with chronic diseases, frailty, cancer, life-threatening conditions, multimorbidity and a longer life span. What is the health care systems' response to this new ageing population? PC has been traditionally the answer to these patients, evolving from medical care and shelter for pilgrims in the fourth century to the modern hospices founded by Cicely Saunders in 1967 that cared for the terminally ill. Then, with the 21st century PC concept as defined by the World Health Organization (2018) care aimed to improve the quality of life of patients with life threatening diseases.

There is an increasing interest in IPCS, which could respond better and could be a cost-effective approach when providing care for the terminally ill and patients with chronic conditions (Bainbridge et al., 2011). Some authors have called for clearer definitions of the term "IPC" and its constitutive elements (Van der Eerden et al., 2014). The literature reviewed contextualised the important concepts, definitions and descriptions, and also provided a deeper understanding of the current state of the questions studied. The conceptual background assisted with the organisation of the different parts of the research, such as the study design, data collection, analysis and discussion. As indicated by some authors, further research is needed to improve IPCS services for patients and their families (Garralda et al., 2016), and it can be done by studying successful IPCS implementations (Tan et al., 2016). Osona has been implementing a coordinated, comprehensive IPCS, and it will be the unit of analysis on this case study research.

Nowadays, IPC presents a new approach to care for PC patients. IPC, as Mondejar-Pont et al. (2019) involves, coordinated and continuous care throughout the different level of care. It is being implemented in many countries and regions around the world, and in Osona (in Catalonia, Spain). Osona historically has been implementing a PC system that is coordinated and comprehensive (Gómez-Batiste et al., 2016) and a model for its integrated care practices (Blay Pueyo, 2017).

Despite increased interest in the study of integrated palliative care the main hypothesis of this research is that since there is no consensus on the definition for neither integrated palliative care nor for the essential elements of an optimal delivery system, the implementation of IPC is diverse across contexts and the analysis of its implementation is complex and difficult to compare.

Therefore, the main purpose of this research was to further explore the meaning of IPC by identifying its constitutive elements by first examining IPC meaning and then analysing a concrete case through a case study. The case study sought to describe the OPCS in Catalonia (Spain) and describe the elements that it includes and lacks as an integrated system when compared to the IPCS definition and essential elements found in the literature. In order to achieve this goal, these objectives were developed: (1) describe the OPCS and related entities; (2) identify the essential elements of an IPC based on the results gained from the study participants; (3) determine which of the essential elements Osona's IPCS includes, excludes and needs; and (4) describe the ethical dilemmas encountered by the providers in Osona's IPCS. The next chapter on methodology will explain how these objectives will be put into practice.

CHAPTER 3

METHODOLOGY

3. METHODOLOGY

The aim of this chapter is threefold. First, to explain the actions taken to investigate the purpose of this research. Second, to elucidate the rationale for the application of specific procedures and techniques used to identify, select, process and analyse the information applied to understanding the OPCS. And third, to make explicit the validity and reliability of the methodology used. It begins with an outline of the research design and follows with an explanation of the case study method and case selection where the data was collected. Finally it presents the data analysis and the ethical considerations.

3.1. Research Design

The research goal will determine most of the methodology design, and the main purpose of this research was to describe the Osona palliative care system (OPCS) and to identify the system's level of integration. The goals and central questions for this research were:

1. Description of the OPCS: How is the palliative care system serving the chronically ill and palliative patients in the Osona region of Catalonia, Spain?
2. Identification of the essential integrative elements of an IPCS: What are the essential elements of an IPCS?
3. Identification of the integrative elements that the OPCS includes and excludes and the ones that are needed: What elements does the OPCS include, exclude and need as an IPCS?
4. Description of the ethical dilemmas encountered by providers in the OPCS: What ethical dilemmas are encountered by the professionals in the OPCS?

3.1.1. Methodological Approach and Research Strategy

As the research purpose indicates, this research is focused on understanding the IPC phenomenon in a comprehensive, holistic way. One can say it is close to an interpretative group of methods which focus on analytically disclosing the meaning-making practices of human subjects while showing how those practices are arranged so that it can be used to generate observable outcomes (Kallet, 2004). For this reason, this research followed a qualitative method, aiming to comprehend a phenomenon in order to later construct knowledge. The qualitative researcher's goal is to comprehend the complex relationships that take place in reality (Stake, 1999). He explores individual meanings and interprets testimonies or events to build an understanding of the complex reality or the case studied (Creswell, 2014; Stake, 1999). This kind of research leads to an inductive exploration of the reality, from which the researcher's interpretations become the study results (Creswell, 2014). These interpretations of reality are later translated into assertions, a form of personal generalisations (Erickson, 1986).

This qualitative study followed a constructivist methodology. According to Stake (1999), knowledge is constructed rather than discovered. The goal of the constructivist approach is to interpret individuals' understanding of the world, to inductively develop theory or pattern meanings (Creswell, 2014). Stake (1999) states that there are three realities in this constructivist process: one that provides us with a stimuli; a second reality that is our own interpretation of the stimuli, and a third that is a universal integration of interpretations of reality. The scientific community aims to create a universal comprehension of reality by constructing a clearer explanation of the second reality and a more solid explanation of the third reality (Stake, 1999). In order to construct knowledge, humans use their senses to understand the external stimuli, which are just personal interpretations of reality (Stake, 1999). As Creswell (2014) explained, individuals try to comprehend their world by creating subjective meanings of their experiences. The constructivist research seeks to include the complexity of all the different meanings created by individuals (Creswell, 2014).

As explained by these authors, the constructivist approach aims to develop a comprehensive understanding of the multiple individual interpretations of reality. Starting with this premise, in our study this transferred to the different views of the professionals in the OPCS. The constructivist methodology then guided this research into searching for a comprehensive understanding of the phenomenon studied, the OPCS, from the multiple interpretations of the professionals included in the case studied. In order to be able to construct this general understanding, the study questions were developed as describe above in point 3.1. These questions were based on the literature reviewed and my own experience. The purpose and objectives of the study responded to the constructivist approach as these questions originated from my own understanding of the phenomenon of OPCS integration, trying to construct a general comprehension from other individuals' interpretation of the same phenomenon.

In order to be able to observe in practice the nature of the care that complex chronic patients receive in an IPCS, it is necessary to be able to observe it in a specific context. After researching IPC in Spain and Catalonia, we could say that Osona is a reference for the experience it has in the field and because it had and has internationally recognised reference people who have led changes in the direction of IPC for complex chronic patients. As a result, and given ease of access to informants for fieldwork, the method of case study was chosen since it allows researchers to investigate a particular case, often a programme, process, event or individuals, which facilitates an in-depth analysis (Creswell, 2014).

3.1.2. Case Study Method and Design

Case studies provide an understanding of complex and contemporary phenomena, allowing researchers to determine a holistic but realistic meaning of the case studied (Yin, 2014). The case is an integrated system (Stake, 1999), a comprehensive description and analysis of the unit of study that has boundaries around it (Merriam, 1998).

There are many types of case studies, depending on their discipline, objective and design. As Yin explained, there are case studies used in disciplines such as anthropology, social work, business, education, nursing, political science, community planning, and economics (Yin, 2014). Moreover, according to Stake (1999), case studies are classified as intrinsic, instrumental or collective. Yin (1994) also described different types of case study, such as the exploratory, descriptive and explanatory. In addition, Yin (2014) classifies case studies according to their design – single case and multiple case - and further subdivided each into holistic and embedded, resulting in four case study designs: single holistic, single embedded, multiple case holistic and multiple case embedded. Table 2 below provides a description of each of these case study types.

Stake (1999)	Intrinsic	Selects the case by its specificity. This process allows the researcher to explain the study purpose, by gaining a general understanding of the case
	Instrumental	Aims to study a particular or typical case to understand another more general query
	Collective	Is the result of many units of study, under the same research
Yin (1994)	Exploratory	Explores a phenomenon, which usually serves to define the research questions for a future research
	Descriptive	Describes the phenomenon studied within its context
	Explanatory	States cause-effect correlations
Yin (2014)	Single case design (single unit of analysis)	Single case: is used when the case is relevant to the research questions and it will be critical to study to test previous theory - Holistic: the case is considered as a unit of analysis - Embedded: the single case study incorporates subunits of analysis
	Multiple case Design (multiple units of analysis)	Multiple cases: is used when there is the selection of two or more cases that are believed to be literal replications -Holistic: the different cases are considered as a unit of analysis -Embedded: the multiple case studies incorporate subunits of analysis

Table 2. *Case Study Types. Source: Own elaboration with information from Stake (1999) and Yin (1994)*

Following the Table 2 descriptions, the case study used in this research can be described as an instrumental, descriptive, single embedded case study. It is instrumental as it aimed to provide a thorough understanding of the case selected, to later generate a response to a broader question in the study. It is descriptive as it intended to explain the issue studied within its context. It is a single case study because the organisation selected is representative and critical to the understanding of the research question. And it can be described as embedded as the organisation's main unit of analysis included subunits of analysis, which in this research included the different professionals' care specialisation.

The case study design used in this research guided the data collection process. As explained by Stake (1999), it is important that a theoretical framework helps structure the case study data collection process. A case study protocol assists the process of data gathering from the study's multiple data sources (Yin 2014). In our case study, an evaluative PC framework and an IPC scoping review study, guided this study data collection questions. In addition, the theoretical propositions found in the literature review were related and compared to the results obtained in this case study. The result of this comparative process and the development of new findings were later formulated in analytical generalisations. Analytical generalisations are used to validate, modify, reject or advance theoretical propositions or new concepts that arise from the case study itself (Yin, 2014).

This research combined a case study design with a constructivist methodology. On the one hand, the case study design provided the opportunity to find a "descriptive" understanding of the "instrumental and single embedded" case study selected, to be understood within its context, which in this research was an organisation within the OPCS. On the other hand, the constructivist approach guided the construction and development of a broader comprehension of the phenomenon researched in this thesis, the integration level of the OPCS, from the particular findings from the case study selected within the OPCS.

3.2. Case Selection

The Osona region has a long-standing practice of cooperative work and service provision, and it has been noted for its good integrated health practice initiatives. In the Osona health care system there is the SISO organisation, *Sistema Integrat de Salut a Osona* (Integrated Health System in Osona), a functional, coordinating structure for health care providers in the area (Blay Pueyo, 2017). The SISO organisation aims to include and provide support to all health care providers in Osona. It includes professionals from different levels of care: primary care, hospitals, nursing homes, convalescent hospitals and mental health (Sistema Integrat de Salut d'Osona, 2016). This organisation helps coordinate health care providers in Osona by providing them with resources such a protocols, pathways of care, services purchase and work groups (Roca & Ramón, 2010). These work teams include leaders in the region from the different health organisations, institutions and service levels that work toward the goal of improving professionals' clinical practice, as well as accomplishing the Catalan health department objectives (Blay Pueyo, 2017). The different work groups are as follows:

- Chronicity group
- Advisory group
- Economic group
- Service Development group (Prevention and Health Promotion and PCC/MACA service pathway)
- Rehabilitation group
- Information System Technical group
- Emergency Continuous Care group ACUT (*Atenció Continuada d'Urgències*)
- Territorial Pharmacy group
- Dementia Service Pathway Development group

In order to respond to the questions posed by this research, the study undertook a case study on the SISO organisation within Osona. As mentioned above, the SISO organisation includes a specific professional work group specialised in chronic and terminally ill patients. It was this group that became the starting unit of analysis for this study. This unit of professionals was selected, as they were a group experienced in PC in the region studied. The health care professionals in this group provide care for the PC patient in different geographical areas in Osona, both urban and rural. This study first explored the work group members' views on OPCS, and later asked them to propose other knowledgeable professionals within their organisation to be part of the study. The professionals had different profiles, including nurses, doctors and social workers. This allowed the study to collect the views of the different professional specialities caring for the PC and terminally ill patient. These referred professionals became the subunits of the study.

In summary, the SISO work team group was selected because it represented an instrumental case (Stake, 1999), a typical case that represents another more general one - in our study, the OPCS. As explained before, the SISO and the selected group coordinates and organises professionals from different levels of care, different entities and from different professional specialisations in different geographical areas in Osona. Due to all of these reasons, choosing the SISO work team group as a case to study became clear, since the views from the different professionals in the different levels of care and entities located in different geographical areas in the region would be able to explain the OPCS.

3.3. Research Participants

With regards to the qualitative orientation of this research, more importance was given to the diversity of the dimensions we wanted to cover than to the number of participants. We therefore selected participants on the basis of who could provide the most meaningful information on the topic.

The study followed a purposive sampling; it used the judgement of PC experts in Osona to arrange the case to study. This type of sampling is useful to gain a deep understanding of the case studied rather than creating generalisations (Mohd Ishak & Abu Bakar, 2014). The study aimed to collect the perspective of the different professionals working in different capacities in the OPCS. On the one hand, it aimed to gather the views of professionals in more strategic decision-making positions; and on the other hand, it wanted to collect the views of the professionals involved in the caring process, providing direct patient care.

The first selected participants in the study were the eight members occupying strategic and managerial positions in the work team group at the SISO, called “leaders” in this research. These professionals are managers of diferent entities and organisations in different levels of care such a hospital, primary care, emergency care and nursing homes. The study then followed a stratified purposive sampling using a snowball technique to explore the views of other professionals in the service care level. This snowball or network sampling technique allowed the researchers to select participants from distinct stratified groups, with a nonbiased approach in their selection (Mohd Ishak & Abu Bakar, 2014). Each leader from the work team group was asked to refer key informants in their organisation in the areas of nursing, social work and medicine specialised in caring for PC patients.

In this case study the participant were: 8 “leaders” from a total of 8 managers in the work team group. Finally, there were 24 participants in this case study: 8 ‘leaders’ - managers in the work group - 8 nurses, 4 social workers and 4 doctors (see Figure 8).

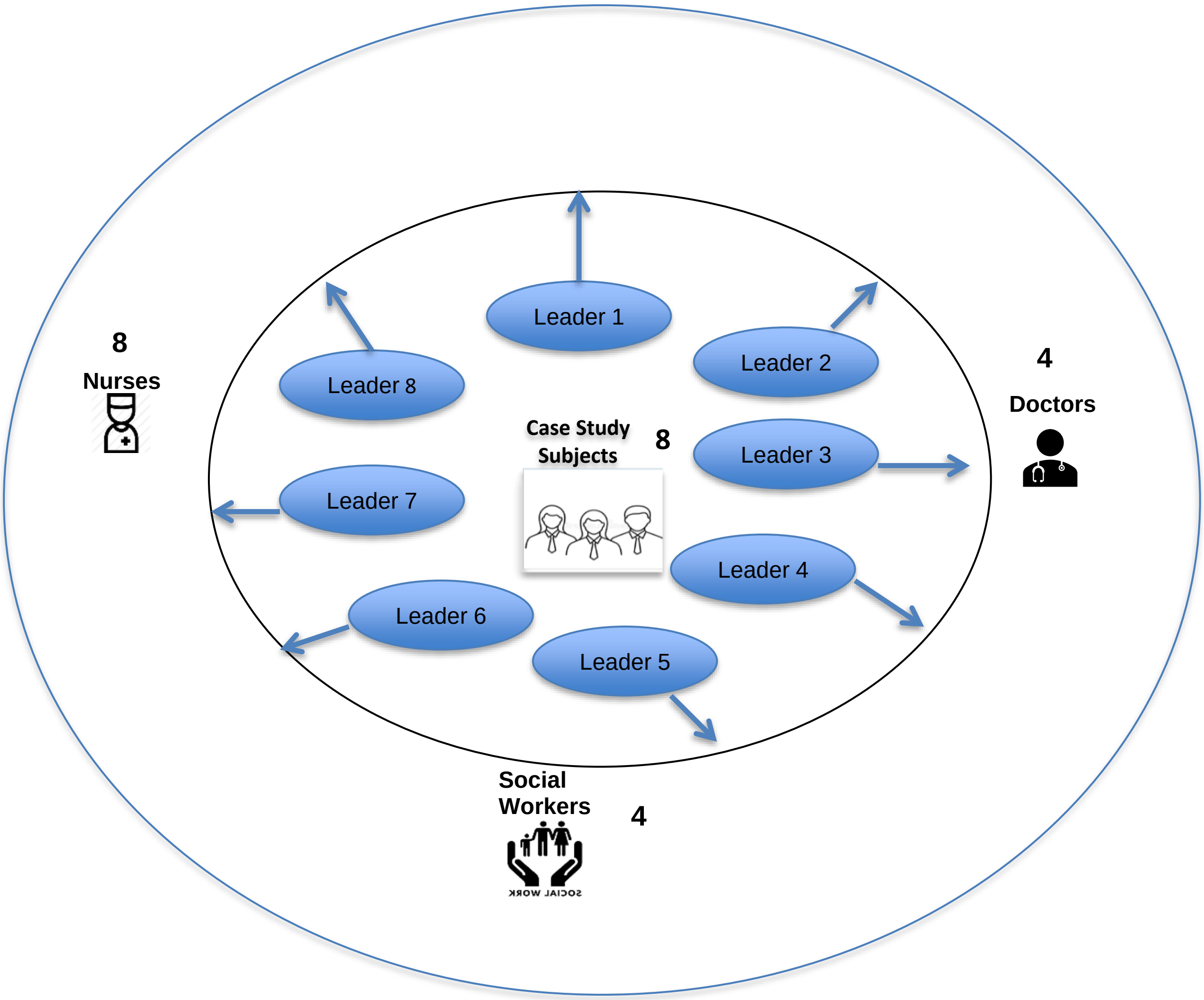


Figure 8. *Study Participants*

3.4. Data Collection

3.4.1. Data Collection Strategy

In order to respond to the study's main purpose, two study phases took place, including both secondary and primary sources of information (see Table 3. Methodological design). Several research techniques were used in this study, such as document review, questionnaires and interviews.

OBJECTIVES	STUDY STAGE	DATA COLLECTION	DATA COLLECTION QUESTIONS	DATA ANALYSIS
1- Description of the OPCS	Phase I	Documents (20)	How is the OPCS serving the chronically ill and palliative patients in the Osona region?	Directed Content Analysis
		Questionnaires (structured) (8)		Directed Content Analysis
2- Identification of the essential integrative elements of an IPCS	Phase II	Interviews (semi-structured) (24)	What are the essential elements of an IPCS?	Directed Content Analysis
3- Identification of the integrative elements that the OPCS includes, excludes and needs			What elements does the OPCS include, exclude and need as an integrated care system?	
4. Description of the ethical dilemmas encountered by the professional in the OPCS		Interviews (semi-structured) (24)	What ethical dilemmas does the professional in the OPCS encounter?	Directed Content Analysis

Table 3. *Methodological Design*

Document review was used to find information to describe the OPCS. As explained by Stake (1994), document review supports qualitative case studies because it provides an extensive description of the phenomenon studied. This qualitative case study comprehensively assessed the OPCS through the review of diverse types of documentation. Document review provides contextual, background and historical information that can better help contextualise the rest of the data collected in a study (Bowen, 2009). In this research, document review provided contextual information about the OPCS, such as the structure, characteristics and organisational factors. Document review and analysis aided the researcher to respond to the first research objective of describing the OPCS.

Questionnaires were used to collect some of the participants' views regarding the characteristics of the OPCS through a set of standardised questions. Questionnaires in qualitative research can be used to collect data through a deductive approach to test previous theory (Beiske, 2002). In this study, the questionnaire aimed to further explain the OPCS and to later compare the results with the descriptive information found in the documents reviewed. The questionnaires collected the views of the "leaders" that worked as managers in different entities and organisations in the SISO coordinating organisation. Questionnaires with a set of standardised questions were only distributed to the eight "leaders" in the SISO work team group. This decision was taken after considering that the managerial level was the group of professionals that would be able to provide a more holistic and comprehensive description of the OPCS as an organised structure than the other participants, who were more involved in the direct patient care level.

The individual in-depth interviews with some of the providers in the system responded to the need to explore different aspects in the OPCS process of care. Interviews are direct conversations with a goal and a structure, allowing the researcher to discover, explain and reflect on the respondents' views (Tracy, 2013). Their purpose is to construct a body of knowledge from the participants' views and experiences. In-depth individual interviews in health care studies help to collect the experiences and thoughts of individuals involved in the health care delivery process (DiCicco-Bloom & Crabtree, 2006). The interviews allowed this study to thoroughly examine and give meaning to the professionals' views on the care processes in the OPCS. The individual in-depth interviews granted the researcher the chance to thoroughly explore the participants' views regarding the OPCS level of integration and the ethical dilemmas encountered by providers in the OPCS.

3.4.2. Phase I. Document Review and Questionnaires

Secondary Sources: Documents

The documents included in the study were collected through three data bases: Pubmed, Scopus and Google Scholar. In order to be included they needed to describe or explain the OPCS, the Osona health system structure, the health plans or strategies at the national and regional levels, or specific documents on the SISO organisation. Twenty sources of information were found, eighteen of which were included (articles, health plans, reports, web sites). Two databases related to health care indicators and Catalonia statistics were then reviewed (see Appendix A for documents list). These databases provided important information and indicators relevant for this study. In order to describe the OPCS, the literature was first reviewed, with the purpose of finding frameworks that could provide guidance into what elements, structures or processes needed to be assessed and described for this system. As Bainbridge et al. (2016) indicated, there are few frameworks that specifically evaluate PC systems, and so Bainbridge et al. (2010) developed their own.

Their framework was adapted for the assessment of the OPCS, in which the context, the system's characteristics, organisation, services, financial situation, professionals and strengths and weaknesses were explored. This research used a set of questions developed from a PC evaluative framework by Bainbridge et al. (2010) to guide the data extraction process regarding the OPCS structure, characteristics and organisation to later compare it with the responses by the system providers (see Appendix A. Documents List).

Questionnaires

The questionnaires, as explained above, aimed to further describe the OPCS from the leaders' views on the system, in order to later compare them with the document review results. The questionnaires were only distributed to the eight managers, called "leaders" in this study, of the work team group. The questionnaire questions originated from the main categories in the PC evaluative framework of Bainbridge et al. (2010) (see Appendix B), which also guided the document review questions template. The main topics sought were about the characteristics of the OPCS care service, financial organisation, patient care process and identification and providers.

Questions were open-ended, giving participants the opportunity to offer a broad range of responses without questions that pre-determined their answers (Beiske, 2002). Specifically, the questionnaire was structured with a SWOT format (Strengths, Weaknesses, Opportunities and Threats). This kind of analysis allows one to see an organisation from two dimensions: The internal factors and attributes from the strengths and weaknesses; and the external factors coming from the environments' opportunities and threats (Gürel, 2017). The SWOT format was chosen because it offered a concise and evaluative format to inquire about the OPCS, as perceived by the managers of entities working under OPCS guidelines. The results obtained by these questionnaires were then compared with the rest of the data results. The selected participants completed the questionnaire and later sent it or gave it by hand to the researcher. Questionnaire respondents were asked to complete it with one-, two- or three-word phrases, and it usually took from 15 to 25 minutes to complete (see Appendix C. Questionnaire questions).

3.4.3. Phase II. Interviews

This phase was designated to answer the following objectives in the study: identify the essential elements for an ideal IPCS; identify the integrative elements that the OPCS includes and excludes and those that are needed; and describe the ethical dilemmas encountered by the professionals.

The goal of the interviews was to describe the OPCS care processes from the results obtained from interviewing all the participants in the study. The individual interviews were in-depth and had a semi-structured format. In-depth interviews are widely used in health research since they enable researchers to gather responses to a broad range of questions on the phenomenon studied. And the semi-structured format organises questions in a predetermined set of open-ended questions (DiCicco-Bloom & Crabtree, 2006).

The questions in the interview originated from two sources: the scoping review on IPC by Mondejar-Pont et al. (2019), and also from the main objectives of this thesis. The interviews were conducted in an individual manner in order to gain an in-depth understanding of the participants' individual perceptions and experiences as OPCS providers. The interviews were done with all the participants those in both the managerial and patient care levels, with the aim of obtaining an overall vision of how the different providers in the different levels of care perceived the OPCS.

These interviews were conducted with each participant individually, either face-to-face or by phone. A total number of 24 interviews were included: 8 were managers in different OPCS entities, called "leaders", 8 nurses, 4 doctors and 4 social workers. The interviews had a semi-structured format, as previously explained, and lasted from 30 to 40 minutes, approximately. These interviews were recorded and later transcribed (see Interview. Appendix D).

3.4.4. COVID-19 Pandemic Update

In 2020, the new coronavirus SARS-CoV-2, commonly known as COVID-19, has become a real threat to the entire world due to its rapid transmission among people. One of the strategies used to slow down transmission has been social distancing (Vidal-Alaball et al., 2020). The study wanted to seize the opportunity to briefly see how this pandemic has impacted the OPCS and PC patient in Osona. This is explained since it was considered that this social distancing and disease has had a significant impact on the PC population studied in this research, and also because all health care systems have had to rapidly adjust to the new pandemic situation. It is for this reason that all the participants of the study were sent an email with a short open-ended questionnaire assessing changes due to the

COVID pandemic (see Appendix E). The questionnaire was emailed to all 24 participants, 9 of whom completed it. The results were included in this research.

3.5. Data Analysis

3.5.1. Data Analysis Strategy

The data collected by this study was evaluated with qualitative content data analysis. With this method the researcher can conceptually explain the phenomenon studied. It is a method appropriate to study sensitive, relevant and varied nursing events (Elo & Kyngäs, 2008). As Hsieh and Shannon (2005) described, this is a method used to analyse and interpret content text data through the development of codes, categories and patterns. The qualitative content data analysis method allows the researcher to systematically code and categorise text information, establishing text word organisation, repetitions usage and relationships in the data (Mayring, 2000). The goal is to evaluate the text information and to describe it by analysing the results (Bloor & Wood, 2011).

Qualitative content analysis can be inductive or deductive (Hsieh & Shannon, 2005). The inductive approach does not contemplate previous studies, so the codes and categories originate directly from the data analysed. Conventional, inductive content analysis aims to describe a phenomenon. In this type of analysis, the codes and categories emerge from the data without using pre-existing theories or categories.

On the other hand, the deductive or directed content analysis approach uses previous research findings to examine the studies' new data in order to identify similarities and differences, and to compare the same categories at different times between previous theory and new data. The goal of directed content analysis is to validate or further develop the theory used (Hsieh & Shannon, 2005). This study's questionnaires, interviews and documents were analysed with a deductive, directed content analysis, using prior theoretical propositions found in the literature to guide the first coding process (see Table 3. Methodological design).

Deductive content analysis, as Elo and Kyngas (2008) stated, involves three main processes: preparation, organisation and reporting. In the preparation phase, the researchers select the unit of analysis, and then they immerse themselves in reading the data to try to make sense of it (Elo & Kyngäs, 2008).

The other two phases, organising and reporting, are thoroughly explained in the model of Assarroudi et al. (2018), which describes the following steps involved in the organising phase:

1) Create a formative categorisation matrix from the existing theory. 2) Develop theoretical definitions for the main categories and subcategories. Define categories accurately from the previous research or theory. 3) Generate the coding rules for the main categories. This will also originate from the previous research to clarify the distinction between categories in the matrix. 4) Pre-test of categories using a pilot study and redefine categories if necessary. 5) Choose and specify anchor samples for each main category. Find an anchor sample in the data that is concise and represents the category well. 6) Perform the main data analysis. The data should be explored and meaning units related to the categories in the matrix should be selected, and later summarised. 7) Develop inductive abstraction of the main categories from preliminary codes. 8) Establish links between generic categories and main categories.

Finally, in the reporting phase, all the steps in the analysis are reported with descriptive information of the data analysed following a systematic reporting of relations between data and categories (Assarroudi et al., 2018).

3.5.2. Phase I. Document Review and Questionnaires

Secondary Sources: Documents

The document review aimed to find data related to the main categories indicated and described in the evaluative framework by Bainbridge et al. (2010). The documents were subjected to a deductive analysis as explained in the model of Assarroudi et al. (2018).

The analysis proceeded with the steps 1-8 described above for deductive content analysis. In the organisational phase, first the documents were collected by the researcher; then a matrix of the main categories sought was developed with a definition of the categories; and third, the researcher developed a coding rules system and anchor samples for each category, in order to make clear what to include and exclude for each category, as seen in Appendix F.

Then, in the analysis phase following the deductive approach, the documents were thoroughly read in order to find and classify data related to the main categories sought: OPCS context and structure, characteristics, financing, providers and organisation. Google Forms was used to organise the data found for each main category. The main categories were formulated as questions to guide the document data extraction and classification. For example, for the category OPCS context and structure, the question formulated was: “What is the nature of the OPCS context and structure?” Then all the information related to the question was classified together.

Later, this data organised by categories was thoroughly reread and analysed to developed units of meaning and related new preliminary codes, and then generic categories were created inductively. Using the *category question*: "What is the nature of the OPCS context and structure? as an example, we would have as *main category*: "density"; *preliminary codes*: "population, area and inhabitants"; and *generic category*: "medium density region". Then, relations between main and generic categories and codes were established. Finally, in the reporting phase, findings between data and categories in the matrix were presented and reported in the results section (see Table 4).

Data Collection Questions	Main Categories	Generic Categories	Preliminary codes
What is the nature of the OPCS context and structure?	Density	Medium density Region	-Population -Area -Inhabitants
	Demography	Demography characteristics	-Age distribution -Ageing -Immigration -Income
		Incidence of diseases in population	-Population distribution in Primary Care centres -Mortality, morbidity, prevalence
What are the system's characteristics?	Services offered	Type of health centres and PC services	- Levels of care centres and services -PC specific services
	Membership size	Number of services used and patients served	- PC patients served - Services used
	Extent of participation in network	-Coordinating organisation	- SISO pluridisciplinary groups
	Networks ideals	Patient-centred Integral services	- Continuity of care - Patient-centred care
	Policies	Health plans and programmes and services to the chronically ill	-Chronicity programmes -Health plans for integral services -PC directory
How is the economic and financial situation?	Network resources	Number of hospitals, clinics, centres and professionals	-Hospitals, clinics, centres -Number of professionals in the health sector
	Presence of 24/7 care	24/7 vision	- Intervention plan and medical History online documents - 12 hours PADES

What are the providers' characteristics?	Cooperation	Cooperation at different levels of care and services	-Collaboration
	Perceived Interdependence	Case management and multidisciplinary teams	-multidisciplinary, interdisciplinary work - case management
	Specialty training	Training strategies	- Training and education
How is the information shared?	Information systems and materials	Digital health related information sharing	- Clinical History - Personal health channel -Si-Siso informatics system
	Standard assessment monitoring patient needs	Patient early identification	- Patient identification - Screening Tools
What are the organisational factors?	Care team composition	Care team professionals	Professionals in hospitals and primary care
	Standard implementation models	Standard models	-Chronicity Programme development -Care pathways
	Programme evaluation	Cost-efficiency	- Emergency hospitalisations and admissions reduction

Table 4. *Document Data Categories and Codes*

Questionnaires

As previously explained, the questionnaire was formatted as a SWOT questionnaire (see Appendix C). The data analysis was done in two manners. First the data was analysed following the SWOT pre-established aspects. The pre-established aspects were: strengths, weaknesses, opportunities and threats. The researcher performed a thorough reading of the responses for each question related to the main aspects sought, then, similarities on the data generated codes were identified, to later create categories related to the main aspects searched about the OPCS strengths, weaknesses, opportunities and threats.

Second, the questionnaires were analysed with a deductive approach. The main categories from the evaluative framework of Bainbridge et al. (2010), as in the document review, guided the first main categories searched: system care processes, financing and policies, and providers' characteristics. This direct content analysis followed the steps proposed by (Assarroudi et al., 2018). First, a matrix for the main category definitions, coding rules and anchor samples was developed (see Appendix F). Then, the questionnaire data was read several times and preliminary codes were found. Next, after further reading, the codes were labelled by meaning, and relationships among codes were established to later develop subcategories and generic categories. Finally, the relations and differences between the main and generic categories were identified to later be reported in the results phase (see Table 5).

Table 5. *Questionnaires Categories and Codes*

Main Categories	Generic Categories	Subcategories	Preliminary Codes
Services and Care	Patient identification	Increase process adequacy	-Appropriate protocol -Label triggers care -Label conflict
		Improvements	-Identify patient early -PT (patient) identification sharing process
		Increase PT identification	-Add PT time -Add training -All professionals identify PT
	Care Provided	Strengths	-Specialised -Holistic -PT centred -Accessibility
		Deficits	-Care time -Faster care -7/24 care -Fragmentation -Integrated care -Shared policies
Funding, resources and policies	Resources/ services	Services provision	-Valuable services -Need for more services
		Resources provision	-Resources importance -Need more resources -Need more professionals -Lack specialised professionals -Need research resources
	Government policies and funding	Funding	-Funding needed -Change financing model
		Policies	-Specific policies
Providers competencies	Appropriate competencies	Training/education	-Specialised training
		Clinical experience	-Clinical competencies
		Teamwork	-Coordinated work
		Motivation	- Motivated professionals
	Insufficient competencies	Training and education	-Need more specialised training
		Teamwork	-Need integrated work
		Research	-Not enough research

3.5.3 Phase II. Interviews

The interviews served three purposes, as mentioned above: to identify the elements that an ideal IPCS should have; to identify which integrative elements the OPCS includes, is missing and needs; and to find a description of the ethical challenges most encountered by the providers offering care to the advanced chronically ill and terminal patients. To achieve the first two purposes, questions were developed guided by the findings in the scoping review study previously mentioned (Mondejar-Pont et al., 2019). The third purpose was achieved by simply analysing the direct question about what ethical dilemmas they encountered. The literature review provided theoretical propositions that guided the analysis.

The interviews were subjected to a direct content analysis following the method proposed by (Assarroudi et al., 2018). First, the interviews were read numerous times by the researcher to understand the content of the interviews. Later, the unit of analysis, in this case each interview, was selected, since an entire interview used as the unit of analysis is a recommendable size to keep the context for the meaning units (Graneheim & Lundman, 2004). The analysis of the interviews followed the steps described above for deductive content analysis by Assarroudi et al. (2018).

In the organisational phase, matrices for the essential elements (see Appendix G) and ethical dilemmas (see Appendix H) were developed, in which category definitions code rules and anchor samples were created. This was followed by the data analysis and the creation of generic categories, subcategories and preliminary codes. Finally, relations, similarities and differences within the main categories, subcategories and generic categories were found, which were later explained in the results section.

Regarding the question: What are the essential elements of an IPCS?, many generic categories were found (see Table 6). Interviewees were then asked to rate in order of priority the essential elements of an IPCS. A ranking of 13 elements or categories was generated organised by the number of repetitions, with 1 being the element most repeated and 13 the least. The results are reported in chapter 4.

Preliminary codes	**Groups of Codes**	**Subcategory**	**Generic Category**	**Main Category**
Professionals	Multidisciplinary team	Multidisciplinary team	Inclusive multidisciplinary team	Multi/interdisciplinary team
Different professionals		Professionals included		
Service Payment	Services funding model	Service funding model	PC specific funding	Funding and resources
Equipment Professionals Services	PC funding services, professionals and equipment	PC single funding model		
Singles system	Information shared in the system	Single system	Single shared information System	Information System
Sharing information	All professionals share information	Shared by all system participants		
Videoconference, video-consults, chats	Communication modalities	Multiple information modalities		
Communication	Professionals coordination	Professionals collaboration	PC professional's collaboration	Coordination
Same vision		Same vision		
Implementation model	Single implementation model	Single PC implementation model	PC standard implementation model	Standard implementation model
Single route, circuit for PC patient		Single PC route		
Professionals new team		PC Integrated team of professionals	New specialised PC integrated team	
Multidiscipline-different care level		Multidiscipline/ multilevel		
24/7	24/7 uninterrupted coverage	24/7 uninterrupted care	PC uninterrupted continuity of care	Continuity of care
Intra-level, network	Network continuity	PC service continuity		
Needs, preferences, opinions	Patient centred	Pt. preferences	Patient centred PC care	Patient centred
PT centred care		PT centred care		
Case manager	PC case manager identification	PC case manager	PC case manager	

Education, training	Education	PC education	PC professional's education and training	Training and education
Same education		Standardised education /training		
Shared tool	Screening tool	Shared screening tool	PC standard screening tool	Standard screening tool
Identification PC PT		PC patient identification		
Specialised care reduces cost	PC services cost	Specialised PC care	Specialised PC cost-efficiency	Cost-efficiency
Homecare cost		Specialised homecare		
Regional policies	Regional policies	Supportive regional PC policies	Supportive PC policies	Supportive policies and leadership
Motivation	Motivation	Motivated professionals	Motivated PC Professionals	
Identify patient and intervene before complications	Early intervention	Early intervention	PC PT early detection and intervention	Early intervention
Community visits	Community involvement	Professionals community involvement	Professional community involvement	
Motivated/empowered	Empowered/motivated patient	Empowered/motivated	Empowered patient	

Table 6. *Ideal IPCS Elements Categories and Codes*

With regards to the question: What elements does the Osona palliative care system include and exclude as an integrated palliative system?, generic categories of the included elements (see Table 7) and excluded elements (see Table 8) were developed, some of which were found inductively since they were new categories from outside the matrix.

Preliminary codes	**Groups of Codes**	**Subcategory**	**Generic Category**	**Main Category**
Various screening tools	NECPAL others screening tools	Shared screening tool	PC standard screening tool	Standard screening tool
Identify and label PC patient		PC patient identification		
Information	Multiple information platforms	Multiple Information systems	Shared information system	Information system
		Multiple information modalities		

Various docs shared (PIIC…)	Documents shared	Information shared by all		
Various professionals	Competent and qualified prof.	Qualified professionals	Professionals, resources and services	Funding and resources
Various services	Existent multiple services	Multiple services		
Communication	Professionals' coordination	Professionals' collaboration	PC professionals' collaboration	Coordination
Same vision	Same vision	Professionals' shared vision		
Patient intervention before complications	Identification/intervention	PC patient effective identification and intervention	PC patient early detection and intervention	Early intervention
24/7	24/7	24/7 care	PC system continuity of care	Continuity of care
Intra-level network	Network continuity	PC continuity		
Leaders	Leaders	Leadership	Supportive policies and leadership	Supportive policies and leadership
Dependency law	Policies	Policies		
Case manager	PC case manager identification	Case manager	PC case management	
Needs, preferences, opinions	Patient centred	PT preferences	Patient centred PC care	Patient centred
PT centred care		PT centred care		
Intermediate care	Intermediate care	PC specialised intermediate care	PC specialised intermediate care	
Motivation of professionals	Motivation of professionals	Motivated Professionals	Motivated PC professionals	
Multi/Interdisciplinary	Multidisciplinary	Multidisciplinary team	Inclusive multidisciplinary team	Multi/interdisciplinary team
Education, training	Education/training	Education/training	Education/training	Training and education
Implementation	Implementation	PC implementation	PC implementation model	Standard implementation model
Specialised care reduces cost	PC services cost	Specialised PC care	Specialised PC cost-efficiency	Cost-efficiency

Table 7. *Included Elements in the OPCS Categories and Codes*

Preliminary codes	**Groups of Codes**	**Subcategory**	**Generic Category**	**Main Category**
24/7	24/7	24/7 care	PC care fragmentation	Continuity of care
No service continuity	Services level no continuity	Intra-level fragmentation		
Health and social services disconnection	Health and social services no continuity	Health and social service fragmentation		
Various professionals	Professionals	Professionals missing	Missing specific PC funding and resources	Funding and resources
Various services	Services	Services missing		
Various resources	Resources	Resources missing		
Funding	PC funding	PC specific funding missing		
Information platforms	Information platforms	Improve single information sys.	Shared single information system	Information system
Modalities: phone, videoconference, etc.	Information modalities	Multiple information modalities		
Communication Coordination	Professionals’ collaboration	Professionals’ collaboration	Improve collaboration	Coordination
Health and social services		Coordination health and social services		
Education, training	Education/training	PC specialised education and training	Need for PC standardised education/training	Training and education
Identification, labelling PC patient	Labelling, identifying PC patient screening tool	PC PT labelling difficulty	Screening tool difficulties	Standard screening tool
Routes, vision, goals for PC patient	PC standard model Implementation difficulties	PC standard implementation difficulties	PC standard implementation model difficulties	Standard implementation model
Infra-identification	PC patient infra-identification and late intervention	PC patient infra-identification and late intervention	PC patient early identification and intervention difficulties	Early intervention
Needs, preferences, opinions	Patient centred	PC patient centred	Patient centred PC care	Patient centred

Policies	Policies	Specific PC policies	Specific PC policies	Policies and leadership
Case manager	PC case manager identification	PC case manager identification	PC Case management	
Volunteers		Volunteers	PC Volunteers	

Table 8. *Excluded Elements in the OPCS Categories and Codes*

Regarding the question: What elements does the OPCS need due to its context?, seven categories were stated and four of them were new and different from the ones considered in the matrix extracted from the literature (see Figure 30, Chapter 4).

And with regards to the last question: What ethical dilemmas are encountered by the professionals in the OPCS?, the same deductive analysis was employed and the following generic categories and codes were found. There was also one that was found inductively: poverty, which was not mentioned in the literature. These are shown in Table 9 below.

Preliminary codes	**Groups of Codes**	**Subcategory**	**Generic Category**	**Main Category**
Family decision	Autonomy threatened by family decision	Autonomy threatened	Autonomy threatened by others' decisions	Autonomy threatened
Professional decision	Autonomy threatened by professional decision	Autonomy threatened by professional decisions		
Therapies and treatments	Therapies and treatments	Discontinue therapies and treatments	Discontinue life-prolonging treatments	Discontinue life-prolonging treatments (nutrition, hydration, blood transfusion)
Sanitation, poverty	Lack of sanitation	Unsanitary contexts	Poverty	
Services, resources poverty	Lack resources, services	Lack resources, services		
Futile treatment/ therapies	Futile treatments/ therapies	Futile treatments and therapies	Provision of futile treatment/ therapies for individual reasons	Provision of futile non-beneficial treatment
Truth negation	Truth negation	Truth telling negated by family	Truth telling negation	Truth telling
Communication difficulties	Communication difficulties	Communication difficulties	Communication difficulties	Communication difficulties
Palliative sedation start time	Palliative sedation start time	Palliative sedation start time	Palliative sedation process	Palliative sedation
Palliative sedation protocol	Palliative sedation protocol	Palliative sedation protocol		
Euthanasia patient	Euthanasia patient	Patient inquiry	Euthanasia inquiry	Euthanasia
Euthanasia professional	Euthanasia professional	Professional inquiry		
Opioids	Opioids	Opioids usage	Opioids usage	Opioids usage

Table 9. *Ethical Dilemmas Encountered by Providers: Categories and Codes*

In addition, a second type of analysis was performed specifically for the third and fourth objectives according to the different professional category groups:

Objective 3. Identification of the integrative elements that the OPCS includes, excludes and those that are needed.
Objective 4. Description of the ethical dilemmas encountered by providers in the OPCS.

The purpose of this second type of analysis was to be able to compare the views of the different professional groups interviewed: leaders, doctors, nurses and social workers. The professional groups were organised and analysed in two different ways, seeking first to find similarities and differences among the different levels of responsibility and care-service specialisation and in between the health or social care areas. The analysis was organised as follows:

- Compare leaders in managerial positions to the rest of the health care workers as a group considered in the service level (doctors, nurses and social workers).
- Contrast the responses from professionals in the health care sector and professionals in the social work sector independently of their professional category (leaders were included in their area of specialty).

3.5.4. Update COVID-19 Pandemic

The COVID questionnaire had several goals. First, to see whether the ideal essential elements of an IPCS found in this study would have a different prioritisation after the pandemic, and also to know if they would include any new elements. Second, to find out the ethical dilemmas encountered by providers while caring for the PC patient during the COVID pandemic. The overall aim of the questionnaire was to observe similarities and differences with the results regarding the IPCS ideal elements prior to and after the COVID-19 pandemic in the OPCS.

These questionnaires were analysed with an inductive approach, and categories emerged from the data analysed. Following the steps proposed by Hsieh and Shanon (2005), the data was first read several times and the first codes were found. Then, after further readings, the codes were labelled by meaning and relationships among them were established. Later, further categories and subcategories were developed. These new codes and categories were then compared to the prior study results regarding the topics mentioned before.

3.6. Ethical considerations

This study was granted approval by the Research Ethics Committee (CER) of the University of Vic-Central University of Catalonia (UVic-UCC). Informed consents to participate in the study were obtained and archived (see Appendix I). The research ensured the right to withdraw from the study at any time, as well as the confidentiality and anonymity of data. Data was protected by the storage of the data on a UVic-UCC storage system that ensures data protection.

This qualitative research study followed the criteria of scientific rigour establishing accuracy and trustworthiness through credibility, transferability, dependability and validation (Lincoln & Guba, 1985). Credibility ensures the appropriateness of data and analysis processes in addressing the studies' main goals. To ensure credibility, the following strategies were used: prolonged engagement in the study context, triangulation, peer debriefing, referential adequacy of materials and checking-in with participants. To guarantee credibility in this research:

- Prolonged engagement and observation were undertaken in year-long commitment, January 2019 to January 2020, of data collection with key professionals at their place of work.
- Triangulation was employed, which involves using multiple methods to diagnose the same construct using an independent observational perspective (Campbell & Fiske, 1959). Specifically, in this study, three different research techniques were used: document review, questionnaires and interviews. The combination of their results provided responses to the research questions. Further the interviews used four different types of informants, based on their different professional specialty, that provided the study with different views and perspectives on the same topic researched.
- Peer debriefing was performed by the two thesis directors, who consistently critically assessed the interpretations and results found. Furthermore, in the phase of piloting the initial matrices as required by the deductive method of Assarroudi et al. (2018), a colleague tested the matrices in parallel with the researcher in order to redefine categories and definitions to develop the final matrices used in the study. Four monitoring committees, with five experts in the field, then provided guidance and critical assessment. Finally, a fellowship stay at a university abroad facilitated peer debriefing with three experts specialised in the research area.

- With regards to material adequacy, two databases were searched for any information related to the PC health system or the SISO organisation to perform the document review. Questionnaires and interviews with key professionals in the system were completed. These actions were aimed at satisfying the referential adequacy materials for the description of the OPCS system.

Transferability establishes that the study results could be transferred to another context. The strategy used is thick description. This study used recollection, transcription and analysis of interviews, documents and questionnaires, which enabled a global and thorough understanding of all the material included. This facilitated dense descriptions of the method used from the data collection to the analysis process to the results phase. This detailed description would facilitate the transferability of the same study to another setting.

Dependability indicates that the findings are reliable and could be repeated in another study. The strategies used in this research were:

- The provision of a list of sources, analysis processes, coding tables and matrices and detailed description of the methods used, so that they could be repeated in another study.
- The provision of an external audit by five collaborating external researchers, members of the thesis monitoring committees, which assessed the adequacy of the research processes at different times. Three external researchers from a foreign university, experts in the thesis' study area, then reviewed and examined the thesis' development.

Validation in research aims to confirm that the information found does not include biases or the researcher's personal interest. In this study, the strategies used to ensure validation include the external audits by the thesis directors and external researchers that have collaborated at different stages in the research; triangulation of information; and reflexive activity by the researcher. Describing in detail the theoretical approaches and analytical methods and strategies used, also aimed to ensure the study's validation.

CHAPTER 4

RESULTS

4. RESULTS

This chapter presents the research results with the aim of answering the study's main purpose and objectives. It is divided into two phases. Phase I describes the structure, services and professionals in the OPCS with the results obtained from secondary sources and questionnaires. Phase II identifies the essential integrative elements for an ideal IPC and then identifies the integrative elements included, excluded and needed by the OPCS. It then describes the ethical dilemmas encountered by the providers in this system with the results obtained from the interviews and, finally, presents the updates on the COVID pandemic.

4.1. Phase I. Description of the OPCS

In order to describe the OPCS the following questions were explored through documents and a questionnaire:

- *How is the PC system serving the chronically ill and palliative patients in the Osona region in Catalonia, Spain?*
- *How is Osona PC system structure, and what are its services and professionals like?*

4.1.1. Description of the OPCS. Secondary Sources: Documents

As explained in the methodology chapter, eighteen documents - articles, health plans, reports, web sites and two data bases - were analysed (see Appendix A). The document analysis followed the PC evaluative framework of Bainbridge et al. (2010), from which the main categories were obtained. These then guided the deductive content analysis.

The main data collection questions were developed from the topics described in the framework by Bainbridge et al. (2010): environmental and contextual factors, system characteristics, financial situation, providers' characteristics, information sharing and organisational factors.

4.1.1.1. Environmental and contextual factors. The main categories were density and demography, and the subcategories were: regions' density, demography characteristics and incidence of diseases in the population, as illustrated below in Table 10.

What are the environmental and contextual factors?	Density	Region's density
	Demography	Demography characteristics
		Incidence of diseases in population

Table 10. *OPCS Context*

Density. The Osona region's population was 160,821 in 2019, with an area of 1,245.20 km^2 and a population density of 129.2 per km^2 in 2020 (Generalitat de Catalunya. Idescat, 2020). The Osona region constitutes 2.1% of the total population of Catalonia (Observatori Socioeconomic D'Osona, 2018) (see Figure 9).

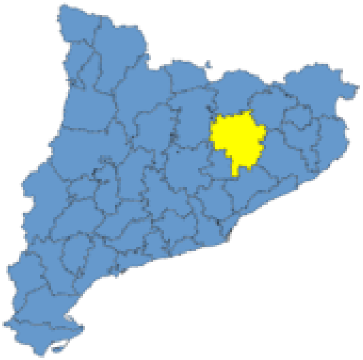


Figure 9. *Map of Catalonia Showing the Osona Region. Source: Generalitat de Catalunya. Idescat (2020)*

Demography Characteristics. The Osona region's population is distributed in urban and rural areas. The most populated cities and towns are Vic, with 46,214 inhabitants, Manlleu, with 20,573, and Torelló, with 14,347 inhabitants, constituting 50.4% of the total population (see Figure 10, which shows them represented in dark blue). The Osona region's population per area allocation is distributed in big cities and towns like Vic (1,511 inhab./ km^2), Manlleu (1,194 inhab./km^2) and in less populated towns such as St. Sadurni d'Osomort (2.5 hab./ km^2), and Tavertet (3.4 hab./ km^2). The population growth takes place in the most populated, urban areas. In these areas there is a higher percentage of younger people and a larger group that is less than 64 years old, with a higher index of immigration. In contrast, there is a larger older population with a higher index of senile dependency in the smaller towns and rural areas (see Figure 14) (Observatori Socioeconomic d'Osona, 2018).

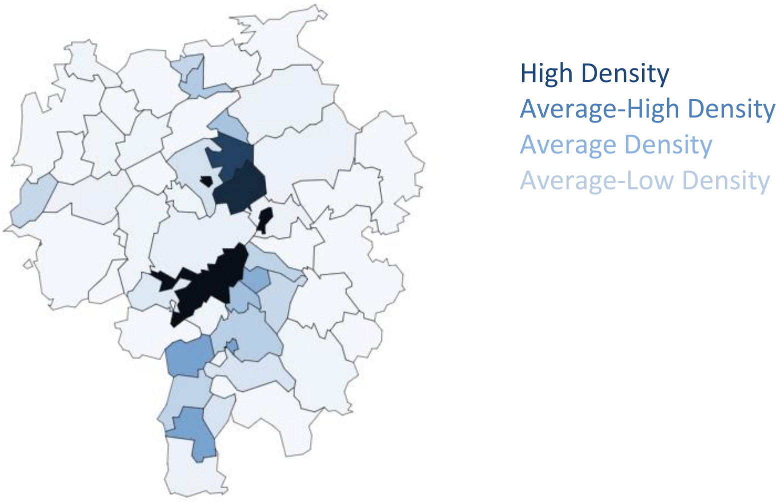


Figure 10. *Population Density in Municipalities of the Osona Region in 2019. Source: Generalitat de Catalunya. Idescat (2020)*

The gender distribution of the population is 80,670 males (50.2%) and 80,151 females (49.8%) (see Figure 11). As shown in table 11 and Figure 13, there are more women over 65 than men, and more than twice as many women than men 85 and older. The age distribution is shown in Table 11.

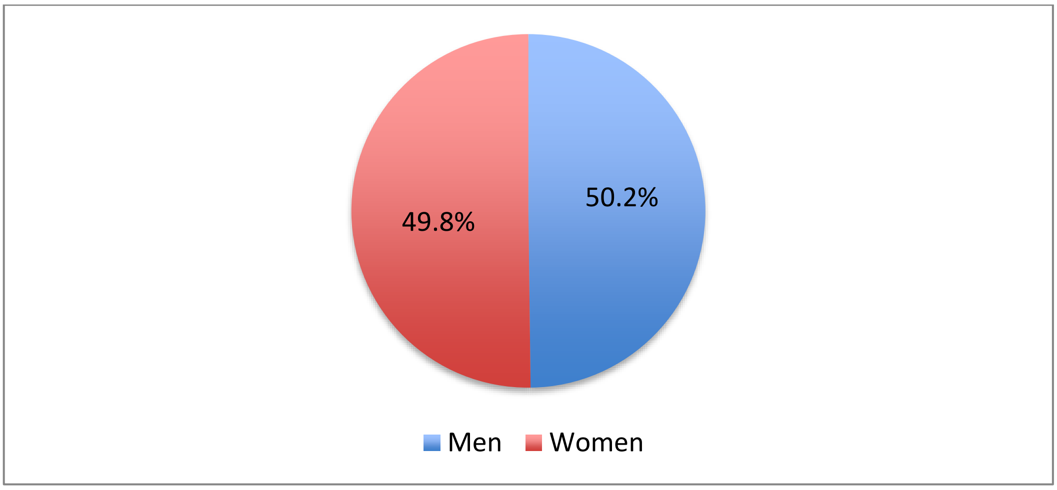
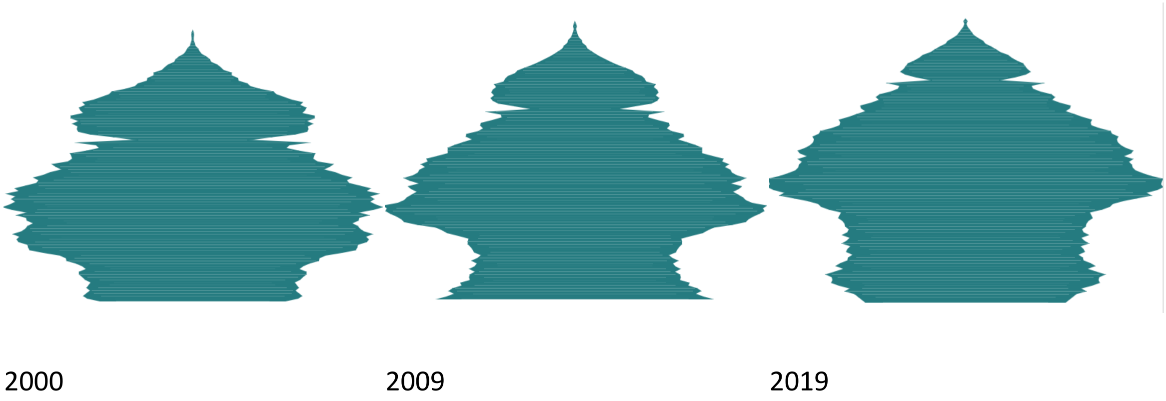


Figure 11. *Gender Distribution in Osona, 2019. Source: Generalitat de Catalunya. Idescat (2020)*



2000 2009 2019

Figure 12. *Osona Population Pyramid per Year. Source: Observatori Socioeconomic d'Osona (2018)*

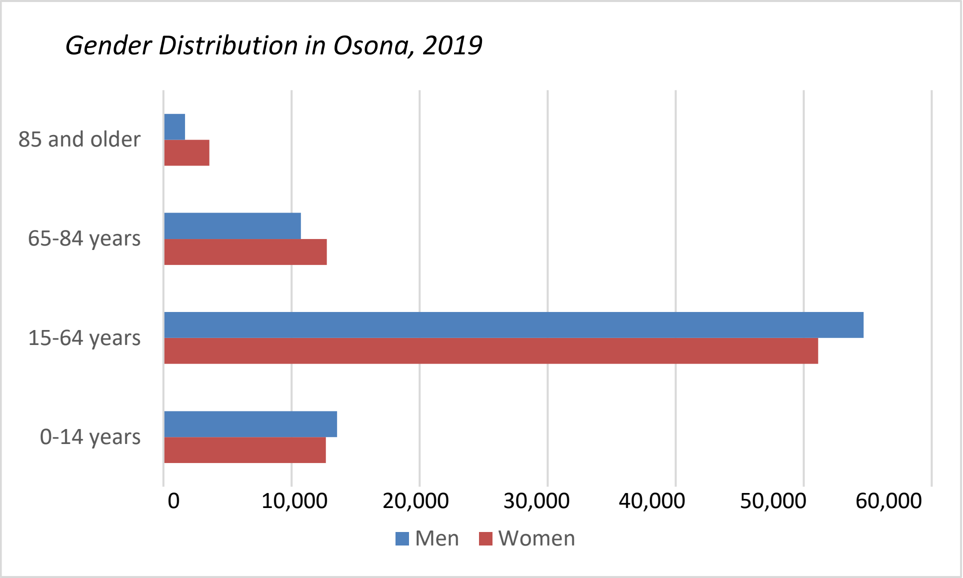


Figure 13. *Gender Distribution in Osona. Source: Generalitat de Catalunya. Idescat (2020)*

Population Age group	**Women**	**Men**	**Total**
0 to 14 years	12,677	13,568	26,245
15 to 64 years	51,143	54,686	105,829
65 to 84 years	12,750	10,735	23,485
85 and older	3,581	1,681	5,262
Total	80,151	80,670	160,821

Table 11. *Population Distribution in Osona by Gender and Age 2019. Source: Generalitat de Catalunya. Idescat (2020)*

In table 12 below, we can see the ageing index (a percentage calculated by the coefficient of number of people 64 and older and number of people 15 or younger) and the over ageing index (a percentage calculated by the coefficient of people 85 and older and the people 65 years and older) for Osona and Catalonia. Osona has a 1% lower ageing index than Catalonia but a slightly higher over aging index of 2% (CatSalut. Servei Català de la Salut, 2019). Therefore, in Osona there is a large group of people 65 years and older (as shown in Table 11), and a larger group of older people, than younger people aged 14 or less (see Figure 12) (Generalitat de Catalunya. Idescat, 2020). This older population represents almost 18% of the total population, with more women than men. There is also a larger population aged 85 and older in the region compared to the rest of Catalonia.

	Ageing index Older than 64	**Over Ageing Index**
Osona	18.4 %	20.0 %
Catalunya	19.4%	18.3 %

Table 12. *Ageing and Over Ageing Index 2018. Source: Catsalut. Servei Català de la Salut (2019)*

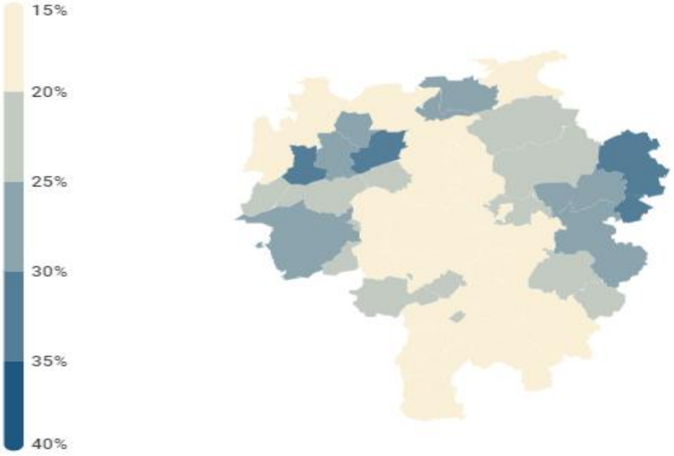


Figure 14. *Distribution of Population 65 years and Older in 2018. Source: Observatori Socioeconòmic d'Osona (2018)*

Osona's population born outside Spain, as indicated by Idescat, *Institut d'Estadística de Catalunya* (Catalan Statistics Institute), is 24,588, 15% of the total population (Generalitat de Catalunya. Idescat, 2020). This immigrant population is concentrated mostly in the two largest cities, Vic and Manlleu. The main countries of origin for this immigration in Osona are Morocco with 36.4%, Ghana 11.5%, India 7.7%, Romania 7.2%, Colombia 4.9% and Ecuador 4.0%. The general population growth prospect indicates that Osona will be one of the regions in Catalonia with greater growth from 2018 to 2030. This growth will not be because of more natural births but due to migratory growth, as we can see in Figure 15, which shows that immigrants born outside Catalonia are the biggest group, and that this growth has been increasing over the years (Observatori Socioeconomic d’Osona, 2018).

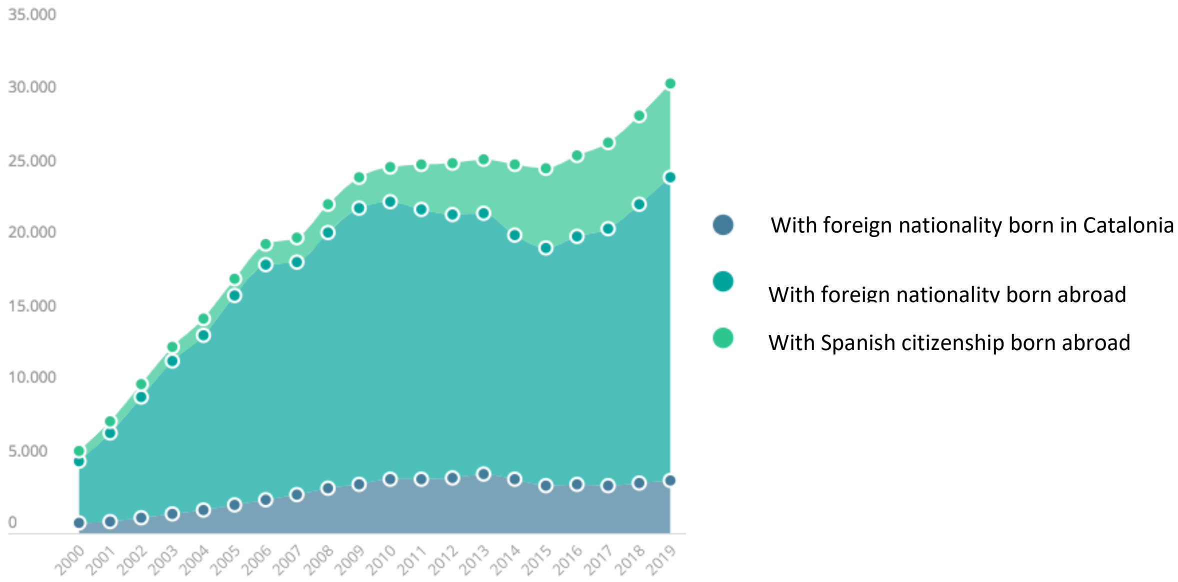


Figure 15. *Immigrant Population in Osona. Source: Observatori Socioeconòmic d'Osona (2018)*

The average gross family income in this region is 16,700 € per inhabitant, compared to 17,000€ in Catalonia. Osona, along with five other regions, is one of the regions with the highest average gross family income. The highest is Barcelones with 19,200 €. The average gross salary in Osona is 21,529.38 € per worker versus the 24,454.64 € per worker in Catalonia (see Figure 16).

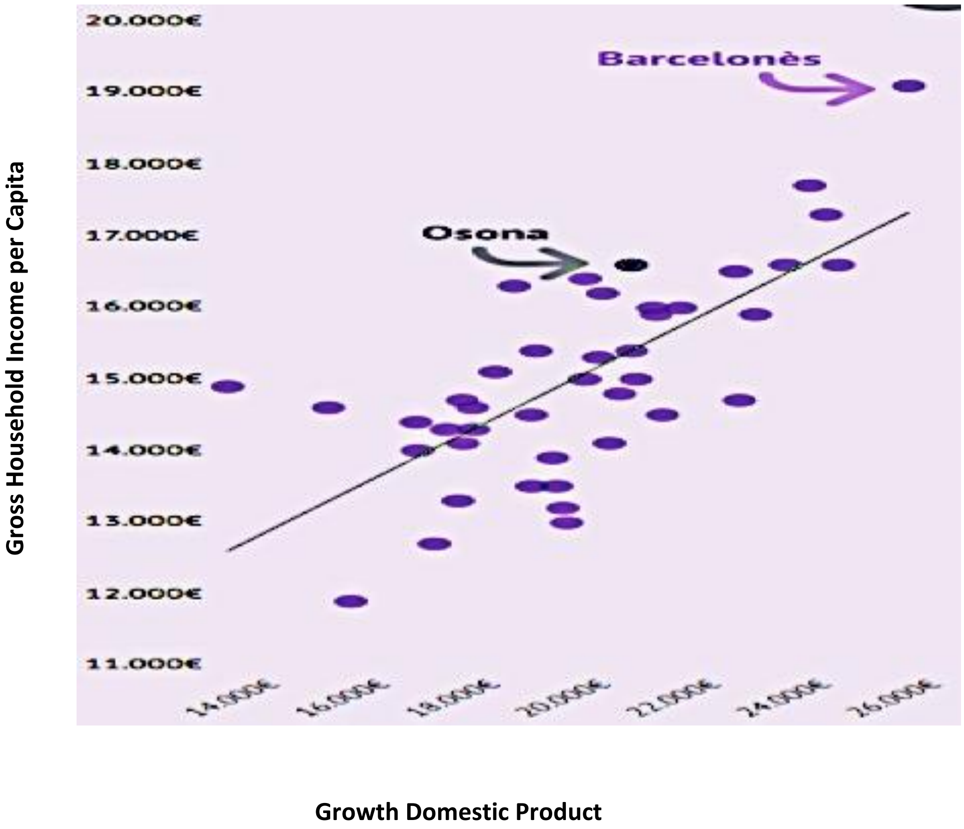


Figure 16. *Osona Gross Household Income. Source: Observatori Socioeconòmic d'Osona (2018)*

The income level distribution is 26.7% of those with declared income making less than 12,000€, 18.9% between 12,000 and 18,000 €, 33.0% making between 30,000 and 60,000 € a year, and 3.8% making more than 60,000 € a year (Observatori Socioeconomic d'Osona, 2018). In Osona, 45.6% make less than 18,000 €, a group close to making less than the average gross family income of 16,700 € per inhabitant, with a large percentage of them probably below the poverty line (see Figure 17).

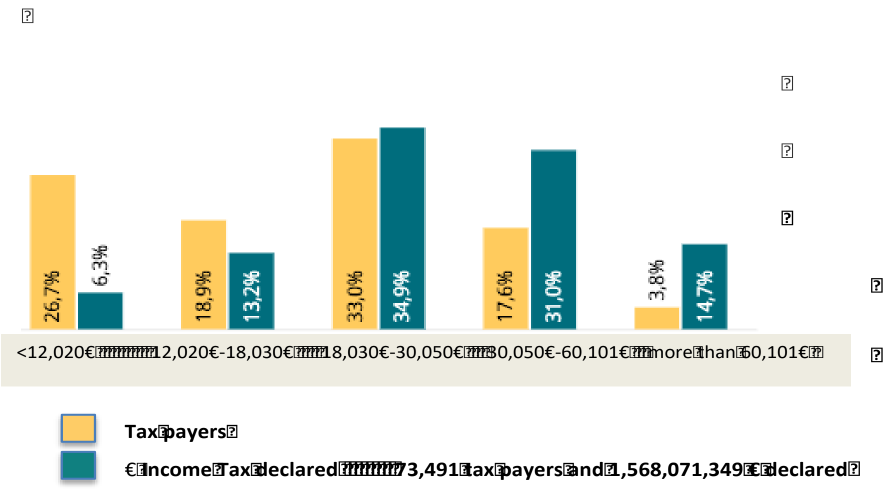


Figure 17. *Tax Payers Distribution and Income Tax Declared. Source: Observatori Socioeconòmic d'Osona (2018)*

Demography: Incidence of Diseases in the population. In Osona, the population identified with advanced chronic disease (MACA) is 755, representing 0.5% of the total region's population. The disease incidence for the general and the MACA population is indicated in Table 13. The general population (GP) suffering from 2 or more chronic diseases is 56.1%, and 2.3% have a neoplasia or malignancy. For the MACA population, this incidence is much higher: 72.2% with 2 or more chronic diseases and 25.7% with a neoplasia (CatSalut. Servei Català de la Salut, 2019).

	General Population	**MACA Population**
Healthy	10.4%	0%
Acute disorders	8.8%	0%
Chronic disease affecting 1 body system	20.7%	0.1%
Chronic diseases affecting 2-3 body systems	30.5%	2.6%
Chronic diseases affecting >3 body systems	25.6%	71.6%
Active Neoplasia	2.3%	25.7%

Table 13. *Disease Incidence Percentage in Osona. Source: Catsalut. Servei Català de la Salut (2019)*

In addition, for the GP aged 65 and older, most women and men have a chronic condition in 2 or more body systems, as shown below in Figure 18. It is important to note that with the MACA population aged between 80 and 84, and even more so aged between 85 and 95, more women are alive and suffer a chronic condition in 2 or more body parts or have neoplasms (see Figure 19).

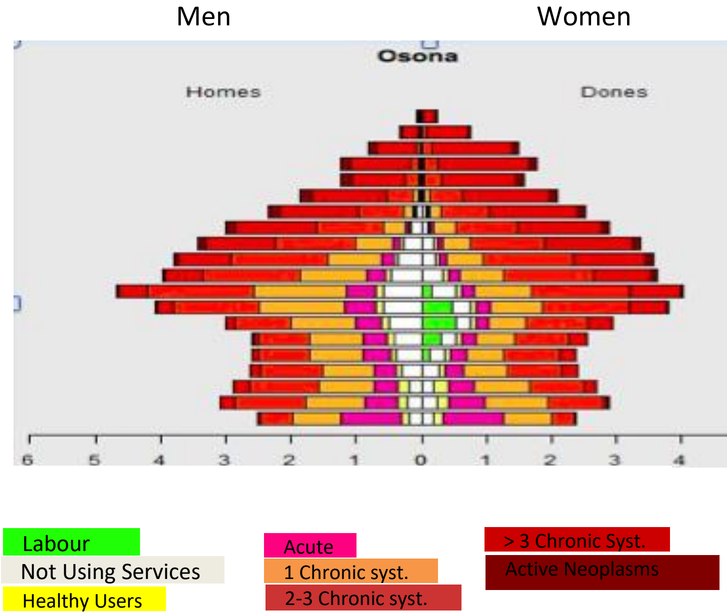


Figure 18. *Health State According to Age and Gender 2018. Source: Catsalut. Serveia Català de la Salut (2019)*

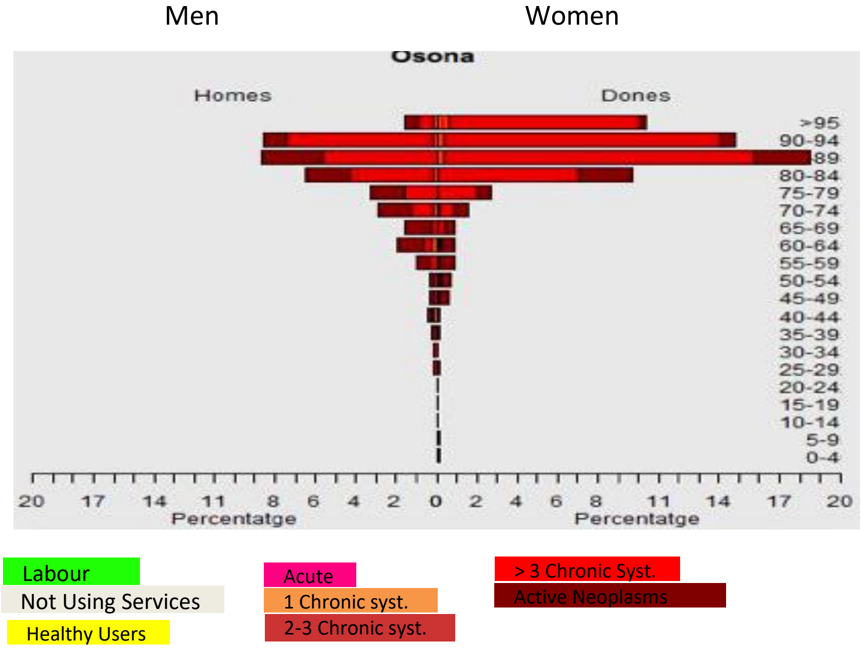


Figure 19. *Osona Chronic Conditions in 2-3 or > 3 body Systems. Source: Catsalut. Servei Català de la Salut (2019)*

Osona's population has been classified by the health care system using the *Grup de Morbiditat Ajustat* (GMA) (Adjusted Morbidity Group), a system that distributes patients according to their risk of death, admission and expense to the system. As illustrated in Table 14, 97% of the MACA population suffer a risk of 3 or 4 in the GMA, thus having a high and very high risk of death, admission and expense to the system (CatSalut. Servei Català de la Salut, 2019).

	% General Population	**MACA Population**
Risk 4 (Very high risk)	5%	71%
Risk 3 (High risk)	14%	26%
Risk 2 (Moderate risk)	31%	3%
Risk 1 (Low risk)	51%	0%

Table 14. *GMA General and MACA Population 2018. Source: Catsalut. Serveia Català de la Salut (2019)*

In 2017, for the GP the disease index in Osona was higher for diseases such as movement disorders, hypertension, arthritis, depression and diabetes. Then, mortality was more frequent for patients suffering from dementia, congestive heart failure (CHF), cerebral vascular accident (CVA) and chronic kidney disease (CKD). The prevalence of disease (proportion of population affected by a condition at a specific time) within the general population that year was higher in diseases such as movement disorders, hypertension, arthritis, depression and diabetes (see Table 15) (CatSalut. Servei Català de la Salut, 2019).

Osona's total identified MACA population in 2018, according to the MSIQ database, was 755 (CatSalut. Servei Català de la Salut, 2019). As indicated in the study on prevalence by Gómez-Batiste et al. (2014b), most patients with an advanced chronic diseases suffer mostly frailty, dementia, cancer and organ failure. In Osona, the general morbidity index was higher for the MACA population than for the GP, (understanding adjusted morbidity index as the coefficient of the observed and the expected cases). The MACA 31.7% morbidity index in Osona was lower than the MACA population of 34.2% in Catalonia.

Regarding mortality in Osona in 2018, there was a total of 1,444 deaths with a mortality index of 8.8 x 1000 inhabitants for the GP, while for the MACA population there was a total of 280 deaths with a mortality index of 370.9 x 1000 inhabitants. Therefore, almost 20% of the total deaths in Osona were MACA patients. Lastly, the prevalence of MACA patients in Osona was of 293.1 per 100,000, much higher than in Catalonia, where it was 198.8 per 10,.000 inhabitants at the end of 2018. The MACA prevalence of 475, and a mortality total of 280 represented 37% of prevalence in patients still living, and 63% of patients diseased in 2018 (see Table 16). On the other hand, the complex chronic patient (PCC) (a stage prior to becoming MACA) represented 2.3% of the total population with a prevalence of 89% and a mortality of 11% (CatSalut. Servei Català de la Salut, 2019).

	Population N	**Mortality %**	**Prevalence Tax per 100,000 hab.**
MACA	755	3.7	293.1
PCC	3,723	11	2,042.1
Diabetes	11,191	4.09	6,732.80
COPD	6,516	6.74	3,812
Asthma	10,560	1.08	6,552.70
Congestive Heart Failure	4,395	13.90	2,373.70
Ischemic Heart Disease	4,492	6.97	2,621.50
CVA	4,604	9.19	2,622.70
Hypertension	31,683	3.44	19,191.15
Chronic Kidney Disease	7,270	8.51	4,171.20
Cirrhosis	1,097	5.65	649.3
HIV/AIDS	349	1.15	216.4
Malignant Neoplasm	9,343	6.30	5,491.40
Movement disorder	57,999	1.75	35,745.30
Osteoporosis	5,237	4.26	3,145.30
Arthrosis	18,912	3.66	11,429.40
Arthritis	7,025	2.55	4,292.90
Chronic pain	802	7.11	467.3
Chronic Mental Health	7,239	2.39	4,432.50
Depression	17,545	2.72	10,06.10
Dementia	2,115	20.43	1,055.70

Table 15. *GP Mortality, Morbidity and Prevalence 2017. Source: CatSalut.Servei Català de la Salut (2019)*

	GP (Catalonia)	MACA (Catalonia)	GP (Osona)	MACA (Osona)
Population at risk N	7,743,490	27,617	163,530	755
Morbidity indicator	6.3%	34.2%	6%	31.7%
Mortality N	66,507	12,357	1,444	280
Mortality %	0.86%	44.7%	0.88%	37.9%
Prevalence N	-	15,260	-	475
Prevalence (per 100,000 hab.)	-	198.8	-	293.1

Table 16. *Osona General Population and MACA Morbidity and Prevalence 2018. Source: CatSalut. Serveia Català de la Salut (2019)*

4.1.1.2. System Characteristics. The main categories found under system characteristics were service offered, membership size, participation in network, network ideal and policies, which will now be explained.

What are the system characteristics?	Services offered	Type of health centres and PC services and in the region
	Membership size	Number of services used and patients served by system
	Extent of participation in network by members	Coordinating organisation
	Networks ideals	Patient-centred Integral services
	Policies	Health plans and programmes ensuring services to the chronically ill

Table 17. *System Characteristics*

Services offered. In the OPCS there are the following health centres: one general hospital, ABS *Àrea Bàsica de Salut* (primary care centres), two intermediate/convalescence hospitals in the biggest cities Vic and Manlleu and one mental health centre in Vic (Blay Pueyo, 2017), and several private and public nursing homes. Osona has the following PC specific services (Generalitat de Catalunya. Departament de Salut, 2017c):

- Pades: *Programa atenció domiciliaria i equip de suport* (homecare programme and support team). There are 13 (in Centelles , South Vic, North Vic, Tona, St. Hipòlit de Voltregà, Prats del Lluçanès, Roda de Ter, St. Quirze de Besora, Sta. Eugènia de Berga, Torelló-Vall de Gés, Manlleu, Vic, St. Creu Hospital team and Manlleu Hospital team).

- Intermediate care: *Atenció Intermitja* (convalescence, rehabilitation hospital). Santa Creu Hospital in Vic and St. Jaume Hospital in Manlleu.

- UFISS: *Unitat functional interdisciplinary sociosanitària (*Functional interdisciplinary convalescence team). There is one in Santa Creu Hospital.

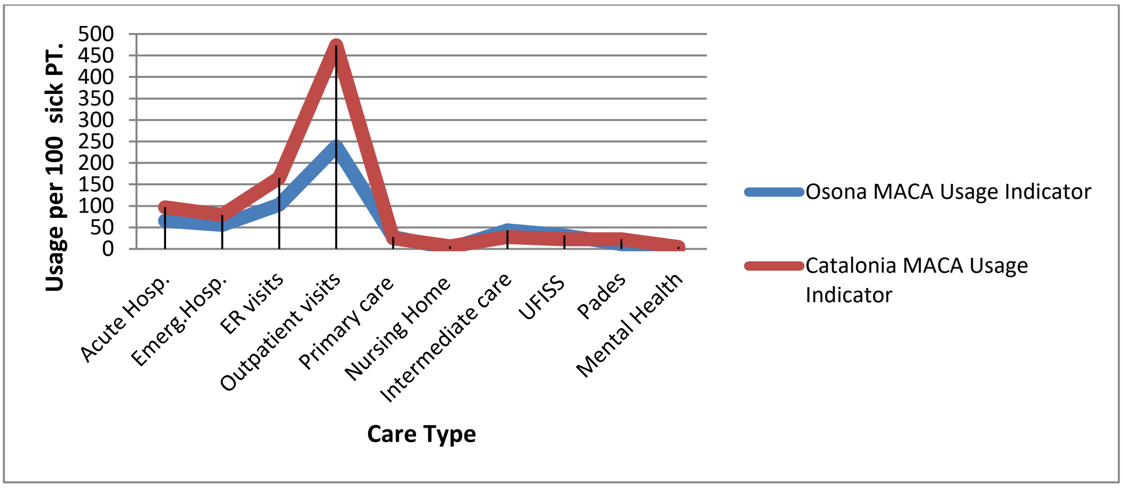
- UCP: *Unitat d'atenció pal.liativa* (Palliative Care units in hospitals), one in St. Creu Hospital.

- EAIA: *Equip d'atenció integral ambulatoria* (Ambulatory integral care team). St. Creu Hospital has one.

Membership Size. This refers to the patients served and services used. The outpatient hospital and the emergency room visits are the most used by the MACA population, both in Osona and in Catalonia. It is also important to note that just 1% of these MACA patients are in nursing homes in Osona, while it is much higher in Catalonia with 6.4%. On the other hand, 43.4% of MACA patients in Osona used the intermediate care while in Catalonia this number was much lower at 27.9%. In addition, PADES used by MACA patients is 11.3%, much lower than 22.7% in the rest of Catalonia. The Osona rate for acute and emergency hospitalisation, emergency rooms and outpatient visits is much lower than the average in Catalonia. In contrast, primary care visits, stays in intermediate care and use of the UFISS services is higher in Osona than in Catalonia, as shown in Figure 20 (CatSalut. Servei Català de la Salut, 2019).

It is interesting to note, that the higher use of the intermediate and primary care services could be the reason for the lower usage rate of acute and emergency services by the MACA patients in Osona when compared to the total Catalonia usage. In addition, Osona, with a standard implementation model for the PC patient, and a primary and intermediate care that responds to and manages well these patients who are mostly living at home, has probably been able to reduce the use of emergency and acute outpatient services.

Figure 20. *Usage of Care Services by MACA Patients Osona and Catalonia (2017). Source: CatSalut. Servei Català de la Salut (2019)*



Extent of participation in network among members - Osona has a coordinating organisation called SISO, created in 2002 (comprehensively explained in Chapter 3, Methodology), where interdisciplinary meetings among the different groups of professionals are held. It has a number of different groups - a coordinating group, economic and financial group, prevention group, assistant groups (MACA/PCC Service Pathway), rehabilitation group, information system group, chronicity group, pharmacy group and dementia group - all of which are multi/interdisciplinary with professionals from all areas and levels of care and from different disciplines (Sistema Integrat de Salut d'Osona, 2016).

Network ideals. The Catalan Health Plan 2016-2020 states as one of its goals the implementation of a continuous service model that is integral rather than fragmented. As the Catalan Health Plan states, fragmentation makes the system less efficient, while an integrated system will be more efficient and it will guarantee service equity for the patient (Generalitat de Catalunya, 2016b). Specifically, in Osona there is a care model for complex patients with good results. This care model enables primary care to admit patients to intermediate care without needing to go through the general hospital emergency room (Generalitat de Catalunya. Departament de Salut, 2017a).

Another goal of the Catalan Health Plan 2016-2020 is to implement a service model that is patient-centred. The PIAISS, Interdepartmental plan for interaction and social care between health and social services, was developed so that the health and social care services could provide integrated care (Generalitat de Catalunya, 2016b). The PIIC, shared individualised intervention plan, is a document designed to be shared by all the team caring for a patient, promoting the collaboration of professionals to work on the same care plan. This plan will be in the patient's medical history in the shared information system (Santaeugènia Gonzàlez, 2017). In addition, there is the PDA (advanced care directive), in which the patient's preferences and values are identified, in order to plan the resources and goals for the future care of the patient (Termcat. Generalitat de Catalunya. Generalitat de Catalunya, 2013).

Policies. This refers to health plans and programmes ensuring services to the chronically ill. In 2011 the PPAC (Chronicity prevention and care programme) was created within the Catalan Health Plan 2011-2015 by the Ministry of Health of the Government of Catalonia (Amil et al., 2016). This 2011-2015 Catalan Health Plan initiated a goal to implement integrated services for patients with chronic diseases, a goal that was then continued and extended in the next Catalan Health Plan of 2016 to 2020. In the Catalan Health Plan there is also a directory that compiles all the PC Services for each region in the Catalan health subdivisions. This directory organises the PC services such as primary care, home care, support teams and units for PC, day hospitals, PC units in hospitals, rehabilitation centres and PC for children (Generalitat de Catalunya. Departament de Salut, 2017c). These different health plans also developed as well as the PIAISS, which tried to unify the health and social sector. They also aimed to provide patient-centred care through the development and sharing of the PIIC and PDA (Generalitat de Catalunya. Departament de Salut, 2017b).

4.1.1.3. Financial Situation*.* The main categories found were network resources and the presence of an after hour service available 24/7.

How is the economic and financial situation?	Network resources	Number of hospitals, clinics, centres and professionals
	Presence of 24/7 care	24/7 care vision

Table 18. *Financial Situation*

Network resources. This refers to the number of hospitals, clinics and centres. According to IDESCAT, the number of available beds in hospitals, clinics and centres in Osona in 2018 were as follows: one general hospital with 292 beds and six health centres with 328 beds, making a total of seven centres with 620 beds. These beds were organised as follows: 292 for acute hospitalisations, 307 for rehabilitation/convalescence, 16 for psychiatric patients and 4 for incubators. With regards to nursing home beds, there were 226 beds from public sector initiative, 832 from the social sector and 296 from the private sector (Generalitat de Catalunya. Idescat, 2020).

According to Blay Pueyo (2017), the services in the Osona part of the SISO organisation are as follows :

- Primary care centres: (9 EAP, *Equip d'atenció Primaria* (Primary Care team), 1 EBA*, Entitat de base associativa* (Primary care entity) in South Vic 1 EBA in South Osona
- General hospital: Vic Hospital
- Intermediate hospitalisation: St. Creu Hospital, St. Jaume de Manlleu Hospital
- The Osona Mental health centre

There were a total of 3,782 professionals in 2018 registered in the health care area, professionals working in hospitals, health care related activities and dental services. Table 19 shows a comparison of the number of health care workers per 1000 inhabitants in regions with similar total populations to Osona (Generalitat de Catalunya. Idescat, 2020). As is indicated, the Osona region has half the number of health care workers compared to Bages, but it has more than double the number of professionals in the Garraf and Selva regions. Osona has 23.8 professionals per 1000 inhabitants.

	Population N	**Health Care Workers N**	**Health Care Workers per 1000 inhabitants**
Osona	158,758	3,782	23.8
Garraf	147,635	1,614	10.9
Selva	168,635	1,461	8.66
Bages	176,891	7,075	39.9

Table 19. *Health Care Workers in Regions with Similar Population 2018. Source: Generalitat de Catalunya. Idescat (2020)*

Presence of 24/7 Care. The Chronicity prevention and care programme and the Health Plan 2011- 2015 integrated a 24/7 vision in which exacerbations complex patients' complications are covered by a planned strategy. These chronic patients have a PIIC in their shared medical history and when these patients call the emergency staff after hours, they get a "warning alert" so they can access key information summaries from the PIIC so better decisions can be taken by the emergency staff (Generalitat de Catalunya. Departament de Salut, 2012b).

It is also stated that the PADES team should provide 12-hour coverage to chronic and oncological patients that require specialised care (Generalitat de Catalunya. Departament de Salut, 2012a).

4.1.1.4. Providers' Characteristics. This include their cooperation, interdependence, training and education, which are described below.

What are the providers' characteristics?	Cooperation	Cooperation at different levels of care and services
	Perceived Interdependence	Case management and multidisciplinary teams
	Specialty training	Training strategies

Table 20. *Providers' Characteristics*

Cooperation. This refers to cooperation in different services and at different levels of care. It is indicated in the Chronicity prevention and care programme of 2015 that when providing care to chronic patients, collaboration should be encouraged among health care and social services organisations and professionals (Amil et al., 2016). As described by Blay Pueyo (2017), the model that best provides care for the chronic patient is the one in which individual health professionals, teams and organisations work collaboratively.

Perceived Interdependence. This involves multidisciplinary teams and case management. The Catalan Health Plan 2016-2020 states as one of its goals the implementation of a service model based on shared decisions and multidisciplinary work. It proposed the promotion of shared decision-making, including case management (Generalitat de Catalunya, 2016b). In addition, the PIIC is elaborated by the health care professionals in which they indicate the goals and critical interventions for a patient. This document with the patient's clinical history can be accessed by all the professionals that care and will care for a patient (Generalitat de Catalunya. Departament de Salut, 2012b).

As Gómez-Batiste et al. (2014a) point out, there is moderate agreement between nurses and doctors when identifying patients requiring PC. They also state that doctors are the ones that request PC services, and this is done only in primary care. They highlighted the importance of reinforcing a more multidisciplinary approach when identifying patients requiring these types of services.

Specialty training. One of the goals of the Catalan Health Plan 2016-2020 and the Chronicity prevention care programme is to develop common strategies for training to provide integrated care (Generalitat de Catalunya. Departament de Salut, 2012a; Generalitat de Catalunya, 2016b).

4.1.1.5. Information Sharing. This describes the documents and information system platforms in the system as well as the established monitoring system.

How is information shared?	Information systems and documents	Digital health related information sharing
	Standard assessment and monitoring patients' needs	Patient early identification

Table 21. *Information Sharing*

Information Systems and Documents. The Catalan Health system has a platform where professionals can share the patients' electronic health records, called the shared medical history. The clinical history is shared by clinicians and health professionals: The PIIC (shared individualised intervention plan) and the PDA (advanced care directive), which are explained above in the section 4.1.1.2. and more extensively in Chapter 2.

These documents are shared with the patient's clinical history, and they are shared by all the professionals caring for them (Generalitat de Catalunya, 2016b).

There are also two other shared platforms: The *Canal personal de salut* (Personal health channel), which facilitates remote care and direct access by patients to their clinical history and services (Amil et al., 2016); and the SI-SISO Information system platform, developed in order to share information with the entities that are part of the SISO organisation (Sistema Integrat de Salut d'Osona, 2016). In sum, there are three platforms where information about the patients is shared, and this can pose difficulties to the providers to know where to record, share and review patients' information in the three systems.

Standard Assessment and Monitoring. The identification of chronic and palliative care patients has increased progressively since 2013 with the Chronicity prevention and care programme (Blay Pueyo, 2017). It is important to consider that even when patients were identified as chronic patients only a quarter of the patients requested PC services; and if they were requested, they were usually requested by the primary doctor (Gómez-Batiste et al., 2014b). Primary care services are in charge of identifying and labelling advanced chronic patients or MACA (Blay Pueyo, 2017).

There are a couple of tools used to label and group advanced chronic patients. The GMA, Grouping Adjusted Morbidity, is a tool used by health organisations that stratifies and identifies the population at risk of hospitalisations, readmissions or death. GMA groups patients according to their morbidity and complexity risk to facilitate a more efficient management, and it also groups patients with chronic diseases. Patients with multimorbidity are further classified with a tag indicating how many body systems are affected. This risk grouping is indicated in the patient's shared electronic files (Amil et al., 2016).

Then, the professionals use the NECPAL screening tool to identify at an early stage advanced chronic patients (MACA) with a survival rate of 12-14 months in need of palliative care. The NECPAL tool tries to find patients with PC needs by asking professionals if they think they will die within the next 12-month period (Gómez-Batiste et al., 2012b) (both these tools are explained extensively in Chapter 2). As indicated, there is one effective screening tool – NECPAL - used and shared by providers that identify the PC patient.

4.1.1.6. Organisational Factors. These consist of the care team composition, the implementation models and the evaluation of the programme and system.

What are the organisational factors?	Care team composition	Care team professionals
	Standard implementation models	Standard models
	Programme evaluation	Cost-efficiency

Table 22. *Organizational Factors*

Care Team Composition. Care team professionals. Osona's hospitals, intermediate care and nursing homes include the following professionals in their team: doctors, nurses, nurse assistants, social workers, psychologists, administrative staff, technicians and management (Consorci Hospitalary Vic, 2019; Fundació Hospital de La Santa Creu, 2018). In contrast, primary care teams basically consist of a general doctor, a nurse and social worker, but they also offer services in pediatrics and odontology (Generalitat de Catalunya. Departament de Salut, 2017a).

Standard Implementation Models and Cost-efficiency. In 2011-2015, the Chronicity prevention and care programme was initiated to set up a strategic plan for the PC patient. Further, some territories in Catalonia have adopted *Rutes Assistencials* (Care Pathways) that are integrated work strategies, aiming to integrate services and respond to the chronic patients in a united manner (Amil et al., 2016). Programme Evaluation and cost efficiency: After the implementation of the Chronicity prevention and care programme by the Health Plan, the rate of emergency admission and readmission related to chronic conditions decreased due to a better chronic disease control. In the period of 2001-2013, the emergency hospitalisation rate for patients with chronic conditions decreased by 13% (Amil et al., 2016). As indicated, the effective identification, standardised interventions and good management of the chronic patient has decreased the rate of admission in emergency services.

4.1.2. Description of the OPCS. Questionnaires

The questionnaire aimed to further describe the OPCS from the perspective of the managers in the SISO work team group. The questionnaire's questions were developed from some of the main categories searched in the document review, such as entities' contextual factors, characteristics and services, funding, policies and providers' characteristics. The analysis was conducted in a deductive manner. The questionnaires were completed by the eight components of the SISO group.

The questionnaire was organised as a SWOT format (see questionnaire in Appendix C). The results are shown in two formats: first, the results are shown by these leaders perceptions of the OPCS' internal strengths and weaknesses and the opportunities and threats from outside (see Table 24). Then the results were organised according to the main topics of the OPCS' system service care characteristics, financial organisation, patient care process and identification, and provider characteristics originated from the PC evaluative framework from Bainbridge et al. (2010) also used in the document review (see Table 23 for details on the participants' demographics).

	Participants (8)
Gender	
Male	2
Female	6
Profession	
Doctors	6
Nurse	1
Social worker	1
Managerial experience	
0-4 years	2
4-8	4
8- or more	2

Table 23. Questionnaires Participants' Demographics

4.1.2.1. Description of Entities. In order to find out the number of professionals working in, and patients served by, the various entities, a questionnaire was given to managers (see Table 25). There were a total of seven entities since two of the managers worked at the same entity in different managerial positions.

	Strengths	***Weaknesses***
INTERNAL	Identification Process Labelling generates type of care Specialisation Patient centred Holistic intermediate care Useful services Resources provision Specialised training Clinical competence Teamwork Motivation	Need to increase patient identification Need additional time with patient Desirable 24/7 coverage at all levels Necessary faster services access Needed more professionals and resources Change financing model Need for integrated teams and more specialised training
	Opportunities	**Threats**
EXTERNAL	Need to increase patient identification Need additional time with patient Desirable 24/7 coverage at all levels Necessary faster services access Needed more professionals and resources Change financing model Need for integrated teams and more specialised training	Earlier patient identification Conflict with patient identification and labelling Not all professionals identify patients Lack integrated work Funding Lack professionals and resources Missing services Missing specific policies Need specialised education

Table 24. *SWOT Questionnaire Results*

	Entity 1	**Entity 2**	**Entity 3**	**Entity 4**	**Entity 5**	**Entity 6**	**Entity 7**
Number of professionals	320	240	62	42	39	39	12
% of PC patients served	2%	0.75%	1.5%	0.75%	1.7%	1.7%	1.5%

Table 25. *Questionnaire for the Description of Entities*

4.1.2.2. Services and Care Provided. The participants were asked to respond mostly about how the patients are identified and what services they provide for the MACA patients are like. Therefore, two main categories naturally emerged: patient identification and care provided (see Figure 21):

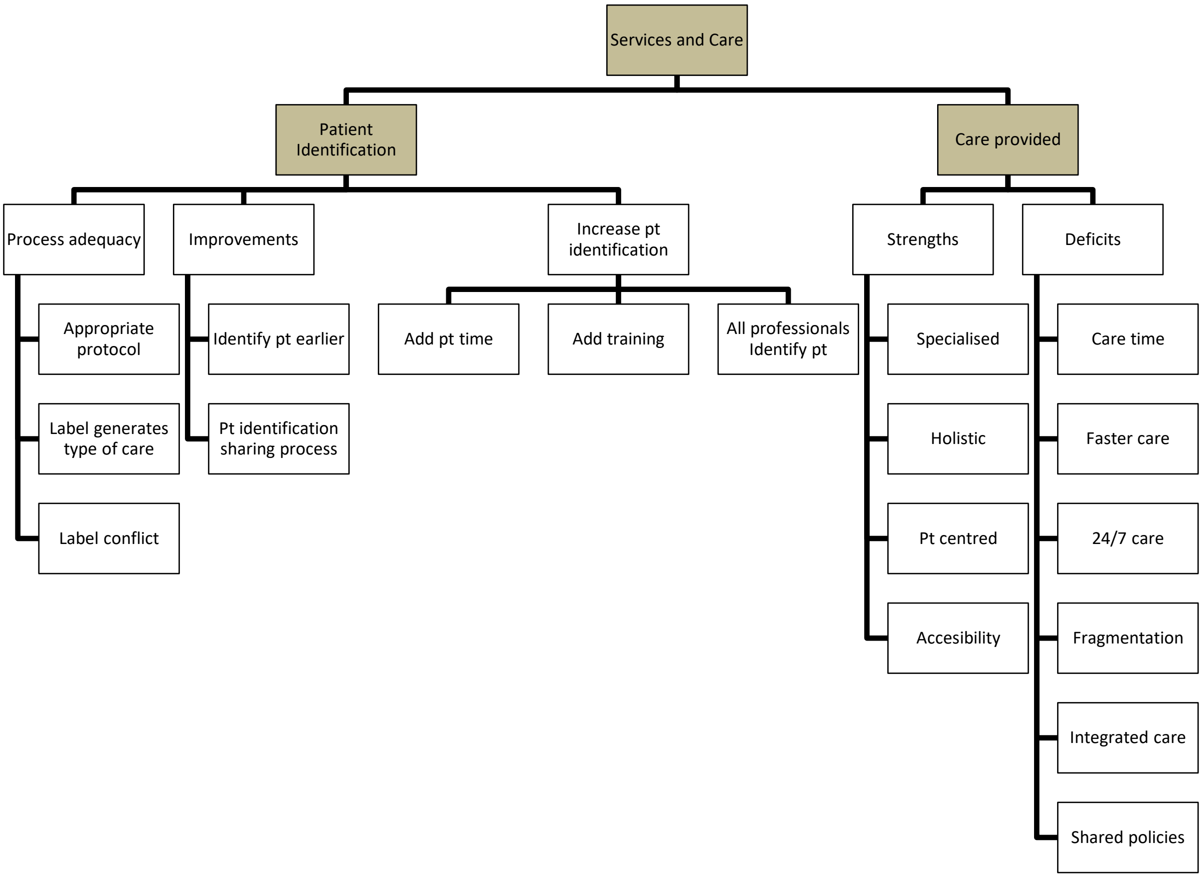


Figure 21. *Services and Care Categories and Codes*

Patient identification process. The adequacy of the identification process was confirmed by four of the professionals, who stated that their entities follow an appropriate process/protocol to identify MACA patients. One of them said: "*There are no false negatives when we identify this kind of patient".* They also ensure that the correct labeling of patients generates a specific care. Four of the professionals said that the correct identification of these patients as needing palliative care brings awareness to the healthcare team and consequently the needed care and services are offered. As one explained, these patients are usually identified at the primary care level, and the other levels of care use this labelling to offer them the appropriate services and an optimal follow up. Two of the professionals did, however, point to some labelling conflict among professionals, since sometimes there is mistrust among professionals when fearing that labelling patients might inhibit the provision of needed treatments.

Respondents pointed to some needed improvements in the identification process. Two mentioned the need to identify patients earlier since earlier detection in their disease would be beneficial at all the levels of care of the patient. Another aspect to improve was the patient identification sharing process. One professional stated the need for more communication between professionals, and another pointed to the need for technological improvements for sharing this information: *"Labelling should arrive from a shared system".*

Another area for improvement was to increase the number of patients identified as MACA. Two professionals said that additional time with patients could facilitate patient identification, while two others suggested additional training in the identification process as a means to increase the number of patients identified as MACA. The possibility that all professionals in the system could identify these patients, and not just those in primary care, was also mentioned.

Care provided. Four professionals stated that the care strengths were the specialised care provided to the PC patient. Two indicated a holistic care approach in which professionals provide with comprehensive care, with one specifying "*Care that supports the patient clinically and emotionally"*. Care accessibility was mentioned by two professionals, who stated that there is an easy access to intermediate care for these kinds of patients. This specialised, comprehensive and accessible care is thus patient-centred as it tries to meet the specific needs of the PC patient.

Seven of the professionals identified one care deficit as the need to increase the time for care per patient, with one saying that "*Professionals are overloaded with patients"*, and five pointing to the need to incorporate more professionals to overcome this deficit. Regarding services, one thought that homecare hours, while given to many patients, may not be enough: "*Home care is offered but with insufficient hours".* Three of them highlighted the need for faster access to some services when the patient needs them quickly, services such as social services or PADES, the home care programme support team. As some pointed out, PADES teams are specialised in home hospitalisation support and acute home care. These PADES teams are therefore not providing care to the majority of PC patients, but rather to those in more acute situations.

Another area in need of improvement is the 24/7 after hours service care. Two professionals said that services should be provided continuously throughout the day and by all levels of care, including primary, intermediate care and social services. Relatedly, six pointed to the way that care is fragmented between professionals, levels of care and areas of care, as manifested in the "*Health and social services".* Finally, three of them mentioned the need for shared policies for health and social services, originating from the government, which would act as a guide for achieving common objectives. As indicated, there is a need to improve the after hours care services coverage, care integration and PC policies. This would avoid care fragmentation as well as promoting a more integrated care approach, in all levels of care and especially in the health and social care area.

4.1.2.3. Funding, Resources and Policies. In this section, the categories resources and services and government policies and funding were found, as well as the subcategories and codes shown below in Figure 22.

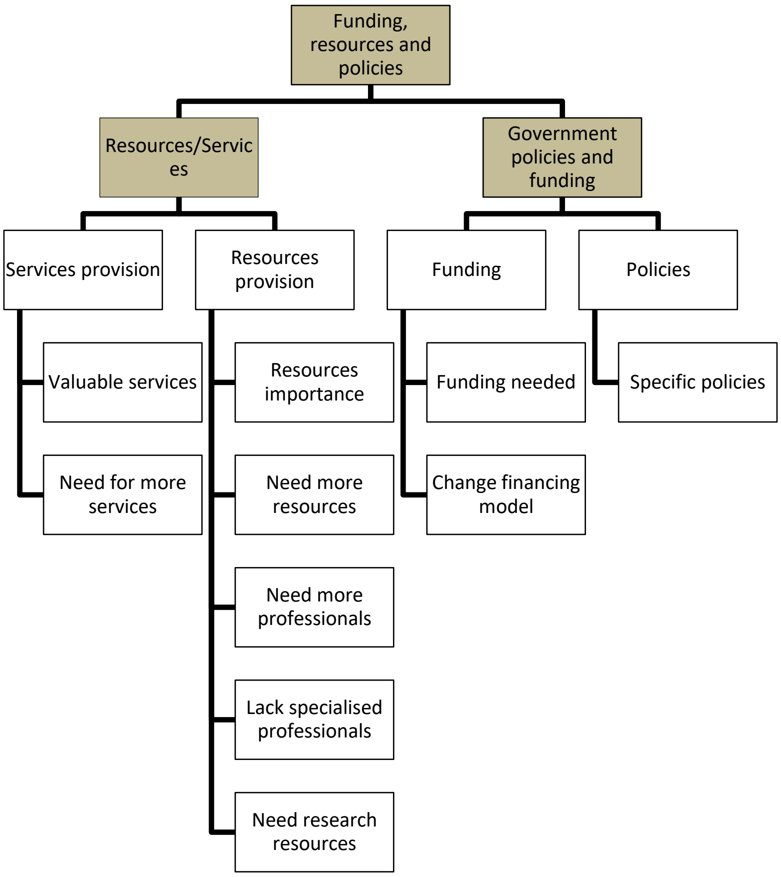


Figure 22. *Categories and Codes of Funding, Resources and Policies*

Resources/services. Services provision such as homecare and day centres, was specified as very valuable supportive services for MACA patients. However, four professionals pointed to a need for more services for these kind of patients, with one saying: *"We need more services, home care, more nursing homes and support for the caregivers".*

Two of the professionals highlighted the importance of resources provision for these patients. However, six of them pointed to the need for more resources that are often offered by social services, as well as sometimes fast access to them, with one stating that "*Sometimes patients need more social services than medical care".* The need for more specialised professionals was noted by six of the professionals, stating that there is a need for specialised professionals such a specialist doctors, general practitioners and psychologists. One also pointed to the need for more resources for research.

Government, policies and funding. Six professionals noted that more funding was needed, with one specifying that *"We need investment for this kind of care".* Two pointed to the need to change the financing model, to replace a model that distributes finances by entities to one that distributes funding according to the patients served. Three highlighted the need for specific policies to regulate the situation of these patients, with one of them saying that *"We need more policies for these patients like the dependence law LAPDA",* a social service law that is specific for fragile and complex patients, which is explained in Chapter 2.

4.1.2.4. Providers Competencies. The leaders in the questionnaire pointed to those provider competences that are optimal and those that need improving (see Figure 23).

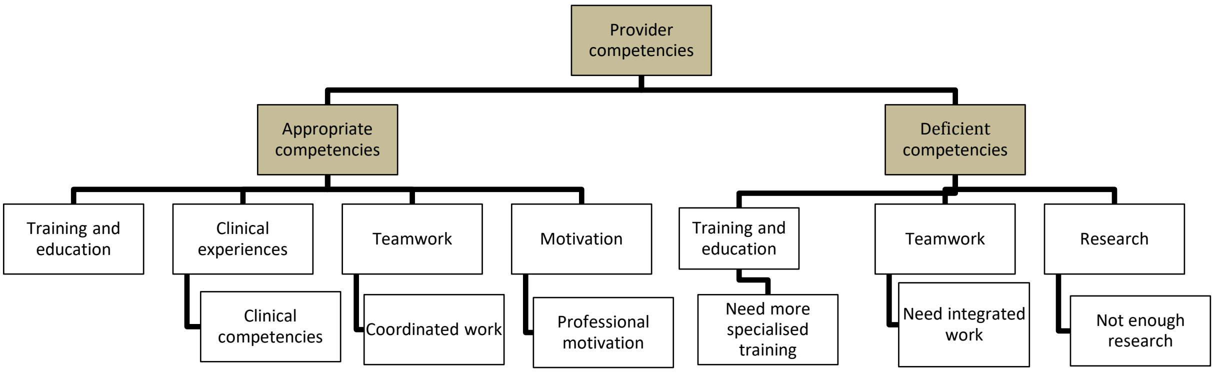


Figure 23. *Categories and Codes of Providers Competencies*

Appropriate Competencies. Five professionals noted that specialised training and education has helped build their competences when treating the MACA patient. Four also pointed to the importance of clinical competence and expertise when working with this kind of patient. Two professionals highlighted coordinated teamwork, stating that teams work in a coordinated manner as part of the culture shared within this healthcare area. And two expressed how these professionals are motivated and have special sensitivity to work with the PC patient.

Deficient competencies. All of the professionals noted that there is a need for more specialised training and education in PC that would improve their competencies. As one noted: *"We need systematised education for the PC providers from the Catalan health department".* Four of them said that a more integrated teamwork is needed - more integrated with other professionals, between different levels of care and among different areas. As one said: *"The health and social sector should share their work".* Lastly, two of them pointed to there not being enough research. As mentioned, although the providers have clinical competencies and receive training, they ask for more PC specific training that is systematised by the system. Although teams work collaboratively, they proposed the need to work more towards an integrative approach with all the professionals in all the system. More research seems to be needed here, as indicated.

4.1.3. Summary of Phase I findings

The Osona region is one with a medium-sized population in Catalonia, inhabited in both rural and urban areas, with a growing immigrant population. The region has 18% of its population aged 65 and older, with a larger group of women than men, many of whom are considered MACA patients. These MACA patients suffer from chronic conditions in two or more body systems, with a high and very high risk of admission to hospital, need for care and death, according to the GMA classification that measures such risks. The system is well equipped with a general hospital, eleven primary care clinics, two intermediate care units, one mental health centre and several nursing homes. It is in general also well equipped with health care professionals.

This region has an organisation called the SISO, which aims to coordinate health efforts in the area. There is, however, as mentioned, still some care fragmentation, mostly between social and health areas and between some other services, and sometimes caused by the after hours care service. The system implements patient-centred PC, following the different Catalan health plans, with the goal of offering services that are specialised, comprehensive, accessible and patient-centred. This MACA patient is well identified with a standard tool, the NECPAL, which is extensively used by professionals in primary care. However, as mentioned, there are some difficulties in the identification process, such as differences in usage of the tool, not identifying patients early enough, not identifying all PC patients in need of this service and not all care levels identifying these patients.

Regarding the standard of implementation, the 2011 Chronicity prevention and care programme set a strategic plan to follow-up with PC patients, developing specific strategies and services for the MACA patient. Professionals in this system are competent, specialised and trained in PC, and they work cooperatively and in a multidisciplinary manner as the Catalan health plans specify. However, there is also a need for more specialised professionals, to increase the ratio of professionals per patient and for continuous specialised PC training. The system has several platforms in which professionals share patient information and several patient documents, such as the patient’s medical history, the PIIC and PDA. It is clear that the OPCS works collaboratively and with a patient-centred goal. Nevertheless, it seems there are too many online platforms on which to share patients’ information, and although the multidisciplinary teams work collaboratively, it has been suggested that teams should try to work in an integrative manner with all care levels serving the patient. There are PC services, resources and policies, but there is a need for more specific PC policies and a larger number of services and more funding and resources to fully cover the patients' needs.

4.2. Phase II. Identification of the Integrative Elements for an IPCS, the OPCS and Ethical Dilemmas

The objective of the interviews was to first identify the integrative elements of an ideal IPCS, and then identify the integrative elements included in the Osona system, those that are missing and those needed. A further aim was to explore the ethical dilemmas encountered by providers in the OPCS. The main questions pursued were:

- What are the essential elements of an IPCS?
- What elements does the OPCS include, exclude and need as an IPCS?
- What ethical problems do professionals in the OPCS encounter?

Interviews were conducted with 24 professionals from various entities associated with the SISO organisation (see Table 26 for further details of the participants). The results found were organised by first comparing the views from the different professional roles, leaders versus service care professionals (doctors, nurses, and social workers); and then by comparing the views from their specific service area: health care versus social care.

	Participants (24)
Gender	
Female	20
Male	4
Study participants' professional role	
Leaders (5 doctors/2 nurses/1 social worker)	8
Doctors	4
Nurses	8
Social workers	4
Study participants' education and training	
Doctors	9
Nurses	10
Social workers	5

Table 26. *Participants Information*

4.2.1. Essential Elements for an IPCS

After performing a deductive analysis of the question “What are the essential elements of an IPCS?” and “In what order would you prioritise these elements?”, the main results were organised and presented in the order of prioritisation (see Figure 24), including the following elements:

1. Funding and resources
2. Multidisciplinary team
3. Continuity of care
4. Collaboration
5. Motivated health care professionals
6. Standard implementation model
7. Shared information system
8. Social Services
9. Patient centred
10. Education and training
11. Case management
12. Screening tool for identifying patients
13. Leadership and policies

Figure 24. *IPCS Elements Ordered by Priority*

PC specific **funding and resources** was the first prioritised element of an ideal IPCS. The respondents suggested a centralised single funding model and new model of payment. Some stated that there should be just one single funding model paid by the Health department that is shared by all entities: *“This is paid by primary care, this is paid by the hospital but the budget is shared at the end; it is the Health department, Catsalut, that pays for everything”.*

A reimbursement per service funding model was suggested by a few, in which reimbursement to care entities should be carried out according to the services they offer to patients. As mentioned, if all the centres have the same budget but some offer more services than others, this will create inequalities since the former have more expenses, but they are not reimbursed differently than the latter that have fewer expenses. Furthermore, others stated that there should be a specific budget for PC. The professionals listed the following aspects for which there should be funding:

- Equipment such as conditioned spaces with adequate lighting, equipment to perform analysis, X-rays, ECG machines, dopplers, pain infusion pumps.
- Professionals such as doctors, nurses, home health aides and physiotherapists.
- Services such as homecare and rehabilitation services, day centres, nursing homes and emergency services.

The second prioritised element was the professionals' organisation in **multidisciplinary teams.** These teams, the interviewees explained, would be constituted by different professionals including nurses, general practitioners, specialists such as geriatric doctors, physiotherapists, occupational therapists, psychologists, social workers, spiritual professionals and home health aides.

The need for uninterrupted continuity of PC. The third element in order of priority was continuity of care in the PC system through all levels of care. Uninterrupted 24/7 care for the PC patient was highlighted, with one interviewee saying: *"We need to serve the patient in a continuous manner, with a system that covers 24 hours, 7 days a week in all levels of care, including homecare".* PC service involving continuity in the different levels of primary care, home care and hospitals was pointed to: *"There should be a good coordination among doctors and nurses from primary care and homecare".*

Professionals' collaboration and motivated health care professionals were the fourth and fifth prioritised elements. The collaboration of professionals' was pointed to by many of those interviewed, who noted noting that professionals need to work in a coordinated manner and have good communication with each other. Also included in this category was having the same vision, with one stating: "*The teams and professionals that are caring for a patient, such as the doctor, the nurse, the social worker, need to work as a team and have the same vision, goals and work plan".* The need to have motivated health care professionals was also highlighted, especially for caring for this kind of patient in the PC area.

PC standard implementation model was in sixth place. A single PC implementation model was explained as having the same work plan, with standardised protocols in all levels of care. As one interviewee stated: *"All professionals should have the same care model with regard to identifying, assessing, diagnosing and performing interventions on the patient".* Single PC routes for the patient should be defined, with care circuits that will aid professionals with patient referrals and transitions to other services.

A single shared information system that used different information sharing modalities was also mentioned by respondents: "*A computer system that is shared and is intra-operable between entities",* as one put it. This system would be also shared by all health care participants and levels of care: *"The system should be accessible from all the entities that can activate and modify the information shared",* one of the respondents said. Multiple information sharing modalities would be included in the shared information system, such as videoconferences with other professionals, video-consults with patients, team meetings and shared chats among professionals and patients.

Inclusion of Social Services and Patient-Centred Care were eighth and ninth in priority. Social services was mentioned as they are indispensable for PC patients' care, since they are the ones responsible for providing them with services and resources otherwise not provided by the health care area. Patient-centred care must be ensured, since it is necessary to always respect patients' preferences, opinions and needs, especially those of patients in PC, some of whom will be confronting end-of-life processes and decision-making.

The Education and Training of PC professionals' and Case Management were the next two mentioned. The respondents highlighted that professionals should receive similar, homogenous standardised training and education: *"If they have the same training they will all have the same knowledge when treating a patient",* said one respondent. PC Case management was eleventh in priority. As the respondents suggested, case managers would be in charge of following the patient through the disease and through the care service transitions.

The penultimate element mentioned was having a PC **shared screening tool.** This tool will allow patient identification and the labeling process. The respondents said that this tool should be a tool shared by all professionals in the system. The final element mentioned was having supportive PC policies. The professionals suggested that there should be regional policies and specific PC leadership that would evaluate and monitor good practices in the system.

There were other elements mentioned as being important to an ideal IPCS that are not included in the list of prioritised elements, and while they may be less important, they are probably needed. These other are explained below and shown in Figure 25.

Figure 25. *Additional Essential Elements IPCS*

A new specialised PC Integrated Support Team. This would be specialised in PC patients, and some of the participants compared it to the *"PADES"* teams that are currently in the system. The respondents described these teams as multidisciplinary, with doctors, nurses and social workers and formed by professionals from different levels of care. A second element was **specialised PC cost-efficiency**, with some interviewees saying that having specialised PC care and specialised PC home care could probably reduce costs to the system. Specialised PC care is seen as a factor that would reduce hospital admissions and therefore costs: "*The PC patient usually goes through a lot of admissions and readmissions, because they require and high amount of care level, I think with a specialised care the cost will decrease",* said one respondent.

Three more elements were mentioned. First, **PC patient early detection and intervention,** which respondents thought should be accomplished by an active PC patient search within the population, and that such early intervention would also avoid future patient complications. Second, **professional community involvement** was pointed to by a few of the respondents, who stated that health care professionals should move to the community and visit patients at their homes or wherever they reside, instead of having the patients come to the clinic. Finally, **empowering the patient** by providing them with information about their health so that they can make informed decisions about their wellbeing, was also suggested. As one stated: *"It is a basic right that they know everything about their condition".*

In summary**,** for the prioritised elements for an ideal IPCS, the three most important referred to funding and resources, a multidisciplinary team and continuity of care. Having services, equipment and professionals were the elements most essential for an IPCS. A multidisciplinary, sometimes also called interdisciplinary, team that works together was the second most important element. Continuity of care, provided 24/7, was next on the list. The need for easy access between services in different levels of care and optimal communication between different health care entities and professionals was also specified. Collaboration was the fourth most stated element, which was described as coordination, communication and united work.

A standard implementation model was also highlighted by all professionals. This care model should have a well-defined patient route or circuit and should be a single model that is followed by all professionals. A shared information system was the seventh most frequently specified element. The respondents emphasised the need for a single united information system that would allow all professionals to read and share information about patients. The eighth element to consider was social services, since they provide the PC patient with services and resources not provided by health care. At a lower level of priority were patient-centred care, education and training, case management, a standard screening tool and leadership and policies specific to PC.

There were also five elements mentioned for an ideal IPCS, but that were not included in the priority list: a new integrated PC team, specialised PC cost-efficiency, early PC patient identification, providers involvement in the community and empowering patients. These elements, while suggested by the respondents, were not considered a priority and can thus be considered additional secondary elements needed.

4.2.2. Included, Excluded and Needed Integrative Elements in the OPCS

In order to find out the elements that the OPCS includes, excludes and needs as an integrative system, the following question was posed to service level participants: “What elements does this system include, exclude and need as an integrated palliative care system?”. The results are presented by first describing the included and excluded elements (see Table 27), and then by indicating the OPCS elements needed in the context of Osona.

4.2.2.1. Included and Excluded Elements in the OPCS. There are 15 elements mentioned by respondents as included integrative elements, 12 of which were also mentioned in the list of excluded elements since these needed some changes or improvements (see Table 27 for a list of included and excluded elements).

OPCS OPCS SERVICE CARE LEVEL VIEW	
Included Elements	**Excluded Elements or Elements to Improve**
PC standard screening tool	Screening tool difficulties
Shared information system	Better shared information system
Resources, professionals and services	Missing PC funding and resources
Professionals’ collaboration	Need to improve collaboration
Early PC patient detection and intervention	Problems in the process of early PC patient identification and intervention
Continuity of care in the PC system	Problems with continuity of care
Supportive policies and leadership	PC specific policies
PC case management	Need more PC case management
Patient-centred care	Need more patient-centred care
PC specialised intermediate care	
Motivated PC professionals	
Inclusive multidisciplinary team	
Education and training	Need standardised education and training
PC implementation model	PC standard implementation model difficulties
Specialised PC for cost-efficiency	PC volunteer network

Table 27. *List of Included and Excluded Elements in the OPCS*

The most frequently mentioned element included in the OPCS was having a **shared screening tool** to identify PC patients. Most of them referred to NECPAL as the tool used to identify PC patients, which labels PC patients with chronic disease as MACA in the Osona system. Some difficulties with the screening tool were mentioned. Many stated that only the primary care level can label patients, and they suggested that all levels of care should be able to label PC patients. Others expressed some hesitation in identifying and labelling a patient as a PC patient since they feel they are leaving the patient out, or fear they might not get the services they need if they go to other health centres: For example, one said: “*Labelling is not an easy process; some feel uncertainty because maybe labelling a patient feels like you are letting them die*”.

A shared Information system was the second most frequently mentioned included element. The respondents explained that the OPCS has multiple information sharing systems, such as internet platforms and multiple communication modalities, to share information. The professionals usually share various documents about the patients, such as their medical history, the PIIC (individualised care plan) and PDA (the advanced care directive). There were some difficulties involved as some explained that there are different computer platforms that are not interoperable. It was also noted that not all professionals have access to the same platforms, and nor can all the professionals provide and write input in all the platforms. As one stated: “*The information processing systems sometimes do not speak to each other, so there* *might be problems in transferring information written in one platform to another one".* Others mentioned the need to incorporate multiple information modalities so as to be able to share information through different channels, such as chats, case conferences, video-consults and video-meetings.

Qualified **professionals and services** were mentioned as an important third element included. While these elements were mentioned as included in the system, the need for specific PC funding that could be used to increase services, professionals and resources for PC patients was also mentioned. Some stated the need for a new model of funding that would distribute funds per patient served. Others mentioned that more services should be incorporated, such as more home care services (nutrition, cleaning and hygiene services), nursing homes, more intermediate and acute hospital beds, day centres and supportive homecare teams. Furthermore, they noted the need for more specialised professionals such as psychologists, physiotherapists, occupational therapists, doctors, nurses, home health aides, case managers and spiritual counselors. Lack of resources, such as certain equipment was also mentioned.

PC professional collaboration was noted by many of the professionals, stating that professionals from different levels of care have good coordination and communication processes. On the other hand, other professionals stated that coordination and communication needed improvement. Some talked about insufficient trust: "*There is some lack of trust among some professionals".* Many expressed the need for better coordination between social and health services, with one saying: *"The patient sometimes needs to go through too many loops, we tell them now to get this service you need to go to the doctor to get this document, then bring it back… we should try to facilitate these processes for the patient, together with the health and social system".*

The fifth element mentioned as included was effective **early identification and intervention**. The professionals stated that this kind of patient is identified usually at the primary care level. Nevertheless, some of the professional indicated that there is an infra-identification of the PC patient, which leads to a late intervention. This becomes a problem, as one professional explained: "*We need more proactivity in this process because sometimes the PC patient is labelled when they might live for just 15 days, and there is not much you can do then".*

In the OPCS, professionals state that **continuity of care** is mostly between primary care and intermediate care. This is seen in easy transfer of patients between services, in needed emergency admissions and in the entities and services communication processes. However, care fragmentation was mentioned by many in the other services, especially between social and health services. Additionally, care fragmentation is said to be caused by not having an effective 24/7 after hours service, which is currently covered by the general emergency phone number, and this situation sometimes leads to PC patients ending up in the emergency room of an acute care hospital.

Supportive leadership and policies was the seventh most frequently mentioned element. Professionals stated that the region has experts and known leaders in the area of PC that are exemplars for the community and professionals. These exemplary leaders are involved in PC research that brings innovative PC projects to the region. On the other hand, some mentioned the importance of the "Dependency law" derived from social service policies, which ensures that PC patients obtain social services and care at home. Yet the need for specific PC policies was emphasised by the professionals. A few also stated the need for policies that would unite the social and health services.

The respondents mentioned the existence of **case managers** in the system, and some explained that some nurses are also case managers and are in charge of helping in urgent admissions into hospitals or coordination with social work. As one explained: "*The nurse case manager meets with social services for complex cases, organises their cases and then does the needed referrals".* They stated that there should be more case managers in the system who are professionals that know the patient well in their care team, and who is the focal point for other professionals and services.

Patient-centred care was the ninth element included in the system. Nonetheless, the respondents said that professionals need to find out about patients' preferences, individual needs and wishes, because although, as one expressed, "It is easier for the professional to take decisions, they should listen to the patient wishes". **Education and training** was another important included element. However, most professionals said that there is a need for specialised PC education and training that is homogeneous for all professionals. A few of the respondents stated that there is a route a protocol that *"*facilitates*"* preparation of the intervention plan. Nevertheless, some expressed that sometimes there is not a standard implementation model, but rather different care interventions from the various levels of care, "Some being more aggressive when they should have been more conservative". Some suggested that there should be a route, a protocol that guides the goals and care plan for all care levels.

The OPCS providers also mentioned the following elements as included but they were not mentioned as excluded elements, or needing improvement. Many of the professionals explained the importance of having an **intermediate care** hospital specialised in PC patients, which is the hospital of St. Creu in Vic. As one put it: *"Here in this region, this care is really centralised in the St. Creu hospital, specialised in geriatrics and the MACA patient".* Some of the participants stated that the OPCS **professionals are motivated**, committed, mindful, sensible, dedicated and with an excellent attitude towards working with the PC patient. **Leadership** in the region was highlighted as their research and new programmes bring innovations in PC. **Inclusive multidisciplinary teams** that work together were also mentioned as being included. Some of the professionals said that providing PC patients with specialised care might be **cost-efficient to the system** since it avoids some unnecessary admissions and unnecessary treatments.

The creation of **a volunteer network** was mentioned only in the excluded elements, as they stated that a volunteer network would be helpful, for example one including members of the patients' community as support for the patient: "This patient needs to have more social relations, a good volunteer network would help the patient to go to the neighbourhood activities, receive visits".

To summarise, the integrative elements that the professionals say are included in the OPCS are: PC specialised intermediate care, motivated PC professionals, leadership, inclusive multidisciplinary teams and specialised PC for cost-efficiency. They also mentioned the following elements as included but needing some changes: a PC standard screening tool, a shared information system, resources, professionals and services, professional collaboration, early PC patient detection and intervention, Continuity of care in the PC system, supportive policies, PC case management, patient-centred care, education and training, PC implementation model. Only one element was mentioned in the excluded elements: the need for a PC volunteer network.

4.2.2.2. Included and Excluded Elements Related to the Different Professional Groups. Leaders and service level health care professionals mentioned the following integrated elements as being included (see Figure 26) and excluded (see Figure 27). The numbers in the x-axis refer to how many times the elements were mentioned. The most repeated elements by both leaders and other health care workers were: first standard screening tool, second shared information system, and third professionals' collaboration. Leaders also highlighted having early patient detection and supportive policies and leadership, while the rest of the health care workers emphasised having resources, professionals and services, continuity of care, and case management.

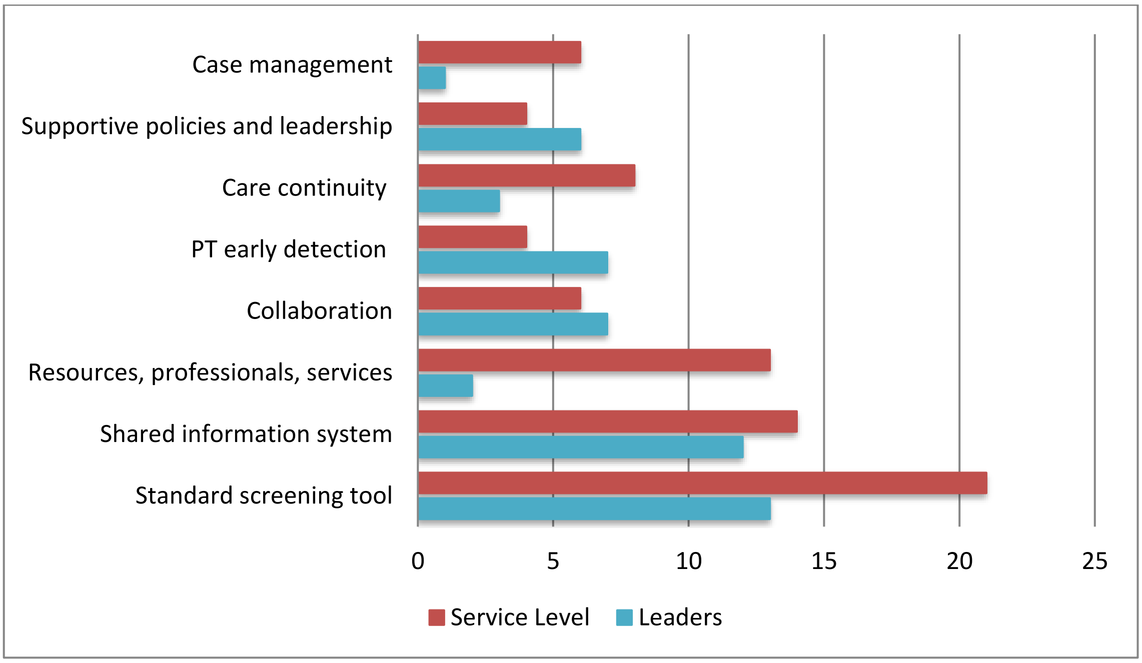


Figure 26. *Included Elements by Care Level*

As to those integrated elements that were excluded or in need of improvement, both the leaders and other professionals agreed on the following: continuity of care in the PC System, fragmentation, missing specific PC funding, professionals and resources, shared single information systems, need to improve collaboration among professionals, and some screening tool difficulties. For the leaders, the next most mentioned excluded element was specific PC policies, while for the other health care workers it was the need for PC standardised education/training and a standard implementation model. They also mentioned the need for a PC volunteer network, which the leaders did not comment on (see Figure 27).

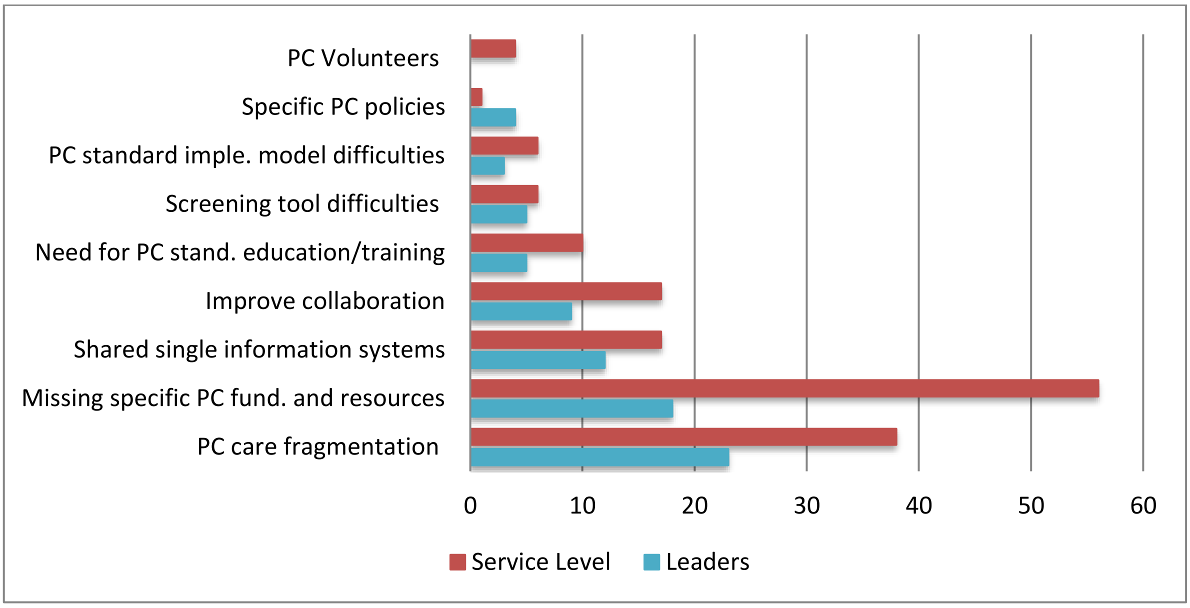


Figure 27. *Excluded Elements by Care Level*

Health care professionals and social workers both mentioned the following elements as being included in the OPCS: standard screening tool, shared information system, resources, professionals and services, and professionals' collaboration. Health care workers also frequently mentioned early detection and continuity of care. Social workers, on the other hand, frequently mentioned supportive policies and leadership (see Figure 28. Again, the x-axis *refers to* how many times the elements were mentioned).

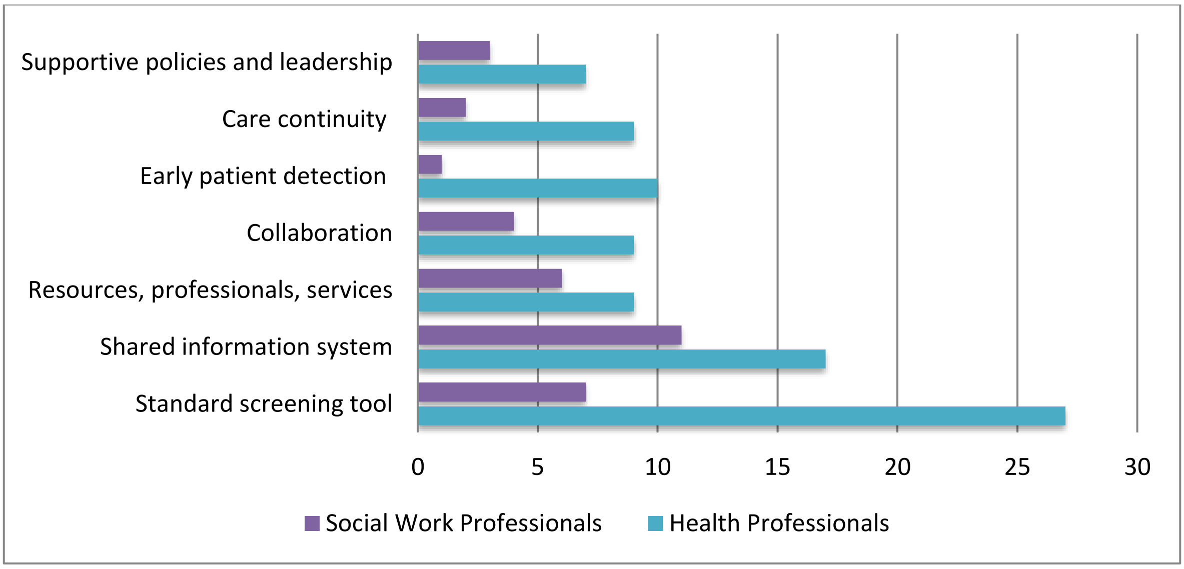


Figure 28. *Included Elements by Service Area*

Health care and social work professionals also agreed on most of the elements excluded by the OPCS, namely: continuity of care, missing pc specific funding and resources shared single information system, need for more collaboration among professionals and training and education, screening tools and standard implementation difficulties. However, health care professionals added problems with early identification and case management, while these were not noted by social workers (see Figure 29).

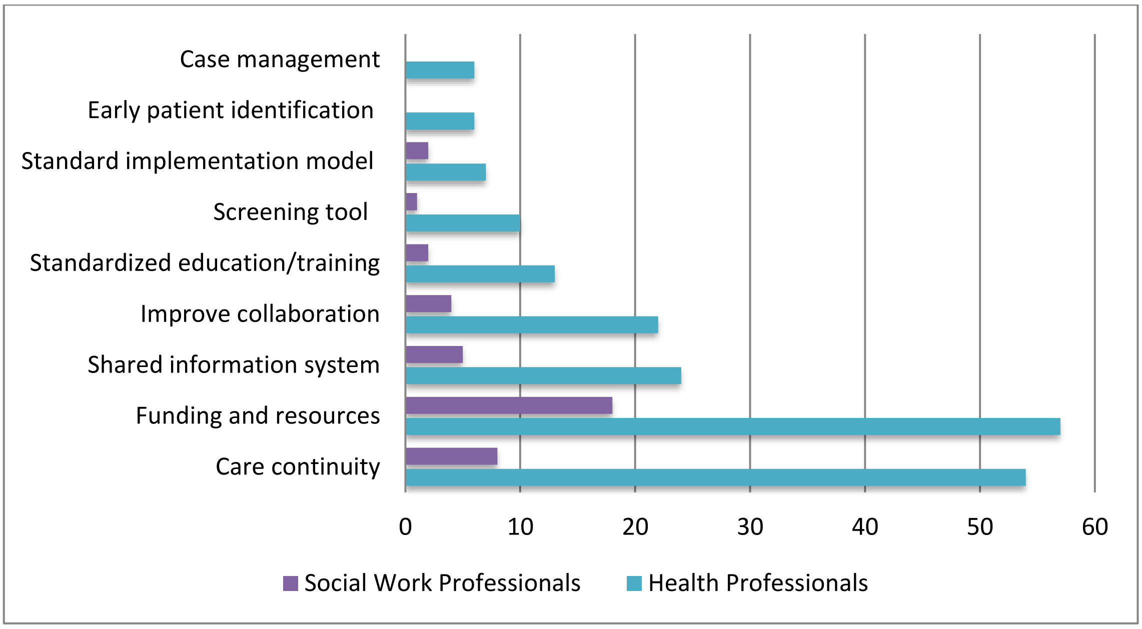


Figure 29. *Excluded Elements by Service Area*

In summary, leaders and healthcare workers agreed on most of the included elements in the OPCS, but leaders emphasised early patient identification and supportive policies, while healthcare workers also mentioned having resources and services, continuity of care and case management. Regarding the excluded elements or those needing improvement, both the leaders and health care workers agreed on most of the elements excluded by the OPCS, but the leaders also included the need for PC specific policies, while the other health care workers mentioned the need for education/training, a standard implementation model and a PC volunteer network, which leaders did not mention.

Similarly, health and social work professionals agreed on most of the included elements, although health care workers emphasised having early patient detection and continuity of care, while social workers indicated supportive policies and leadership. As to the excluded elements or those needing improvement, health and social workers also agreed on most, but health care workers also emphasised difficulties with early identification and case management, which were not mentioned by the social workers.

4.2.2.3. Element Needed in the OPCS due to its Context. The interviewees were asked to specify which integrative elements the OPCS needed due to its context (population, geography, culture) that other regions with other contexts would not need or would need others due to their context. The elements mentioned are explained below (see Figure 30):

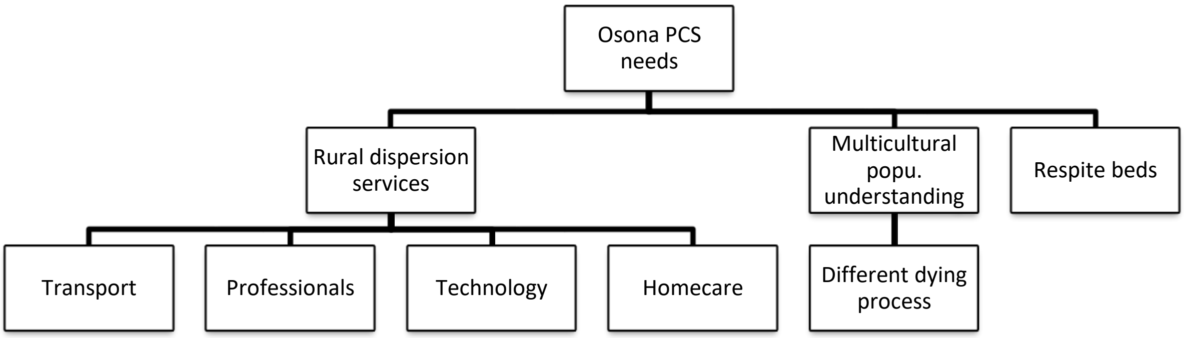


Figure 30. *OPCS Elements Needed due to Context*

Sixteen of the professionals said that patient **rural dispersion** was an aspect to be considered. Rural area patients living far away from urban centres might have less care services available than they need. Likewise, professionals have less accessibility to patients, as one of them indicated: *"Many of the Osona patients don't live in the city but live in rural areas, some living very isolated and having problems to access services".* They proposed different strategies to confront this situation. First, they suggested improving and increasing transportation to services and patients. As one said: *"Mobilising patients is complicated, there are not enough adapted transport services, no ambulances, and using taxis is very expensive".* Another remarked that *"Sometimes a patient would benefit from going to a day centre for older people, but there is no way possible to take them there".* Yet another explained that *"Going to some of these rural areas requires a lot of time, and adds extra car use and petrol expense to your work day"*, and one more indicated that "*Maybe due to dispersion we should have some equipped cars to go to these areas". The* second strategy proposed was to *increase* the number of professionals for homecare that work in these distant rural areas since "*Dispersion requires more professionals to respond*". And as another explained: *"You can visit many patients in a day if working in Vic, but if you go to a rural area you can't do so many visits in the same time".* A third proposal was for technology to be used to contact patients living in distant rural areas: telemedicine, chat communication and phone systems were proposed to improve communication between professionals and patients. Finally, better homecare was also mentioned as a solution for rural patients.

Having a **multicultural population** was the second most frequently mentioned element by the professionals. They pointed out that *"Now here, 25% of the population is from a foreign country, and there are significant differences with our culture".* Cultures can be very different and they can interfere with the healthcare interventions suitable for these multicultural patients: "You can tell an African hypertensive patient to change their diet to a more Mediterranean diet, but they have diets that include many spices and curries. How are they supposed to change what they are used to eat for a diet they don't know?".

They further explained that there are many people coming from Africa and India with different cultures and religions and with a different understanding of the dying process. As one of them said: *"We try to make them fit within our framework but a Moroccan probably has another perception of the dying process, and even different than a person from Ghana. We should be able to respect their cultures".* A female professional indicated that there is a need to learn more about these cultures: *"I went to a patient's wake and I sat in the main room. After a while I realised there were just men in the room, so I stood up and went to find out where the women were meeting. I am not sure if I was disrespecting their culture by sitting with the men".*

Respite beds was the third element mentioned. These are needed for family members caring for PC patients when they are ill or when they need a break after caring for the patient for a long time. As one remarked: *"We need beds for the care givers. In Barcelona they have centres with these kind of beds, but we don't have them here now".* Another added: "If *the caregiver gets sick and is admitted to the hospital, what do you do with the person the caregiver is taking care of?".*

4.2.3. Ethical Dilemmas Encountered by the Professionals in this Study

In order to find out what ethical dilemmas are common in the OPCS, health care professionals were asked the following question: "What ethical problems do the professionals in the OPCS encounter?". The respondents mentioned nine ethical problems, which are shown and explained below in order of how frequently they were mentioned (see Figure 31).

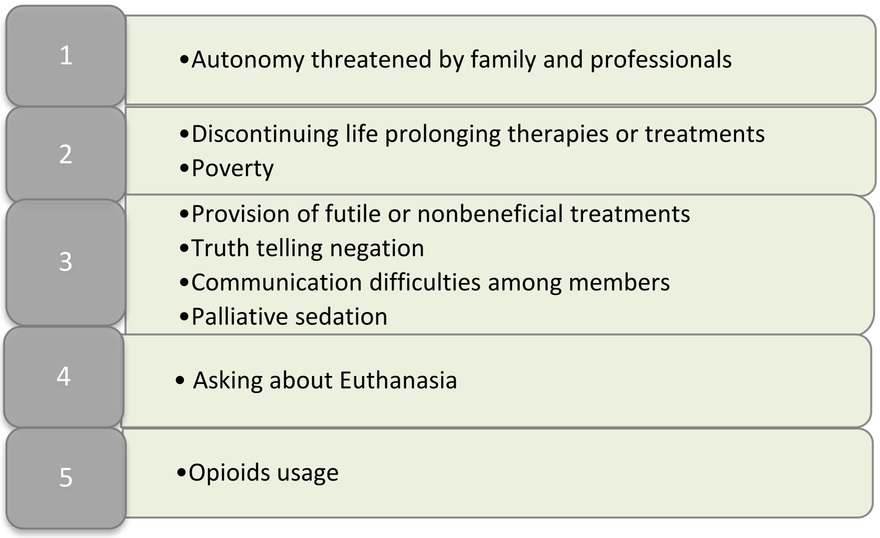


Figure 31. *Ethical Dilemmas Encountered by OPCS Providers*

Threats to the patients' autonomy was mentioned by fourteen of the twenty-four respondents, and it was caused by either family members or professionals. Autonomy threatened by family decisions was identified in cases in which the patient and family had different opinions about treatment, place of care or other differences, but the family made the final decision. The study professionals viewed this as an ethical problem: "*You end up doing what the family wants although the patient stated it should be the other way*". Another remarked that "*Ethically it is wrong not to do what the patient wants*".

Autonomy threatened by professionals' decisions was described in situations when a professional from a health and safety perspective suggests a care plan, but the patient disagrees with the care suggestions. In these cases, some recommended really listening to patients' preferences: *"If a patient with a biliary condition shouldn't eat some type of food because it will make them sicker, but they are a PC patient, you have to consider if you should really worry about that"*. Others suggested that in certain situations in which safety is at risk, the professional's decision should prevail: *"Sometimes you need to process a patients' inability to live alone at home, although they don't want to move out, they have to move to a care centre for their safety"*.

Discontinuing life prolonging therapies was the second dilemma most mentioned. The respondents expressed uncertainty about when to discontinue certain treatments and therapies, especially when they are no longer beneficial to the patient, such as continuing certain medications: *"How do you decide when a patient should stop taking his blood pressure medication?".*

They also expressed doubts as to when to stop medical treatment for diseases, infections or nutrition provision, if none of those treatments would change the patients' overall prognosis. As one doctor put it: *"It is an ethical dilemma when you are treating respiratory and urinary infections in patients that are totally bed bound with very advanced dementia. You have already treated these infections for symptom management, but until when should you be treating them when you see that the patient is not improving and is at the end of life?".*

Poverty was mentioned mainly as the cause of unsanitary leaving condition*s* where the patient lives: *"Sometimes you find that the socioeconomic aspect is the problem, a patient in a situation where the home hygiene is bad. You see the home dirty, black walls, pet hair all over the bed, and you think oh my!".* Lack of resources and services was also mentioned by the professionals because of their inability to provide patients with the resources and services needed: *"The patient might need to put bars on the bed or the bath, but they might not have the financial means and the system cannot provide that assistance, so you try to help them finding cheaper solutions".* Another stated: "You *would like to give them the services they need, but sometimes you can't find any resources in the system to help them, and as a professional it is really frustrating".*

Provision of futile or nonbeneficial treatment was another ethical concern of professionals. This is related to not providing certain tests, surgeries and medical therapies that wouldn't change the patients' prognosis or health. Sometimes this care is provided because the family or patient request it due to cultural, personal or psychological reasons.

Withholding or not telling the truth is a problem and is sometimes done by family members in order to protect the patient from knowing their diagnosis. This practice is still present in our culture and as one provider put it: "*It is changing but the family's opinion still carries weight".* Other professionals questioned how the diagnosis communication is done: "Why *do we need to tell the family first? Shouldn't we tell the patient first?".*

Communication difficulties between the patient, family and professionals were also mentioned, since they are present as a consequence of misunderstanding. As stated by the professionals, sometimes there are communication problems between the patient and family, while other difficulties are between different relatives and/or among professionals in different health services: *"Maybe you have agreed with a family on an intervention plan for a terminal* *patient and suddenly a son that has not been involved shows up, and he disagrees with the plan wanting to do things differently. What do you do then?".*

The palliative sedation process was another ethical concern, not regarding the rightness or wrongness of palliative sedation but rather the rightness or wrongness of the timing. Specifically, the respondents worried that the palliative sedation had been started too late, so the patient suffered more than they needed to. For example, as one of them said: "*In some cases you need to decide to start palliative sedation and I have my doubts, is it the right moment? Should I have done it earlier?".* Some professionals felt limited by the demands of the protocol: *"There are some cases in which the patient suffers through the dying process for too long. Maybe a shorter time would be best, but we still depend on the stipulated medication doses".*

Some of the interviewees explained that some patients enquire about the possibility of **euthanasia,** while sometimes the professionals discuss this possibility. The latter occurs when palliative sedation does not seem to relieve the patients' agony and they wonder about the prospect of euthanasia being legalised. As one provider stated: *"Euthanasia is a big step that still needs to be organised and legalised".*

Opioids usage was identified as an ethical concern because their use was not well understood by families. As one providers stated: "*Sometimes the family doesn't understand why you give the patient morphine since they know it might accelerate their death and you need to explain that it is to relieve the pain".* Another ethical challenge was for nurses to have to wait for orders from a doctor when the patient was in severe pain: "*You might visit a patient at home in pain and agony and maybe you as a nurse can't start the pain medication immediately, and they need to wait to get relief until you talk to the doctor and get the order".*

To sum up, the ethical dilemmas encountered by professionals, from most to least frequently mentioned, are: autonomy threatened by decisions made by others; discontinuation of life prolonging therapies; poverty; provision of futile or nonbeneficial treatments and therapies; withholding or not telling the truth; communication difficulties among the patient, family and staff involved; the palliative sedation process; asking about euthanasia; and opioid usage. Poverty was a new dilemma mentioned by the respondents that was not included in the list of dilemmas most mentioned in the literature.

4.2.3.1. Ethical Dilemmas Related to the Different Professional Groups. When comparing leaders and service level health care professionals, we found that the ethical problem most frequently mentioned by the latter was the threat to the patient's autonomy as a result of family intervention (see Figure 32. This is likely explained by the fact that these professionals work directly with families. In contrast, leaders identified the most common problem as the provision of futile or nonbeneficial treatments. This makes sense because of the institutional implications for the continuation or withdrawal of these treatments. It is also interesting to note that leaders did not mention the ethical problems of poverty or the family not telling the truth, probably due to their more managerial duties and having less direct contact with the patient. It is interesting to see that for both euthanasia was the third dilemma most frequently encountered.

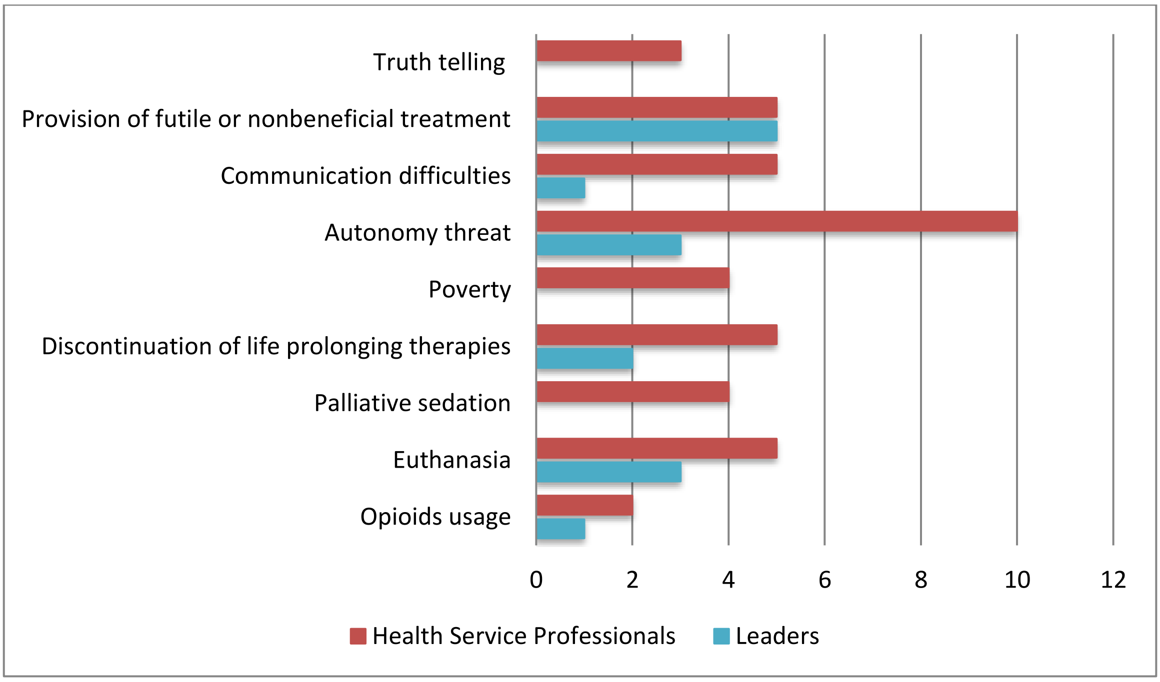


Figure 32. *Ethical Dilemmas by Care Level*

Health care professionals and social workers. As shown in Figure 33, both health care professionals and social workers agree that the threat to patient autonomy by families and professionals is the most important ethical dilemma. They disagreed, however, with regards to the next most common ethical dilemmas. For health care professionals these were: euthanasia, discontinuation of life prolonging therapies, communication difficulties and provision of futile treatment - ethical dilemmas more related to the medical profession. For social workers, on the other hand, they were truth telling and poverty. Health care workers are responsible for symptom management and therefore their concerns reflect these responsibilities. In contrast, social workers more commonly deal with social issues affecting the patient, including poverty. It is unclear, however, why truth telling was so important to them.

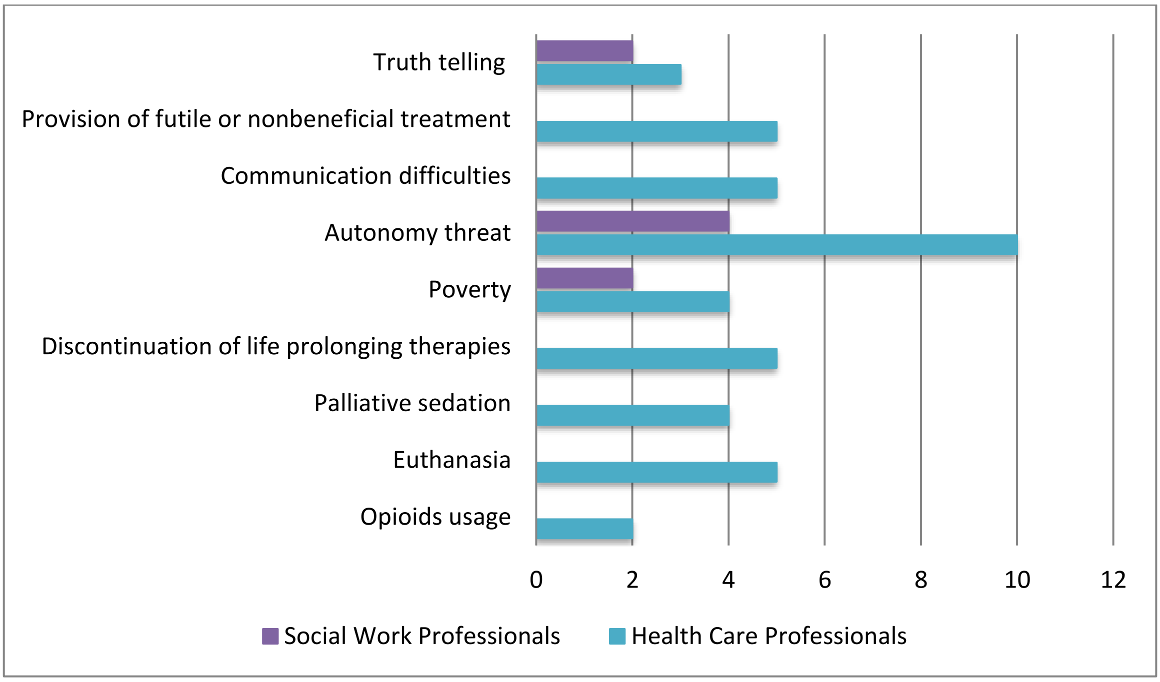


Figure 33. *Ethical Dilemmas By Service Area*

4.2.4. COVID-19 Pandemic Update

As explained in the methodology chapter, the respondents were sent a questionnaire with a few questions related to COVID and the integrative elements. They were presented with a list of the essential elements for an IPCS, developed from the results of the interviews. They were asked to prioritise these elements with the five most essential elements that an IPCS should have, this time considering the consequences of the COVID pandemic on the system and PC patients. The first seven elements prioritised were as follows (see figure 34):

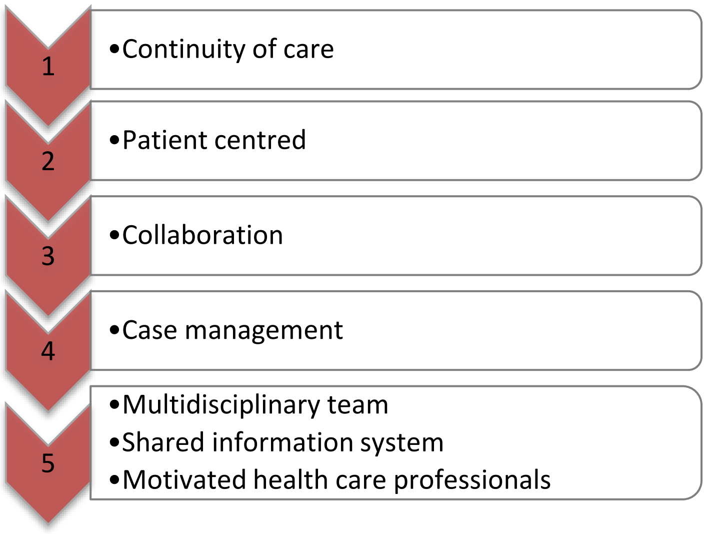


Figure 34. *IPCS Elements Ordered by Priority after COVID*

Continuity of care was the first element, with professionals stating that there should be 24/7 service care available for patient and families, afterhours care in which a professional follows up and monitors patients and can aid the patient when needed. As one of them stated: *"If the pandemic came back, we should be able to ensure a 24 hour service at home, and consequently day care should be able to give the patient's report to the afterhours team in charge of monitoring the patient".* Respondents also explained that the patient is the starting point, and **patient-centred care** needs to be ensured, since it is a fundamental right. As some stated, quality PC should be offered to the patient and their family when they need it, always responding to their needs and wishes indistinctly of which professionals intervene.

Collaboration was the third element, with professionals stating that cooperation and trust among professionals were essential. They highlighted the need for collaborative professionals that are all informed about the patient's changes, through shared information, and for coordinated work where the professionals follow the same vision and apply the same interventions.

The need to c**ollaborate with social services** was also mentioned, in order to be able to provide PC patients with, for example, homecare services that are offered by social workers. This was a vital need during the pandemic since many patients were isolated at home. **Case management** was the fourth element**,** described as the health professional who has a global vision of the patient and who follows and monitors the patient, thus ensuring continuity of care. As one professional explained, this is essential, especially in situations like the pandemic where all health services were overwhelmed. This professional is able to ensure that all patients receive care, no matter how far they lived form the big cities. One suggested that case managers should be primary care nurses, since they know the patient well.

Finally, three elements were mentioned in in fifth position: a **shared information system, multidisciplinary teams** and **motivated health professionals.** The first unifies the information sharing process and therefore simplifies monitoring patients. This is especially essential in times of crisis. As one explained: *"A real time shared information system is crucial. In this crisis we have seen the problems of not having a patient's single medical history shared. For example we have a system where we share information about the patient but as is it is deficient"*. Having multidisciplinary teams that work around patients' needs and motivated professionals that care for these PC patients and their families were also mentioned. With regards to the latter, one stated: *"If we don't have motivated professionals we won't be able to solve any situation, whether it is related to COVID or any other situation that the patient is going through during the pandemic".*

Five further elements were mentioned, some of which were not on the main list of essential elements as seen in figure 34. The need to c**ollaborate with social services** was mentioned, as well as the need to respond to **patients' dispersion,** so that rural PC patients would have the same services available as the other patients. As one stated: *"In our clinic, during the pandemic, we had to resolve problems without any support at all, because we were too far away. But distance shouldn't be a barrier to access a service if it is needed by a patient".* Another one was having more **homecare services** so patients could be cared for while they were in lockdown at home. Finally, the importance of having the **resources and funding** and also **training** in order to be ready to confront a possible new wave of this COVID pandemic.

Some of the professionals mentioned some moral concerns related to **decision-making** when caring for PC patients during the pandemic. They said it has been problematic for the health care system deciding whether a PC patient with COVID was admitted or not to the ICU, whether they got invasive techniques due to their ageing and disease process at the peak of the curve during the pandemic. However, as one of the interviewees said: "This decision-making was usually assessed with the support of an ethics committees". Another participant mentioned a situation related to the **threat of patient autonomy**, where patients needed to go to the hospital because of their disease but families afraid of the virus do not want the patient to be admitted. As one stated: *"What do you do? Do you get them admitted to hospital or not if the patient's family doesn't want them to go".*

Another moral concern was **patient isolation,** highlighted by four respondents. They explained how after the start of the lockdown, many of the PC patients stopped receiving regular care at home or were not able to go to their day care centres or clinics. One explained how these vulnerable patients have become even more fragile. Others explained how sometimes these patients, if hospitalised, died alone without their families since the protocol did not allow it. As one said: *"Patients dying without their families close to them, a terrible experience".*

Distant care and **patient-centred care** were described as concerns by five of the nine respondents. They said they did not know if they were providing the care needed while doing it remotely. As one put it: *"It was such a different way to what we are all used to. They cannot come inside the clinic and so you visit them from inside their car to ensure safety"***.** Another explained how protective equipment created physical distance from the patient: *"Masks, gloves, gowns totally created a barrier".* This is especially difficult for PC patients, as another pointed out: "*There was so much care pressure that you didn't want to miss anybody's needs, especially those of PC patients that are so fragile".*

Professionals' fear was also noted by two of the participants. They said there was some fear to get the disease versus their duty as health care providers. Finally, **lack of resources needed and unpreparedness** were also mentioned. Respondents explained there was a need for protective equipment to visit patients and lack of testing. As one said: "*At some point, you assumed the patient was dying from COVID since you didn't have a test to confirm it".*

4.2.5 Summary of Phase II Findings

In summary, the interviews provided responses to the following research questions. First, **the ideal elements for an IPCS** were, in order of priority: funding and resources, multidisciplinary teams, continuity of care, collaboration, motivated health care professionals, a standard implementation model, a shared information system, social services, patient-centred care, education and training, case management, a screening tool to identify patients and policies and leadership. There were five new elements mentioned: the creation of a new specialized integrated PC team, PC cost-efficiency, early patient detection, the involvement of professionals in the community and patient empowerment.

Second, **the integrated and excluded elements, or those needing improvement, in the OPCS** that were mentioned were: a PC standard screening tool, which, as suggested should be improved by including all providers usage and training. A shared information system, which, as suggested, should be centralised into one platform and inter-operability for all improved.

Resources, professionals and services all need to be increased for PC, as does professional collaboration among the providers. It was also stated that an increase in early PC patient detection was needed, and continuity of care in the PC system needs improving between some services and areas such as the health and social area. More supportive policies and their implementation, PC case management, education and training, PC implementation model and patient-centred care were also mentioned. Having good leadership, PC specialised intermediate care, motivated PC professionals, inclusive multidisciplinary teams and specialised PC for cost-efficiency were all mentioned as elements that the system has and that work efficiently.

Third, with regards to differences and similarities within the professional groups, both the leaders and healthcare workers agreed on most of the included elements, but the leaders emphasised early patient identification and supportive policies, while healthcare workers also highlighted having resources such as professionals and services, continuity of care and case management. Similarly, health and social professionals agreed on most of the elements, although health care workers emphasised early detection, patient-centred care and continuity of care, while social workers highlighted supportive policies and leadership. Regarding the excluded elements, the leaders and health care workers agreed on most of the elements, but the leaders included PC specific policies, while the other health care workers mentioned the need for a standard implementation model. Finally, health and social professionals agreed on the excluded elements, but health care workers emphasised difficulties with the screening tool and early patient identification process and case management, while social workers didn’t indicate them.

Fourth, **the elements needed by the OPCS due to its specific context** were as follows: PC services that take care of the rural dispersion, an understanding of the multicultural population, and respite beds for PC families. **Fifth** the **ethical dilemmas encountered by the professionals** were: autonomy threatened by other people’s decisions, discontinuation of life prolonging therapies, poverty, provision of futile or non-beneficial treatments, unwillingness to tell the truth, communication difficulties among the members involved, palliative sedation, discussing euthanasia and opioids usage. Poverty was a new dilemma mentioned by the respondents that was not included in the list of dilemmas most mentioned in the literature.

The elements prioritised by respondents with regard to COVID 19 were continuity of care that would ensure after hours care and continuity, and then patient-centred care, collaboration and case management to better monitor PC patients at home and in rural areas during times of crisis. Finally, a motivated team of professionals that work at a multidisciplinary level and share information, collaborating with social services, offering home care services and more training resources and funding would be essential to ensure effective care during a possible new pandemic.

CHAPTER 5

DISCUSSION

5. DISCUSSION

The research results explained in Chapter 4 helped to find a description of the OPCS, identify the essential elements of an IPCS and pinpoint the ethical dilemmas encountered by PC professionals. This chapter will interpret the results obtained regarding the essential elements of an IPCS, the OPCS description, the ethical dilemmas discovered and an update on the impact of COVID on the system and the PC patient. It will then discuss the implications of these research results for future practice and research.

5.1. How is the Palliative Care System Serving the Chronically Ill and Palliative Patients in the Osona Region of Catalonia, Spain?

In order to respond to this question, the results obtained from the questionnaires completed by the system managers and the documents reviewed about the OPCS were compared with the IPC essential elements proposed by the scoping review carried out by Mondejar-Pont et al. (2019). This comparison aimed to find the integrative elements that the OPCS includes at a more structural level, and to assess how these elements facilitate or hinder the system's integration (see Figure. 35):

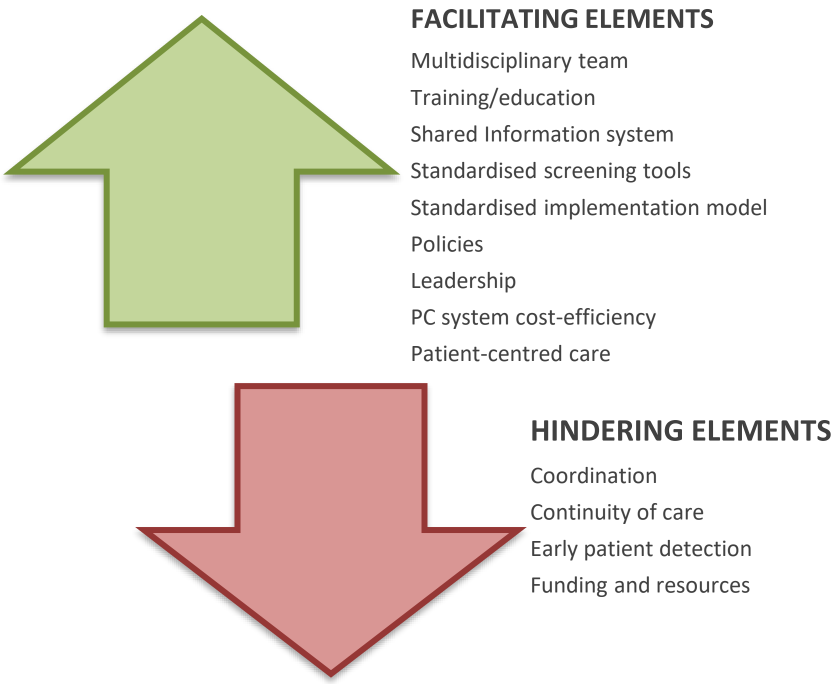


Figure 35. *OPCS Elements that Facilitate and Hinder Integrative Care at the Structural Level*

Elements that Facilitate Integrative Care in the OPCS at the Structural Level

As was stated in the documents, Osona care **teams are multidisciplinary** as they integrate the different professionals caring for the patient. Further, the 2016- 2020 Catalan Health Plan states as one of its goals the implementation of a service model based on shared decisions and multidisciplinary work. This shared decision-making process by the multidisciplinary team is used to elaborate the patients' interventions plans, such as the individualised care plan (PIIC), advanced care directive (PDA) and medical history. In the questionnaires, the leaders also indicated that the motivated professionals in the system work in teams. Multidisciplinary teams consist of professionals within an association or entity (Gilbert et al., 2012) that share a common goal to meet the patients' needs (Kuzmarov & Ferrante, 2011). It is clear that professionals in the OPCS are organised in multidisciplinary teams, which facilitates the overall integration of care from the different professionals caring for the PC patient. Furthermore, as Gómez-Batiste et al. (2014a) point out, the Osona health professionals should work in a multidisciplinary manner to better identify PC patients. Therefore, working in multidisciplinary teams will not just enable the integration of care intervention but it might also facilitate the identification of PC patients in the system.

Patient-centred care is a goal stated in the different Catalan health plans. Furthermore, the guidelines to develop a PIIC and a PDA for the PC patient clearly indicates that care aims to achieve patients' needs and preferences. Furthermore, it is interesting to note that more MACA patients live at home than in nursing homes in Osona while they are very sick, and sometimes even in a terminal phase as their GMA very high risk for admission, care and treatment indicates. In their study, Wheatley and Baker (2007) stated that although 70% of PC patients desire to be cared for and die at home, a large quantity end up out of their homes, often for health reasons, and only 25% actually die at home. It is therefore interesting to note that, in general, a large number of PC patients wish to live at home and that in Osona they do as confirmed in the study by Gómez-Batiste et al. (2014b).

PC patients in Osona need intense care like any PC patient in any system, and as seen in the documents reviewed there is a significant use of primary, homecare and intermediate care services by MACA patients in this region, while fewer of them are hospitalised and remain at home with those care services. The fact that more MACA patients are identified as living at home in this region could have a number of explanations such as an infra identification of these patients in nursing homes. However, taking into account that they also use more care services that manage their conditions at home, it could also mean that patients are well managed at home and can stay longer there, following their wishes as Wheatley and Baker (2007) pointed out. Therefore the system will be providing care where the patient wished and providing patient-centred care.

Training and education were established by the 2016-2020 Health Plan and the Chronicity prevention programme to provide professionals with training for integrated care. In this regard, in the questionnaires the leaders specify that professionals are specialised and well trained and show clinical competence when treating MACA patients. In their study, Anstey et al. (2016) pointed out that although education is considered one of the most important factors for improving end-of-life care, the existing educational programmes seem inappropriate in many areas of care to promote better care provision, since providers still encounter problems with symptom control, communication with patients, families and other providers, and coordination between services. The leaders mentioned the need for specific training in, for example, the process of identifying MACA patients and in the implementation models, among others. They pointed to the need for more systematised training from the health department that will unify the providers' knowledge and practices. Participation in lifelong training to develop and improve their own skills is a core competence for PC providers (Gamondi et al., 2013). It is clear that providers in the OPCS have training and are clinically competent, but as the literature suggests professionals that attend to PC patients have a special need for continuous training with adequate educational programmes that improve their abilities. It is important to mention that, although training is part of the OPCS professionals' development, and therefore a facilitator element, it needs to be continuously promoted and provided by the system to ensure adequate PC provision.

Standard implementation is a common intervention care model that was first established with the 2011-1015 Health Plan and the Chronicity prevention and care programme (Amil et al., 2016) and the 2016-2020 Health Plan (Generalitat de Catalunya, 2016b). As previously mentioned, these health plans establish different patient clinical documentation that should set the standard of care to follow in all the interventions provided. As Bainbridge et al. (2016) pointed out a standard model of care is a key element for effective IPC delivery and it should be ensured. Questionnaire respondents failed to mention standard implementation models as either a strength or weakness of the system, which leads us to infer that a standard of care for PC patients in the OPCS has been established and is implemented by some entities in the system. This element thus seems to be a facilitator.

In relation to the system **policies,** since 2011 Osona has followed several plans and programmes developed from policies aimed at improving PC services, as previously mentioned, with several policies, health plans and initiatives trying to organise and provide services to achieve an integrative PC. A couple of respondents stated that there is a need for more specific PC policies. Freeman et al.

(2016) state that IPC policies are necessary and need to be established at the national level for their implementation at the service level. According to the document and questionnaire results it is evident that PC policies are in place, although some that are more specific to PC might help further this area of care, as mentioned.

In Osona, according to the documentation reviewed, there are three platforms and three documents where **information on patients is shared** by professionals. A sharing information system facilitates patient information collection, reporting and accessibility to care providers (Bull et al., 2012) and ensures effective IPC care delivery (Bainbridge et al., 2016). The OPCS has a sharing information system at the structural level that facilitates effective information sharing and effective IPC delivery.

The system has two classifying and grouping tools to identify patients as PC: the adjusted morbidity grouping, which stratifies patients by their level of risk; and the **screening tool** NECPAL, aimed at identifying patients early in their chronic stage, which is usually used by primary care doctors (Gómez-Batiste et al., 2012b). In addition, in their responses the leaders identify PC identification and the labelling process as strengths in the system. Blay Pueyo (2017) points out that a standard assessment, and thus PC patient identification, has increased progressively in Osona over the years from the past to the present. This might be consequence of the use of standard screening tools by the system's professionals.

The use of a standard screening tool helps professionals to identify and determine patients' prognosis (Gómez-Batiste et al., 2016), and also generates needed healthcare referrals (Rabow et al., 2015). In the questionnaire, the leaders mentioned some difficulties in using the screening tool, explaining that there is some disagreement among professionals with regards to when a patient should be identified and labelled as MACA. They also stated that not all professionals can implement this identification and labelling process. While there seem to be some difficulties in working with the screening tool, it is clear that there are screening tools that are being used in the system to identify these patients.

PC in Osona **shows some greater cost-efficiency** in comparison to other regions since the rate for acute and emergency hospitalisations in Osona is much lower than the average in Catalonia. After the implementation of the Chronicity prevention care programme, admissions and readmissions for the chronic patient decreased by 13% in Osona (Departament de Salut.Generalitat de Catalunya, 2012b). Amil et al. (2016) explained that the decreased usage of the emergency services is due to better disease control. As shown in the documents, the services most used by PC patients in Osona are primary care, intermediate care and UFISS services, none of them emergency or acute care services (CatSalut. Servei Català de la Salut, 2019).

In addition, as Blay Pueyo (2017) points out, the decrease in acute admissions that could be preventable by good patient management indicates a success of the chronicity integrated strategies in Osona. IPCS shows some degree of cost-efficiency since they can decrease inappropriate emergency visits and admissions, and can avoid problems related to being hospitalised, such as infections, delirium or confusion that could prolong stays (Lee & Titchener, 2016). The OPCS, with a standard implementation model, seems generally to manage the PC patient living at home well, through primary, homecare and intermediate care. Consequently, the OPCS might have benefited from a cost reduction from the decreased use of the emergency services and has thus become to some degree more cost-efficient as an integrated system.

Elements that Hinder Integrative Care in the OPCS at the Structural Level

Coordination and collaboration have guided professionals from the 2015 Chronicity prevention and care programme to the Catalan Health Plan that also states they should work in coordination with other professionals. There are also several initiatives from the system level to develop coordinated care and services. As Scott et al. (2009) point out, system level support is essential to provide integration in the service care level. One of these integrative initiatives at the system level was the creation of the SISO organisation in 2002, with the purpose of coordinating professionals and services in the area (Sistema Integrat de Salut d'Osona, 2016). In the SISO, professionals from different entities and levels of care work in an interdisciplinary manner to enhance the health service in this region. Furthermore, the leaders in the questionnaires named working in teams as one of the professionals' strengths.

Nevertheless, the leaders stated that professionals need to work more in an integrated manner than in a teamwork manner. Kodner and Spreeuwenberg (2002) define integrated work as a logical set of models and methods in all levels of care to develop connection and cooperation between the professionals in order to provide continuous care for the patient's benefits. Integrated care is thus different from multidisciplinary or collaborative work. While the system seems to have multidisciplinary/collaborative teamwork that ensures the professionals organisation in teams and collaboration among them, it does not seem to have integrated work. The latter goes one step further, as it ensures first the involvement of all the professionals in all the levels of care, and second that their collaborative work will facilitate continuity of care for the patient. There are still some problems of coordination between some services, which is explained below.

The Catalan Health Plan states the need for collaboration between health care and social services (Amil et al., 2016; Blay Pueyo, 2017), and the PIAISS plan aimed to implement integration between social and health services. Despite these plans aimed at bringing integration between social and health care services, the leaders mentioned that there is still fragmentation between these two areas of care for the PC patient. Therefore, although there is collaboration among professionals, mostly within an organisation, it seems this is still at a premature stage, and cannot be considered integrative teamwork. The collaboration of all the professionals in all the areas of care does not yet seem to have been accomplished, as seen, for example, in the fragmented collaboration of health and social area professionals mentioned by the leaders in the questionnaires.

Early intervention and identification. In the Osona system, in 2018, the percentage of identified MACA patients according to statistics found was 0.5% (CatSalut. Servei Català de la Salut, 2019). It is important to note that, as Gómez-Batiste et al. (2014b) explained, the prevalence of MACA patients in Osona in 2011 was 1.5% in a prospective study. A more recent study indicated that the prevalence for MACA patients was 1% (Blay et al., 2019). It thus seems that there are many fewer MACA patients identified in later years. It is interesting to note that while the mortality rate for MACA patients was 63%, expected since there is the provision that they will die within one year, the mortality rate for the PCC patient was 11%.

PCC is the chronic complex patient, a stage before becoming a MACA patient. We therefore need to ask why so many PCC patients died, given that they are at a previous stage of complexity and illness severity than a MACA and not expected to die that year. Bearing in mind that the identification of MACA patients has decreased with respect to the past, and that 11% of PCC patents died, this could mean that some possible MACA patients were identified wrongly as PCC patients, decreasing the total number of real MACA patients identified. Similarly, the questionnaire results indicated that the average MACA patient served in the OPCS organisations was an average of 1.34% of MACA patients, which is closer to the prevalence rate of 1% indicated by the study of Blay et al. (2019).

In addition, questionnaire respondents indicated some problems with early PC patient identification, for example not being done early enough and having consequences for the patients' optimal care, and needing to increase the number of patients identified. As Bone et al. (2016) point out, the identification of PC patients should be done early on in the disease process to benefit the PC patient.

In the OPCS PC patients are identified, but insufficiently so at present, it seems. This is likely due to sometimes being wrongly labelled as less advanced in their disease as a PCC, or not being identified at all, which prevents them from having the services they need. It is clear that these patients would benefit from PC services if they were identified earlier. It therefore seems that early identification is a barrier to the integration process of the OPCS since it has not yet been fully accomplished, and further work needs to take place to identify these patients early on in their disease.

Continuous care within the systems is a goal of the different Catalan health plans and Chronicity prevention programme. It is ensured when there is a bridging of care across settings and services in a system (Bull et al., 2012). Specifically in Osona, there is a care model for complex patients to enhance care continuity that facilitates primary care referrals into intermediate care without needing to go to the hospital emergency room (Departament de Salut. Generalitat de Catalunya, 2017a). The document and questionnaire responses show that continuity of care between primary care and intermediate care is present in the OPCS.

Furthermore, the Chronicity prevention and care programme has a planned strategy to provide 24/7 care through the sharing of medical records with the emergency services and the PADES support teams that provide coverage after hours. The OPCS has established this system, and mostly the emergency services provide afterhours care. It is important to indicate that in the questionnaires the leaders expressed the need to provide a better 24/7 coverage for the different levels of care and more accessibility to some services, such as the social services, during the after hour period. They stated that sometimes the after hours system is unable to provide continuous care and PC patients end up in the wrong care service.

It seems that continuity of care between some service levels, such as primary and intermediate care, and overall in the system’s services is ensured by the OPCS. There is provision of afterhours care established in Osona by the emergency services but, as indicated by the respondents, it might sometimes malfunction, causing fragmentation of care, and might not ensure easy access to some services, such as social services. There seem to be some aspects of continuity of care that need improving, especially the afterhours services and social services.

With regards to **resources and funding,** the documents indicated that the OPCS is well equipped with centres, services and providers, although in the questionnaires the leaders stated that there is a need for more services and resources in general to better support the PC patient and their families at home or in hospital. Furthermore, some of the leaders said that the funding model needs to change and that a more PC specific funding should be established.

With regards to professionals, in 2018 the region had a total of 23.8 health care workers per 1,000 inhabitants, and although this percentage included dental services and professionals working in the public and private sector, it seems adequate since it is five times higher than the 4.45 minimum health care worker requirement of the World Health organization (2016). Likewise, when comparing the Osona ratio of healthcare workers with other regions with similar populations, it seems that Osona is adequately equipped. The questionnaire respondents indicated that there is a need to increase the number of professionals in general so that more time can be spent with this kind of patient, as well as a need for more professionals specialised in PC. It is obvious that although the OPCS offers the PC patient services, resources and professionals, more are needed to properly cover their needs. As explained, PC patients generally suffer from multiple conditions and have a high complexity level. Furthermore, as the GMA classification tool indicates, these patients have a high risk of using primary care, emergency room and hospital services. It is clear that the PC patient needs many services, resources and professionals to respond, monitor and manage their wellbeing, and it seems that not having enough of these elements might become a barrier to providing them with optimal care.

To summarise, the facilitating elements found at a structural level of the OPCS were having multidisciplinary teams that are competent and well trained and that share information in the diverse platforms in place in the system. These professional teams detect PC patients with a standardised screening tool called NECPAL. They follow a patient-centred vision of care and use a standardised implementation model of intervention to treat the PC patient. There are policies in place since 2011 that have guided the PC initiatives in the region. The system has mostly managed this patient well, and as a result the PC system has become more cost-efficient. On the other hand, there are some aspects that, while included in the system, need further improvement such as coordination and care continuity between certain service levels and between the health and social care areas. Furthermore, earlier patient identification seems to have some problems in detecting all PC patients and detecting them early enough in their disease. And finally, more resources, services and a financing model are required to meet the PCS needs and demands.

5.2. What are the Essential Elements of an Integrated Palliative Care System?

The essential elements of an IPCS identified by the study respondents matched those enumerated in the scoping review carried out by Mondejar-Pont et al. (2019). Nevertheless, it is interesting to note from these research results that although all the elements from the scoping study were mentioned, there are some similarities and differences: some were prioritised differently, some elements were included but not considered a priority, and some new elements, not included in the scoping study, were suggested by these study respondents (see Figure 36). These three aspects will be explained below.

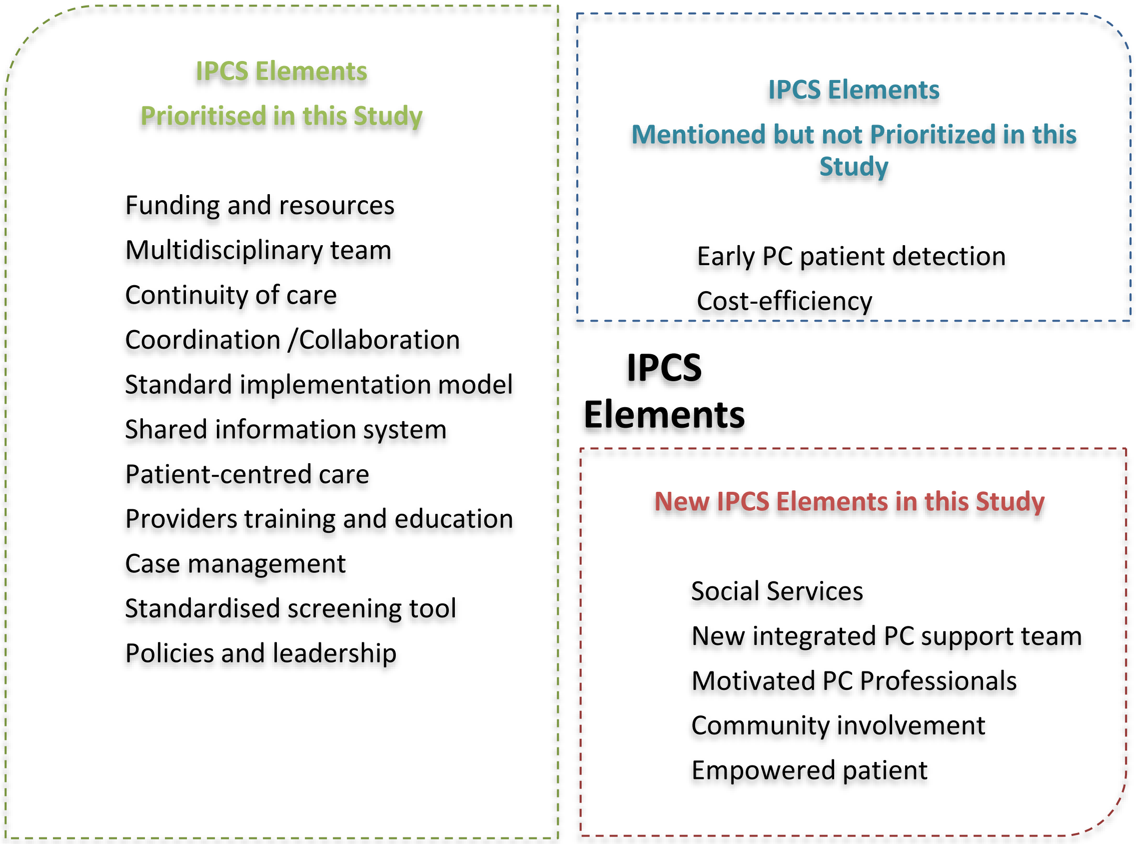


Figure 36. *IPCS Elements Prioritised, Mentioned and New*

5.2.1. IPCS Elements Prioritisation in the Literature and Study Results

The scoping review presented twelve essential elements, organised in order of importance (extensively described in Chapter 2). This study obtained thirteen elements considered essential that were also prioritised by order of importance, as described in Chapter 4. There were thirteen in this study since case management was included in the multidisciplinary element in the scoping review, but here it was mentioned as a separate element. Four elements – multidisciplinary team, collaboration, continuity of care and standard implementation model – coincided in the first six elements for both the scoping review and the study results, so they were considered the most essential ones for an IPCS. These elements are briefly explained below.

A **multidisciplinary team** is important since it includes all professionals providing services to the patient. A difference with this study's results is that in this team they mentioned also including professionals working mostly in the community and in home care. Given that, as stated before, it seems that in Osona there is a large number of PC patients living at home, it is easy to see why the study professionals would include these providers in these teams. Another essential element was

professionals' collaboration, which should be at all levels of care and services in the system. The scoping review indicated collaboration in all levels of care more at the structural level, but the study respondents referred to professionals' collaboration at the service level, which is understandable since most of these professionals provide care at this service level.

Uninterrupted continuity of palliative care, 24/7, was the third element common to both the scoping review and this study. Continuous care should be ensured throughout all levels of care, organisations and services, as indicated in the literature (Boeckxstaens et al., 2011; Fernando et al., 2014). The study respondents added that service care should be provided 24/7. As indicated as well in the literature, in order to adequately respond to the PC patient care should be provided in the community, at home and after hours when needed (Ramanayake et al., 2016). It is also important that the same PC **standard implementation model** – the fourth common essential element – care protocols and circuits are applied by all entities and care levels. Some of the interviewees added that there should be specialised and unique PC routes to facilitate the same interventions and same patient services referrals.

It is important to point out that **funding and resources** was the first element prioritised in this study, but the last one in the scoping review. In this study, the need to have a PC funding model that would reimburse entities per service provided rather than by equal entity allocation was specified. Respondents also suggested the need for more resources, such as basic care equipment like more X-rays, ECG machines and infusion pumps, as well as the need to increase the quantity of services and professionals specially trained for these patients that requires high demands of care. It is clear that an adequate provision of resources, services and professionals is essential for providing quality IPC, and are probably very much needed in the OPCS since it was prioritised in first position.

PC case management was indicated in both the scoping review and this study. The scoping review included this element together with the multidisciplinary team, whereas the interviewees in this study listed case management as a separate element. Being separated and considered an element in itself and prioritised suggests that it is a very important element of an IPCS and for the PC patient.

It is also interesting to note that **leadership and policies** were the last elements prioritised in this study and third to last in the scoping study. Although mentioned at, or near, the bottom of the list in both, the literature emphasises the importance of having PC policies at the national level (Connor & Sepulveda Bermedo, 2014; Freeman et al., 2016), and the interviewees in this study stated the need for specific PC policies. As indicated in the literature, development of PC services in the world has been increasing since it began in 1990. Today, 58% of countries, mostly developed countries, offer

PC provision (Connor & Sepulveda Bermedo, 2014). It has probably helped that regularisation by international organisations like the WHO and the UN have promoted and regularised PC provision. The scoping study and this study's results originated mostly from developed countries where PC policies have been developed and PC programmes established. We can therefore, assume that PC policies are regarded as existing and although needed they do not now seem a priority.

With regards to the rest of the elements, some were prioritised differently but included in this list of priority elements, such as **shared information system, patient-centred care, education and training and screening tool,** which indicates that they are essential for an IPCS**.**

5.2.2. IPCS Elements Mentioned but not Prioritised in this Study

There are two elements that, while mentioned in both the scoping review and this study, were not included in the list of prioritised elements by the professionals. These elements, early patient detection and specialised PC cost-efficiency, are therefore considered necessary but for some reason not the most essential in this study.

Early patient detection, as stated by the authors in the scoping review and study, should be performed early on in the patient's disease to avoid future complications. As already explained, and as the statistics showed, the OPCS seems to have decreased PC patient detection with respect to the past, from 1% indicated in the study of Blay et al. (2019) to a 0.5% as indicated by the statistics in the present. The reason for the decline in detection could have a number of explanations, some of them discussed later in this chapter. Although, as seen there is an effort to identify PC patients, some of them are not identified. This could indicate that providers have misinterpreted their effective detection level, and assume that it is not an element to prioritise since it is already effectively achieved in the system and is probably considered an easily achieved element in a system. In reality, as indicated in the literature, it is not an effortless element but should rather be an active strategy used to prevent and relieve PC patient suffering (Ramanayake et al., 2016; Von Roenn et al., 2013).

As Lee & Titchener (2016) explained, **specialised PC is cost–efficient** since it decreases emergency visits, readmissions and hospitalisations stays. The interviews and scoping results agreed that specialised PC is more cost-efficient due to the decrease of emergency services. As the documents reviewed indicated, the establishment of a PC programme in this region reduced the use of emergency and acute services by 13%. Therefore, there has been a real usage reduction of these expensive services, and although providers in this region recognise that a specialised PC programme is cost-efficient, they do not consider it a priority since they see it as already functioning in their system.

One could think that if an element is mentioned but not prioritised it is because either the element's importance is not recognised or because it is already in place and it does not need to be emphasised. It seems that early patient detection might not be recognised as a priority, although as the lower detection rate shows it should be prioritised. With regards to PC cost-efficiency, it seems that it is already in place and its benefits recognised by providers in the OPCS. This probably explains why providers failed to prioritise these two elements, which are still very important for an IPCS as the literature indicates.

5.2.3. New IPCS Elements Suggested in this Study

The study results suggested five new elements that were not mentioned in the scoping review. One of these elements, **social services**, was also prioritised, while the other four were just suggested: having motivated professionals, specialised integrated support teams, professional community involvement and empowered patients. The providers explained their importance, which will be discussed below.

Social services was mentioned as essential and a priority since social work is indispensable for the PC patients' care, given that it provides them with services and resources required for their wellbeing and is not provided by the health care system. The study respondents also mentioned a second element, a **PC integrated support team**, highlighting the need for a new group of professionals consisting of multiple professionals from the health and social work areas, from different disciplines and from different levels of care specialised in PC patients.

Having **motivated professionals** was a third essential element mentioned, which is understandable since working with this type of patient requires high medical attention and would thus demand extra motivated professionals. Another element, **professionals' community involvement**, was also suggested by a few of the respondents, explaining that care professionals should go where the patient is, instead of having patients come routinely to the clinics, sometimes for unnecessary visits. As indicated in the literature, continuity of care for PC patients should be ensured in all settings of care (Rabow et al., 2015), in this case in the home or wherever the patient resides. A final element identified by professionals in the study, was the need to have **empowered patients** that are knowledgeable about their health and diseases and can make informed decisions. As suggested by the study of Lian et al. (2019), educating patients about their disease can be cost-effective in the long run. An empowered patient might reduce unnecessary visits to health services due to better self-management.

In summary, the fact that these four elements – **multidisciplinary team, collaboration, continuity of care and standard implementation** – were prioritised and mentioned in both the scoping review and this study signifies that they are indeed essential and very important to have in an IPCS. The rest of the elements prioritised or just mentioned in both – **shared information system, patient-centred care, education and training, screening tool, funding and resources**, **case management, leadership and policies** – should also be considered important since the scoping review, a more theoretical study, and this study's results, a more service practical view, coincided in considering them necessary. The new elements should be further contemplated and researched to determine whether they are the results of the providers' specific system needs and whether they are transferable to the needs of other IPCS.

5.2.4. IPCS Elements Combining Theory and Practice: A Blended Model

It is important to reflect on a possible mixed model based on a combination of the essential elements of an IPCS proposed from a theoretical level, and those proposed from a practice level. Since, as stated by Brazil et al. (2005), there is a gap between theoretical research findings and their use in the health care practice, collaborative models between research and care services would improve research and would encourage its applicability in health care settings (Farquhar et al., 2002).

This study, although on a small scale and very specific to the Osona system, proposes a blended model that combines theoretical and practice level views. The scoping review results provide more theoretically-based findings from the review of 43 articles found in databases on the essential elements of an IPC. And this study's interviews provide a more practical service level view of the essential IPCS elements. Combining the essential elements from both theory and practice could provide a more comprehensive view of the essential elements of an IPCS, as pointed out by Farquhar et al. (2002). The blended model for Osona is depicted in Figure 37. It is clear that this blended model can not be considered universal since the practical view is specific to the Osona context and the specific needs of its health care system. However, it should be noted that this study proposes the creation of a blended model strategy that could be applied to other PC systems and contexts that, by integrating their own practical view, could create their own blended model.

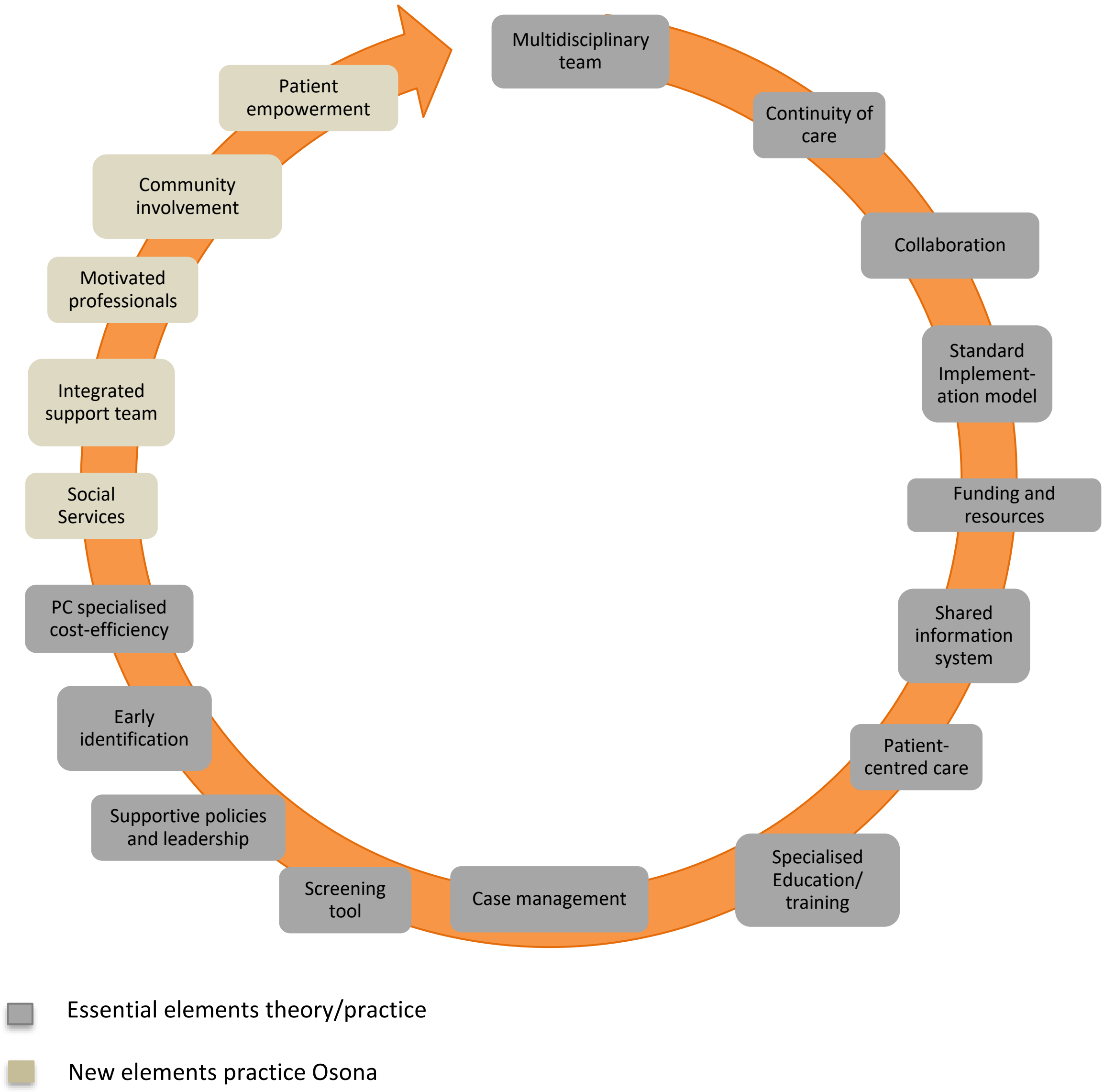


Figure 37. *Essential IPCS Elements: Blended Model of Theory and Practice*

5.3. What Elements Does the Osona Palliative Care System Include, Exclude and Need as an Integrated System?

Many of the essential elements mentioned in theory and practice in the IPCS blended model are mentioned by providers as included elements in the OPCS, although some still need improvements or changes to be made. In this section, the results will be fully discussed from different perspectives, presented as follows: 5.3.1., the OPCS elements mentioned by the service care level compared with the IPCS elements of the blended model; 5.3.2., the OPCS service care level elements compared with the OPCS facilitating and hindering elements at the structural level; 5.3.3., new elements mentioned at the service care level needed in the Osona context; 5.3.4., the interrelations of the OPCS included/excluded elements; and 5.3.5., the OPCS included/exclude elements related to the different professional groups (see Table 28 for a display of all the IPCS elements and the OPCS elements from service and structural level view).

5.3.1. Service Care Level OPCS Elements Compared with IPCS Elements of the Blended Model

Most of the elements mentioned as included in the OPCS coincided with the essential elements that an IPCS should have according to the blended model (see Figure 38), although there are four situations that need highlighting. First, from all the OPCS elements mentioned in the service care level, there were five that where only mentioned as included elements. Second, there was only one noted as excluded. Third, most of the elements coinciding with the IPCS blended model were mentioned as included in the OPCS but needing changes. And fourth, some of the elements mentioned in the IPCS blended model were not mentioned either as included or excluded for the OPCS. These four situations are discussed below.

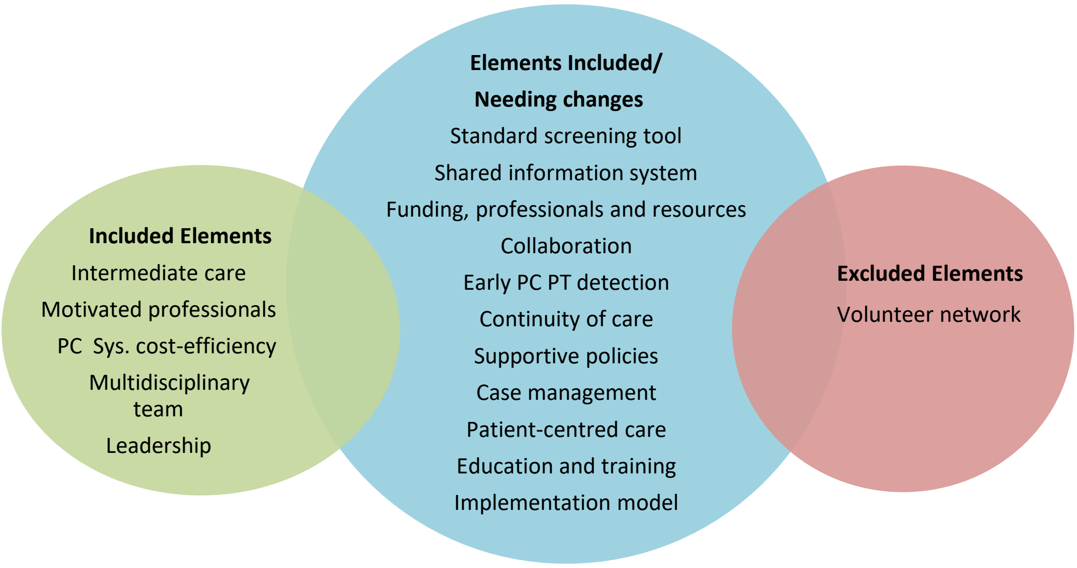


Figure 38. *OPCS Included and Excluded Elements from the Service Care Level View*

First, the four elements mentioned as just included elements that coincide with the elements for an IPCS in the blended model were: multidisciplinary teams, good leadership, motivated professionals and specialised PC system that is cost-efficient. A fifth element, intermediate care was mentioned as included in the OPCS but not mentioned in the IPCS blended model. The fact that these elements are just included indicates that they are definitely included and do not need changes or further developments. Professionals in the OPCS are **motivated** and work in **multdisciplinary teams** that include the different providers - doctors, nurses, nurse assistants - and from different levels of care, such as social workers and homecare professionals. The results also highlighted the importance of having experts and known l**eaders** in the region that bring research and innovation to PC.

PC specialised programmes and plans have brought **cost efficiency** to the system by reducing unnecessary admissions and treatments. Amil et al. (2016) explained that since the incorporation of the Chronicity prevention and care programme in 2011, readmission rates for PC patients in Catalonia have decreased. In addition, Blay Pueyo (2017) stated that the international success measure of a good chronicity programme is the reduction of PC patient admissions, due to good patient management through other services. The use of primary and **intermediate care** is higher in Osona, which may indicate just what Blay Pueyo (2017) stated regarding a well-functioning primary, homecare and intermediate care, which reduces the use of emergency services and readmissions, resulting in an overall cost-efficiency to the system.

Second, the only element excluded at the service level and not mentioned in the blended model for an IPC was PC volunteers. The providers indicated the need for the development of a **PC volunteer network** as a reinforcement structure, originating from the patients' community, that could support and aid the MACA patients and their families. The fact that this element is only mentioned as excluded in the OPCS might indicate that, while desirable and supportive, it is not essential. As Sallnow et al. (2017) indicated in their study, volunteers may feel gaps in social support when it cannot be provided by professionals or family. As suggested, volunteers might help and provide support with social needs, but it is not an essential element for the proper functioning of an IPCS. There is **one** project, called *Vic ciutat cuidadora* (Vic Caring City), **that points** towards developing more supportive communities. It aims to improve social and cultural views of chronic conditions and **end-of-life processes**, as well as improving social support **for** MACA **patients** and their families (Ajuntament de Vic, 2018).

Third, the elements that were included but still need changes were as follows. First, the **standard screening tool**, which although in place and used, involves some uncertainties as to when and how to use it, therefore some training is indicated. A second element suggested was having a **single shared information system** instead of having three platforms, which can be confusing. One that is interoperable for all providers and that would also include multimodal ways of communication that, as Pang et al. (2013) indicated, supports effective health information sharing.

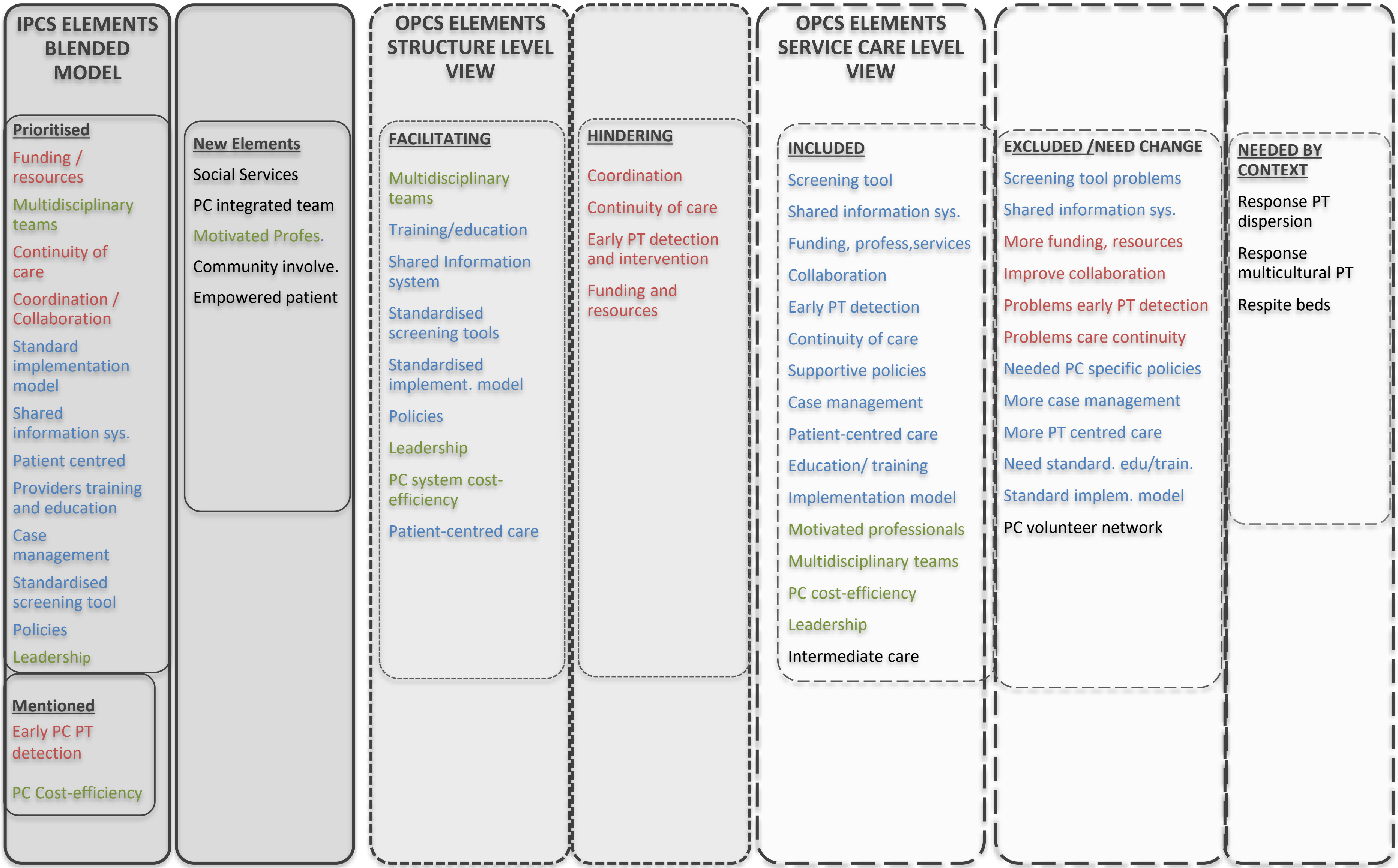
Funding, professionals and resources offered at the different health care levels covers overall patient needs. Nonetheless, lacking PC specific funding, professionals and resources was also mentioned, with respondents stating that a new funding model should be considered. The literature suggests a capitation method of financing as a way to promote integrated care, a method that has been used in the past in Osona (Roca, 2013) and whose continuity should be explored. This payment method ensures the coverage of the health needs of a specific target population, in this case those with chronic conditions, through all services (Gómez-Batiste & Connor, 2017). Furthermore, the results indicated the need for more health care professionals and services specifically trained for the PC patient. **Professionals' collaboration** was mentioned as being present overall, although the need to improve collaboration with social services was specifically mentioned. As indicated by Blasco (2017), the directives of the Social Affairs department and the Health department do not always coincide. It is essential that both areas work collaboratively to achieve the health and social goals of PC patients.

Continuity of care is well established between primary care and intermediate care, but there is still fragmentation with other service levels. A group of respondents expressed the need to have better 24/7 after hours coverage that will ensure continuity of care. As Ramanayake et al. (2016) concluded, in order to care for and keep the PC patient at home, provision of after hour coverage and access to a PC team is required. Interviewees mentioned that **early PC patient detection** is performed by primary care professionals, for whom it is easy to detect. Nevertheless, only primary care professionals label patients (Gómez-Batiste et al., 2012b), and the study participants stated that all providers should be able to do this labelling process in order to proactively and together identify them and ultimately increase identification rates.

With regards to **case management, patient-centred care and PC implementation model**, although the system includes them it seems that further development and a more homogeneous application would benefit the PC patient. While the system includes supportive **policies,** and **education and training,** more specific policies and education for the PC provider is required to better serve these patients.

Fourth, it is interesting to note that although providers indicated these new elements – **integrated teams, empowered patients, professionals more involved in the community and the need for social services -** as important for an ideal IPCS in the blended model, they were not mentioned as included or excluded in the OPCS (see Table 28). Social services was included with regard to the need for the social services and health care to improve collaboration and continuity of care, but it was not mentioned here as an excluded individual element. The other elements were not mentioned at all in the OPCS elements.

The benefits that these elements could bring to the OPCS is clear. One possible explanation for not mentioning them is that although they are desireable for a PC sytem, they are not yet a priority for the developmental stage of the Osona system. As Connor and Sepulveda Bermedo (2014) explained, Spain has not yet reached the stage of complete PC integration in the mainstream. In the advanced stage of PC integration there is mass PC activism, PC provision, health care awareness, education and policy development. Therefore, these more advanced elements are suggested as future goals for when the Osona PC system reaches the most advanced developmental stage. As will be explained next, there are other more essential elements that need improvement and better development in the current OPCS.



IPCS ELEMENTS BLENDED MODEL

Prioritised
- Funding / resources
- Multidisciplinary teams
- Continuity of care
- Coordination / Collaboration
- Standard implementation model
- Shared information sys.
- Patient centred
- Providers training and education
- Case management
- Standardised screening tool
- Policies
- Leadership

Mentioned
- Early PC PT detection
- PC Cost-efficiency

New Elements
- Social Services
- PC integrated team
- Motivated Profes.
- Community involve.
- Empowered patient

OPCS ELEMENTS STRUCTURE LEVEL VIEW

FACILITATING
- Multidisciplinary teams
- Training/education
- Shared Information system
- Standardised screening tools
- Standardised implement. model
- Policies
- Leadership
- PC system cost-efficiency
- Patient-centred care

HINDERING
- Coordination
- Continuity of care
- Early PT detection and intervention
- Funding and resources

OPCS ELEMENTS SERVICE CARE LEVEL VIEW

INCLUDED
- Screening tool
- Shared information sys.
- Funding, profess,services
- Collaboration
- Early PT detection
- Continuity of care
- Supportive policies
- Case management
- Patient-centred care
- Education/ training
- Implementation model
- Motivated professionals
- Multidisciplinary teams
- PC cost-efficiency
- Leadership
- Intermediate care

EXCLUDED /NEED CHANGE
- Screening tool problems
- Shared information sys.
- More funding, resources
- Improve collaboration
- Problems early PT detection
- Problems care continuity
- Needed PC specific policies
- More case management
- More PT centred care
- Need standard. edu/train.
- Standard implem. model
- PC volunteer network

NEEDED BY CONTEXT
- Response PT dispersion
- Response multicultural PT
- Respite beds

From IPCS Blended model OPCS Facilitating/Included **From IPCS Blended model OPCS Hindering/Excluded** **From IPCS Blended model OPCS Facilitating/Included need change** **New elements**

Table 28. *IPCS Blended Model Elements and OPCS Elements from a Structural and Service Level View*

5.3.2. OPCS Elements from the Service Care Level view Compared with the Structural view Facilitating and Hindering Elements

There are several elements for the OPCS that are common at the structural view and at the service care level view that although included still need improvement, as explained in the previous section. Nevertheless, there are a few that were only considered facilitators and included, and others that were considered hinderers and excluded or needing changes, which will be explained below. (See Table 28: OPCS Elements Structural level view and Service care level view).

The elements that were only mentioned as facilitators and included in the OPCS at the structural and service care levels were having a **multidisciplinary team, leadership,** and a **specific PC system that was cost-efficient.** It seems clear that these elements are well established and functioning properly in this system. At the structural level, the different health plans and PC specific programmes have set the strategies and goals to organise professionals in multidisciplinary teams, which have translated into their organisation into these multidisciplinary teams at the service level, as previously indicated. Providers also mentioned having known leaders and researchers in the region that advance and bring innovative projects to the system. It was stated in the literature how Osona has been recognised internationally for its good practices and results managing the chronic and palliative patient (Blay Pueyo, 2017). Furthermore, it has been shown in this study, with the statistics from MSIQ database on PC patients' usage and in the literature as Amil et al. (2016) indicated, that since the health plans focusing on PC services and the PC Chronicity prevention and care programme, PC patients have been better managed and their use of acute and emergency services has decreased, leading to a more cost-efficient system.

Further, there are some elements that were pointed out as hindering the well-functioning of the OPCS, which were also mentioned as excluded or needing some changes. These elements were: **improving collaboration, continuity of care, problems identifying early patients** and **lack of specific funding, professionals and services**. It was reported that better collaboration and continuation of care between the social and health services and even between some of the PC health services should be given close attention for the proper functioning of the system. Further, despite having a tool like the NECPAL screening tool which is used to identify patients, there is still a lower than expected identification rate. This low identification was explained as being due to improper usage of the tool therefore more training in this regard was suggested. Finally, providers stated that an increase of specific resources, professionals and services for PC patients should be provided to properly cover the needs of the PC patient. It was highlighted that these three elements, as they are currently set up, do not properly function, and providers suggested more attention should be placed in improving them.

5.3.3. Elements Needed Specifically for the Osona Context from a Service Care Level View

The elements reported as needed for the OPCS due to its context were **service response to the rural dispersion**, **improved response to the multicultural population** and r**espite beds**. These elements are further explained below (see Table 28: OPCS Elements Service Care Level View Needed by Context).

Rural dispersion and the need for professionals was highlighted regarding patient distribution in rural areas. In Osona, 50% of the population lives in smaller towns and non-urban areas, with a higher number of older people in these areas. Some rural areas patients experience barriers to access health care. As Fernando et al. (2014) point out, limited access might be due to the travel cost, limited transportation and the patients own functional impairments. It is therefore interesting to note how one of the first strategies proposed by the OPCS professionals to this barrier was the provision of transportation for rural patients. It is also interesting to note that with regard to transportation, there is no mention of providing transportation for either patients or providers, either in the documents reviewed or interviews or questionnaires. In a report found recently in this study by the social services, adapted transport for the disabled or dependent person is mentioned, which requires a disability certificate due to mobility restrictions (Ramos, 2017). Some of the MACA patients might be eligible for this service due to their mobility restrictions or ageing process. However, as stated by the study professionals, this service provision does not cover some of the patients in the more rural areas, which means they are unable to gain access to some services. Therefore, the provision of transportation for patients, especially those living in rural areas, seems to be a very significant element to be included in order to overcome the barriers faced by rural MACA patients.

A second strategy indicated was the provision of more professionals and services for these rural areas since, as they explained, going to these rural area represents longer care visits, due to the traveling time, than a regular visit in a city: As one stated: *"While in the city you would see many patients in a day, when going to these distant areas you can only visit a few"*. This need for more professionals is clearly explained by Keim-Malpass et al. (2015), who point out that PC in rural areas faces service demands that exceed available professionals. According to the document review, there are primary care centres that cover the bigger cities and towns in the region, including towns in these rural areas, and the total number of professionals, 23.8 per 100,000 inhabitants, seemed adequate for the region based on the 4.45 per 100,000 inhabitants minimum indicated by the WHO report (World Health Organization, 2016). However, we have not examined how these professionals are distributed per areas, rural and urban. As explained earlier, there is a bigger concentration of the older population in the rural areas, and probably more MACA patients. This should be something to consider when distributing PC professionals, since these rural MACA patients are located further away and are more difficult for professionals to access.

With regards to homecare services in these rural areas, as Viñas Segalés (2016) points out, in Osona home care is provided to those patients who need it, but not with enough hours to respond to all their needs. It seems that a larger provision of professionals and homecare services for these rural areas should be considered since, as Pesut et al. (2013) note, it is important to respond to the patients' needs, especially in rural areas, with sufficient professionals and homecare service, which would better monitor and follow up the rural patient while at home (Fernando et al., 2014). A third strategy proposed by the OPCS professionals was greater use of technology such as tele-visits, chats, and tele-monitoring for patients in geographically remote areas. As Fernando et al. (2014) explain, the use of tele-health in general has a real impact on patients' self-care adherence, and also provides a solution to the distance barrier.

Overall, the strategies proposed – the provision of transportation, an increase in the number of providers, better home care and greater use of technology – would probably provide a better response to the rural MACA patient. Furthermore, having a more integrated OPCS might provide a solution to some of the rural area dispersion barriers since, as Pesut et al. (2013) explained, an integrated system with multidisciplinary teams and continuous, coordinated and PC specific policies could improve the PC system response to the population in rural areas. A fully integrated OPCS would ensure better support for the rural area patient.

The second most mentioned needed aspect in the Osona context was to provide a better **response to the multicultural population** now living and dying there. The immigrant population in the region is 15%, most of whom are concentrated in the larger cities. This immigrant population comes from geographically distant countries that are culturally different, such as Morocco, Ghana, India, Romania, Colombia and Ecuador. It was also stated that in 2030, Osona will be one of the regions in Catalonia with a greater increase in immigration, not because of more births but rather due to the increase of immigrants coming to live in the region. As Jansky et al. (2019) point out, immigrants bring specific aspects that should be considered when caring for them at the end of life. They have language barriers, cultural differences, mistrust of the system and preferences that might contradict local professionals' views. In order to overcome these barriers, the PC providers should attain cultural competence on the immigrants' backgrounds. As indicated by the professionals in the OPCS, there is a great need to acquire greater multicultural competence on the different cultures now living in the region. There is a need to learn and adequately respond to the immigrants' needs and preferences during the course of their disease and dying process. As suggested by the OPCS providers, multicultural training and education regarding these cultures could help overcome this barrier.

The third needed element in the Osona context was that of **respite beds**. Providers indicated that there are no respite beds in the region for MACA patients if family and caretakers need an urgent break or caretakers become ill. The document review described the distribution of beds in the region by areas of care, but there were no respite beds (Generalitat de Catalunya. Idescat, 2020). As Bone et al. (2016) explained, it is necessary to provide care givers with support to maintain their well-being so that they can continue caring for the PC patient's increasing needs. As requested by the professionals, the inclusion of respite beds would make them available for the PC patients when their family and caretakers become ill or need a break, which would ultimately help them in those situations and ensure they continue caring for the MACA patient.

5.3.4. Interrelations of OPCS Included Facilitating and Excluded Hindering Essential Elements

The scoping review (Mondejar-Pont et al., 2019) explained that It is important to note that many of the IPCS elements found as facilitators if they were present were considered also hinderers if they were absent in a system. Mondejar-Pont et al. (2019) explained that this interrelation could indicate that these are the most relevant, possibly essential, elements in an IPCS. According to the results in our study, the common facilitating/included elements were **motivated multidisciplinary teams, leadership, having a specific PC that is cost efficient;** and the hindering/excluded elements or those elements that needed changes were **collaboration, continuity of care, early patient identification and not having enough funding, professionals and services**. These same authors pointed out that having a facilitating element usually enables another facilitating element, while a missing or malfunctioning element becomes a barrier to IPCS implementation and usually impedes or affects the efficiency of other elements.

In the OPCS there are researchers and leaders that bring innovation to the system and proper guidance to implement PC plans and programmes proposed at the state level. The highly motivated and competent providers, who are specifically trained in PC, organise themselves into multidisciplinary teams with the professionals working in the different levels of primary, intermediate and homecare. These teams use a shared information system with multiple modes of communication that helps them implement the same intervention. These PC interventions aim to better manage patients and that reduce unnecessary admissions and treatments, which result in a more cost-efficient system.

In contrast, not having the professionals, resources and services needed for the PC patient is likely to lead to them being less well managed. Having fewer professionals than required will give professionals less time to plan to work in coordination with other services and levels of care such as the health system and social work services and primary, immediate and homecare levels with acute services, which would bring care fragmentation. These non-collaborative professionals and entities perhaps do not identify some patients, who therefore do not receive the PC care they need.

5.3.5. Included/Excluded Elements Related to the Different Professional Groups

All the professionals, both leaders and the service level workers agreed on the main elements included in the OPCS, although these same elements are also indicated as needing improvement or some changes in order to work better. The only two elements that both considered to be excluded were continuity of care and the need for more funding, resources and services. These might indicate that these two elements do indeed need greater improvement for their proper functioning.

With regards to these excluded elements, the leaders stated that the system is missing specific PC policies. It is important to note that, as Al-Sawai (2013) explained, healthcare leadership needs to encourage professionals to work towards the same goals and organise resources efficiently. This could explain why the leaders see the organising policies as a priority, since this measure could lead to a better use resources and a more organised system. On the other hand, the health care workers stated the need for further improvement of elements like education and training, the implementation model and a PC volunteer network. As Reid et al. (2005), those professionals at the second level of care are the ones that provide services to patients, and so it is understandable that they would highlight these three elements that will improve the care service for the patient.

When comparing the health sector and social work professionals, they mostly agreed on the included and excluded elements, they both also agreed that the excluded elements or those needing changes were continuity of care and training and education. It is interesting that both recognised problems in the continuity of care since, as mentioned earlier, it seems there are some problems in the coordination between the health and social care areas. There was difference, however, with regards to case management, which health care workers, unlike social workers, said needed to be improved. Another difference was that social workers pointed to the presence of supportive policies, while some of the health care workers stated that more specific PC policies were needed. Health care and social work are managed under two different departments in the Catalan system. These last two differences might point to some structural differences in the different departments, perhaps because case management and PC policies are more developed and established in the social services area.

5.4. What Ethical Dilemmas Do the Professionals in the Osona System Encounter?

The providers in the OPCS pointed to the following ethical dilemmas: threat to patient autonomy, discontinuation of life prolonging therapies, poverty, provision of futile or non-beneficial treatment, unwillingness of families to tell the patient the truth, communication difficulties, palliative sedation, enquiring about euthanasia and opioids usage. These are discussed below in order of most to least frequently mentioned.

Threat to patient autonomy was the most repeated ethical dilemma encountered by the OPCS providers, a threat that came from the patient's family or care provider. As stated by the Universal Declaration of Human rights, the Spanish General Health Law (Sangüesa Cabezudo, 2012) and the Belmont Report in the US (US Department of Health and Human Services, 1979), the autonomy principal to freely decide is a patient's right. As the professionals point out, sometimes family members or professionals still decide for patients. It is clear, given the above declaration and law, that the autonomy to decide should be ensured for all patients capable of decision-making processes. In addition, as Arce García (2006) suggested, more training and knowledge on the ethics and laws regarding PC patients might help professionals when they encounter autonomy-threatening situations.

Furthermore, the patients' informed consent after receiving the needed information is required by law (Sangüesa Cabezudo, 2012). Therefore, unless patients are unable to decide, family members or professionals should not be determining treatment or care for patients. In cases where patients are not able to decide, as explained by Huang et al. (2018), the advanced care directive can help professionals since they describe patients' wishes and choices regarding their care. In Osona, these are called PDA, as previously explained. Having MACA patients complete a PDA, advanced care directive, early on in their disease could additionally aid professionals at times when patients are no longer able to decide, or when the autonomy threat is present through a family member or other professionals.

Family members not telling the truth to patients, which is related to the threat to autonomy, was also pointed to by professionals. A Spanish study of 2015 that evaluated the reasons why some families refuse to inform patients about their diagnosis, concluded that the main reason was to protect the patient from further anxiety. However, as Espinoza-Suárez et al. (2017) explain communication that is open, clear and contemplates the patient as the owner of their health information is a preventive strategy to this dilemma. Similarly, Chiu et al. (2000) point out that continuous communication between family and patient throughout the disease process can resolve this truth-telling dilemma in many cases. This communication process could ensure the best approach to individualised care, as it helps respond to patients' and families' preferences and avoids decisions to not tell the truth (Espinoza-Suárez et al., 2017).

Discontinuation of life prolonging therapies was the second most repeated dilemma and the fourth was **provision of futile or non-beneficial treatment,** where providers have to decide whether to stop or continue medications, treatments and therapies such as hydration or nutrition. As Cheon et al. (2015) point out, today health care has the ability to prolong life and the dying process, although as they indicated, these processes should be ethically appropriate. Life-supporting measures such as dialysis, nutrition, hydration, antibiotics and blood transfusions, might be considered aggressive treatments when patients have a short life expectancy (Guevara-López et al., 2015). Cheon et al. (2015) also indicate that this ethical dilemma often involves a context and multiple aspects that need to be considered and understood when deciding whether or not to discontinue a therapy. Sometimes patients or family members may want to continue with life-sustaining treatments or therapies while others might not, and it is their right to decide, as established in the Spanish legal context (Bello, 2019).

Similarly, providers treating symptoms for the PC patient might encounter situations in which they need to balance treatment benefits versus harmful effects on the patient. As Brown (2018) suggested, providers may have to confront the question of whether the treatment will prolong or relieve the patient's suffering, and therefore need to consider if their decision to continue or stop treatment is ethically and legally acceptable. Health care providers are not obliged to treat PC patients if there are no possible therapeutic or curative options available (Brown, 2018). Thus, if continuing treatment may cause harm and there are no possible curative effects, there is no obligation to continue with it, although these are still difficult decisions to make for providers. Cheon et al. (2015) explained that health care workers are often able to resolve these kind of dilemmas by consulting ethics committees, providing support to families, clarifying care goals and educating family and patients about ethical principles (Cheon et al., 2015).

Poverty was an ethical dilemma not mentioned in the literature but explicitly stated by the providers in Osona. They explained that poverty can make patients live in unsanitary situations, and also cause them to not being able to afford needed resources and services. This becomes an ethical dilemma for providers since they cannot provide them with the resources or responses needed if the system does not have it, but they know about their patients' needs and situation. As indicated in the document review, 28% earn a salary under 12,000 €, much lower than the minimum wage of 13,300 € a year established for Spain (Servicio Público de Empleo Estatal, 2018). There is therefore a large group of people below the minimum wage level in this region, some of whom are likely to be MACA patients.

The study of Anderson and Grant (2017) explains that although PC is a human right just 14% of people in need of it receive it, largely in high-income countries. They go on to explain that the absence of resources and services in low resource settings results in patients absorbing the cost, causing families continued financial loss and perpetuating their poverty. The professionals in this study stated that more resources, services and professionals for PC should be provided in order to overcome this problem. It is likely that investment in more resources, professionals and services for the PC and MACA patient could respond better to the poorer patients' needs by not forcing these already vulnerable patients to bear these costs, and thus relieve them of an additional burden.

Communication difficulties between health providers, patients and families were also mentioned by the professionals as an ethical dilemma, and should be taken into account from the beginning of the disease. Enquiring about what they know, their questions, beliefs and prospects would allow providers to develop care plans that reflect their goals (Espinoza-Suárez et al., 2017). As indicated by Cheon et al. (2015), there are sometimes communication difficulties among professionals due to their disagreement about patients' care. One would suppose that if providers worked in multidisciplinary teams with the same vision, they should not have many disagreements if following an integrative approach.

Similarly, this should apply to the end-of-life process, since if a multidisciplinary team has been taking decisions collaboratively, with common goals, they will also likely agree on how to help the patient in the dying process. In contrast, teams that have not worked cooperatively and experience more care fragmentation may have more disagreements and communication problems. In the OPCS, as we have seen, the MACA patient is treated by a multidisciplinary team that works collaboratively and develops individualised care plans and an advanced care directive that follows patients' preferences. As a result, there should logically not be many communication problems among the multidisciplinary team members. Furthermore, as Chiu et al. (2000) point out, one strategy to overcome communication difficulties is PC education and training.

Opioids use was mentioned by providers with regards to how some families evaluate the appropriateness of its usage, and to the providers' concerns about dosage. With respect to the former, the study providers stated that some family members feared the use of opioids because of possible harmful effects on patients, such as losing consciousness or possible acceleration of the dying process. Good communication and education about the need and use of opioids to families, as Chiu et al. (2000) point out, might overcome this problem. In addition, providers expressed some concerns regarding the dosage of pain medications, wanting to make sure they provide patients with enough medication to relieve pain but not too much so that patients lose consciousness, thus making them think they are starting palliative sedation.

Both the study by Cheon et al. (2015) and this study show that both of the above concerns are common. Cheon at al. (2015) also showed that some nurses also struggled with this concern of giving enough pain medication to provide patients with comfort but not too much so that the patient might become sedated. It is clear that opioids can have benefits for the PC patient. As Broglio and Cole (2011) point out, opioids therapy can provide pain relief to most of the patients at the end of life, and there are many options to choose from. However, they also indicated that health care providers should be knowledgeable and skilled in the use of these medications to better treat the symptoms of patients at the end of life (Broglio & Cole, 2011). It seems that knowledge and probably more training on the use of opioids could help providers care for the PC and end-of-life patient.

Palliative sedation and euthanasia were the last ethical dilemmas mentioned by the providers. Palliative sedation was described as a dilemma since there is some concern about when to start and also how to follow a standardised sedation protocol when death is prolonged and it seems it does not cover the needs. Palliative sedation in Spain is commonly used by PC services to treat uncontrolled symptoms that cause the terminal patient uncontrollable pain and suffering. Palliative sedation is largely accepted in the community and by PC professionals unlike euthanasia, although sedation can often lead to a patient's death (Núñez Olarte & Gracias Guillén, 2001). Furthermore, palliative sedation is mostly indicated for the dying patient in cases of disease progression with cachexia and multi-organic failure, and failure of palliative treatments to treat symptoms. The decision to begin palliative sedation in Spain is performed by a multidisciplinary team of providers, patient, family and/or surrogate decision-maker, considering that the disease is irreversible and death is expected in one or two weeks (López & de la Lama, 2020).

The OPCS providers also indicated that some patients and professionals enquire about euthanasia. Perhaps due to the Spanish Catholic tradition, euthanasia has not been well accepted historically in Spain. It is understood as the process that causes the patient's death, executed by a health provider. This is requested by the patient due to the uncontrollable pain and suffering caused by an incurable disease for which symptoms have not been able to be alleviated (Serrano Del Rosal & Heredia Cerro, 2018). One study in Spain showed that most individuals supported the legalisation of euthanasia in cases of irreversible and extremely painful disease processes (Serrano Del Rosal & Heredia Cerro, 2018). Recently, the euthanasia debate was reinitiated in Spain after a husband was convicted for helping his terminally ill wife die in 2019.

In February of 2020, the government voted in favour of a euthanasia draft bill for further consideration by the congressional health committee and the head of the Senate. The law will try to ensure that a patient with an incurable disease can access this euthanasia process, done no later than one month after the request, pending approval of a team of doctors and a final assessment by another committee. If the law passes in Spain, it will be the fourth country in Europe to adopt this kind of law along with Belgium, Luxembourg and the Netherlands (Health Plan, 2020).

Today, Spanish law does not regulate euthanasia, and doctors' providing assisted suicide or euthanasia would certainly end up convicted. According to the study just reviewed and the recent news about euthanasia, it seems that a majority of the Spanish population along with some members of the government support euthanasia to some degree, moving forward towards its legalisation. The legalisation of euthanasia might provide a response to patients and families facing the suffering and struggles of incurable diseases. Furthermore, its legalisation could give health care providers a new legally approved medical option and protocol to treat and alleviate the suffering of these patients and possibly better respond to their preferences and needs. As indicated by Serrano Del Rosal & Heredia Cerro (2018), it is important to consider the process of dying, and a common idea of a good death is socially shared. But as the same authors stated, although this ideal process could be achieved, today it is not yet a legal option in many countries like Spain and regions like Osona in Catalonia.

5.5. COVID-19 Pandemic Update

The seven elements prioritised after the Coronavirus pandemic are depicted in Figure 34 below. On comparing the prioritisation of elements for an IPCS before and after the pandemic, it seems that, overall, most of the elements were still prioritised at the top: having a multidisciplinary team, continuity of care, collaboration and shared information system. However, there are three important differences to point out. First, continuity of care was placed at the top of the elements after the pandemic. Second, there were three elements incorporated into these prioritised top elements after the COVID pandemic: patient-centred care, case management and motivated professionals. Third, there is one element indicated prior to the COVID pandemic, funding and resources, that is not prioritised at the top of the list after the pandemic. These differences will be discussed below.

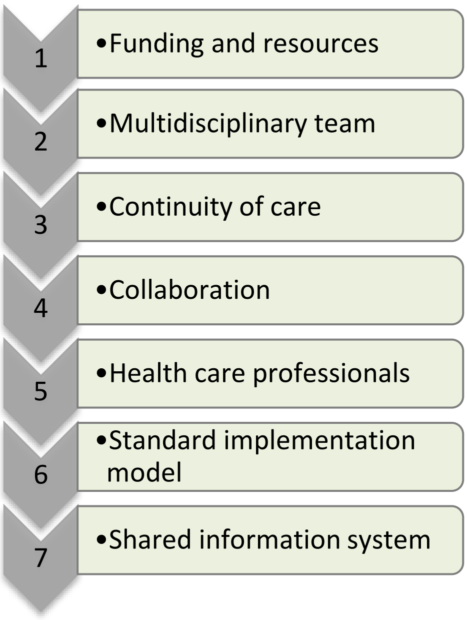


Figure 24. *Priority of IPCS Elements*

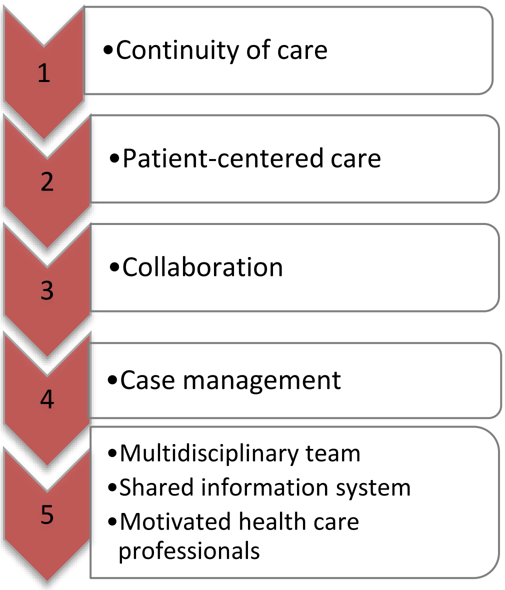


Figure 34. *Priority of IPCS Elements after COVID*

Continuity of care was indicated as the top priority element after COVID since, as providers indicated, ensuring provision of continuous care during day and night was essential for these patients. As previously explained, overcoming fragmentation of care between some levels of care and 24/7 after hours care provision seems to be entail some difficulties in this system. It is therefore is clear that during the pandemic, when more PC patients were isolated at home and unable to access some of their regular care services, such patients would need their homecare and out-of-home providers to be coordinated even more with care at a distance. In order to overcome the care at a distance barrier but still be able to provide collaborative and continuous care, Vidal-Alaball et al. (2020) proposed telemedicine as a suitable tool to connect health care providers both among themselves and with patients.

A shared information system was indicated in the prioritised elements after the COVID pandemic. Telemedicine and multiple communication modalities should be taken into account, as they have been shown to be very useful during the recent Coronavirus pandemic. Telemedicine during the pandemic has helped healthcare professionals to contain the spread of the virus by providing care through videoconferencing and phone, and thus this crisis has shown telemedicine's potential for the future (Vidal-Alaball et al., 2020). It is clear that the pandemic made visible communication and information sharing modalities and care-providing alternatives modes that were not used as often prior to the COVID pandemic. These new ways of caring for the PC patient during the pandemic facilitated in many cases care provision, information sharing, and communication and care continuity.

Patient-centred care, case management and motivated professionals were included as the top elements after the pandemic. It is always important to have these elements, but it is clearly important in times of crisis. As Vidal-Alaball et al. (2020) explained, having the healthcare system overwhelmed with COVID cases might leave other regular patients out of sight, since they are less prioritised during the crisis. However, the other patients still need care and services, and this is especially true for the PC patients that often require a high level of care. As suggested by providers, having appointed people, case managers that assess and monitor individual PC patients and look after these patients' needs and preferences might ensure that these patients needs are fulfilled even during a pandemic.

Motivated professionals are obviously essential during a pandemic. The great effort made by motivated health care professionals to respond to the COVID pandemic patients has been made evident all over the world. It is also important to consider the high levels of stress that health care providers had and are still enduring due to the Coronavirus pandemic. As described by providers, health care professionals had to confront their own fears of getting infected alongside their duty to go to work.

A report by the US department explained the different stressors for health care providers during the COVID outbreak, such as risk of disease transmission, multiple medical demands, employing new biosecurity measures, and stigma placed on them by others because they are caring for COVID patients. The same report stated the need to provide health care workers with training on new COVID measures, as well as with psychological support and stress management strategies in order to ensure their wellbeing (US Department of Veterans Affairs, 2020). The report also said that is essential to keep offering training and support to health care workers in order to keep them well and motivated to go to work, especially during times of crisis like a pandemic.

Finally, it is interesting to highlight that funding, resources and professionals’ training was ranked at the bottom of the priority list after COVID, while it was at the top before the Coronavirus. Funding, training and resources were indicated as important in order to confront a new critical wave of infections in the near future, but still other elements such as collaborative, continued care that is patient-centred and provided by motivated professionals were considered more important during times of crisis. As the World Health Organization (2018) stated, PC should improve the quality of life of patients and families confronting life threatening illnesses. Through the COVID pandemic many patients, families and providers are confronting extreme, critical and some end-of-life situations due to a life-threatening disease. It seems that with the Coronavirus pandemic providers could see clearly how important it is to provide quality care and therefore emphasised the elements that would ensure a better response to patients’ needs.

CHAPTER 6

CONCLUSION

6. CONCLUSION

6.1. Main Conclusions

Today, the ageing population encounters chronic diseases, frailty, cancer, life-threatening conditions, multimorbidity and a longer life span. What is the health care system's response to this new ageing population? The purpose of this research was to explore this response and, specifically, to further study the integrative response by the health care system in the context of Osona, Catalonia. This research is the first to our knowledge that describes in detail the PC system in this area and aims to evaluate its level of integration. The research findings are summarised below.

The OPCS is a medium-sized region in the north of Catalonia, Spain, with the older population counting for 18% of the total, a large group of which suffers from advanced multiple chronic conditions. These ageing individuals are evenly distributed in both urban and rural areas. The system at a structural level is well provided with health care services, professionals and leaders, and there are already several systems, processes, health care policies and plans that regulate care coordination and intervention with PC patients that is cost-efficient.

Coordination is effective among providers and some levels of care, and there is even a coordinating agency called SISO. Continuity of care is well established between primary and intermediate care and a screening tool called NECPAL is used to identify PC patients. The system has an information sharing system, although it was indicated that a unique interoperable system would be better. There is a standardised intervention model that originated from the different health plans in Catalonia and is implemented by competent and trained professionals working in multidisciplinary teams that seek to offer patient-centred care.

Nevertheless, with regard to hindering elements at the structural level it was noted that the OPCS needs a more integrative, continuous and collaborative way of working between care services. The need for earlier patient identification and more specific PC policies, resources, services and professionals was also mentioned.

In order to find the essential elements of an IPCS, a comparison of the study results and the essential elements found in the literature was undertaken. This approach offered a comprehensive way to combine theoretical and practice level views. This combination resulted in the development of the blended model, which integrates the essential IPCS elements gained from a theoretical level and a practice level view from the Osona healthcare providers. This blended model included the following: funding and resources, multidisciplinary teams, continuity of care, collaboration, standard implementation model, shared information system, patient-centred care, education and training, case management, screening tool, policies and leadership, early PC patient detection, PC system cost-efficiency, new specialised PC integrated team, social services, motivated health care professionals, community involvement and patient empowerment.

Additionally, the study identified the integrative elements that the OPCS includes from a service care level view. The ones that are well established are: multidisciplinary teams, leadership, specialised PC intermediate care, motivated professionals, PC for cost-efficiency. Then there are the elements that are included but were also indicated as excluded or needing changes: having a standard screening tool, shared information system, resources, professionals and services, collaboration, early PC patient detection, system continuity, supportive policies, case management, patient-centred care, education and training, PC implementation model. One element, developing a volunteer network, was indicated only in the excluded elements and is therefore one the system definitely does not have.

The integrative elements of the OPCS when combining the structural level and service care level views shows that the common facilitating and included elements are: motivated professionals that work in multidisciplinary teams, having innovative leaders and a specific PC system that is cost-efficient. The hindering excluded or needing change elements are: collaboration, continuity of care, early patient identification and not having the needed funding, professionals and services. Furthermore, due to its context Osona seems to require an improvement in the care services for patients living in rural and distant areas, a better understanding of the multicultural population and the inclusion of respite beds for PC families.

The study also found that most of the elements of an IPCS after the COVID pandemic were still prioritised as the top elements, mainly continuity of care, collaboration, case management, shared information systems, multidisciplinary teams and motivated professionals. The study also highlighted the importance of telemedicine during the Coronavirus pandemic and its future prospects in health care services.

Finally, the study identified the most common ethical dilemmas encountered by providers in the OPCS, ranging from threat to patients’ autonomy by family members or professionals’ decision-making, the decision whether to discontinue or continue nonbeneficial treatments or life-prolonging therapies, poverty and withholding the truth regarding diagnosis from the patient to communication difficulties between the various people involved, palliative sedation, enquiries about euthanasia and opioids usage.

6.2. Recommendations for Practice

The most important recommendations for practice from this research are as follows: improve continuity of care; provide specialised PC training; provide health care workers with multicultural competence; increase early patient identification and intervention; improve the shared information system; ensure patient-centred care; and increase the number of professionals and PC services.

Continuity of care. Continuity of care should be improved in general in the OPCS but especially with social services and between primary care, homecare and acute care services, as was indicated by the study results. In addition, the need for a better 24/7 after hours service was indicated since the efficiency of current services were questioned. As stated by Ramanayake et al. (2016), in order to care for and keep the PC patient at home, provision of homecare visits, after-hour coverage and access to a PC team is required. Secondly, it was noted that half of their older population in Osona lives in rural areas, but it is more difficult for services to arrive to these patients due to distance. The study results suggested that better transportation for these patients and more professionals and services for patients in homecare might improve service coverage and continuity of care in these distant rural areas. Lastly, the need for a new kind of team, called an integrated care team by some, was suggested. This so-called integrated care team would be composed of members from all levels of care and professionals providing service to the patient. As the providers indicated, this kind of team could ensure and efficient and continuity of care for the PC patient.

Specialised PC training and education. Training that is homogenous and continued for PC providers was also suggested by the study results**.** This kind of training could solve other problems identified by the study, such as difficulties in using the screening tool due to mistrust among providers stemming from different usage and understanding of the tool. Proper screening tool usage by all providers involved could ultimately increase PC patient identification rate. Further, training providers in standard implementation interventions and routes for the PC patient could ensure the same interventions and routes for all PC patients.

Multicultural Competence. As indicated in the study, 15% of the population in Osona is of immigrant origin, and this population is projected to grow in the future. As shown in the study results, providers need to better understand their culture and end-of-life processes to better respond to their preferences. Training in multicultural competence could help providers in this matter.

Early patient identification and intervention was indicated as something to improve since the identification rate is currently lower than expected. It seems that providers assume that most PC patients are identified, whereas the statistics show that the number of identified MACA patients has decreased over the years. Another possible explanation for this is that some of these patients are wrongly classified as a PCC, a previous stage of complexity, when in reality they are more advanced in their disease and they are indeed MACA patients. Nevertheless, it is clear that the need to identify PC patients should be an active strategy in order to provide them with the care required and avoid preventable suffering (Ramanayake et al., 2016; Von Roenn et al., 2013). The study showed that there are some difficulties and differences in how the NECPAL identification tool is used by providers, who themselves suggested that more homogeneous training in the tool and identification process might help increase the correct usage and consequently increase the MACA patient identification rate.

Shared information system. The study suggested the use of one single platform for information sharing, which all service levels and professionals are able to access and input information in the same capacity. In addition, the inclusion of new communication modalities such as video meetings, video consultations and chats were mentioned, as they could aid with current population needs. It is clear that after the Coronavirus pandemic, telemedicine has become a useful tool to connect patient and health care providers while ensuring the social distancing measure. As stated by Vidal-Alaball et al., (2020) this pandemic has revealed the potential for telemedicine in the future. It is clear that having an effective shared information system with the use of telemedicine in PC could support and improve communication between providers and patients and could better reach patients in distant rural areas.

Ensure patient-centred care. This is a goal of the various Catalan health care plans and of the professionals. Patient-centred care could be improved by empowering the patient, since a knowledgeable patient might better be able to express their care preferences and needs. In addition, the establishment of a case manager for PC patients might enable the system to provide more individualised care interventions to PC patients. Further, the development of a more direct contact with patients and their community was suggested by professionals. Professionals that meet patients where they reside and volunteers from the patients' community that support the patient might help to provide better PC patient-centred care.

Increase the number of professionals for PC services. The study indicated the need to increase the number of professionals for PC services in general, but also specifically for homecare and rural areas. The need for professionals in the following specialities was also suggested: psychologists, case managers, specialised doctors, physiotherapists, occupational therapists, spiritual counsellors and home health aides. In addition, the study results suggested the need to increase some PC services such as homecare, day centres, the number of beds in nursing homes, and intermediate and respite care. These services could enable some PC patients to receive better care at their home and to remain there longer.

6.3. Limitations of the Study

There were several limitations in this research, both in the data collection and data analysis phases, which will be explained in this section. In the phase I document collection, just 18 documents that described the Osona health care system were found, plus two databases. This might have limited the information regarding some descriptive aspects of the system, since this was the shared and published documentation that was found, but it is very probable that there are more internal reports and documents describing the OPCS to which the researcher did not have access and could not include in the study.

Further, an evaluative framework for PC systems from the literature was used in this research. While this framework seemed appropriate because it was also used by its authors (Bainbridge et al., 2010) to evaluate a medium-sized region PC system in Canada, there might be some different aspects related to the culture, geographical area and the system structure between Canada and Spain. There are, for example, different levels of PC system integration in the mainstream service provision in different countries. In a report by Connor and Sepulveda Bermedo (2014), Spain was classified as being in an earlier stage of IPC development than Canada, which was categorised in the advanced stage. All these differences might not be properly reflected in the evaluative framework and miss some particularities on the Spanish system.

This study collected the views from eight managers, eight nurses, four doctors and four social workers - a total of 24 participants. When combining their areas of specialisation, not their professional role, there were ten doctors, nine nurses and five social workers. It would have been interesting to have more social work professionals included in order to have their view more equally represented. Furthermore, a larger sample size that included more professionals in other disciplines in health care, from all the services in the area, would have provided further insights. However, due to the nature of the qualitative methodology and since it seems to be a novel research project in this region trying to describe the PC system and its integrative level, a smaller sample study might provide the needed information that can be used in a future larger scale study, in which patients could also be included.

Finally, the content analysis of this research was mostly completed by one person, the primary researcher, and her experiences and knowledge might have interfered in the interpretation of the data. To minimize this possibility, discussion with supervisors and external assessment from three different researchers were performed at different stages of the content analysis. Additionally, measures to insure validity credibility, transferability, dependability and validation processes, as indicated by Lincoln & Guba (1985), were used as described in the methodology chapter.

6.4. Recommendations for Future Research

Despite the numerous IPC studies reviewed in the literature, it is evident that this is an incipient and evolving area in PC, and further research is needed to better understand IPCS implementations like the OPCS research undertaken in this study. Successful IPCS implementation studies might help other researchers develop a standard evaluative model for IPCS or guides to assess the level of integration in a system that is applying IPC.

In addition, this research was able to describe in detail the OPCS structure, characteristics and processes of care, from both a structural level and a service care level view. Patients are an important part of the health care process, but in this research their views were not included. Further research on the OPCS or other PC system studies might try to include the patients' perspective to provide a more complete assessment of the health care process.

Future research may also be undertaken to further explore the key elements of an ideal IPCS, as was done in this study with the IPCS elements blended model, which combined data from both a theoretical and practice level, with a larger and more diverse service care level sample. This study was able to combine theory and practice data, but from a small number of professionals and from a specific area in Catalonia. Therefore, a study aiming to combine IPCS data gained both theoretical and practice level and to develop a more comprehensive IPCS elements blended model should undertake a study with a larger number of professionals from diverse regions and cultures.

Furthermore, the findings obtained in this case study could provide information and suggestions to other IPCS. However, this study’s results were very specific to the context and health care system in Osona, and some of the findings might not fully transfer to other systems, areas and regions with different characteristics.

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8. APPENDICES

8.1. **Appendix A.** *Documents List*

	Sources
Documents	
1	Amil, P., Constante, C., González Mestre, A., Sarquella, E., Ledesma, A., Cabezas, C., Zara, C., Contel, J. C., Puigdollers, M., & Blay, C. (2016). Chronic and integrated care in Catalonia. *International Journal of Integrated Care*, *15*(2). https://doi.org/10.5334/ijic.2205
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10	Gómez-Batiste, X., Martínez-Muñoz, M., Blay, C., Amblàs, J., Vila, L., Costa, X., Villanueva, A., Espaulella, J., Espinosa, J., Figuerola, M., & Constante, C. (2012b). Identifying patients with chronic conditions in need of palliative care in the general population: Development of the NECPAL tool and preliminary prevalence rates in Catalonia. *BMJ Supportive and Palliative Care*, *3*(3), 300–308. https://doi.org/10.1136/bmjspcare-2012-000211
11	Gómez-Batiste, X., Martínez-Muñoz, M., Blay, C., Amblàs, J., Vila, L., Costa, X., Espaulella, J., Espinosa, J., Constante, C., & Mitchell, G. K. (2014b). Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: A cross-sectional study. *Palliative Medicine*, *28*(4), 302–311. https://doi.org/10.1177/0269216313518266
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8.2. Appendix B. *Document Analysis Questions and Main Categories*

Main Categories

1. How is the context and environmental factors?
Density
Demography

2. What are the system characteristics and organisations?
Services offered
Membership size
Extent of participation in network among members
Networks ideals (continuity of care)
Policies

3.How is the economic and financial situation?
Network resources
24/7 care
4. What are the providers' characteristics and their level of collaboration?
Cooperation
Perceived Independence (multidisciplinary)
PC Specialty/ training

5. How is the information shared?
Information systems and materials
Standard assessment and monitoring patients
Early assessment and screening tools
6. How are the organisational factors?
Care team composition
Patient-centred care
Standard implementation models
Programme evaluation

8.3. Appendix C. *Questionnaire Questions ENGLISH*

PART 1. Demographic sheet / Information Entity:

MACA Patients with advanced chronic disease

Demographic information:

· Position:
____
· Entity:
____
· Training / specialty: ____
· Number of years working in the current position
____
· Where did you work before taking up this position? ______________________________________
· How many years have you worked in the palliative area and / or with **MACA** patients (advanced chronic disease)? ____

· **Information about your organisation:**

(Estimate numbers and percentages)

· How many professionals work in this entity? __________________________________
· What percentage of these specialise in palliative care and / or provide services to **MACA** patients?
____
· How many users receive services from this entity per year in general? _______________________
· What percentage of these users are **MACA** or palliative patients and receive services in your organisation? ____

PART 2. Description of the Palliative Care System in Osona.

From your point of view, indicate which aspects within these dimensions are strengths or weaknesses, opportunities or threats to your organisation:

Consider:

- **Strengths:** positive aspects within the organisation or entity.
- **Weaknesses:** internal negative aspects of the organisation or entity.
- **Opportunities:** positive external possibilities that could be taken advantage of in the context of existing strengths and weaknesses.
- **Threats:** problems, obstacles or external limitations that may prevent or limit the development of the organisation or entity

MACA Patients with advanced chronic disease
SPCO Palliative Care System of the Osona Region
Answer with three words or short sentences

STRENGTHS	
What aspects does SPCO do well in the process of identifying MACA patients?	- - -
What does the SPCO do well in caring for MACA patients and their families?	- - -
What resources and funding, policies help the SPCO provide a good service to MACA patients?	- - -
What skills and ways of working does the team of SPCO professionals have that facilitate optimal MACA patient care?	- - -
WEAKNESSES	
What aspects could SPCO improve in the process of identifying MACA patients?	- - -
What could the SPCO improve in caring for MACA patients and their families?	- - -
What resources and funding are missing and cause the SPCO to not provide a good service to MACA patients?	- - -
What skills and ways of working does the SPCO team of professionals lack for optimal MACA patient care?	- - -
OPPORTUNITIES	
What external aspects could facilitate the process of identifying MACA patients in the SPCO?	- - -
What external aspects could facilitate the care of MACA patients and their families in the SPCO?	- - -
What external aspects, in terms of resources and funding, could help the SPCO to provide a better service to MACA patients?	- - -

What external factors could help improve the competencies of professionals at the SPCO caring for MACA patients?	- - -
THREATS	
What external aspects hinder the process of identifying patients as MACA in the SPCO?	- - -
What external aspects hinder the optimal care for MACA patients and their families in the SPCO?	- - -
What external aspects, in terms of resources and funding are an obstacle for the SPCO to provide a good service to MACA patients?	- - -
What external aspects hinder the improvement of the competencies of the SPCO professionals who care for MACA patients?	- - -

Appendix C. *Questionnaire Questions CATALAN*

PART 1. Full demogràfic/ Informació Entitat:

MACA-Pacient amb malaltia crònica avançada
Informació demogràfica:

- Càrrec:____
- Entitat:____
- Formació/especialitat:____
- Número d'anys treballant en el càrrec actual?_________________________________
- De què va treballar abans d'adquirir aquest càrrec?______________________________
- Quants anys ha treballat a l'àrea pal·liativa i/o amb pacients **MACA (**malaltia crònica avançada?____
- Ha rebut formació específica en cures pal·liatives o malalties cròniques avançades? Quines?

____

Informació de la seva entitat:
(estimi números i percentatges)

- Quants professionals treballen en aquesta entitat?______________________________
- Quin percentatge d'aquests està especialitzat en cures pal·liatives i/o donen serveis a pacients **MACA**?____
- Quants usuaris reben serveis d'aquesta entitat a l'any en general?____________________
- Quin percentatge d'aquests usuaris són **MACA** o malalts pal·liatius i reben serveis a la seva entitat?____

PART 2. Descripció Sistema de Cures Pal·liatives a Osona.

Des de el seu punt de vista, indiqui quins aspectes dins d'aquestes dimensions són fortaleses o debilitats , oportunitats o amenaces a la seva entitat:

Consideri:
- **Fortaleses (punts forts):** aspectes positius interns a l'organització o entitat.
- **Debilitats (punts febles):** aspectes negatius interns de l'organització o entitat.
- **Oportunitats :** possibilitats externes positives de les que es podria treure'n profit en el context de les fortaleses i debilitats existents.
- **Amenaces:** problemes, obstacles o limitacions externes que poden impedir o limitar els desenvolupament de l'organització o entitat

MACA-Pacient amb malaltia crònica avançada
SPCO- Sistema Pal·liatiu de la Comarca d'Osona
Respón amb paraules o frases curtes màxim tres per categoria:

FORTALESES	
Quins aspectes fa bé el SPCO en el procés d'identificar els pacients MACA?	- - -
Què fa bé el SPCO en l'atenció al pacient MACA i a les seves famílies?	- - -
Quins recursos i finançament, polítiques ajuden al SPCO a donar un bon servei al pacient MACA?	- - -
Quines competències i maneres de treballar té l'equip de professionals del SPCO que faciliten una atenció òptima al pacient MACA?	- - -
DEBILITATS	
En quins aspectes podria millorar SPCO en el procés identificar els pacients MACA	- - -
En què podria millora el SPCO en l'atenció al pacient MACA i a les seves famílies?	- - -
Quins recursos i finançament falten i fan que el SPCO no doni un bon servei al pacient MACA?	- - -
Quines competències i maneres de treballar li falten a l'equip de professionals del SPCO per a una atenció òptima al pacient MACA?	- - -
OPORTUNITATS	
Quins aspectes externs podrien afavorir el procés d'identificar els pacients MACA en el SPCO?	- - -
Quins aspectes externs podrien afavorir l'atenció al pacient MACA i a les seves famílies en el SPCO?	- - -
Quins aspectes externs, a nivell de recursos i finançament, podrien ajudar al SPCO a donar un millor servei al pacient MACA?	- - -

Quins aspectes externs podrien ajudar a millorar les competències del professionals del SPCO que atenen els pacients MACA?	- - -
AMENACES	
Quins aspectes externs desafavoreixen el procés d'identificar els pacients MACA en el SPCO?	- - -
Quins aspectes externs desafavoreixen l'atenció òptima al pacient MACA i a les seves famílies en el SPCO?	- - -
Quins aspectes externs, a nivell de recursos i finançament són un obstacle pel SPCO per a donar un bon servei al pacient MACA?	- - -
Quins aspectes externs obstaculitzen la millora de les competències del professionals del SPCO que atenen els pacients MACA?	- - -

8.4. Appendix D. *Interview ENGLISH*

Interview

MACA patients with advanced chronic disease
SPCO Palliative System of the Region of Osona

1. Imagine a perfect or ideal model of an integrated palliative care system that is for MACA patients (advanced chronic patients). What elements should it have?

Please specify, within this perfect / ideal model of an integrated palliative care system for MACA patients, what these factors would be / how would they function? (if not stated above):

- **professionals** providing palliative services in an integrated system.
- **collaboration** within the system of an integrated system.
- **sharing information** within an integrated system.
- **patient detection**
- **organisation** in the system as an integrated system.
- the **services** offered to palliative patients

2. If you think about these elements for an ideal/perfect integrated palliative care system:
2.1. Please tell me which of them would be the **most important** elements, from the most to least important? And why?

3. Now I would like you to think about the SPCO. Comparing the SPCO with an Ideal Integrated Palliative Care System, what factors/elements <u>does the SPCO have</u> as an integrated palliative care system for the MACA patient?

3.1. What factors / elements mentioned above are missing or lacking in the SPCO? Why don't we have them?

4. Please tell me, from the factors / elements mentioned, which would be the most important to have (from the most to least important) given the context of the system in the Osona region (due to its geography, population, culture etc)

5. In your professional practice, what kind of ethical dilemmas (complicated situations as a professional) do you find yourself in when providing integrated services to the palliative patient with advanced chronic disease?

Appendix D. *Interview CATALAN*

Entrevista

Entrevista

MACA-Pacient amb malaltia crònica avançada
SPCO- Sistema Pal·liatiu de la Comarca d'Osona

1. Et pots imaginar un model perfecte o ideal de sistema integrat de cures pal·liatives i per pacients MACA (malats crònics avançats).Quins elements hauria de tenir? Desenvolupa-ho.
Especifica dins d'aquest model perfecte/ideal de sistema integrat de cures pal·liatives i pel pacient MACA. Digue'm com serien/funcionen? (si no s´han esmentat anteriorment):
-**els professionals** donant serveis pal·liatius en un sistema integrat.
-la col·laboració dins el sistema d'un sistema integrat.
-el **compartir informació** dins d'un sistema integrat.
- **Detecció** de pacients
-l'organització del sistema com a sistema integrat.
-els **serveis** oferts al pacients pal·liatius
2. Pensa en aquest factors elements d'un sistema integrat de cures pal·liatives ideal
2.1. **Digue'm**, dels factors/elements esmentats, quins serien els elements **més importants** en ordre de més a menys? I perquè?

3. Ara vull que pensis en el SPCO . Comparant el SPCO amb un Sistema Ideal integrat de cures pal·liatives. Quins factors/elements té el SPCO com a sistema integrat de cures pal·liatives pel pacient MACA ?
3.1. Quins factors/elements esmentats anteriorment li falten o no té al SPCO? Perquè no els tenim?

4. Digue'm, dels factors/elements esmentats, quins serien els elements més importants a tenir (en ordre de més a menys) pel context del sistema a la comarca d'Osona (els tinguem o no)?

5. En la teva pràctica professional, en quin tipus de dilemes ètics (situació complicades com a professional) us trobeu alhora de donar serveis integrats al malalt pal·liatiu o amb malaltia crònica avançada?

8.5. Appendix E. *COVID Questionnaire ENGLISH*

The following are the elements that you identified as necessary for an ideal integrated palliative care system:

- Multidisciplinary teams and the creation of an integrative team for all services for the palliative care patient or MACA.
- Specific funding for palliative care and a single funding model.
- A unique shared information system with the use of multiple modes of communication between professionals and users.
- Collaboration between professionals with a unique vision for the user.
- Standard intervention models for the MACA patient with specific routes.
- Continuous palliative care between all services, with 24/7 services.
- Patient-centred care.
- Case management.
- Education and specific training in palliative care for professionals.
- Use of a standard tool to detect the MACA patient.
- Specialised palliative care that may be more economically efficient for the system.
- Specific policies for palliative care.
- Detection and intervention with the MACA patient in the early stages of the disease.
- Intervention of professionals in the community, support of volunteers.
- Patient empowerment.
- Professionals motivated to work with the MACA patient.

1- Indicate in numerical order which 5 elements you would prioritise for an integrated palliative care system as a result of the COVID pandemic.
No. Prioritisation

	Multidisciplinary teams and the creation of an integrative team for all services for the palliative patient or MACA.
	- Specific funding for palliative care and a single funding model.
	- A unique shared information system, use of multiple modes of communication between professionals and users.
	- Collaboration between professionals with a unique vision for the user.
	- Standard intervention models for the MACA patient with specific routes.
	- Continuous palliative care between all services, with 24/7 services.
	- Patient-centred care.
	- Case management.
	- Education and specific training in palliative care for professionals.
	- Use of a standard tool to detect the MACA patient.
	- Specialised palliative care that may be more economically efficient for the system.
	- Specific policies for palliative care.
	- Detection and intervention with the MACA patient in the early stages of the disease.
	- Intervention of professionals in the community, support of volunteers.
	- Patient empowerment.
	- Professionals motivated to work with the MACA patient.

2- Why would you prioritise these five? Please explain.
3- Is there any item you would add that is not on this list? Why?
4- What ethical dilemmas do you think health personnel have encountered as a result of the pandemic?

Appendix E. *COVID Questionnaire CATALAN*

El següents són els elements que vau identificar com a necessaris per un sistema ideal de cures pal·liatives integrades:

- Equip multidisciplinaris i creació d'un equip integrador de tots els serveis pel pacient pal·liatiu o MACA.
- Finançament específic per cures pal·liatives i un únic model de finançament.
- Únic sistema d'informació compartida amb utilització de múltiples modalitats de comunicació entre professionals i amb usuaris.
- Col·laboració entre professionals amb una visió única per l'usuari.
- Models d'intervenció estàndards pel pacient Maca amb rutes específiques.
- Cures pal·liatives continuades entre tots els serveis, amb serveis 24/7.
- Cures centrades en el pacient.
- Gestió de casos.
- Educació i entrenament específic en cures pal·liatives pels professionals.
- Utilització d'una eina estàndard per detectar el pacient MACA.
- Cures pal·liatives especialitzades que poden ser econòmicament més eficients pel sistema.
- Polítiques específiques per les cures pal·liatives.
- Detecció i intervenció en el pacient MACA als primers estadis de la malaltia.
- Intervenció dels professionals a la comunitat, suport de voluntaris.
- Apoderament del pacient.
- Professionals motivats per treballar amb el pacient MACA.

1- Indica amb ordre numeral quins <u>5 elements</u> prioritzaries per un sistema de cures pal·liatives integrades com a conseqüència de la pandèmia de la COVID.

Nº. Priorització

	Equip multidisciplinaris i creació d'un equip integrador de tots els serveis pel pacient pal·liatiu o MACA.
	- Finançament específic per cures pal·liatives i un únic model de finançament.
	- Únic sistema d'informació compartida amb utilització de múltiples modalitats de comunicació entre professionals i amb usuaris.
	- Col·laboració entre professionals amb una visió única per l'usuari.
	- Models d'intervenció estàndards pel pacient Maca amb rutes específiques.
	- Cures pal·liatives continuades entre tots els serveis, amb serveis 24/7.
	- Cures centrades en el pacient.
	- Gestió de casos.
	- Educació i entrenament específic en cures pal·liatives pels professionals.
	- Utilització d'una eina estàndard per detectar el pacient MACA.
	- Cures pal·liatives especialitzades que poden ser econòmicament més eficients pel sistema.
	- Polítiques específiques per les cures pal·liatives.
	- Detecció i intervenció en el pacient MACA als primers estadis de la malaltia.
	- Intervenció dels professionals a la comunitat, suport de voluntaris.
	- Apoderament del pacient.
	- Professionals motivats per treballar amb el pacient MACA.

2- Per què prioritzaries aquest cinc? Explica

3- Hi ha algun element que afegiries que no està en aquesta llista? Per què?

4- Amb quins dilemes ètics creus que s'ha trobat el personal sanitari a conseqüència de la pandèmia

8.6. Appendix F. *Matrix Documents Categories Definitions*

The following definitions were obtained from the framework used in the study and developed by (Bainbridge et al., 2016).

- **How is the context and environmental factors?**
  -Density: population distribution considering urban and non-urban areas.
    -Coding rules: inhabitants total.
  -Demography: population characteristics such as age, ethnicity, income, mortality.
    -Coding rules: information describing the population characteristics.
- **What are the system's characteristics?**
  -Services offered: system and service structure.
    -Coding rules: services, health centres.
  -Membership size: participants within the system, both patients and healthcare workers.
    -Coding rules: participants and professionals.
  -***Extent of participation in the network among members:*** system members involvement within the network.
    -Coding rules: organisation coordination.
  -Networks ideals: networks ideals and philosophy encouraged by system leaders.
    -Coding rules: *ideals, philosophy*
  -Policies: guidelines, rules that support and guide the system's actions.
    -Coding rules: system's plans and networks.
- **How is the economic and financial situation?**
  -Network resources: system's funding, equipment, spaces, technology, hospitals, nursing homes.
    -Coding rules: funding, equipment, technology, health centres.
  -Presence of 24/7 care: around-the-clock PC care coverage.
    -Coding rules: service coverage.
- **What are the providers' characteristics?**
  -Cooperation: professionals engaging in collaborative practices enhancing their relationships and providing a shared care plan and provision.
    -Coding rules: collaboration at different levels of care and entities.
  -Perceived Interdependence: work teams in which professionals depend on each other for care.
    -Coding rules: multidisciplinary teams and case management.
  -Specialty training: palliative care training opportunities to professionals such as skills and education.
    -Coding rules: education and training.
- **How is the information shared?**
  -Information systems and materials: systems that facilitate the exchange of information among professionals, be they technological or others.
    -Coding rules: information sharing documents and platforms.
  -Standard assessment and monitoring: medical tools assessments used to identify patients.
    -Coding rules: patient identification tools.
- **What are the organisational factors?**
  -Care team composition: variety of professionals within the professional team**.**
    -Coding rules: professionals in the care teams.
  -Standard implementation models: same benchmarks to guide professionals working in a client-centred manner.
    -Coding rules: standard models.
- ***Programme evaluation:*** on-going performance and activities assessment.
    -Coding rules: cost-efficiency.

8.7. Appendix G. *Matrix Interviews Categories Definitions*

- ***Multidisciplinary /Interdisciplinary teams,*** as explained by Siouta, Van Beek, et al. (2016), include professionals from different specialities, and disciplines such a doctors, specialists, nurses, psychologists, chaplains, physiotherapists and nutritionists. Teams organised from the inpatient to primary care (Kaye et al., 2015) and within organisations (Gilbert et al., 2012) with a common goal to meet the patients' needs (Kuzmarov & Ferrante, 2011).
  -Coding rules: organisation of professionals *from different specialities, disciplines, levels of care and organisations. The process of being organised in a team.*
  -Anchor sample: *"Teams that include all the professionals involved, such as a doctor, nurse and social worker".*
- ***Case management*** provides comprehensive care for the patient's physical, functional, pharmacological, social, emotional and financial needs (Boeckxstaens et al., 2011) that will interact with patients through care transitions (Kamal et al., 2013).
  -***Coding rules:*** *comprehensive care for all patient dimensions that interacts with patients through care transitions.*
  - Anchor sample: *"A liaison nurse that works with the all the other services".*
- ***Coordination,*** meaning collaboration of services and organisations (Boeckxstaens et al., 2011) between primary and secondary services (Fernando et al., 2014), home services (Kaye et al., 2015) from different specialties (Siouta, Van Beek, Preston, et al., 2016) and across professionals (Lyngsø et al., 2014).
  -***Coding rules: collaboration*** *between professionals, services, specialities and organisations. The* process of working together.
  -Anchor sample: *"The process of collaboration among the professionals from all the services".*
- ***Continuity of care*** can be achieved with the integration of outpatient and inpatient services provided by health systems by bridging across settings (Bull et al., 2012). It is provided between all agents involved in the IPC services (Garralda et al., 2016) and all the health care settings (Von Roenn et al., 2013). The continuity process occurs when there is sharing of patients' documentation electronically, by care conferences, and with electronic, phone and in-person communication within the team members (Kaye et al., 2015).
  -***Coding rules:*** *Services integration, bridging of levels of inpatient care and outpatient services.*
  -***Anchor sample****: "The connectivity of care between the different levels of care that work as a network".*
- ***Early Intervention*** **of IPC** with patients with advanced chronic conditions (Gómez-Batiste et al., 2016) in need of this care (Evans et al., 2015). The identification of these patients should be early on in their disease process (Bone et al., 2016; Davison, 2011; Fernando et al., 2014) by performing early geriatric evaluations (Wilhelmson et al., 2011) and by applying it right at the beginning of diagnosis (Davison, 2011).
  -Coding rules*: Identify patient early on in their disease (by labelling him a palliative care patient (terminal/ advanced chronic) diagnosis.*
  -Anchor sample: *"Detect the MACA patient with the first signs".*
- ***Patient-centred*** means that IPC focuses the care on fulfilling the needs and preferences of patients, their families and caregivers (Lyngsø et al., 2014).
  -Coding rules*: care focuses on the patients' and their families' needs and preferences.*
  -Anchor sample*: "Care that responds to the patients' preferences".*

- ***Training and education*** involves the provision of educational opportunities to promote further learning (Bainbridge et al., 2016). Training and education are necessary for the IPC provider in order to give them confidence in service provision (Freeman et al., 2016) and to develop their competence (Rabow et al., 2015).

  -Coding rules: *develop competencies.*

  -Anchor sample: *"To educate and train these professionals in the PC model".*
- **A standard implementation model** should be applied in IPC direct services and health practices (Bainbridge et al., 2011; Bull et al., 2012; Gilbert et al., 2012). A standard model is a key element for effective care delivery (Bainbridge et al., 2016) and is developed by all stakeholders (Kar et al., 2015).

  -Coding rules: *a standard model is implemented in all care practices by all the professionals. The same model is applied everywhere by all the professionals.*

  -Anchor sample*: "Basic model of care that in which all professionals are trained and that is agreed, explained, repeated and trained by all the professionals, a way of doing, a culture".*
- **Supportive Policies and leadership:** formal and informal guidelines, agreements, rules that guide and support the programme (Bainbridge et al., 2016). Specific policies for IPC are necessary and they need to be established at the national (Freeman et al., 2016; Stjernsward, et al., 2013) and regional level (DeMiglio & Williams, 2013). Leaders that inspire and encourage an optimal process for the organisation's proper functioning (Bainbridge et al., 2016).

  -***Coding rules****: supportive guidelines, rules or professionals that are positive for the programme.*

  -Anchor sample*: "Policies, territorial governance", "leadership", "good leaders that are concerned about PC and provide the other professionals with a lot of feedback".*
- **Shared Information Systems:** structure that facilitates the exchange of information via technology sharing (electronic health records, videoconferencing) or written/visual aids (Bainbridge et al., 2016). This system facilitates the collection, reporting and availability of patient information to care providers (Bull et al., 2012) and it insures effective IPC care delivery (Bainbridge et al., 2016).

  -***Coding rules:*** *system that facilitates exchange of patients' information by all professionals (videoconference, electronic records sharing, written material etc).*

  -***Anchor sample****: "An information sharing system that allows for interconnectivity".*
- ***A standard screening tool*** helps providers to identify the IPC patient and determine prognosis (Gómez-Batiste et al., 2016). It screens for symptoms and assesses the patient (Von Roenn et al., 2013) and generates service referrals (Rabow et al., 2015).

  -Coding rules: tool to identify IPC patient and produce care referral.

  -Anchor sample: *"A screening system that allows us to detect the population that will most need PC".*
- ***Funding* for IPC** financial resources (Bull et al., 2012) is essential at the country and regional level (DeMiglio & Williams, 2013; Stjernsward, et al., 2013). Deficient funding is an inhibitor for IPC and its proper functioning (Bainbridge et al., 2016). *Resources*, both human (Freeman et al., 2016) and social (Morita et al., 2013), are essential for the effectiveness of an IPCS.

  -Coding rules*: finances, human and social resources provided to the IPC system.*

  -Anchor sample: *"To have sedation kits", "more professionals", "more services like rehabilitation".*
- ***Cost-efficiency*** can be the result of the implementation of an IPCS, since it decreases emergency visits and inappropriate admissions, reduces the time in hospitalisation stays, reduces infection acquisition and delirium/confusion development from hospitalisations (Lee & Titchener, 2016). It also reduces the cost of care in general for the IPC patient (Johnstone et al., 2012; Ann H. Partridge et al., 2014; Rabow et al., 2015).

  -***Coding rules:*** *reduces IPC cost for care. Could result from IPC.*

  -***Anchor sample****: "It reduces over diagnosis and overtreatment".*

8.8. **Appendix H.** *Matrix Ethical Dilemmas Categories Definitions*

- **Discontinue life-prolonging therapies:** discontinuation of therapies (Guevara-López et al., 2015; Huang et al., 2018).
  -***Coding rule****: discontinue therapies such as treatments, nutrition, hydration and blood transfusions.*
  -***Anchor sample****: "Up to what point do we need to keep treating and giving medications? When do you decide how to tell the patient that you won't do more imaging, or that they no longer need to take their blood pressure medication".*
- **Use of opioids**: management and use of opioids (overmedication, undermedication) and appropriate limits in their use (Cheon et al., 2015).
  -***Coding rule:*** *opioids use, overmedication, undermedication, appropriate usage limit.*
  -**Anchor sample:** *"sometimes they are in a lot of pain, in agony, but maybe you don't have the services that can help you".*
- **Truth telling.** Nurses and physicians avoid providing information to the patient about prognosis on the basis of not causing harm to patient (Cheon et al., 2015; Guevara-López et al., 2015; Huang et al., 2018). Also, information kept from patients because of families' wishes.
  \- ***Coding rule****: patients' loss of autonomy due to families wishing to keep information from them* (Cheon et al., 2015).
  \- **Anchor sample:** *"and the family insist on not telling the patient about their condition in order to protect them".*
- **Communication difficulties** between healthcare and patients and family, and between patient and family (Cheon et al., 2015).
  Coding rule: communication difficulty among all the members involved: healthcare providers, family and patients.
  \- ***Coding rule****: difficulty in communicating diagnosis to the patient, to avoid causing harm.*
  \- **Anchor sample:** *"when a professional at a service level decides on a more conservative care plan while another group of professionals would like a more intense one" or "when the patient would like a more conservative treatment and the family would like a more aggressive plan".*
- **Provision of futile treatment or non-beneficial care:** using curative treatments when they might no longer be indicated for a patient. Inadequate provision of non-beneficial care by giving/continuing non-beneficial treatments by health providers or due to family wishes (Cheon et al., 2015).
  -***Coding rule****: provide care that no longer might benefit the patient.*
  -**Anchor sample:** "sometimes in the intense care, we have to decided whether or not to do surgery and wonder, what will or won't happen?"
- **Patient autonomy threatened** by decisions made by the healthcare team or family. Loss of patient's autonomy to decide for themselves at the end of life, leading to treatment decisions being taken by professionals when the patient is not competent and there is a need for a rapid response, or by the family if there is excessive family involvement in the process (Bátiz & Loncán, 2006; Cheon et al., 2015).
  -**Coding rule:** *patients' loss of autonomy regarding care due to not being competent, and* decisions made by the health care team or family.
  \- **Anchor sample:** "when, for example, the patient can't decide, and the opinions of the different relatives are different, but you need to agree on a plan with them".

- **Palliative sedation:** Use of analgesia and sedatives. Passive euthanasia can be done by the cessation of therapeutic strategies; or indirect euthanasia (or double effect), where death might be accelerated as a result of sedative and analgesic treatments (Bátiz & Loncán, 2006; Guevara-López et al., 2015).
    -***Coding rule****:* use of analgesics/sedation to accelerate death.
    - Anchor sample: *"in some cases, in the decision to start sedation, I sometimes I doubt if it is the right moment, or if I should have done it before".*
- **Euthanasia**: with the cessation of therapeutic strategies or provided by a healthcare provider.
    -Coding rule: use of cessation of treatment *to accelerate death* (Cheon et al., 2015; Huang et al., 2018).
    - **Anchor sample:** *"when you see the family suffer, and the death process extends and you think why is there no active euthanasia, we do have passive sedations but these long death processes make me think about Euthanasia".*

8.9. **Appendix I.** *Informed Consent Form ENGLISH*

Information sheet for participants

The members of the research team for the doctoral thesis of doctoral student Meritxell Mondejar Pont, led by Anna Ramón Aribau and Xavier Gómez-Batiste, are carrying out the research project: Palliative Care System in the Osona region.

The project aims to evaluate the Palliative Care System in the Osona region. This case study will first review documentation on the subject, and then gather information through a questionnaire and interviews with professionals within these care services. In the context of this research, we are asking for your participation in order to describe the system where you work, as you meet the following inclusion criteria: you are a professional in the Palliative care system in the Osona region.

This collaboration involves participating in both a questionnaire and an interview, or in just one of them. All participants will be assigned a code, which guarantees anonymity and confidentiality. The pseudonymisation system will be destroyed once the analysis is completed to ensure the anonymity of the data. The data obtained from your participation will not be used for any purpose other than that explicit in this research and will become part of a data file for which the main researcher (MR) will be primarily responsible. This data will be protected by storing it in OneDrive, a UVic-UCC server that guarantees data protection, and only the people on the computer will have access to the data.
The data file of the study will be under the responsibility of the MR, before whom you can exercise at all times the rights established by *Organic Law 3/2018, of 5 December, on the Protection of Personal Data and guarantee of digital rights and General Regulation (EU) 2016/679 of 27 April 2016 on data protection and supplementary regulations.*

We are at your disposal to resolve any questions you may have. You can contact the main researcher at any time at this e-mail: meritxell.mondejar@uvic.cat

Informed consent

I, _______________________, of legal age, with DNI, _______________________
acting in my own name and interest I

DECLARE THAT:
I have received information about the project that has been given to me about the Palliative Care system in the Osona region, including the information sheet attached to this consent and for which my participation has been requested. I have understood its meaning, my doubts have been clarified and the actions that derive from it have been explained to me. I have been informed of all aspects related to the confidentiality and protection of data with regard to the management of personal data involved in the project and the guarantees given in compliance with Organic Law 3/2018 of 5 December on the protection of personal data and guarantee of digital rights and General Regulation (EU) 2016/679 of 27 April 2016 on data protection and supplementary regulations.

My collaboration in the project is entirely voluntary and I have the right to withdraw at any time, I have the right to withdraw at any time, revoking this consent, and without this action affecting me negatively in any way. In case of withdrawal, I have the right to have my data deleted from the study file.
With all this taken into account, I GIVE MY CONSENT:

1. To participate in the research project: Palliative Care System in the Osona region.
2. That the research team for the doctoral thesis of doctoral student Meritxell Mondejar Pont, directed by Anna Ramón Aribau and Xavier Gómez-Batiste, can manage my personal data and disseminate the information generated by the project. It is guaranteed that my identity and privacy will be preserved at all times, with the guarantees established in Organic Law 3/2018, of 5 December, on the protection of personal data and guarantee of digital rights and General Regulation (EU) 2016 / 679, of 27 April 2016, on data protection and complementary regulations.
3. That the main researcher keep all records made of me in electronic form, with the guarantees and terms provided by law, if established, and in the absence of legal provision, for the time necessary to fulfill the functions of the project for those whose data were collected.

_______________, a___________________
[CITY] , a [DAY / MONTH / YEAR]

_______________________ ___________________________
[PARTICIPANT SIGNATURE] [MR SIGNATURE]

Appendix I. *Informed Consent Form CATALAN*

Full d'informació per als participants

Els membres de l'equip d'investigació per a la tesi doctoral de la doctoranda Meritxell Mondejar Pont, dirigida per Anna Ramón Aribau i Xavier Gómez- Batiste, portem a terme el projecte d'investigació: Sistema de serveis pal·liatius a la comarca d'Osona.

El projecte ha d'avaluar el sistema de Serveis pal·liatius a la comarca d'Osona. Aquest estudi de cas en primer lloc, revisarà documentació sobre el tema i, en segon lloc, recollirà informació a través de: un qüestionari, i entrevistes a professionals dins d'aquests serveis.

En el context d'aquesta investigació li demanem la seva col·laboració per a que hi participi amb l'objectiu que descrigui el sistema a on treballa ja que vostè compleix els següents criteris d'inclusió: és un professional en el sistema de serveis pal·liatius a la comarca d'Osona.

Aquesta col·laboració implica participar en: un qüestionari, una entrevista o una de les dues coses. Tots els participants tindran assignat un codi pel qual és impossible identificar al participant amb les respostes donades, garantint totalment la confidencialitat. El sistema de pseudonimització, es destruirà un cop finalitzat l'anàlisi per assegurar l'anonimat de les dades. Les dades que s'obtindran de la seva participació no s'utilitzaran amb un altre fi diferent de l'explicitat en aquesta investigació i passaran a formar part d'un fitxer de dades del que serà màxim responsable l'investigador principal. Aquestes dades quedaran protegides mitjançant el seu emmagatzematge al OneDrive un servidor de la UVIC que garanteix la protecció de dades i únicament les persones de l'equip tindran accés a les dades.

El fitxer de dades de l'estudi estarà sota la responsabilitat de l'IP davant del qual podrà exercir en tot moment els drets que estableix la Llei Orgànica 3/2018, de 5 de desembre, de Protecció de Dades Personals i garantia dels drets digitals i el Reglament general (UE) 2016/679, de 27 d'abril de 2016, de protecció de dades i normativa complementària.

Ens posem a la seva disposició per resoldre qualsevol dubte que la mateixa hagi suscitat. Pot contactar en qualsevol moment amb la investigadora principal al correu electrònic: meritxell.mondejar@uvic.cat

Consentiment informat

Jo, ______________________, major d'edat, amb DNI,________________________

actuant en nom i interès propi

DECLARO QUE:

He rebut informació sobre el projecte Sistema de serveis pal·liatius a la comarca d'Osona del que se m´ha lliurat el full informatiu annex a aquest consentiment i pel qual es sol·licita la meva participació. He entès el seu significat, se m'han aclarit els dubtes i m'han estat exposades les accions que es deriven del mateix. Se m'ha informat de tots els aspectes relacionats amb la confidencialitat i protecció de dades pel que fa a la gestió de dades personals que comporta el projecte i les garanties donades en compliment de la Llei orgànica 3/2018 de 5 de desembre de protecció de dades personals i garantia dels drets digitals i el Reglament general (UE) 2016/679, de 27 d'abril de 2016, de protecció de dades i normativa complementària.

La meva col·laboració en el projecte és totalment voluntària i tinc dret a retirar-me'n en qualsevol moment, revocant aquest consentiment, sense que aquesta retirada pugui influir negativament en la meva persona en cap cas. En cas de retirada, tinc dret a què les meves dades siguin cancel·lades del fitxer de l'estudi.

Per tot això, DONO EL MEU CONSENTIMENT A:

1. Participar en el projecte Sistema de serveis pal·liatius a la comarca d'Osona

2. Que l'equip d'investigació per a la tesi doctoral de la doctoranda Meritxell Mondejar Pont, dirigit per Anna Ramón Aribau i Xavier Gómez-Batiste puguin gestionar les meves dades personals i difondre la informació que el projecte generi. És garanteix que es preservarà en tot moment la meva identitat i intimitat, amb les garanties establertes a la Llei orgànica 3/2018, de 5 de desembre, de protecció de dades personals i garantia dels drets digitals i el Reglament general (UE) 2016/679, de 27 d'abril de 2016, de protecció de dades i normativa complementària.

3. Que la investigadora principal conservi tots els registres efectuats sobre la meva persona en suport electrònic, amb les garanties i els terminis legalment previstos, si estiguessin establerts, i a falta de previsió legal, pel temps que fos necessari per complir les funcions del projecte per les que les dades fossin

Recaptades.

________________ , a____________________

[CIUTAT] , a [DIA/MES/ANY]

________________________ ____________________________

[SIGNATURA PARTICIPANT] [SIGNATURA IP]

8.10. **Appendix J.** *Research Ethics Committee Favourable Decision Letter. ENGLISH*

CER
Comitè d'ètica
de la Recerca
Uvic Ucc

Report opinion
Favorable research project
Internal code: 80/2019 10
June 2019

Dr. Jordi Collet Sabé
President of the Ethics Committee for Research at UVic-UCC

CERTIFIES

That CER UVic-UCC at its meeting on 1 April 2019, has evaluated the project: research
Title: Palliative Care System
Code: 80/2019.
IP: Meritxell Mondejar Pont.

It considers that: -
The necessary requirements of suitability in relation to the objectives and the methodological design are fulfilled.
-Ethical requirements are met, both in obtaining informed consent and in aspects related to confidentiality.
-The competence of the IPs and the available means are appropriate to develop the study.

Therefore the CER issues a FAVORABLE DECISION.

10/06/2019
Signature of the President

Appendix J. *Research Ethics Committee Favourable Decision Letter. CATALAN*

CER
Comitè d'Ètica
de la Recerca
UVIC·UCC

Informe dictamen favorable
Projecte d'investigació
Codi intern: 80/2019
10 de juny de 2019

Dr. Jordi Collet Sabé
President del Comitè d'Ètica de la Recerca de la UVic-UCC

CERTIFICA

Que el CER de la UVic-UCC en la seva reunió del dia 1 d'abril de 2019, ha avaluat el projecte de recerca:
Títol: Sistema de serveis pal·liatius.
Codi Intern: 80/2019.
IP: Meritxell Mondejar Pont.

Considera que:
-Es compleixen els requisits necessaris d'idoneïtat en relació amb els objectius i el disseny metodològic.
-Es compleixen els requisits ètics, tant en l'obtenció del consentiment informat com en els aspectes vinculats a la confidencialitat.
-La competència de les IP i els mitjans disponibles són apropiats per a desenvolupar l'estudi.

Per la qual cosa el CER emet un **DICTAMEN FAVORABLE**[1].

10/06/2019
Firma del president

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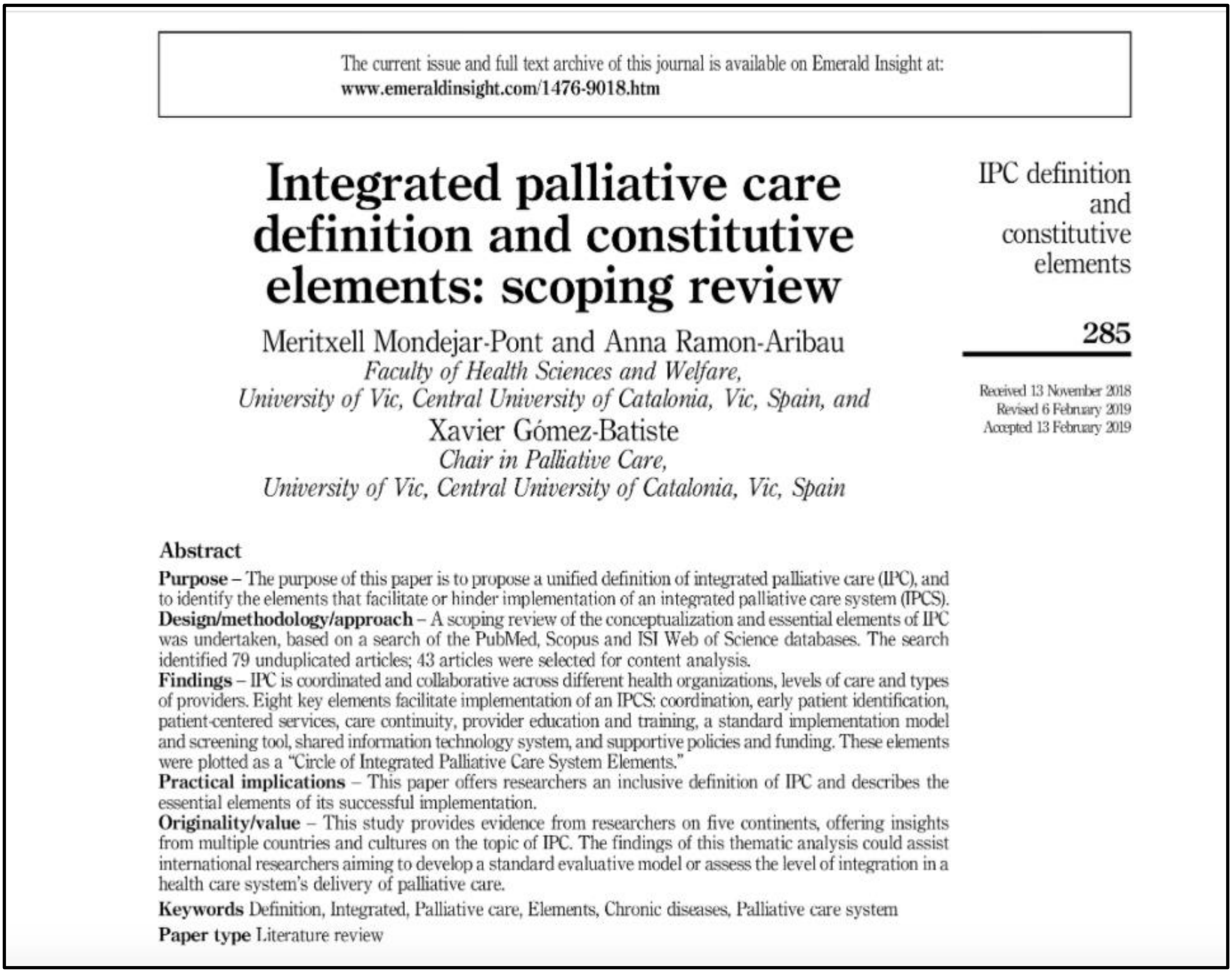
[1] Un dictamen favorable comporta per l'investigador principal les següents obligacions:
a) Presentar, si escau, el projecte a convocatòries externes (competitives o no) amb els mateixos elements essencials que han estat avaluats favorablement pel CER.
b) Desenvolupar, si escau, el projecte amb els mateixos elements essencials que han estat avaluats favorablement pel CER.
c) Presentar una memòria justificativa de compleció del projecte a la seva finalització, incloent un resum de màxim 5000 caràcters i tots els documents que es consideri necessari fer arribar al CER. Aquest material es conservarà als arxius de la UVic-UCC per a futures revisions.

8.11. Appendix K. *Article. Integrated palliative care definition and constitutive elements: Scoping Review. In Journal of Integrated Care (2019)*



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Integrated palliative care definition and constitutive elements: scoping review

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Abstract

Purpose – The purpose of this paper is to propose a unified definition of integrated palliative care (IPC), and to identify the elements that facilitate or hinder implementation of an integrated palliative care system (IPCS).
Design/methodology/approach – A scoping review of the conceptualization and essential elements of IPC was undertaken, based on a search of the PubMed, Scopus and ISI Web of Science databases. The search identified 79 unduplicated articles; 43 articles were selected for content analysis.
Findings – IPC is coordinated and collaborative across different health organizations, levels of care and types of providers. Eight key elements facilitate implementation of an IPCS: coordination, early patient identification, patient-centered services, care continuity, provider education and training, a standard implementation model and screening tool, shared information technology system, and supportive policies and funding. These elements were plotted as a "Circle of Integrated Palliative Care System Elements."
Practical implications – This paper offers researchers an inclusive definition of IPC and describes the essential elements of its successful implementation.
Originality/value – This study provides evidence from researchers on five continents, offering insights from multiple countries and cultures on the topic of IPC. The findings of this thematic analysis could assist international researchers aiming to develop a standard evaluative model or assess the level of integration in a health care system's delivery of palliative care.

Keywords Definition, Integrated, Palliative care, Elements, Chronic diseases, Palliative care system
Paper type Literature review

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