

Palliative care integration for patients with advanced chronic obstructive pulmonary disease (COPD): An action research study

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

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**ABSTRACT**

**FACULTY OF HEALTH AND MEDICINE**

Doctor of Philosophy

**PALLIATIVE CARE INTEGRATION FOR PATIENTS WITH ADVANCED  
CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD): AN ACTION  
RESEARCH STUDY**

by Tanja Fusi-Schmidhauser

**Background:** Chronic obstructive pulmonary disease (COPD) is a life-limiting condition where patients have palliative care needs. Despite increasing awareness about the role palliative care could play in care provision for patients with advanced COPD, integration in standard care remains underdeveloped. The disease unpredictability and misconceptions about palliative care being only relevant for patients in oncological settings and being equivalent to end-of-life care prevent a timely integrated approach in advanced COPD.

**Aim:** To understand how to integrate palliative care provision for patients with advanced COPD in a respiratory care service in Southern Switzerland.

**Methods:** A participatory action research approach was conducted in two sequential phases. Phase I explored the experiences and perceptions of five advanced COPD patients and five informal carers during the illness trajectory. Phase II focused on developing knowledge on palliative care integration in advanced COPD through six action research cycles with healthcare professionals working in both palliative (three healthcare professionals) and respiratory care settings (four healthcare professionals).

**Results:** Living day to day with COPD, psychosocial dimension of the disease and management of complex care were the main themes identified in the first phase of the study. During the second phase key elements of integrated palliative care in advanced COPD such as multidimensional assessment, healthcare professionals' education, interdisciplinary team meetings and knowledge dissemination were identified. These elements converged in a new integrated palliative care model for patients with advanced COPD.

**Conclusion:** The new integrated palliative care model in advanced COPD includes essential elements with a focus on patients, healthcare professionals and care delivery. Further research on model testing in clinical practice, service development, implementation processes and possible outcomes, including evaluation of the financial impact of integrated palliative care provision is necessary to foster this care approach across all possible settings.

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## Abbreviations

COPD	Chronic obstructive pulmonary disease
CIG	Collaborative inquiry group
ESCR	Economic and Social Research Council
GOLD	Global Initiative for Chronic Obstructive Lung Disease
IC (number)	Informal carer (number)
InSup-C	The Integrated Palliative Care in Cancer and Chronic Conditions Study
MeSH	Medical Subject Heading
NHS	National Health System
NICE	National Institute of Clinical Excellence
OECD	Organisation for Economic Cooperation and Development
P (number)	Patient (number)
Pa (number)	Participant (number)
PC	Palliative care
PhD	Doctor of Philosophy
SIAARTI	Società Italiana di Anestesia, analgesia, rianimazione e terapia intensiva
SPICT	Supportive and Palliative Care Indicators Tool
SPLF	Société de Pneumologie de Langue Française
ToC	Theory of Change
WGEC	Working Group of the Swiss Ethical Committees for Research with Human Subjects
WHO	World Health Organization

## **CHAPTER 1: INTRODUCTION**

In this chapter the research context is briefly introduced, the research aim is described and the research question is stated. The thesis development and the description of each chapter are outlined in the last section.

### **1.1 The research context**

COPD is a leading cause of worldwide morbidity and mortality in adults (World Health Organization, WHO, 2014). Advanced disease is characterised by a decline in overall function, a progressive loss of independence and an important multidimensional symptom burden (Hayle et al., 2013). Although the recognition of COPD as a life-limiting condition with palliative care needs is increasing, palliative care provision in COPD remains difficult (Elkington et al., 2004). The disease unpredictability, the misconceptions about palliative care being restricted to cancer and perceived to be only relevant in the last days of life prevent a timely integrated care plan for patients with advanced COPD (Pinnock et al., 2011). Integrated palliative care aims to create continuity of care within a patient's care network, thus avoiding care fragmentation within all actors involved (Siouta et al., 2016; Siouta et al., 2016a). This research tried to answer the question on how to integrate palliative care provision for patients with advanced COPD in a respiratory care service in Southern Switzerland through a participatory action research approach.

### **1.2 Research aim and research question**

This study addressed one specific research aim: to understand how to integrate palliative care provision for patients with advanced COPD in a respiratory care service in Southern Switzerland.

Specific objectives identified were:

1. To review the current practices in palliative care provision for patients with advanced COPD
2. To assess different modalities for palliative care integration in COPD
3. To explore facilitators and barriers for palliative care provision and integration in COPD
4. To explore patients' and informal carers' experiences in living with advanced COPD
5. To use collaborative working methods to develop a new model for palliative care integration in advanced COPD

The first three objectives were addressed by the literature review of this thesis, while objective four was addressed by phase I and objective five by phase II of this research.

The focus of this study was integrated care, the process to understand was the organisational change for care integration. Therefore, the research aim was addressed through the formulation of a specific research question: how to integrate palliative care provision for patients with advanced COPD in a respiratory care service in Southern Switzerland?

### **1.3 Researcher's voice**

As a senior consultant in palliative medicine and internal medicine specialist, I am interested in research about palliative care integration in non-oncological settings, especially in the respiratory care field. During this participatory action research study, my own voice as a researcher and as a clinician was heard and acknowledged through reflexivity. This explains the use of first-person pronouns in this thesis, as my role and

my voice as researcher are described and reviewed. These aspects and the process of reflexivity are explored more explicitly in the methodology chapter of this thesis (chapter four).

## **1.4 Thesis outline**

The thesis will be structured in eight chapters (including the current one), each chapter focusing on a different aspect of the research process.

### **1.4.1 Chapter 2: Background**

The research within the fields of COPD, palliative care and care integration is contextualised in chapter two. Furthermore, policies and practices of palliative care delivery in advanced COPD are explored, showing what is lacking in care provision. In the last sections, national and regional palliative care provision in Switzerland are outlined and the local setting where the research was conducted is described.

### **1.4.2 Chapter 3: Literature review**

In chapter three the available knowledge on palliative care provision and integration in advanced COPD is introduced through a systematic integrative literature review, identifying knowledge gaps to be addressed by this research.

### **1.4.3 Chapter 4: Theoretical and Methodological Perspectives**

The conceptual lens and the epistemological and ontological foundations of this research are presented in chapter four. The methodological choices made are justified and action research as a research methodology in healthcare and within this research is contextualised.

#### **1.4.4 Chapter 5: Methods and Results Phase I**

Methods and findings of the first research phase (interviews with patients and informal carers) are described in chapter five.

#### **1.4.5 Chapter 6: Methods and Results Phase II**

Methods and findings of the second research phase (action research cycles with a collaborative inquiry group) are described in chapter six.

#### **1.4.6 Chapter 7: Discussion**

Main findings from both research phases are summarised in chapter seven, while critically contextualising them within the available literature. Furthermore, synthesis and interpretation of findings on palliative care integration and service development for patients with advanced COPD in Southern Switzerland are presented and future developments and research limitations are discussed in the last sections of this chapter.

#### **1.4.7 Chapter 8: Conclusion**

In the last chapter of this thesis the new evidence which arose from this research is reiterated and implications for practice and recommendations for future work are suggested.

Citation and Referencing are based upon the conventions set by the Harvard Referencing System (Lancaster University Library, 2019).

## CHAPTER 2: BACKGROUND

In this chapter the research is contextualised within the fields of COPD and palliative care and care integration for patients with life-limiting diseases is explained.

Furthermore, current policies and practices of palliative care delivery in advanced COPD are outlined, with particular attention to what is lacking, thus justifying the importance of this research for the understanding of collaborative palliative care delivery in advanced COPD. In the last section of this chapter the research is positioned within the local context in Southern Switzerland, where it was developed and conducted.

### 2.1 COPD: an overview

COPD is a leading cause of worldwide morbidity and mortality in adults (WHO, 2014). A recent health status report confirmed that respiratory diseases account for 8% of all deaths in countries in the European Union, thus representing the third main cause of mortality (Organization for Economic Cooperation and Development, OECD, 2018). COPD and pulmonary infections account for 70% of all respiratory diseases related deaths, with pneumonia being often a complication of advanced COPD (OECD, 2018). Estimated future projections predict that COPD will become the third leading cause of death worldwide in 2030, further increasing its economic and social burden (WHO, 2014; Global Initiative for Chronic Obstructive Lung Disease, GOLD, 2017). Nonetheless, it is difficult to estimate the global prevalence of COPD, because of the variation across countries and differences among the population in relation to health and socioeconomic status within a nation (Adeloye et al., 2015; GOLD, 2017). Furthermore, according to international epidemiological studies performed over the last 20 years (Yach et al., 2004; Løkke et al., 2006), COPD prevalence data also show

inconsistencies related to differences in methodology, data collection and diagnostic criteria for COPD across published studies. The latter may also reflect an under-recognition and subsequent underdiagnosis of COPD and its related overall disease impact (Halbert et al., 2006).

COPD is defined as a “common, preventable and treatable disease that is characterised by persistent respiratory symptoms and airflow limitation that is due to airway and/or alveolar abnormalities usually caused by significant exposure to noxious particles or gases” (GOLD, 2017, p. 2). The pathophysiology of COPD may be illustrated through four distinct features: airflow limitation, lung hyperinflation, impaired gas exchange and alteration of the pulmonary circulation with pulmonary hypertension (Braunwald et al., 2001). Several risk factors were identified as triggers for the disease development and its progression (Gershon et al., 2011). Tobacco smoking strongly correlates with the incidence and prevalence of chronic bronchitis and emphysema (Afonso et al., 2011). Genetic background, age, gender, lung growth and development, exposure to particles and infections are among other factors which may play a role in the pathophysiological pathway of COPD, thus possibly modifying its natural history (GOLD, 2017). Moreover, population-based characteristics such as social and material deprivation and low level of education were identified as risk factors for the development of COPD (Pandolfi et al., 2015; Kaul et al., 2018).

The overall severe disease burden is defined by the natural history of COPD, which is characterised by chronic airway inflammation with mucus production (“productive” cough) and the constant loss of lung function, with subsequent breathlessness and impaired exercise tolerance (Barrecheuren and Miravittles, 2014; GOLD, 2017). Furthermore, COPD also results in an overall systemic involvement (Romieu and

Trenga, 2001). The oxygen depletion, the release of pro-inflammatory cytokines and the subsequent oxidative stress at a cellular level are not only responsible for a decline of the global lung function, but also for the systemic manifestations, such as renal and hormonal dysfunction, generalised cachexia and peripheral muscle dysfunction through protein loss (Carter, Tiep and Tiep, 2008).

These aspects explain the high symptom burden reported by COPD patients, among which breathlessness (shortness of breath, dyspnoea) is a key clinical feature (Afonso et al., 2011). Breathlessness directly influences the exercise capacity and is a significant predictor of a reduced functional performance (Reishtein, 2005). Patients with COPD present with shortness of breath, which is progressive and worsens over time, is persistent and increases with physical effort (GOLD, 2017). This leads to unintentional activity limitation, which may be associated with progressive social isolation, increased daily symptom burden and reduction of the perceived quality of life in patients with COPD (O'Donnell et al., 2009).

COPD is a life-limiting illness with an unpredictable disease trajectory (Raghavan et al., 2011). A progressive decline in overall function and a loss of independence in daily life activities which influences health-related quality of life is well-described in this particular healthcare population (Gershon et al., 2011). Moreover, the course of COPD is marked by acute exacerbations, which further deteriorate the overall health status and daily functioning (Murray et al., 2005). As previously described, disease progression in COPD is correlated with an increased symptom burden (Carter, Tiep and Tiep, 2008; Sorenson, 2013). The high prevalence of physical symptoms and psychological distress in advanced COPD is comparable with, or worse than, the symptom burden reported in the lung cancer population (Hayle et al., 2013).

Progressive recognition of COPD as a life-limiting condition with multidimensional needs is increasing among healthcare professionals caring for these patients and their families (Elkington et al., 2004). National and international guidelines for the management of patients with COPD include aspects of multidimensional care, while suggesting a palliative care approach and the involvement of a palliative care team for advanced disease stages (Vogelmeier et al., 2007; Società Italiana di Anestesia, analgesia, rianimazione e terapia intensiva, SIAARTI, 2013; Haute Autorité de santé, 2014; GOLD, 2017). The following section of this chapter focuses on current palliative care policies and guidelines for patients with advanced COPD.

## **2.2 Palliative care policies and guidelines for patients with advanced COPD**

According to statistics from the WHO, each year 40 million people are affected by life-limiting diseases with palliative care needs, however only 14% of those patients have access to and benefit from palliative care provision (WHO, 2017). The WHO considers palliative care as an essential part of comprehensive healthcare service delivery for patients with life-limiting diseases. Therefore, fostering worldwide access to palliative care was the content of a World Health Assembly resolution in 2014 (WHO, 2017).

The development of national palliative care strategies over the last 20 years supported the awareness about palliative care provision and promoted access to palliative care services (Ministry of Health, 2001; Department of Health, 2008; Department of Health, 2010; Federal Office for Public Health, 2013). National strategies tried to define the appropriateness and effectiveness of palliative care interventions, to promote leadership and governance to improve and implement palliative care service provision and to foster training and education about palliative care delivery, both for primary healthcare

providers and specialists in palliative care (Department of Health, 2010; Federal Office for Public Health, 2013).

Furthermore, several national and international initiatives were developed to support healthcare providers in identifying patients with a life-limiting disease who might benefit from palliative care provision (SIAARTI, 2013; Gold Standards Framework, 2016; Gómez-Batiste et al., 2017). The recognition of general indicators of decline and specific clinical indicators for different disease trajectories, such as oncological diseases, organ failure and frailty with multimorbidity might help healthcare providers in all care settings consider the assessment of palliative care needs (Gold Standards Framework, 2016). Nonetheless, even if COPD is recognised as a life-limiting disease with palliative care needs, palliative care provision is seldom integrated in standard care for this population (Pinnock et al., 2011). This is demonstrated by the fact that several national and international guidelines on care provision for patients with COPD published by respiratory care societies, mention the role of palliative care in advanced disease, suggesting a palliative care approach and involvement of a palliative care team (Vogelmeier et al., 2007; National Health System, NHS, 2010; National Institute for Clinical Excellence, NICE, 2010; Société de Pneumologie de Langue Française, SPLF, 2010; Miravittles et al., 2012; Bettoncelli et al., 2014; Montes de Oca et al., 2015; GOLD, 2017). However, except for one specific guideline which proposes palliative care integration for patients with respiratory diseases (Lanken et al., 2008), the other guidelines do not approach how to provide palliative care in advanced COPD services, fostering debates on key components of palliative care delivery in this particular population. In the next sections of this chapter elements of integration of care are described. Furthermore, integration of care is illustrated as a modality to deliver palliative care in advanced COPD.

### **2.3 Integration of care**

The lack of consistency in the definition of care integration is widespread in the available literature. The term “integrated” may define different approaches to care provision, depending on care settings and involved stakeholders (healthcare providers and consumers) (Van der Klauw et al., 2014; Van der Linden, Spreeuwenberg and Schrijvers, 2001).

Integrated care may be defined as the systematic coordination of patient-focused care (Kodner and Spreeuwenberg, 2002). The WHO describes integrated care as “a concept bringing together inputs, delivery, management and organisation of services related to diagnosis, treatment, care, rehabilitation and health promotion, where integration is a means to improve services in relation to access, quality, user satisfaction and efficiency” (Gröne and Garcia-Barbero, 2001, p.7). Care integration may be implemented on three different levels: integration on a health system level, integration on a service (or organisational) level and integration on a clinical, individual-based level (Valentijn et al., 2015). Moreover, care integration within standard care can be implemented through a collaboration between different healthcare professionals in terms of a multidisciplinary approach (horizontal integration) and through the involvement of healthcare providers in different settings (vertical integration between primary, secondary and tertiary care) (Van der Linden, Spreeuwenberg and Schrijvers, 2001). Integration on a service level and on a clinical, individual-level were both aspects considered as essential for this research on palliative care integration for patients with advanced COPD.

## **2.4 Palliative care integration in advanced COPD**

According to the internationally acknowledged definition of palliative care, its role is to “improve the quality of life of patients and their families, facing the problems associated with a life-threatening illness” (WHO, 2013). This definition recognises patients affected by a life-limiting disease, irrespective of its typology and COPD as a life-limiting illness falls within the WHO definition.

A definition of palliative care integration was proposed by an expert consensus, as described by Siouta et al. (2016a). This definition of care integration was developed linking aspects identified in the literature and agreed through consensus by palliative care experts (The Integrated Palliative Care in Cancer and Chronic Conditions Study, InSup-C, 2014; van der Eerden et al., 2014). Palliative care integration is described as “bringing together administrative, organisational, clinical and service aspects in order to realise 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 care givers (paid and unpaid)” (Siouta et al., 2016a, p.2).

Different options for palliative care integration in standard care for patients with life-limiting diseases were proposed (Burton and Payne, 2012; Lingard et al., 2013; Lockett et al., 2014; Van der Klauw et al., 2014). Coordination of service and improved communication between healthcare professionals, patients and informal carers were studied (McIlfratrick, 2007; Bekelman et al., 2011; Johnson et al., 2011; Lingard et al., 2013). Furthermore, several integrated care interventions in advanced COPD were studied (Aiken et al., 2006; Horton et al., 2013; Higginson et al., 2014; Kirkpatrick et al., 2014; Cassel et al., 2016). Holistic needs’ assessment, symptom control, discussion

of illness limitations and prognosis, advance care planning and palliative care team involvement were identified as integrated care criteria in these interventions (Emanuel et al., 2004). Ewert and colleagues (2016) developed a taxonomy of integrated palliative care initiatives, which considered different aspects of care, such as type of disease (oncological vs non-oncological condition), type of care initiative and focus of intervention, level of care, care setting and timing of intervention, involved stakeholders and modalities of collaborative working. An integrated palliative care approach was defined by the presence of two specific items per category in at least one of the different aspects of care described above (Ewert et al., 2016).

Whilst the recognition of palliative care needs in COPD is supported by the literature (Crawford et al., 2013; Horton et al., 2013; Elkington et al., 2004), the question on how to integrate palliative care in the management of advanced COPD remains open (Vejlgaard and Addington-Hall, 2005). Stakeholders have different viewpoints on palliative care itself and on how to integrate it within disease-directed therapies (Lingard et al., 2013). These and further barriers which may prevent a timely integrated care approach for patients with advanced COPD are discussed in the following section.

## **2.5 Barriers to palliative care access in advanced COPD**

The provision of supportive care should not be limited by prognosis and may be delivered at the same time as disease-directed therapies (Temel et al., 2010; Shin and Temel, 2013). The integration of palliative care was recognised as effective in improving quality of life during the disease trajectory in oncological patients (Nijboer et al., 2000; Temel et al., 2010; Davis, Strasser and Cherny, 2015). Integrated palliative care provision for patients with advanced cancer involves a multidimensional focus

addressing issues such as complex symptom burden, patients' empowerment through advance care planning and maintaining quality of life (Greer et al., 2013).

As previously mentioned, patients with advanced COPD report an increased symptom burden as the disease progresses (Hayle et al., 2013). Therefore, integrated palliative care provision may be relevant for people with advanced COPD (Gardiner et al., 2010). It is important to acknowledge that the understanding of palliative care needs in this particular population is progressively increasing (Crawford et al., 2012; Elkington et al., 2004). Nonetheless, palliative care provision and integration in the disease trajectory is infrequently part of a care plan in this population (Hardin, Meyers and Louie, 2008).

Barriers to integrated provision of palliative care in COPD patients are multifactorial (Crawford et al., 2013; Horton et al., 2013). Palliative care services remain historically rooted in oncological settings (Davis, Strasser and Cherny, 2015). Therefore, the lack of knowledge dissemination on palliative care provision in COPD amongst healthcare professionals and the misinterpretations about palliative care being restricted to a cancer population limit the provision and integration of care (Crawford et al., 2013).

Moreover, patients and carers related barriers might be grounded in the common perception that palliative care is merely equivalent to care in the last days of life (Ostgathe et al., 2011). The misconceptions amongst some healthcare professionals that a palliative care approach is exclusively relevant in the last days of life prevent a timely integrated care plan for patients with advanced COPD (Ostgathe et al., 2011). Therefore, discussions on advance care planning, patients' directives and preferred end-of-life care are frequently neglected or postponed (Lanken et al., 2008).

Finally, the disease trajectory in COPD is unpredictable (Pinnock et al., 2011). Uncertainty in survival prognostication in COPD reduces healthcare professionals' confidence about the adequate timing of palliative care introduction (Crawford et al., 2013). Furthermore, the reduced availability of formal training for healthcare professionals who work in primary care and in other medical specialties, leads to a lack of expertise and prevents the early recognition of patients who meet national and international criteria for assessing palliative care needs (Gold Standards Framework, 2016; Federal Office of Public Health, 2013).

Overcoming these barriers might increase the awareness about the role of palliative care provision in advanced COPD and develop models of care delivery along the patients' disease trajectory (Curtis, 2008). National and international policies were developed to foster palliative care implementation for patients with life-limiting diseases. Knowledge dissemination through these policies might increase healthcare professionals' awareness on the importance of the role integrated palliative care may play in advanced COPD care. Furthermore, local healthcare initiatives and available resources may foster in-depth understanding on palliative care integration in advanced COPD (Bolan, Ainscough and Mahdi, 2014).

## **2.6 Voices and debates**

As previously discussed, patients and carers related barriers to palliative care provision might be grounded in the common perception that a palliative care approach is exclusively relevant in the last days of life and for oncological patients (Dalgaard et al., 2014). These misconceptions prevent an integrated care approach for patients with advanced COPD. Furthermore, it appears difficult to support patients and carers during the disease trajectory, as timing of palliative care provision remains unclear (Pinnock

et al., 2011). Severely impaired lung function, episodes of acute care, long-term oxygen treatment and decline of overall functions with reduction of daily life activities may represent hallmarks of underlying palliative care needs (Seamark, Seamark and Halpin, 2007).

Patients with advanced COPD report an elevated symptom burden (Elkington et al., 2004). Nonetheless, physical, psychosocial and existential issues are often underreported (Pinnock et al., 2011). This could be explained by the perception of this burden as being part of the chronic condition, which entails a progressive decline and a functional impairment (Landers et al., 2015). Furthermore, the lack of information on their condition and their prognosis prevents discussions about patients' related values and wishes for the forthcoming disease trajectory and shared advance care planning (Gott et al., 2009). The awareness on the role palliative care might play in relieving multidimensional suffering, while addressing these issues is therefore lacking (Hayle et al., 2013).

Public dissemination of palliative care may reduce the well-established misconceptions among patients and carers and foster the provision in all care settings (Federal Office for Public Health, 2013). Engaging with palliative care services will further support an understanding about the role of palliative care in life-limiting diseases and increase communication on advance care planning between patients, their families and all involved healthcare professionals (Hayle et al., 2013). In this context it is important to highlight that patients rarely initiate conversations about their preferences related to their declining condition, even if they would like to discuss issues about their disease, their anxiety about the future and how symptoms could be managed (Mousing et al., 2014). Fostering palliative care training among primary healthcare professionals with

particular attention on increasing communication skills may support advance care planning and shared decision making (Spence et al., 2009). According to Emanuel et al. (2004), all these aspects are part of broader definition of integrated palliative care, which might help to establish shared policies and guidelines to support and foster palliative care integration for patients with advanced COPD. The next sections of this chapter will explore how palliative care is embedded in the healthcare system in Switzerland and how it is provided across the cantons.

## **2.7 Healthcare system in Switzerland**

Switzerland (or Swiss Confederation) is a European country in the centre of the continent. It borders with France in the western region, with Germany in the northern region, with Austria and Liechtenstein in the eastern region and with Italy in the southern region (Federal Department of Foreign Affairs, 2014). Four official languages are spoken in Switzerland, indicating common roots with all neighbouring countries: French, German, Rumantsch and Italian (Federal Department of Foreign Affairs, 2014). The total population of Switzerland is approximately 8.5 million, with most of the population living in larger urban areas (Federal Statistical Office, 2018). Switzerland is a federation of 26 cantons, which possess a high degree of sovereignty regarding education, taxation and healthcare (Federal Council, 2018).

Everyone living in Switzerland is entitled to healthcare through a compulsory health insurance and the healthcare system is regulated by the Swiss Federal Law on Health Insurance (Federal Office of Public Health, 2018). Health insurance covers most of the costs of medical treatment, the insured person pays an annual premium and a small percentage of the annual total costs (Federal Office of Public Health, 2018). Healthcare provision may be delivered through primary care providers (general practitioners, home

care nurses, healthcare professionals such as physiotherapists, occupational therapists and dieticians, among others), emergency services, specialist outpatient services and hospitals (both public and private) (De Pietro et al., 2015).

## **2.8 Palliative care provision in Switzerland**

The federal government implemented a national palliative care strategy from 2010 to 2015. Palliative care provision, education and public dissemination were key measures of the strategy (Federal Office for Public Health, 2013). Since 2017 the national palliative care strategy was transformed into a national platform for palliative care. This national platform offers opportunities for all people involved in palliative care to access to information and expertise, share knowledge and experiences in the field (Federal Office for Public Health, 2013). Even if these federal initiatives provide a national framework, cantonal and regional peculiarities need to be considered when discussing palliative care provision in Switzerland.

Firstly, it is important to highlight that healthcare provision is regulated by cantonal laws (Federal Council, 2018). Therefore, every single canton has the sovereignty to legislate about healthcare provision for the resident population, provided that these laws are compatible with the federal regulations (Federal Council, 2018). Cantonal palliative care initiatives are the results of this legislative power (Gesundheits- und Fürsorgedirektion des Kantons Bern, 2013; Dipartimento Sanità e Socialità, 2015). Secondly, different cultural backgrounds across the cantons may influence how palliative care is provided for life-limiting conditions (Hurst et al., 2018). Lastly, the availability of educational programs and institutions which guarantee specialists' training differs among regions, with a higher concentration in large urban areas, thus limiting palliative care provision in more rural regions.

## **2.9 Palliative and respiratory care provision in Southern Switzerland**

The southernmost part of Switzerland (Republic and Canton of Ticino) is defined by peculiar geographical characteristics, being surrounded by the Lepontine Alps and their valleys throughout its 2'812 square kilometres surface area (Federal Statistical Office, 2018). The Canton of Ticino is split in two parts by the Monte Ceneri pass: the northern part, called Sopraceneri and the southern part, called Sottoceneri, where 58% of the total population of this canton (approximately 350,000) lives in larger urban areas (Federal Statistical Office, 2018). The Canton of Ticino borders to Italy to the south, west and east and to the rest of Switzerland to the north, through the Gotthard Range (Federal Department of Foreign Affairs, 2014).

Healthcare services in Southern Switzerland are provided across the entire territory, with public hospitals located in six different regions, covering the entire territory, while private clinics are available in urban areas only. Palliative and respiratory care services are offered both through public and private institutions, while certified palliative care consultations for in- and outpatients are only available through the public healthcare system (Dipartimento Sanità e Socialità, 2015; Qualité Palliative, 2018). The Palliative and Supportive Care Clinic which was involved in this research provides palliative care in different settings, such as a seven-bed inpatient unit, two integrated care wards, four outpatient services and in-hospital consultations for inpatients in all public hospitals in Southern Switzerland. Multidisciplinary palliative care teams are available for the acute unit, which is located in the northern part of the canton and is embedded in the oncological centre and for the two integrated care wards (one located in the radiotherapy service in the northern part of the canton and one embedded in an internal medicine ward in the southern part of the canton). The multidisciplinary team consists of

physicians and nurses, a social worker, a dietician, a psychologist, a physiotherapist and a spiritual care provider. In-hospital consultations are managed by a specialised palliative care physician and a specialised palliative care nurse. This provision reflects the lack of specialised resources and financial constraints due to the lack of reimbursement of specialised in-hospital palliative care consultations (Federal Office for Public Health, 2013).

## **2.10 The local research context**

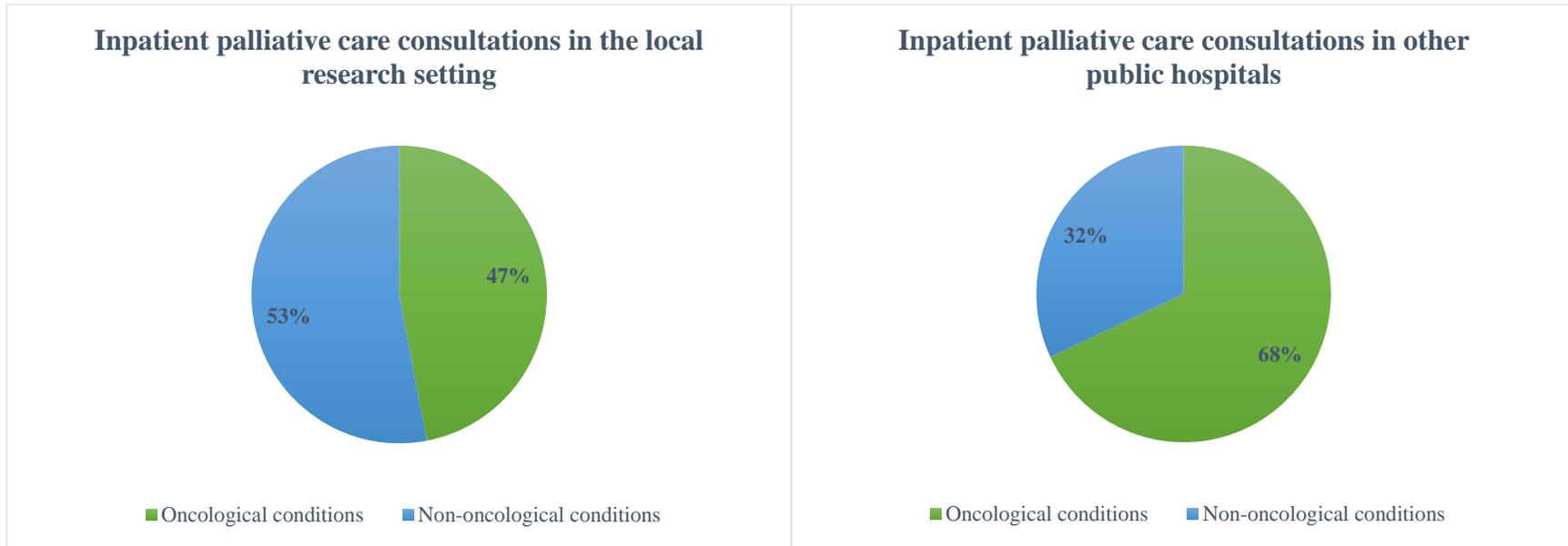
The local respiratory care service provides in-hospital consultations and manages an outpatient clinic. 2,700 patients with COPD were followed as outpatients during 2018 and 2,100 of them suffered from advanced disease (GOLD stages 3 and 4, group D). Pulmonary rehabilitation programmes for patients with advanced COPD are provided by the respiratory care service for outpatients and through an extensive collaboration with a public rehabilitation clinic also on an inpatient basis. The respiratory care team consists of seven respiratory care physicians, six nurses and four physiotherapists. Other healthcare professionals such as dieticians, occupational therapists and social workers are available on demand through the hospital facility. A multi- or interdisciplinary team approach was underdeveloped in the respiratory care service prior to this research. Healthcare professionals provided care within their professional role boundaries, while systematic sharing of information and common goal setting for patients' care delivery was rarely performed.

The respiratory care service is well-positioned in a care network consisting of general practitioners, home care nursing services, home care physiotherapists and a partner organisation providing home support for patients with advanced COPD.

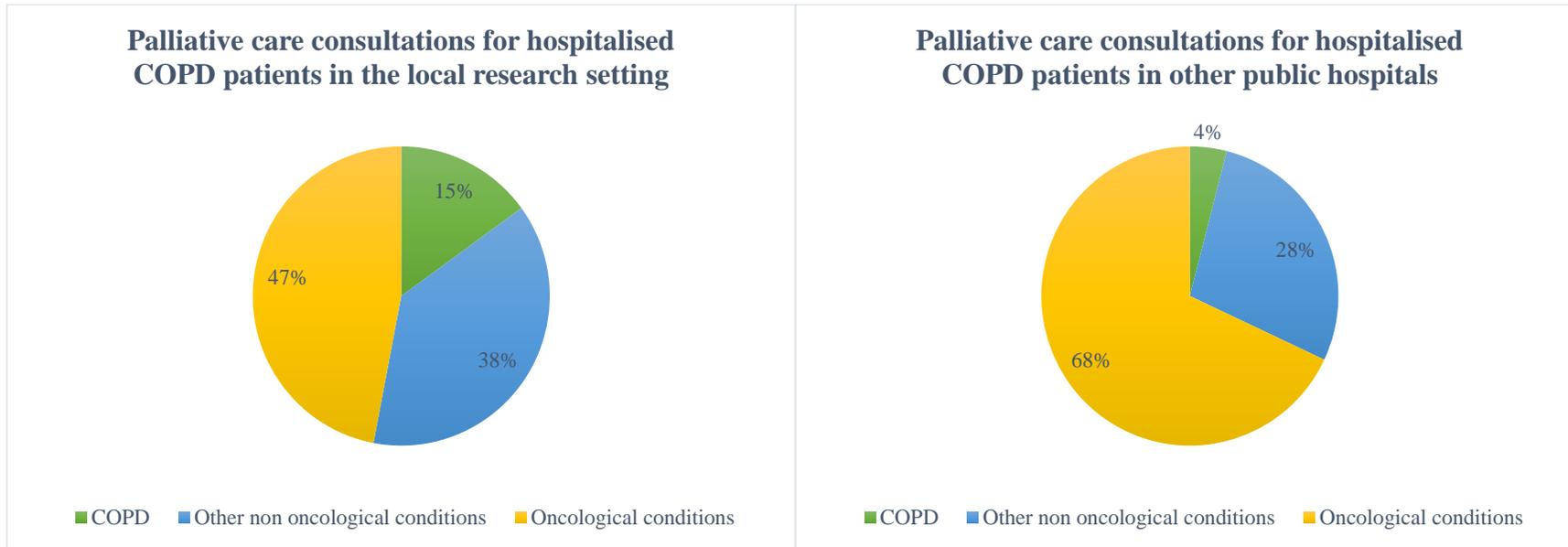
The role of general practitioners in managing patients with advanced COPD is variable and differences are seen even in the local setting. General practitioners provide overarching care for this population and they usually request a specialist consultation for the formal diagnosis and staging of COPD. Furthermore, the disease-directed treatment is initiated by the respiratory care physician and adapted by the general practitioner, in collaboration with the pulmonologist during follow-up visits with a frequency of twice a year.

The local palliative care team is composed of a specialised palliative care physician and a specialised palliative care nurse. Since 2015 the researcher is responsible for local palliative care consultations, which are delivered in the major teaching hospital in Southern Switzerland, previously as a senior registrar and more recently as a senior consultant. This public institution is the reference centre for complex visceral and vascular surgery, for polytrauma, for neuro- and cardiac surgery, for stroke and invasive cardiology. Respiratory care patients are hospitalised within internal medicine wards with respiratory care service consultations available as needed. The internal medicine department followed almost 3,000 patients with complex multiple co-morbidities in 2018, for a total of 18,000 days of hospitalisation (Ente Ospedaliero Cantonale, 2018). Age, frailty and life-limiting conditions are increasing in hospitalised patients and awareness among internal medicine house staff about the importance of palliative care delivery for patients with advanced respiratory conditions such as COPD led to regular consultations for hospitalised patients with advanced COPD. This awareness and the interest to develop an innovative project for joint palliative care provision led to the development of integrated care wards within the internal medicine department.

At the end of 2018, 1,280 patients were followed by the Palliative and Supportive Care Clinic. The inpatient unit, the two integrated care wards and the four outpatient services delivered care for 639 patients, 90% of them being diagnosed with an oncological disease. The local palliative care team followed 223 patients through in-hospital consultations in 2018. 118 patients (53%) were diagnosed with a non-oncological condition and 33 (15% of all patients) had advanced COPD. This differs from other regional contexts, where patients with non-oncological diseases and especially with advanced COPD seldom benefit from a palliative care approach while being hospitalised for acute exacerbations. As depicted in Figures 2.1 and 2.2, inpatient palliative care consultations services in other cantonal hospitals provided care for 418 patients. 133 patients (32%) were affected by a non-oncological disease and 19 of them (4% of all patients) had advanced COPD.



**Figure 2.1:** Inpatient palliative care consultations in Southern Switzerland



**Figure 2.2:** Palliative care consultations for inpatients with COPD

These regional differences among the population accessing palliative care are explainable through an established collaboration between the respiratory and the palliative care team, which was developed during several years of common management of hospitalised patients with COPD. These good working relationships with mutual respect among healthcare professionals with different backgrounds, the raised awareness about palliative care needs of patients with advanced COPD and the fact that even with these facilitating factors shared outpatients' follow-up visits were sporadic led to the question on how to implement palliative care provision for patients with advanced COPD.

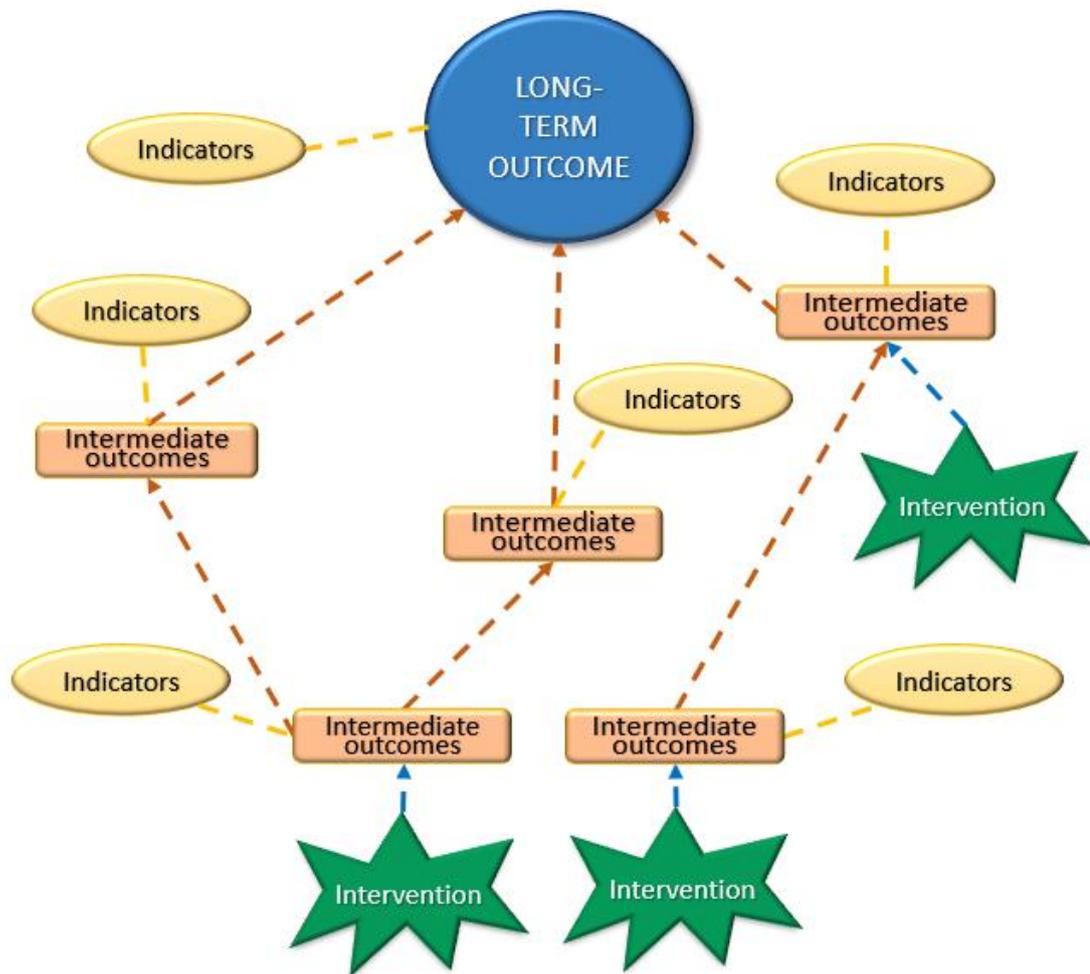
### **2.11 Theory of Change**

The development and implementation of a new healthcare intervention requires an understanding about whether, how and why it works in a specific context (Anderson, 2005). Defining the specific context is paramount to explain the interplay between healthcare initiatives and their outcomes (Blamey and Mackenzie, 2007). In addition, it is crucial to map all the steps which are required during the developmental process in order to identify short- and medium-term goals that foster and promote long-term goals in healthcare interventions (Breuer et al., 2016).

The development and implementation of healthcare interventions can be theory-driven (De Silva et al., 2014). A theory-driven process of healthcare initiative design and subsequent evaluation answers the aforementioned question on whether, how and why interventions work in a specific context (Anderson, 2005). Four key elements which are fundamental for the backing and functioning of healthcare initiatives can be identified through theory-based evaluations (Weiss, 1995). The first aspect to consider is that a

theory-driven evaluation focuses on the most important components of the initiative. Secondly, results from the evaluation generate new evidence on the initiative, both practical and theoretical. The third aspect to consider is that theory-based evaluations require an explicit declaration of assumptions, methods and goals from involved stakeholders for the developing intervention. Lastly, evaluations that focus on the theoretical underpinnings of care initiatives might have a higher impact on healthcare policies and broader public dissemination (Weiss, 1995).

Theory of Change (ToC) is a “theory of how and why an initiative works which can be empirically tested by measuring indicators for every expected step on the hypothesized causal pathway to impact” (De Silva et al., 2014, p.2). Moreover, ToC approaches may include additional elements defining an initiative, such as service users, research evidence supporting the ToC, stakeholders who are crucial in a specific context, timelines and institutional factors (Vogel, 2012). The development of healthcare initiatives that are driven by a ToC approach is shared with key stakeholders through workshops, meetings and/or interviews and a pathway of change is outlined (Breuer et al., 2016). A few key elements of ToC need to be defined, as they are crucial to understand the ToC process. They are depicted in Figure 2.2 and described in the following chapter’s section.



**Figure 2.3:** Elements in a pathway of change in ToC

The pathway of change visually represents the central role of long-term outcomes in healthcare initiatives. Moreover, it underlines the relationships between key elements which are essential to achieve pre-specified long-term outcomes. These key elements can be listed as follows (Anderson, 2005):

- 1) *Interventions* are defined as those actions which lead to intermediate outcomes. An example of intervention in a healthcare initiative is the implementation of

educational programs for healthcare professionals to develop theoretical and practical skills

- 2) *Intermediate outcomes* represent the results of performed interventions. Moreover, an intermediate outcome may lead to another intermediate outcome without the need of any direct intervention. Intermediate outcomes are necessary to reach pre-specified long-term outcomes. An example of intermediate outcome is the increased healthcare professionals' theoretical and practical knowledge through educational programs
- 3) *Indicators* are elements which measure the successful achievement of each outcome. An example of indicator is the number of healthcare professionals who were trained through educational programs

According to De Silva et al. (2014), this pathway of change can be constructed backwards, starting with a pre-specified long-term outcome, while identifying intermediate outcomes and interventions which are required to achieve the long-term outcome. Moreover, indicators to evaluate intermediate outcomes may be defined (De Silva et al., 2014).

ToC was used to outline and map evidence identified during this research about how to integrate palliative care in advanced COPD. The elements which were identified as essential in a pathway of change for palliative care integration in advanced COPD will be further described in the discussion chapter and contextualised within the research.

In conclusion, it is important to highlight that even if advanced COPD is recognised as being a life-limiting condition with palliative care needs, patients with this illness do not benefit from palliative care provision to the same extent as their oncological counterparts do. Understanding how palliative care is delivered in advanced COPD is essential to

develop a model for palliative care collaboration with respiratory care services, aiming at care integration for these patients and their families. Therefore, a systematic literature review on service delivery and models of palliative care integration was performed to gain knowledge about the mainstays of palliative care provision in advanced COPD. The results of this systematic literature review are presented in the following chapter of this thesis.

## **CHAPTER 3: LITERATURE REVIEW**

In this literature review chapter, the available knowledge on palliative care provision and integration for patients with advanced COPD will be introduced. Knowledge gaps in literature to be covered by this research were identified through a systematic integrative literature review. This literature review was published as a paper in December 2018 in a respiratory care journal (Fusi-Schmidhauser et al., 2018). The time frame covered by the paper ends on November 30, 2017. The literature review presented in this chapter was updated, including papers published until March 31, 2019.

### **3.1 Aims of the literature review**

This literature review aimed to retrieve, critically analyse and synthesise the available body of knowledge on palliative care provision and integration in advanced COPD services. The review helped develop the research question for the subsequent study, to gain methodological insight in the topic, to discover important issues that were relevant to the research question and to identify relationships between different ideas and applied practices. Ultimately this contextualised the research in relation to what is already known. Moreover, this literature review identified a gap in knowledge, which the research attempted to address.

### **3.2 Literature review methodology**

A scoping literature review performed during the early stages of drafting the research protocol identified a broad spectrum of both experimental and non-experimental research on palliative care provision in advanced COPD services. This led to the choice of an integrative methodological approach for this literature review.

Through the process of systematically analysing and summarising the research literature, a well-prepared integrative review can precisely represent the state of the current research literature (Cooper, 1982). The integrative literature review can also be used to evaluate the strength of the scientific evidence, identify gaps in research, identify the need for future research, build a bridge between related areas of work, identify central issues in an area, generate a research question, identify a theoretical or conceptual framework, and explore which research methods were used successfully (Whittemore and Knafl, 2005).

This integrative review followed the conceptual process described by Whittemore and Knafl, consisting of five distinct stages: problem identification, literature search, evaluation of data, data analysis and interpretation and presentation of the results (Whittemore and Knafl, 2005). The choice of this conceptual process over the one described by Cooper (1998) is justified by the challenge of data source diversity and their combination in the integrative review. This aspect is not fully considered in the conceptual framework proposed by Cooper, which is more committed to quantitative systematic reviews (Cooper, 1998; Whittemore and Knafl, 2005).

### **3.2.1 Problem identification**

The problem identification should include conceptual definitions of the topic that will be studied (Whittemore and Knafl, 2005). In the current research context (palliative care integration in advanced COPD services), the concept of integration needed to be clearly defined and which aspects had to be included. It was important to adequately balance the operational definitions between being too narrow, which might have led to low quality findings and too broad, where study details might have been overlooked, leading to an incorrect interpretation of the results.

### **3.2.2 Literature searching**

The literature search focused on a particular target population (e.g. end-stage COPD), which was represented in the integrative review. The search strategy needed to be guided by clear inclusion and exclusion criteria (Ganong, 1987). Papers were sought that explored palliative care provision in services for patients with advanced COPD. Enhancing validity of this stage of the integrative review was obtained by conducting an exhaustive search strategy that included all available data sources. At the same time, it was important to increase generalisability to the target population by diversifying retrieved studies in terms of methodologies (Russell, 2005).

### **3.2.3 Data evaluation**

During the data evaluation phase, the reviewer must decide whether a determined data element may remain in the study data set (Whittemore and Knafl, 2005). Unreliable values and findings must be compared with other results from different studies. In this process, it was important to acknowledge the reviewer's epistemological background (Beyea and Nicoll, 1998). This led to an increased reflexivity on the eligibility process in terms of included and excluded studies in this review. Moreover, evaluating the quality of eligible studies through a validated quality assessment tool for disparate data allowed the identification of studies for inclusion of high-quality standards, thus enhancing methodological rigour.

### **3.2.4 Data analysis**

Data analysis is the step defined as “reducing the separate data points collected by the inquirer into a unified statement about the research problem” (Cooper, 1998, p. 104). Threats to validity in this review stage are related to assumptions made by the reviewer

in terms of causality and generalising evidence stemming from a single study, instead of underpinning the review-based conclusions. According to Whitemore and Knafl (2005), data analysis followed a four-step process: data reduction, data display, data comparison and conclusion drawing.

Data reduction determined a classification system for data management coming from different methodologies. In this review, primary sources were divided in subgroups according to their methodology (qualitative studies, quantitative studies, mixed-methods studies). Data were extracted and coded from primary sources and inserted in a duly created data extraction form, which helped to characterise the data and organise them in a concise format, as suggested by the literature (Beyea and Nicoll, 1998). This data extraction form also facilitated data display, enhancing the identification of specific patterns and themes across primary data sources. During the data comparison step, data displays were iteratively examined for identification of themes and patterns. These themes were subsequently elaborated and compared across all subgroups, creating the integrative review in its entirety.

### **3.2.5 Interpretation and presentation of the results**

The presentation stage is the conclusive step of an integrative review. The exhaustive description of the review process is paramount for enhancing its validity and rigour (Torraco, 2005). In this integrative review, an overview of all included studies was depicted according to the main themes that emerged during the data analysis process.

### **3.3 Focus of the literature review**

This literature review focused on research outcomes described in the scientific literature on palliative care provision in advanced COPD services. Moreover, the application and

practices of palliative care integration in advanced COPD services were explored. Although this literature review did not focus on methodologies or review theories, they represented data, which were extracted if explicitly mentioned in included papers.

### **3.3.1 Integrated palliative care**

The definition of integration is not consistent in the available literature. Depending on care settings, healthcare providers and consumers, the term “integrated” defines different approaches to care delivery (Van der Klauw et al., 2014; Van der Linden, Spreeuwenberg and Schrijvers, 2001). An expert consensus developed a new definition of integrated palliative care, linking aspects identified in the literature and highlighted by palliative care experts (InSup-C, 2014; van der Eerden et al., 2014). According to this definition, “integrated palliative care involves bringing together administrative, organisational, clinical and service aspects in order to realise 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 care givers (paid and unpaid)” (Siouta et al., 2016a, p.2). Furthermore, Emanuel et al. (2004) developed a tool with 11 criteria, which identifies integrated palliative care. These criteria supported the critical appraisal of this literature review.

### **3.3.2 The review question**

The literature review question is clearly interlinked with the aims and objectives of the proposed research, in order to include all the available literature as a theoretical starting point for the study. The philosophical underpinnings of the study are grounded in critical social theory. Therefore, the formulation of the review question according to the

PICoS (Population, Phenomena of Interest, Context and Study Design) acronym was a suitable way to formulate the question for this integrative review (Methley et al., 2014). The justification for this choice is related to the aims of this literature review. The exploration of palliative care integration and the development, application and practices of this integration in advanced COPD are a phenomenon of interest rather than an intervention. Therefore, other formulations of the review question, such as the PICO (Population, Intervention, Comparison, Outcome) acronym were not suitable to retrieve the whole body of literature available and necessary to inform the research.

The PICoS criteria selected for the review question may be summarised as follows:

<b>Population</b>	Adults living with end-stage COPD
<b>Phenomena of Interest</b>	Development of palliative care integration
<b>Context</b>	Any healthcare service (hospital, community and hospice settings)
<b>Study Design</b>	Any study design (qualitative, quantitative, mixed methods)

From these starting criteria, it was possible to develop and formulate the review question: “How are palliative care services working with services for patients with advanced COPD?”

### **3.4 Search process**

#### **3.4.1 Search strategy**

The search strategy process encompassed several tasks and each is illustrated as follows.

The time period that was covered started from January 1, 1960 to November 30, 2017

and an update was performed on April 2019, including all studies published until March 31, 2019. The chosen time lapse is consistent with the first available publication on definitions of COPD and foundation for the current classification, which was paramount as inclusion criteria for this review (American Thoracic Society, 1962). All retrieved studies were published after 1990, depicting the growing research activity in palliative care and the subsequent attention received by healthcare providers and policy makers (Bettoncelli et al., 2014; Lanken et al., 2008).

### **3.4.2 Electronic bibliographic databases**

Consistent with the purpose of the literature review, the following databases were selected for a search on the chosen topic:

1. MEDLINE (EBSCO Host interface)
2. EMBASE (Ovid interface)
3. The Cochrane Central Register of Controlled Trials (CENTRAL) (website)
4. AMED (complementary medicine) (EBSCO Host interface)
5. CINAHL (EBSCO Host interface)
6. Database of Abstracts of Reviews of Effectiveness (DARE) (website)
7. HSRProj (Health Services Research Projects in Progress)
8. OpenGrey

According to the literature review question, the search terms (or keywords) were chosen in order to broadly cover the literature review topic, yet narrow the results in order to improve the accuracy of the search performed. The accuracy of the selected terms was tested during a pilot search. 10 key papers that were expected to be found by the database search were retrieved during this pilot phase, thus confirming the adequacy of

the chosen search terms. Furthermore, search terms were compared with other literature reviews on palliative care service delivery (Gomes et al., 2013), in order to enhance the quality of the performed database search.

The use of synonyms, free text term and Medical Subject Heading (MeSH) led to the proposed key terms that were used for the database search. These terms are described in Appendix I. Boolean operators (“OR”, “AND”) and truncation tools were used to broaden and narrow the search when considered necessary.

### **3.4.3 Systematic reviews**

Systematic reviews identified by the search in electronic bibliographic databases were not considered as primary sources for this literature review. Nonetheless, all retrieved systematic reviews were checked to verify that all relevant papers meeting the selection criteria were included in the literature review. An overview of all searched systematic reviews is listed in Appendix II.

### **3.4.4 National and international guidelines on care provision for COPD**

International guidelines on care provision for COPD were consulted to identify references related to empirical research. Except for one specific guideline which proposes palliative care integration for patients with respiratory diseases (Lanken et al., 2008), national and international COPD guidelines do not specifically discuss how to implement palliative care provision in advanced COPD services. They were not included in the literature review, as they do not represent empirical research. A complete list of the consulted guidelines is described in Appendix III.

### **3.4.5 Citation tracking and reference list checking**

All included papers were citation tracked using Google Scholar to identify additional papers. Reference lists from included papers, which were identified by the electronic database search, were scanned for possible additional studies that might have meet the inclusion criteria for the literature review.

### **3.4.6 Evaluation of trial registers and dissertation databases**

Internet resources were searched both for ongoing trials to identify results' papers that may have followed and for unpublished dissertations or master theses. A complete list of the consulted internet resources is illustrated in Appendix IV.

### **3.4.7 Inclusion and exclusion criteria for studies**

Inclusion criteria for retrieved studies were defined as follows:

**Population:** *adults (18 years old and over) living with end-stage COPD*

Studies were included either when they considered COPD patients alone or in combination with other life-limiting illnesses (e.g. cancer)

**Phenomena of interest:** *development of palliative care integration*

A scoping literature review identified a broad spectrum of research on palliative care provision in advanced COPD services. The developmental process towards palliative care integration, as described by Siouta et al. (2016a), was the phenomena of interest of this literature review

**Context:** *any health service (inpatient, outpatient, homecare) worldwide*

Language restriction to studies reported in English, French, German, Italian and Spanish

**Study design:** *any study design (qualitative, quantitative, mixed methods)*

Exclusion criteria for retrieved studies were defined as follows:

Papers describing non-empirical research were excluded. Furthermore, papers were not considered if a clear distinction for the COPD population in terms of results was not possible and when the full text in English, French, German, Italian and Spanish was not available (for any reason).

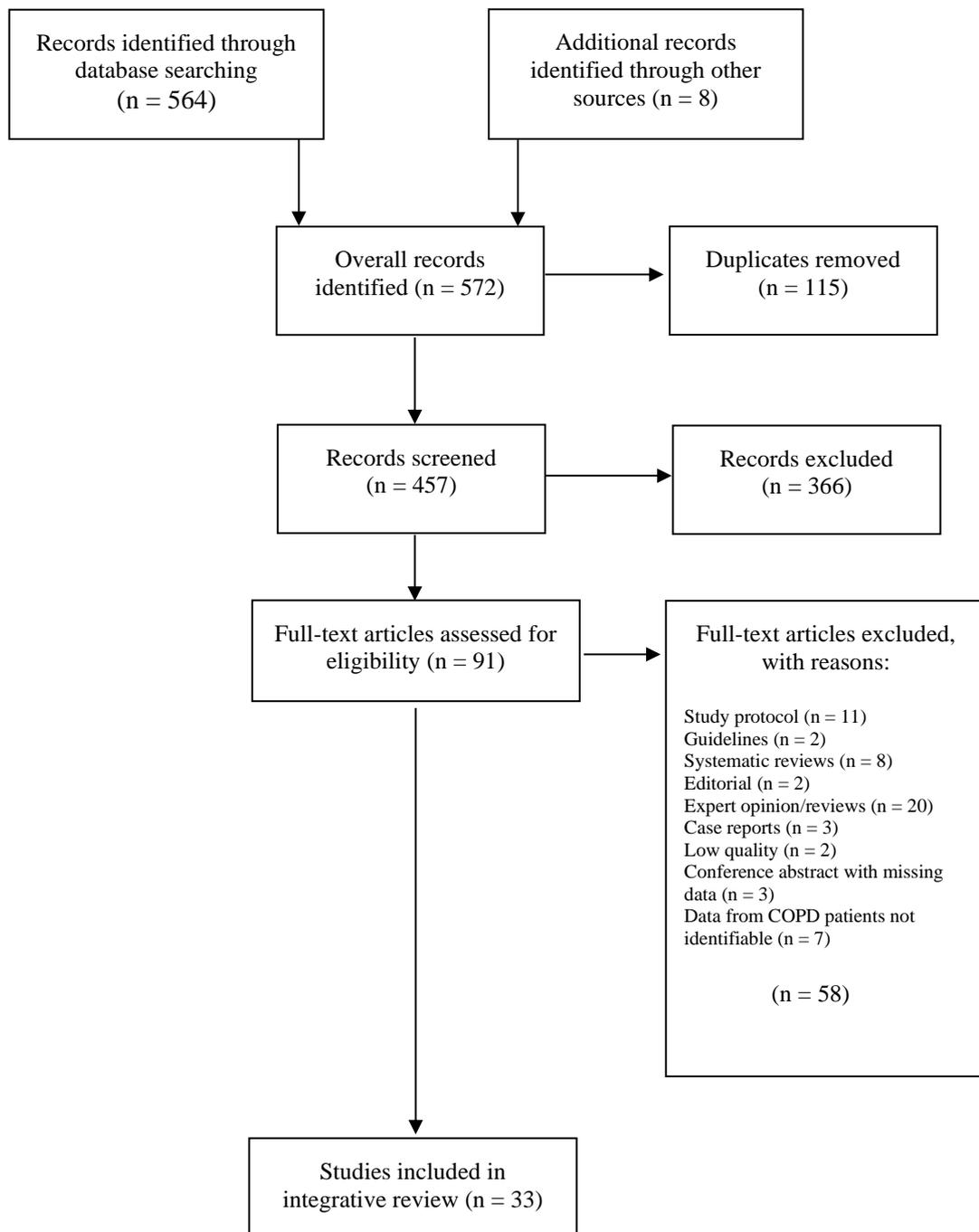
### **3.5 Critical appraisal tool**

Study eligibility was preceded by a pilot phase, where the aforementioned inclusion criteria were applied to a sample of papers. In this preparatory phase, a researcher working in the respiratory department helped to test the reliability of inclusion and exclusion criteria including their consistent application throughout the review and estimated the time needed for the entire selection process (Dundar and Fleeman, 2014). Study quality assessment was performed through a critical appraisal tool for all study designs. For this purpose, the checklist from Hawker et al. (2002) for evidence appraisal in both qualitative and quantitative studies was used and electronically managed (MS Excel Template). The reviewer alone performed scoring for methodological rigour for all eligible studies. Scores < 30 were considered of low quality and were excluded from the literature review. This benchmark was chosen according to the scoring system defined by the quality appraisal checklist, where items were defined with a scoring scale from one (very poor) to four (good) (Hawker et. al, 2002).

## **3.6 Appraisal of the literature**

### **3.6.1 Selected papers**

An overview of the paper selection process and exclusion is depicted in Figure 3.1. 33 papers were included in the integrative review. The selected articles were published between 2004 and 2019. Of these papers, 13 adopted a qualitative approach, 18 adopted a quantitative approach and two were mixed-methods studies. Sample sizes ranged from eight to 88 participants for qualitative studies and from 36 to 181'689 participants for quantitative studies.



**Figure 3.1:** Flow diagram for study inclusion

### **3.6.2 Data analysis**

As previously mentioned, data analysis for this integrative review followed a four-step process: data reduction, data display, data comparison and conclusion drawing (Whittemore and Knafl, 2005). Primary sources were divided into subgroups according to their methodology. Data were extracted, coded and inserted in a duly created data extraction form. Through this electronically managed (MS Excel Template) form, information on study language and country of implementation, definition of the research question and aims, study setting and design, sampling and participant characteristics were collected. Furthermore, data collection methods, data analysis approach, key themes that emerged and recommendations made by the authors were noted. Identified themes about palliative care integration in advanced COPD were also collected for each study. The quality assessment score was also assessed and recorded for each paper during the eligibility process. A sample of a completed data extraction form is presented in Appendix V. Data display on the same spreadsheet fostered the identification of specific themes and patterns through an iterative examination during the data comparison phase. These themes were elaborated, compared across all subgroups and synthesised in the literature review. An overview of the identified themes is presented in Table 3.1.

**Table 3.1:** Identified themes and subthemes

<b>Main themes</b>	<b>Subthemes</b>		
<b>Needs and views about advanced COPD and palliative care</b>	<b>High symptom burden and holistic assessment of needs</b>	<b>COPD as a “way of life”</b>	<b>Need for enhanced communication (advance care planning, end-of-life care)</b>
	Multidimensional needs, often underreported (Elkington <i>et al.</i> , Cawley <i>et al.</i> , Schroedl <i>et al.</i> )	Living with COPD becomes “normal”, adjusting to progressive worsening of symptoms over months and years (Landers <i>et al.</i> , Pinnock <i>et al.</i> )	Patients’ awareness of their disease trajectory and discussions about advance care planning reduce misconceptions about palliative care provision (Hayle <i>et al.</i> , Scheerens <i>et al.</i> , Schroedl <i>et al.</i> , Spence <i>et al.</i> , Smallwood <i>et al.</i> , 2018a)
<b>Palliative care timing</b>	<b>Milestones of decline</b>	<b>Specific palliative care criteria</b>	
	Events which define disease progression and should promote palliative care provision (Cawley <i>et al.</i> , Landers <i>et al.</i> , Philip <i>et al.</i> , Pinnock <i>et al.</i> , Scheerens <i>et al.</i> )	Consensus on criteria which identify palliative care patients (Duenk <i>et al.</i> , Partridge <i>et al.</i> , Rush <i>et al.</i> )	
<b>Service delivery</b>	<b>The “Solo Practice Model”</b>	<b>The “Congress Practice Model”</b>	
	Skilled primary care teams can deliver high-quality palliative care (Beernaert K <i>et al.</i> , Buxton <i>et al.</i> , Bove <i>et al.</i> , Smallwood <i>et al.</i> , 2018)	Specialist consultations as needed (Buckingham <i>et al.</i> , Goodridge <i>et al.</i> )	
<b>Models of care integration in advanced COPD</b>	<b>Development of integrated care</b>	<b>Integrated palliative care models</b>	
	<i>Reduction in care fragmentation</i> Integration of care may foster coordinated care with patient-centred models (Goodridge <i>et al.</i> , Crawford <i>et al.</i> )	Different models for palliative care integration (Aiken <i>et al.</i> , Cassel <i>et al.</i> , den Herder-van der Eerden <i>et al.</i> , Gainza-Miranda <i>et al.</i> , Higginson <i>et al.</i> , Horton <i>et al.</i> , Kirkpatrick <i>et al.</i> , Philip <i>et al.</i> , Smallwood <i>et al.</i> , 2018a, Smallwood <i>et al.</i> , 2019)	
	<i>Shift in care organisation</i> Need to raise awareness in healthcare organisations (Beernaert <i>et al.</i> , Hayle <i>et al.</i> , Hynes <i>et al.</i> , Strang <i>et al.</i> )		
	<i>Care-coordinator</i> Model for a care-coordinator to support patient-centred care (Burgess <i>et al.</i> , Elkington <i>et al.</i> , Epiphaniou <i>et al.</i> )		

A summary of all 33 included studies is presented in Appendix VI. The number of included studies differs from the published paper, where 24 papers were considered in the integrative literature review (Fusi-Schmidhauser et al., 2018). The integrated data are discussed under four main themes, which were identified during data elaboration and comparison across all primary sources' subgroups: 1) needs and views about advanced COPD and palliative care, 2) palliative care timing 3) service delivery and 4) palliative care integration.

### **3.6.3 Needs and views about advanced COPD and palliative care**

Exploring the needs and views of patients, informal carers and healthcare professionals in advanced COPD was the research aim and focus of several published papers (Crawford et al., 2012; Cawley et al., 2014). Exploring needs and views about advanced COPD and palliative care provision promotes the identification of unmet areas in palliative care provision in this population and supports a developmental process of palliative care integration (Pinnock et al., 2011; Hayle et al., 2013).

#### **3.6.3.1 High symptom burden and holistic assessment of needs**

Most papers reported that advanced COPD patients present with an elevated symptom burden (Elkington et al., 2004; Cawley et al., 2014). Schroedl and colleagues conducted a retrospective study on patients with advanced COPD attending a palliative care clinic in the United States. Their results confirmed high symptom prevalence among COPD patients, which had not been previously assessed and treated in a systematic manner (Schroedl et al., 2014). This study did not evaluate the effectiveness of treatments proposed by the palliative care team on symptom control and outcomes for patients with COPD. Nonetheless, effective symptom management to reduce suffering was identified

as an integrated care criterion (Emanuel et al., 2004). For this reason, fostering a holistic assessment of multidimensional needs with symptom improvement may promote care integration (Siouta et al., 2016a).

### **3.6.3.2 COPD as a “way of life”**

As previously described, patients with advanced COPD describe an elevated symptom burden, but physical, psychosocial and existential issues are often underreported, because COPD is less commonly considered as a life-limiting illness (Pinnock et al., 2011). Patients and informal carers perceive advanced COPD as a *way of life*, thus considering the progressive decline and the functional impairment as part of a life with the disease (Landers et al., 2015). They adjust to a progressive worsening of symptoms over months and years. Therefore, misconceptions around the relevance of palliative care in the disease trajectory are frequent, among patients, their families and healthcare professionals (Crawford et al., 2013; Hayle et al., 2013).

### **3.6.3.3 Need for enhanced communication (advance care planning, end-of-life care)**

Enhanced communication between patients, their families and healthcare professionals on advance care planning and end-of-life issues acknowledges patients' values and wishes for the forthcoming declining disease trajectory (Spence et al., 2009; Schroedl et al., 2014). This could modify their views on palliative care provision in COPD, as described by Hayle and colleagues (Hayle et al., 2013). In their study, they interviewed eight patients accessing specialist palliative care in the UK. Perceived benefits included improved symptom control and reduced social isolation. Furthermore, it emerged that patients were aware of their disease trajectory and engagement with palliative care services reduced their misconceptions about palliative care involvement in their care provision. Despite the fact that poor access to palliative care for patients with advanced

COPD and the need for further service development is highlighted, models of care provision within existing services are not discussed (Hayle et al., 2013).

#### **3.6.4 Palliative care timing**

As previously described, patients and informal carers perceive the progressive decline as part of living with the disease (Landers et al., 2015). Therefore, the timing of palliative care provision in COPD is difficult to establish (Crawford et al., 2012). Worsening COPD is characterised by disease exacerbations that require hospitalisation, progressive decline of all functions, need for assistance with self-care and long-term oxygen treatment. The identification of these milestones in the disease trajectory may be used to promote a holistic assessment and start palliative care provision in advanced COPD services (Pinnock et al., 2011; Cawley et al., 2014; Landers et al., 2015; Scheerens et al., 2018).

In their study, Cawley and colleagues interviewed 52 among patients, informal carers and healthcare professionals to identify events in the disease trajectory which could act as door opener for palliative care provision. All participants identified increasing carer burden, progressive decline of global functions and hospitalisation for acute exacerbations as milestones in disease progression. These events should be used as triggers to guide the introduction of supportive interventions for advanced COPD (Cawley et al., 2014).

Furthermore, as discussed by Duenk et al. (2017), these key events in a patient's disease trajectory need to be developed as specific criteria that can foster the initiation of a timely palliative care approach. In their survey study, they explored the view of 256 pulmonologists in the Netherlands on palliative care provision for patients with COPD.

The majority of participants stated that many different criteria to identify patients who would benefit from palliative care provision were used, but no consensus could be determined on which specific criteria might indicate a timely palliative care initiation (Duenk et al., 2017). The authors underlined the need for further research on establishing specific criteria, while including them in clinical guidelines to help healthcare professionals to identify patients with potential palliative care needs (Duenk et al., 2017). These conclusions were supported by Partridge and colleagues, who conducted a similar survey among 107 respiratory care physicians in the UK (Partridge et al., 2009).

The progressive decline of global functions in advanced COPD may promote discussions about palliative care provision (Landers et al., 2015). Spence and colleagues conducted interviews and focus groups with 23 health- and social care professionals, exploring their perceptions on barriers faced by healthcare professionals in delivering palliative care (Spence et al., 2009). They concluded that among several interventions that may improve palliative care provision it is important to systematically offer focused education and training on communication skills to healthcare professionals who are involved with advanced COPD. Beernaert et al. (2013) supported the same conclusion in their retrospective, population-based study within a general practitioners' network. They collected data on deceased patients and assessed timing of referral to palliative care services. Patients with COPD were less likely to be referred to palliative care services than cancer patients and if referred, experienced a late referral, close to death. The authors underlined the importance of training general practitioners in delivering high-quality palliative care, while being supported by specialist palliative care teams and respiratory care physicians for more complex cases (Beernaert et al., 2013). Rush and colleagues (2017) retrospectively analysed an advanced COPD patients' cohort

with home oxygen therapy who was hospitalised for an acute exacerbation. Referral to palliative care services happened if patients were close to death, if they experienced a longer hospital stay and if they had a concomitant oncological disease. Understanding the role of palliative care in advanced COPD and identifying the benefits of this approach for patients should be fostered among healthcare professionals (Rush et al., 2017). To date, none of the mentioned studies explored tools or interventions to foster palliative care training and education for healthcare professionals. This leaves the question on how to increase healthcare professionals' confidence on palliative care provision open (Spence et al., 2009; Duenk et al., 2017).

### **3.6.5 Service delivery**

Different models of palliative care service provision for patients with advanced COPD were studied. Bruera and Hui (2012) have summarised three different care provision models in a cancer setting, but similar approaches were described in advanced COPD services (Buxton et al., 2010; Epiphaniou et al., 2014; Higginson et al., 2014). In the "Solo Practice Model" the treating physician (general practitioner or specialist) provides the entirety of care, including general palliative care. A step towards increased collaboration is proposed in the "Congress Practice Model", where the treating physician refers the patient for all supportive care issues to different healthcare professionals. Finally, in the "Integrated Care Model", continuity of care is fostered through a palliative care team approach, including all healthcare professionals involved in a patient's care (Bruera and Hui, 2012).

### **3.6.5.1 The “Solo Practice Model”**

Buxton et al. (2010) conducted an electronic web-survey across 239 hospital units in the UK assessing current and planned palliative care provision for advanced COPD. They described poor palliative care provision and highlighted the role of primary healthcare providers in delivering palliative care. The primary care team should be confident with general palliative care approaches and care models should empower healthcare professionals who provide support for COPD patients. This will increase available resources who deliver high-quality palliative care in different care settings, while covering the gap of expertise which may lead to inadequate management of palliative care needs (Buxton et al., 2010; Beernaert et al., 2013). Bove et al. (2018) explored healthcare professionals’ experiences with a novel nurse-led outpatients’ structure for advanced COPD in Denmark. They underlined the importance of multidisciplinary work between the respiratory care team (physicians and nurses) and community nurses in order to guarantee an optimal continuity of care and deliver high-quality general palliative care.

### **3.6.5.2 The “Congress Practice Model”**

Buckingham et al. (2015) assessed the feasibility of a nurse-led intervention to explore holistic needs in patients with advanced COPD as part of a palliative care approach. Although the intervention proved to be feasible, it emerged that it overlapped with existing services. The referral to various healthcare professionals for supportive care issues may result in service delivery fragmentation, which is reported as burdensome by patients and their informal carers (Goodridge et al., 2009; Crawford et al., 2012).

Smallwood et al. (2018) analysed data from a survey across New Zealand, Australia and the UK on respiratory and palliative care physicians’ views about specialist

palliative care and advance care planning in advanced COPD. Respiratory care physicians felt comfortable in providing palliative care to their patients, referrals to palliative care specialist happened when patients presented with psychosocial or spiritual needs or approached end-of-life care. Bidirectional education was discussed as an important topic for respiratory care physicians: basic competences in respiratory medicine should be requested from palliative care physicians caring for patients with advanced COPD, thus fostering better care, while establishing collaborative relationships with the respiratory care team (Smallwood et al., 2018).

### **3.6.6 Palliative care integration**

#### **3.6.6.1 Development of integrated care**

Inadequate management of palliative care needs and care fragmentation are among the risks of models which do not provide integrated palliative care (Bruera and Hui, 2012). The development of an integrated care strategy is initialised by patients and carers' needs (Pinnock et al., 2011). Crawford et al. (2012) explored patients, informal carers and healthcare professionals' views on palliative care provision in COPD and assessed service availability and accessibility. A patient-centred coordinated care model was proposed, fostering the integration of a multidisciplinary palliative approach within standard care (Crawford et al., 2012). Recommendations to promote care integration included a holistic needs' assessment, discussions on advance care planning and the definition of the interface between primary healthcare providers and specialist palliative care team. The study did not mention which outcomes should be measured to assess the effectiveness of integrated palliative care (Crawford et al., 2012). Goodridge et al. (2009) held a consensus meeting with key stakeholders (healthcare professionals, patients and informal carers) on how to provide end-of-life care for patients with

advanced COPD. They stressed the importance of continuity of direct care providers and access to a multidisciplinary team for optimal end-of-life care (Goodridge et al., 2009).

The development of integrated care requires a fundamental organisational change, as Hynes et al. described in their action research study (2015). Knowledge on the possibility of team work with specialised palliative care and care coordination is frequently lacking (Strang et al., 2013). Strang and colleagues described in their web-survey among 93 respiratory care physicians that less than half of the respondents were aware of palliative care service development within their own institutions. Therefore, healthcare policy makers and patient's organisations need to be involved in raising awareness on palliative care provision in COPD, both for the public and for healthcare professionals (Beernaert et al., 2013; Hayle et al., 2013).

New models of palliative care integration in advanced COPD explored the role of a care-coordinator (Elkington et al., 2004; Burgess et al., 2013; Rocker and Verma, 2014). Burgess and colleagues explored service availability and accessibility through interviews and focus groups with patients, informal carers and healthcare professionals. Elkington et al. (2004) conducted semi-structured interviews with bereaved relatives, trying to capture the experiences of the last year of life in COPD. Both studies promoted a patient-centred model of care for advanced COPD, supporting a structured multidisciplinary approach in each care setting. They identified healthcare professionals that could act as care-coordinator for these patients. Care-coordinators could ensure patient-centred care, while guaranteeing continuing, appropriate and accessible palliative care (Elkington et al., 2004; Burgess et al., 2013).

The importance of a care-coordinator is also mentioned by Epiphaniou et al. (2014). In their longitudinal qualitative study, they explored the experiences in coordinating care among patients with COPD and lung cancer. COPD patients experienced reduced access to a keyworker in home care settings compared to cancer patients. This role in healthcare settings may provide coordination of care in patients with life-limiting diseases. Epiphaniou and colleagues described less access to multidisciplinary services of advanced COPD patients in comparison to their oncological counterparts (Epiphaniou et al., 2014). Nonetheless, a gap of knowledge on the role and impact of a care-coordinator remains open, since the available studies did not assess any outcomes of the use of this professional role in advanced COPD (Burgess et al., 2013; Epiphaniou et al., 2014).

#### **3.6.6.2 Models of care integration in advanced COPD**

Palliative care integration in advanced COPD services implicates an important effort for the care network of patients benefitting from palliative care (Siouta et al., 2016). Continuity of care between relevant healthcare professionals is the main goal of providing integrated care services (Emanuel et al., 2004). The evaluation of integrated palliative care provision in advanced COPD was the research aim of several published studies (Aiken et al., 2006; Cassel et al., 2016; Rocker and Verma, 2014). Nonetheless, heterogeneity among studied interventions is important (Higginson et al., 2014). For this reason, it is essential to employ identification criteria (Emanuel et al., 2004) which describe integrated palliative care, supporting service development and outcomes' evaluation. An overview of included studies exploring integrated palliative care is presented in Table 3.2.

**Table 3.2:** Included studies with integrated care criteria

<b>Authors</b> <b>Year, Country</b>	<b>Integrated care interventions</b>	<b>Integrated palliative care criteria</b> <b>(Emanuel <i>et al.</i>, 2004)</b>	<b>Outcomes for integrated care</b>
<b>Aiken et al.</b> 2006, USA	Home-based palliative care (PC) intervention services Registered nurse case manager provided service and coordinated care with PC team and general practitioner Support by social worker and pastoral counselor Scheduled visits for the team, on call visits if needed	Advance care planning Holistic needs 'assessment PC interventions to reduce suffering (physical and psychological symptom control) PC team involvement	Increased self-management of illness and knowledge of resources Higher percentages of advanced care planning Better symptom control No difference between intervention and control group in emergency department visits
<b>Cassel et al.</b> 2016, USA	Home visits by multidisciplinary team (nurse, social worker, spiritual care provider and PC physician), added to disease-focused care All staff trained in general PC, PC physician acts as supervisor	Discussions of illness limitations and prognosis Advance care planning PC team involvement	Reduced hospital costs, reduced overall hospitalisations and in the last month of life No impact on overall costs (non-hospital)
<b>den Herder-van der Eerden et al.</b> 2018, Europe	Integrated care initiatives across Europe (InSup-C study)	PC team involvement PC interventions to reduce suffering	Patients' satisfaction with integrated care

<b>Authors</b>	<b>Integrated care interventions</b>	<b>Integrated palliative care criteria</b>	<b>Outcomes for integrated care</b>
<b>Year, Country</b>		<b>(Emanuel <i>et al.</i>, 2004)</b>	
<b>Gainza-Miranda et al.</b> 2019, Spain	Home-based palliative care (PC) intervention services	Advance care planning Holistic needs 'assessment PC interventions to reduce suffering (physical and psychological symptom control) PC team involvement	Increased advance care planning discussions Reduced emergency department admissions Reduced in-hospital deaths (patients dying at home or in palliative care settings)
<b>Higginson et al.</b> 2014, UK	Breathlessness Support Service: multiprofessional service (respiratory, physiotherapy, occupational therapy and PC assessment) Outpatient visit: PC and respiratory care clinicians Home visit: physiotherapist and/or occupational therapist	Holistic needs 'assessment PC interventions to reduce suffering (physical and psychological symptom control) PC team involvement	Improving breathlessness mastery in intervention group Improved survival rate in intervention group

<b>Authors</b>	<b>Integrated care interventions</b>	<b>Integrated palliative care criteria</b>	<b>Outcomes for integrated care</b>
<b>Year, Country</b>		<b>(Emanuel <i>et al.</i>, 2004)</b>	
<b>Horton et al.</b>	Home-based PC interventions	Discussions of illness limitations and prognosis	Home-based PC interventions are feasible
2013, Canada	PC physician and nurse consultations at home	Holistic needs 'assessment	Lack of impact on managing terminal symptoms (patients
	Discussions with primary care team	PC interventions to reduce suffering	were hospitalised for terminal care despite home
	Scheduled visits for the team, on call visits if needed	(physical and psychological symptom control)	consultations)
		PC team involvement	
		Continuous goal adjustment as the illness progresses	
<b>Kirkpatrick et al.</b>	Inpatient multidisciplinary team (respiratory and	Advance care planning	Reduced risk for 30-days readmission
2014, USA	palliative care professionals, nurse practitioner, social	Holistic needs 'assessment	
	workers, pulmonary rehabilitation, home health	PC interventions to reduce suffering	
	workers)	(physical and psychological symptom control)	
	Follow-up appointments and post-discharge phone	PC team involvement	
	calls		

<b>Authors</b>	<b>Integrated care interventions</b>	<b>Integrated palliative care criteria</b>	<b>Outcomes for integrated care</b>
<b>Year, Country</b>		<b>(Emanuel <i>et al.</i>, 2004)</b>	
<b>Philip et al.</b>	Conceptual integrated care model	Discussions of illness limitations and prognosis	PC integration in ambulatory respiratory services
2018, Australia	All care settings	Holistic needs 'assessment	
		PC interventions to reduce suffering	
		(physical and psychological symptom control)	
		PC team involvement	
<b>Smallwood et al.</b>	Integrated palliative care service	Advance care planning	Better symptom control
2018a, Australia	All care settings	Holistic needs 'assessment	Increased self-confidence in overall illness management
2019, Australia		PC interventions to reduce suffering	Increased advance care planning discussions
		(physical and psychological symptom control)	Reduced in-hospital deaths (patients dying at home or in palliative care settings)
		PC team involvement	
		Discussions of illness limitations and prognosis	

Philip et al. (2018) developed a conceptual model for integrated palliative care with the help of an expert advisory board who integrated data from different studies on patients' and carers' experiences and service use (Crawford et al., 2013; Philip et al., 2012; Philip et al., 2012a; Philip et al., 2014). Main key components of this integrated care model were already discussed by other papers, such as multidimensional assessment and triggers to integrate palliative care provision (Elkington et al., 2004; Landers et al., 2015). Furthermore, this conceptual model suggests to embed palliative care provision in routine ambulatory respiratory care, while fostering patients' and healthcare professionals' awareness about palliative care being part of routine care provision (Philip et al., 2018).

Aiken et al. (2006) determined the feasibility of a homecare-based palliative care intervention in a randomised controlled trial. 100 patients were followed at home by a multidisciplinary team, led by a registered nurse case manager and both the primary care and specialist palliative care team. Integrated palliative care criteria addressed by the intervention concerned holistic needs' assessment and palliative care interventions to reduce suffering, advance care planning and the involvement of a palliative care team. Care integration fostered better anticipation of events and patients' self-confidence, increased end-of-life discussions and allowed better symptom control compared to the control group. No difference was registered in terms of emergency department service utilisation.

The multidisciplinary intervention studied by Horton et al. (2013) in an observational longitudinal study consisted of a home-based palliative care consultation with a physician and a nurse and involvement of the primary care team with the general practitioner. Discussions about illness limitations and prognosis and continuous goals'

adjustment along the disease trajectory were discussed. Furthermore, holistic needs' assessment and symptom management were other integrated care criteria addressed by the study. Patients and carers reported an overall satisfaction with the intervention, nonetheless overall quality of life assessed through questionnaires remained unchanged. Furthermore, as reported by Aiken et al. (2006), a lack of impact on emergency department utilisation was observed.

Holistic needs' assessment and optimal symptom management are listed among criteria defining integrated care (Emanuel et al., 2004). Integration of care in disease-modifying approaches may promote better symptom control. Higginson et al. (2014) described in their randomised controlled trial the effectiveness of a breathlessness support service, integrating palliative care, respiratory medicine, physiotherapy and occupational therapy on symptom management. Patients in the intervention group reported a significant improvement of their breathlessness compared to controls.

Smallwood et al. (2018a, 2019) discussed in their single-group observation cohort study and in their survey outcomes and patients' and carers' experiences of a novel long-term, multidisciplinary, integrated service for patients with advanced respiratory diseases. They observed an increase in advance care planning discussions and lower rates of in-hospital deaths, with patients dying at home or in palliative care settings (Smallwood et al., 2018a). Patients reported better symptom control, increased self-confidence in overall management of the illness, time to discuss their views and values and enhanced continuity of care (Smallwood, 2019). Patients' satisfaction with integrated care was also reported by den Herder-van der Eerden and colleagues (2018). In their study about integrated palliative care initiatives across Europe, they highlighted that patients were

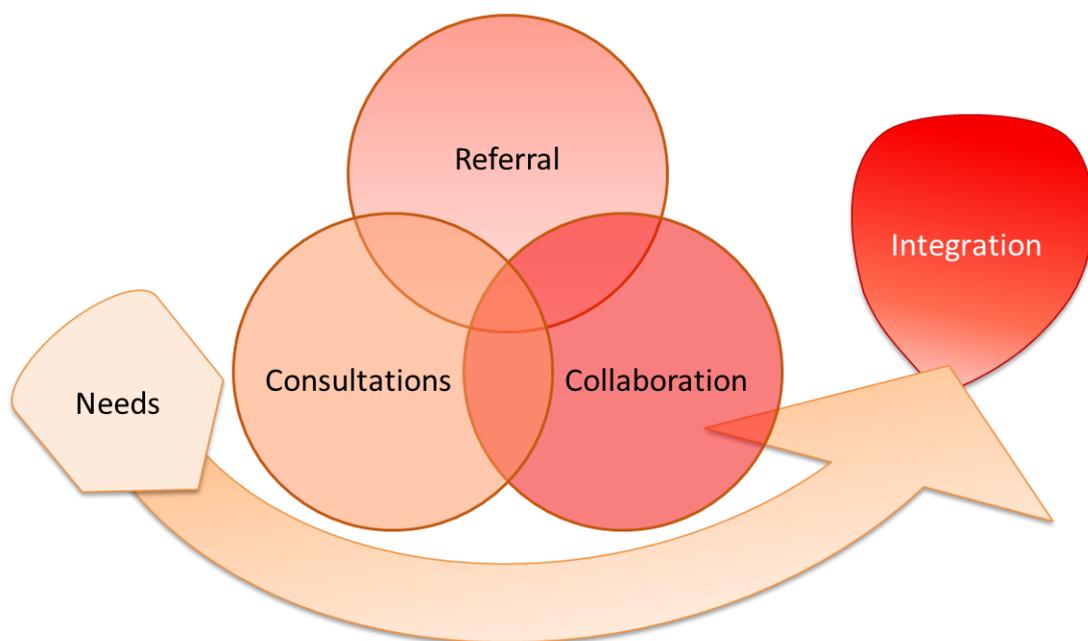
satisfied with integrated care provision when this approach guaranteed continuity of care.

Lastly, economic evaluations of palliative care integration in services for patients with advanced COPD are very scarce (Kirkpatrick et al., 2014; Rucker and Verma, 2014; Cassel et al., 2016; Gainza-Miranda et al., 2019). In their observational retrospective study, Cassel et al. (2016) described the effect of a home-based palliative care program for patients with COPD, cancer, chronic heart failure and dementia in the United States. A multidisciplinary team trained in palliative care and consisting of a nurse, a social worker, a spiritual care provider and a palliative care physician (mostly acting as a supervisor) visited patients at home at scheduled intervals. Discussions of illness limitations and prognosis and advance care planning defined integration of care. COPD patients reported an overall good experience with the proactive palliative care intervention. Hospitalisations and length of stay were significantly lower than in the control group, although non-hospital costs did not significantly differ between the two groups. Kirkpatrick et al. (2014) highlighted similar results in a small study about an inpatient integrated practice unit in the United States. A multidisciplinary team (respiratory and palliative care professionals, nurse practitioner, social workers and home health workers) provided care for patients with acute COPD exacerbations. Furthermore, follow-up appointments and post-discharge phone calls were planned. Holistic needs' assessment, symptom management and advance care planning reduced the 30-days readmission rate (Kirkpatrick et al., 2014). Gainza-Miranda et al. (2019) evaluated the impact of a palliative home care team for patients with advanced COPD in Spain. In their prospective observational cohort study, they assessed a decreased number of hospitalisations and of in-hospital deaths with patients dying at home or in palliative care settings, as already outlined in other contexts (Smallwood et al., 2018a).

Nonetheless, cost-effectiveness of palliative care integration in advanced COPD and economic outcomes need to be further investigated to support the development of new care models (Epiphaniou et al., 2014; Kirkpatrick et al., 2014; Cassel et al., 2016).

### 3.7 Discussion

This integrative literature review identified four main themes as part of a model for palliative care provision in advanced COPD. These findings describe how palliative care is provided for patients with advanced COPD, how services work together and which components of integrated care are implemented. This model involves different levels of care provision and integrated care is the last step of this dynamic process, as illustrated in Figure 3.2.



**Figure 3.2:** Model of palliative care provision in advanced COPD

The process is initiated by patients and informal carers' needs and views. Patients with advanced COPD present with a high symptom burden and an important need for ongoing communication with their healthcare professionals (Spence et al., 2009). A holistic multidimensional assessment and management, and continuous discussions about illness limitations, prognosis and goals of care are acknowledged as criteria defining integrated palliative care (Emanuel et al., 2004).

The timing of palliative care provision in advanced COPD remains unclear (Crawford et al., 2012). The identification of milestones that define a decline in the disease trajectory should trigger the introduction of supportive interventions for this population, while fostering the development of integrated care (Lander et al., 2015).

Palliative care service delivery in advanced COPD remains in a developmental phase. Different models of care provision with progressive levels of integration were proposed (Buxton et al., 2010; Epiphaniou et al., 2014; Higginson et al., 2014). Siouta et al. (2016a) identified a framework for integrated palliative care in chronic diseases. This framework promotes palliative care integration in the disease trajectory concurrently with disease-modifying therapies. Furthermore, symptom control, consultations for patients and family members and healthcare professionals' training are provided by a trained multidisciplinary palliative care team (Siouta et al., 2016a).

In this context, it is important to highlight the need for a profound organisational change (Hynes et al., 2015). Healthcare policy makers should be motivated to support new care models and patients' organisations need to increase the awareness on the right of accessibility to palliative care for advanced COPD patients (Strang et al., 2013). This motivation may be reinforced by outcome measures underlining the positive impact of palliative care provision in advanced COPD. Therefore, further evidence on the benefit

of palliative care service delivery is needed to support the developmental process of care integration in advanced COPD (Cassel et al., 2016).

This integrative literature review was published as a paper in a respiratory care journal (Fusi-Schmidhauser et al., 2018). The 24 included papers were published before November 30, 2017. An update search until March 31, 2019 retrieved nine additional papers. Identified themes and subthemes remained unchanged, the description of palliative care provision in advanced COPD developed with further understanding of the process and differed from the original published model (Fusi-Schmidhauser et al., 2018).

Strengths and limitations of this literature review were acknowledged and addressed. This literature review synthesised empirical evidence from papers with various methodological backgrounds. This helped to enrich data synthesis, while strengthening the results. Nonetheless, the use of a sole critical appraisal tool for disparate data might have increased the risk for quality rigour. To address this limitation, the threshold for quality assessment was set in the higher scores of the chosen appraisal checklist.

### **3.8 Conclusion**

This literature review identified a developmental model of palliative care delivery in advanced COPD. The definition of care integration (InSup-C, 2014; van der Eerden et al., 2014) and the application of specific criteria assessing the degree of integrated care (Emanuel et al., 2004), supported the evaluation of existing interventions and service delivery.

Palliative care involvement, holistic needs' assessment and management and advance care planning were the main components of integrated palliative care services in

advanced COPD. By contrast, the timing of palliative care integration and referral criteria were not considered in integrated palliative care initiatives. This represents an important gap of knowledge in service delivery.

In addition, interventions promoting training and empowerment of healthcare professionals as discussed by Siouta et al. (2016a) were lacking. Therefore, the current models do not explore the extent and quality of palliative care services provided by primary care teams and what kind of leadership they could assume working in an integrated care team.

The present research will try to address these gaps, while proposing and testing modalities for palliative care integration in advanced COPD in a local setting in Southern Switzerland.

## **CHAPTER 4: THEORETICAL AND METHODOLOGICAL PERSPECTIVES**

In this chapter the theoretical underpinnings of this study focused on how to integrate palliative care provision for patients with advanced COPD in a respiratory service in Southern Switzerland are discussed. Following an introduction to action research, the theoretical background and the philosophical foundations of the study and justifications for the choices made during the research development are presented. Action research as a research methodology will be described in healthcare and within this research. The challenges of action research are also addressed; their impact on this research will be debated in the discussion chapter.

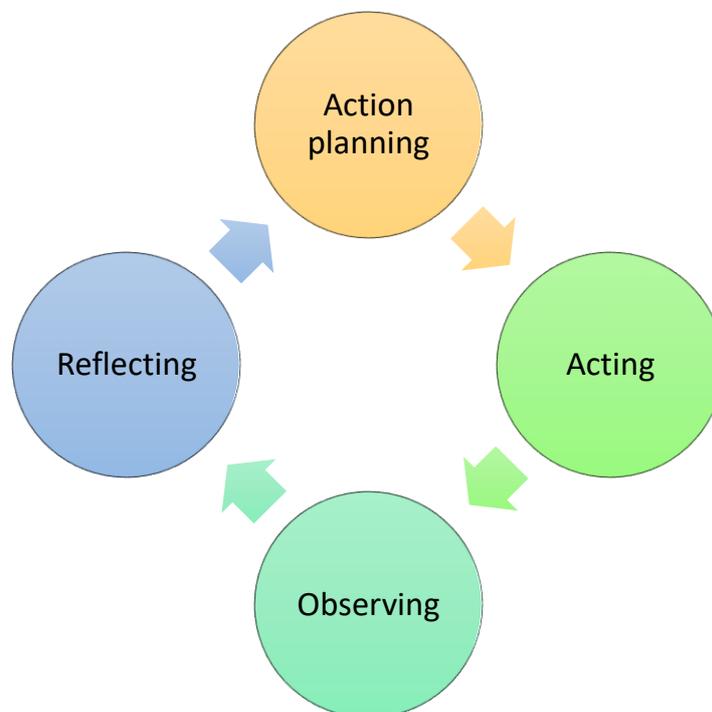
### **4.1 Defining action research**

As previously described in the introduction chapter, this research seeks to answer the question: how to integrate palliative care provision for patients with advanced COPD in a respiratory care service in Southern Switzerland? The involvement of key stakeholders in developing shared knowledge that supports this integration may foster its acceptability and its implementation in a pre-specified context (White and Lynch, 2013). In contrast to other research approaches, the involvement of key stakeholders within the research group may lead to a “bottom-up” modification of current practices in palliative care integration into standard care (White and Lynch, 2013).

According to Reason and Bradbury (2008, p.1) action research is “a family of practices of living inquiry that aims, in a great variety of ways, to link practice and ideas in the service of human flourishing”. Action research is about generating new theories from practice through a collaborative partnership between researchers and participants (Waterman et al., 2001). Action research was developed by Kurt Lewin in the mid-1940

as a response to critical aspects in social action (Kemmis and McTaggart, 1988). The main pillars of Lewin's action research model were group decisions and commitment, both essential to foster improvement in practice (Dickens and Watkins, 1999).

Several terms were used to describe action research, such as participatory research, co-operative inquiry, action science and action learning (Koshy, Koshy and Waterman, 2011). The purpose of action research is to foster changes which improve practice in a specific context (Parkin, 2009). Key elements of action research include the participatory nature, the egalitarian and democratic effort and the concurrent contribution to knowledge and changes in practice (Carr and Kemmis, 1986, p.164). Action research involves a continuum of action planning, action performing and observing and subsequent reflection on what happened in this process (Kemmis and McTaggart, 2005), as depicted in Figure 4.1. Crucial in this cyclic process is critical reflexivity, which supports changes in practices (Greenwood, 1994).



**Figure 4.1:** Action research stages

## **4.2 Epistemological and ontological stance**

The philosophical underpinnings of this action research study are located in critical social theory (Leonardo, 2004; Princeton, 2015). The perspective of critical social theory as “the empowerment of individuals in an attempt to confront the injustice of a particular society or sphere within the society” (Kincheloe and McLaren, 1994, p. 140), is evoked in the principles of action research, where ensuring participants’ empowerment in social inquiry is fundamental (Baum, MacDougall and Smith, 2006). Initiated by the Frankfurt School (Horkheimer and Adorno, 2013), critical social theory was further developed by different theorists, such as Habermas (1981), while introducing the concept of self-reflection and the subsequent acting on previous self-reflections (Kemmis, 2001; Baum, MacDougall and Smith, 2006). Another step in defining the philosophical underpinnings of this participatory action research more precisely may be taken by referring to the work of Carr and Kemmis (1986). In their approach to action research, they highlight the importance of critical questioning, while fostering the dialogue within a specific organisation, in order to build a space for communication and problem solution (Carr and Kemmis, 1986). Therefore, the critical understanding of a situation leads to a learning process, which changes the individual practice and may influence and modify the culture within a society (Loewenson et al., 2014).

The epistemological foundation of this study recognises that knowledge is gained from different perspectives and viewpoints. According to the researcher’s epistemological stance, it is fundamental to understand how people are experiencing knowledge in a pre-specified context. Knowledge is generated from practical experience and derives from those who are actively involved in practice in a specific context (organisation,

system) (Koshy, 2005). At the same time, knowledge is provisional as it is subject to numerous interpretations and critical analysis (Thomas and Bergold, 2012) and it is this critical analysis and reflection that may help to develop theory that originates from practice (Rolfe, Freshwate and Jasper, 2001).

From an ontological perspective, it is important to acknowledge the importance of social justice within this action research study. Palliative care was recognised by the WHO as a fundamental component of people-centred and integrated healthcare services (WHO, 2015). Moreover, palliative care is considered by many as a human right (Gwyther, Brennan and Harding, 2009), with a call for compulsory accessibility for all patients and their families with life-limiting diseases. As previously discussed, palliative care provision is not systematically implemented in advanced COPD, thus generating inequalities in care provision (Epiphaniou et al., 2014). Closing this practice gap and allowing patients with advanced COPD to access palliative care was the driving force in this research.

### **4.3 Models of action research**

Although the cyclic process depicted in Figure 4.1 is central to all action research models, differences in epistemological stances may change how this process is developed and on which steps of the cycle the attention should be focused on (Dickens and Watkins, 1999). Planning, acting, observing and reflecting may acquire different levels of attention according to a chosen action research approach (Cunningham, 1993). Moreover, the level of participation may vary across types of action research. Whyte (1991) proposes an action research model with a professional researcher leadership. This may answer questions on how processes are being developed and implemented in institutions, nonetheless the participatory way in which new knowledge is shaped and

practice changed is less visible. Other models underline participants' commitment as a key element of action research. According to McTaggart (1991) there is a difference between action research and participatory action research, where the latter involves participants' full commitment to the research. Furthermore, participatory action research is designed and conducted by all participants and reflection on changes in practice is shared (McTaggart, 1991). Hughes (2008) describes three models of participation:

- 1) *Action research*: improving practices through cycles of action and reflection. Practitioners are not involved in decision-making
- 2) *Participatory research*: practitioners, key stakeholders and patients research together. A pre-specified health intervention is not the core of the study
- 3) *Participatory action research*: this approach considers key stakeholders as decision-makers in research (*collaborative inquiry group*) which aims at changing a pre-specified healthcare intervention

Participatory action research as described by McTaggart (1991) was the approach chosen for this research study and building the collaborative inquiry group (CIG) was facilitated by common goals in changing practice.

#### **4.4 The choice of action research**

As illustrated in the previous sections, action research is about generating new knowledge and improving practice through changes which are developed in a collaborative partnership between researchers and participants (Waterman et al., 2001). The use of action research in healthcare research and development was long debated (Waterman et al., 2001; Hughes, 2008, pp. 381-393). In a systematic review on the role

of action research in healthcare settings in the UK, Waterman and colleagues (2001) found that practitioners who chose action research favoured this approach because it was participatory for stakeholders, also leading to their empowerment as both researchers and stakeholders. Furthermore, action research fostered process evaluation and contributed to generating knowledge which was applied to change practices. Knowledge generation in action research may have an informative character, but it may shift to the generation of transformative knowledge when action-oriented outcomes arise during the research process (Reason and Bradbury, 2008). Action research may also benefit from a process evaluation through a ToC approach (Apgar et al., 2017). Although ToC is often applied to quantitative study designs (trials), the evaluation of elements which are needed for an initiative to work is essential in action research (Valters, 2015).

The growing interest in addressing palliative care needs in advanced COPD patients within standard care in a local setting in Southern Switzerland was the trigger for this research. The availability of a palliative care consultation service for inpatients with life-limiting diseases increased healthcare professionals' awareness of palliative care needs in patients with advanced COPD. The collaboration between the hospital staff, respiratory care physicians and the palliative care consultation team may result in appropriate palliative care for inpatients hospitalised for acute COPD exacerbations. Nonetheless, this "Congress Practice Model" of care provision did not meet integrated care criteria, as proposed by Emanuel and colleagues (2004) and already discussed in the literature review of this thesis.

Moreover, as discussed in chapter two, stakeholders have different viewpoints on how to integrate palliative care within disease-directed therapies (Lingard et al., 2013).

Palliative care integration within standard care can be implemented both horizontally through a collaboration between different healthcare professionals and vertically through the involvement of healthcare providers in different care settings (Van der Linden, Spreeuwenberg and Schrijvers, 2001). The debate on how to integrate palliative care in the management of patients with advanced COPD remains open and the involvement of key stakeholders in developing shared knowledge that supports this integration through participatory action research may foster its acceptability and its implementation in a pre-specified context. Bridging the theory and practice gap on how to integrate palliative care in advanced COPD may generate practical knowledge on palliative care approaches within respiratory medicine, which in turn may lead to an organisational change for the researched community (White and Lynch, 2013). The engagement of different healthcare professionals in building learning relationships and generating new knowledge on palliative care approaches in this specific field may help to review practices applicable to the researched local setting (Stoecker, 1999; Reason and Bradbury, 2008; MacDonald, 2012). The key dimensions of this study fit with all the main components of action research (Koshy, Koshy and Waterman, 2011):

- 1) *Addressing practical problems*: palliative care integration in advanced COPD is perceived as an important clinical issue by healthcare professionals working in the respiratory care service
- 2) *Building knowledge*: the question on how to integrate palliative care in advanced COPD relies on building knowledge to foster changes in practices and on implementing changes to deliver new knowledge about integrated care
- 3) *Foster changes in current practice*: developing new ways of caring for patients with advanced COPD through palliative care integration

- 4) *Participatory nature of action research*: empowering stakeholders caring for patients with advanced COPD to build new knowledge about palliative care integration. It will represent their developed knowledge to change practice (“bottom-up approach”)
- 5) *Cycle of planning, acting, observing and reflecting*: continuum of situational analysis, action, observation (data collection) and reflection about the process in order to understand what happened before and how to shape further cycles

These elements which shaped the research planning and development were seen as mainstays for an organisational change in how palliative care may be integrated into care provision for patients with advanced COPD. The action research model described by McTaggart (1991) as participatory action research was therefore selected for this study, as it reflected my epistemological and ontological stance.

#### **4.5 First, second and third person inquiry in action research**

As discussed, action research aims to change practice through shared knowledge which is generated by a group of committed practitioners (Reason and Bradbury, 2008). It is important to highlight that action research is founded on knowledge generation and development, which clearly differentiates this approach from others which are focused on changing practices rather than building new knowledge during the process (Coghlan and Brannick, 2010). In action research knowledge generation occurs through a timeline, where past, present and future are considered. Furthermore, it is conducted on three entities: the researcher, the group and the institution (or institutions) which aims to change practices (Torbert and Taylor, 2008). The different inquiries on these entities are described as first person, second person and third person inquiry (Hynes, 2013).

Through first person inquiry the lead action researcher inquires into his/her positions and motivations regarding the research, reflecting on his/her subjectivity and on the process unfolding during the continuum of action research cycles (Marshall, 2016). As the lead action researcher, I reflected on my practice and on my worldview and engagement within the study, acknowledging behaviours and impact of actions (Reason and Torbert, 2001). All these aspects help to identify two levels of reflection in action research. The first one (“reflection in action”) happens during interactions within the research group or process, the second one (“reflection on action”) is more focused on understanding retrospectively how the process unfolds and how participants react to it (Schön, 1983).

Second person inquiry arises within a group of practitioners developing knowledge together. The process of planning, acting, observing and reflecting is founded on interpersonal dialogue and discussions (Torbert and Taylor, 2008). The egalitarian and democratic principles of action research guide the development of new knowledge in a participative way. This is fostered by the creation of a communicative space where the group initiates the process, while acquiring awareness about themselves and the building of relationship with others (Wicks and Reason, 2009). In contrast to inquiry within the group, third person inquiry develops through dissemination of action research across local boundaries. The aim of third person inquiry is to disseminate knowledge about different studies and to gain connections within the researcher community and the broader public (Hynes, 2013).

First, second and third person inquiry are challenging for action research in healthcare settings, as according to several authors (Chandler and Torbert, 2003; Reason and Bradbury, 2008) these different types of inquiry should be encompassed in a robust

action research study. As highlighted by Hynes (2013), aspects such as patients' engagement in action research, reflections on both participants' and institutions' goals and values and knowledge dissemination over the studies' limits and boundaries challenge action research in healthcare and in particular in a palliative care setting. These aspects were considered throughout the research and will be debated in the next sections and chapters of this thesis.

#### **4.6 Assessing quality and rigour in action research**

Questions about how to demonstrate quality and rigour in action research were debated (Froggatt, 2013). As with other qualitative research paradigms, criteria which define research quality from a positivist point of view do not address the epistemological stances which support action research. Research reliability and generalisability may therefore not be the appropriate criteria to judge quality of action research (Guba and Lincoln, 1994). Furthermore, key elements of action research such as real-life experiences in a pre-specified context and reflections on these experiences and practices clash against the positivist perceptions of reliability and generalisability (McTaggart, 1994). For these reasons, the question on how to assess quality and rigour in action research remains and different approaches to address this query were proposed.

Through their systematic review on action research studies in the UK, Waterman and colleagues (2001) elaborated 20 questions necessary to assess quality of action research. Among those questions, a few were considered both as quality criteria and as key characteristics of action research: 1) Clarity and transparency of methods employed, 2) Consideration of local context for change implementation, 3) Description and justification of involved practitioners and stakeholders, 4) Consideration of potential power imbalance and relationships within the research group.

Williamson and colleagues (2012) identified common quality criteria for the evaluation of action research within different models for quality assessment. In comparison to the criteria proposed by Waterman et al. (2001), they focused on elements such as knowledge building, fostering changes in practice and the participatory nature of research. The last example of quality criteria addressing fundamentals of this research are suggested by Reason (2006). These criteria consider that action research is of high-quality if the study fulfils the following characteristics: 1) Evaluate worthwhile practical purposes, 2) Participative and democratic inquiry, 3) Inclusion of different forms of knowledge, 4) Maintain a continuum of research development over time. The criteria defined by Reason (2006) were adopted to help lead to as high-quality research as possible for this study.

#### **4.7 Challenges of action research**

The key elements of action research such as its participatory nature, the egalitarian and democratic effort and the concurrent contribution to knowledge and changes in practice also represent the strength of action research in general and for this study in particular (Carr and Kemmis, 1986, p.164). As an action researcher I acknowledged the importance of identifying challenges and potential pitfalls of this approach, thus addressing them during study planning and development (Grant, Nelson and Mitchell, 2008).

##### **4.7.1 Relationships and power imbalance**

Action research within a practitioners' group with hierarchical relationships is challenging. Asymmetrical power relationships and subsequent difficulties in individuals voicing their own opinions and views need to be constantly acknowledged

and addressed through reflexivity prior and during the whole research process (Casarett, 2010). Furthermore, it is important to highlight the role the lead action researcher plays as facilitator (Grant, Nelson and Mitchell, 2008) and in this particular setting myself, as the person undertaking the PhD, therefore driving the study (Zuber-Skerrit, 2011). The principle of action research of common research ownership is only partly fulfilled in this study. Clarity and transparency about roles and expectations is fundamental for building trusted relationships (Reason, 2002). Therefore, the researcher role in this research setting and the potential conflicts arising from hierarchical relationships were addressed by ongoing reflexivity by both the CIG members and myself as a researcher and by discussions about power and sources of inequity (Grant, Nelson and Mitchell, 2008).

#### **4.7.2 Encouraging and supporting participation**

Commitment to CIG participation is essential for any action research study. Prior to and throughout the whole study, participation was encouraged and supported through collective continuous evaluation of possible barriers (time constraints, power imbalance, institutional aspects), while identifying options and solutions to overcome those barriers. I clearly debated with the group members all acknowledged potential pitfalls which might appear along the process. This helped to ensure open discussions about these issues when encountered during the research development (Roberts and Dick, 2003).

#### **4.7.3 Fostering change**

Fostering change involves sharing the same goals within the CIG of an action research study. Furthermore, it is important to explain to all participants that change develops

slowly and that change which is implemented through an action research study may be small and less tangible in institutions or services. Nonetheless, these changes may foster a large-scale transformation of clinical practices in the researched setting. Negotiating purpose and pace of change is thus fundamental to develop a cohesive and committed CIG which in turn will foster future changes across the borders of this research (Grant, Nelson and Mitchell, 2008).

#### **4.8 Conclusion**

The application to the local clinical context, the involvement of key stakeholders within the research group and the “bottom-up” modification of current practices in palliative care integration into standard care are mainstays for an organisational change that results in the integration of palliative care into disease-directed therapies (White and Lynch, 2013). Participatory action research was therefore chosen as the approach for this research (McTaggart, 1991). The commitment of healthcare professionals to support, share and extend the generated practical knowledge amongst healthcare professionals providing care for patients with life-limiting respiratory diseases was one of the driving forces of this study (White and Lynch, 2013). These elements will be further identified in the next chapters as the research methods and results of both phases of the research are presented sequentially by phase.

## **CHAPTER 5: METHODS AND RESULTS PHASE I**

As previously discussed in the introduction of this thesis, this research was developed and conducted in two phases. In this chapter the first situational analysis of the whole study where patients' and informal carers' perspective was foregrounded (phase I of the study), is presented. The aim of this first study phase was to explore patients' and informal carers' experiences along the disease trajectory and to understand their perception of palliative care provision in advanced COPD through individual interviews. A detailed description on sampling, recruitment, data collection, data analysis and findings of the first phase of this study will be provided. Furthermore, ethical aspects of this phase are also discussed.

### **5.1 Methods**

#### **5.1.1 Study design**

The first phase of this study consisted in undertaking qualitative interviews with patients diagnosed with advanced COPD and informal carers recruited through and undertaken in an outpatient setting of a respiratory care service located in a major public teaching hospital in Southern Switzerland.

#### **5.1.2 Recruitment and selection**

Study participants were selected through stratified purposive sampling in order to identify patients diagnosed with advanced COPD (GOLD stages 3 and 4, group D) and informal carers providing care for these patients. Potential participants were identified through medical records by personnel not involved in the study. The proper identification according to their disease stage was subsequently confirmed by a

respiratory care physician. Participants received a recruitment letter either by postal mail or from trained personnel working at the respiratory care service (but not directly involved in the study), prior to scheduled consultations (Appendix VII). Patient-carer dyads were not necessary for sampling. Therefore, patients and informal carers were not prevented from study participation even if their carer (for patients) or the family member they were taking care of (for informal carers) declined to join the study. Informal carers were identified by patients as being their main informal carer and they received the recruitment letter either by postal mail or from trained personnel working at the respiratory care service when accompanying the family member to scheduled consultations. A signed consent form was collected on the interview day (Appendix VIII). Inclusion and exclusion criteria, as listed in Table 5.1 were applied during the process.

**Table 5.1:** Inclusion and exclusion criteria for patients and informal carers

Inclusion criteria patients	Exclusion criteria patients
<ul style="list-style-type: none"> <li>• Adults (&gt; 18 years old)</li> <li>• Formally diagnosed (spirometry) and documented (in medical chart) advanced COPD (GOLD classification 3-4, group D)</li> <li>• Outpatients in the respiratory care service</li> <li>• Fluent in Italian</li> <li>• Competent and willing to sign informed consent sheet</li> </ul>	<ul style="list-style-type: none"> <li>• Inability to join consultations as outpatient</li> <li>• Hospitalisation at the time of recruitment</li> <li>• Palliative care recipients (as outlined in medical charts)</li> <li>• Concurrent oncological disease</li> </ul>
Inclusion criteria informal carers	Exclusion criteria informal carers
<ul style="list-style-type: none"> <li>• Adults (&gt; 18 years old)</li> <li>• Identified by patients with COPD as relative/friend who provides care at home</li> <li>• Fluent in Italian</li> <li>• Competent and willing to sign informed consent sheet</li> </ul>	<ul style="list-style-type: none"> <li>• Inability to join consultations as informal carer</li> </ul>

### 5.1.3 Data collection

Individual semi-structured interviews were conducted in Italian from September 2016 to March 2017. The interviews lasted between 30 and 45 minutes and were conducted in a conference room on clinic premises during working hours. They were digitally recorded, anonymised, transferred to a password-protected computer and transcribed verbatim in Italian. An interview guide duly created for this study ensured that the same issues were explored during each interview. Data saturation was considered to be achieved when further coding was not feasible (Ando, Cousins and Young, 2014). Since

transcription and coding were performed after each interview, themes and subthemes were identified after the first nine interviews. One more interview allowed to confirm that further coding was not feasible and that new themes were not identifiable.

#### **5.1.4 Data analysis**

Individual interviews were analysed using thematic analysis (Braun and Clarke, 2013). Transcripts were analysed using a qualitative data analysis software package (NVIVO<sup>®</sup>). An inductive approach was chosen during data coding and analysis, in order to capture patients' and informal carers' experiences (Braun and Clarke, 2006). Data analysis was performed according to a step-wise approach, where six different phases can be outlined during the data analysis process (Braun and Clarke, 2006).

Engagement with raw data represented the first step of data analysis. Transcribed verbatim and digital recordings were read through and listened to several times to engage with the collected data. In this phase it was crucial to pay attention to what participants were saying and how they were expressing their views and experiences. According to Braun and Clarke (2006), the second step of thematic analysis relates to the identification of initial codes. These codes were both semantic where the code came closely out of what was said or interpretative (or latent) where what was said was interpreted. The third step of data analysis was represented by the development of themes and subthemes, the latter defined as elements composing a theme. The development of themes and subthemes was fostered by clustering codes which enabled to identify common pattern across the collected data (Braun and Clarke, 2006). After identification of themes and subthemes in Italian they were translated to English. A sample of codes and subthemes are depicted in Appendix IX.

The fourth step of data analysis involved reviewing identified themes and relating them to the collected data. Reflections on how collected data supported the identified themes in terms of coherence and meaningfulness in relationship to the research question helped to confirm that the identified themes represented the perceptions and experiences of patients with advanced COPD and of their informal carers. This reviewing process was performed several times and was supported by the use of NVIVO<sup>®</sup>. This tool helped to create a diagrammatic representation to help connecting the themes. Furthermore, transcriptions were read once more to review the identified themes against the collected data (Braun and Clarke, 2013). The fifth and sixth step of data analysis addressed the final definition of the identified themes and how to present them in the results' section. According to Braun and Clarke (2006), high-quality thematic analysis should foster the development of themes with a single focus, with a relationship to the other themes and which address the research question. These aspects were considered during the last steps of data analysis and are outlined in the results' section of this chapter.

#### **5.1.5 Data management plan**

Electronic data were stored on the researcher's institutional Storage Area Network. A dedicated folder for this research was created by the IT service and was made accessible only to the researcher. This restricted access ensured data availability, integrity, confidentiality and traceability of attempted access. The daily backup was centrally managed. Highly sensitive data were encrypted using WinZip. Paper documents such as completed consent sheets, interview verbatim and the reflective journal were stored in a fireproof cabinet with prior defined limited key access to the researcher. Data were deleted from encrypted recorders once downloaded. All computers used for this research were password protected.

## **5.2 Ethical aspects**

In consideration of the particular status of this research, which was developed and conducted in Switzerland, under the guidance of Lancaster University, a duplicate ethical approval was obtained from both the Swiss Ethics Committee (Appendix X) and the Faculty of Health and Medicine Research Ethics Committee (FHMREC) at Lancaster University (Appendix XI). According to the Swiss legislation, it is important to highlight that the study required the adherence to federal and cantonal regulations (Working Group of the Swiss Ethical Committees for Research with Human Subjects, WGEC, 2009). Six key ethical principles were considered during the development and conduct of this research phase: rigour in qualitative research, confidentiality, voluntary participation, harm avoidance, research independence and research transparency (Economic and Social Research Council, ESRC, 2015).

### **5.2.1 Rigour in qualitative research**

Low quality research which lacks of rigour is unethical towards participants (Rosenthal and Blanck, 1993). Participants are engaged in research, with important time requirements. Lack of rigour in research wastes these essential resources, while preventing participation in high-quality studies leading to accurate conclusions (Rosenthal and Blanck, 1993).

As discussed by Lincoln and Guba (1985), qualitative research needs to be assessed according to criteria which establish the level of quality and rigour. Credibility, authenticity, critical appraisal and integrity were considered throughout all stages of this first research phase. Specific sampling decisions, in-depth engagement with data, data saturation, grounding the data in available literature and providing evidence that

supports findings were some of the used techniques to comply with rigour required for high-quality qualitative research (Whittemore, Chase and Mandle, 2001).

### **5.2.2 Confidentiality and anonymity**

Data were managed in accordance with both, the Swiss Federal Act on Data Protection and the UK Data Protection Act (Federal Council, 2019; UK Government, 1998). Anonymisation was guaranteed using an identification number on paper, electronic and audio data and encrypting the matching list with limited access to the researcher. Furthermore, interviews were recorded using an encrypted digital audio recorder and the original recordings were deleted after the transformation in an mp3 format file. Paper documents such as completed consent forms and interview verbatim were stored in a fireproof cabinet with prior defined limited key access to the researcher. The data management plan states that hard copies of data will be stored for 10 years after the completion of the study.

Findings and quotes from patients' and informal carers' interviews were shared with the research group and with the supervisors. Although the possibility of harm to self or others was remote, the informed consent sheet mentioned that confidentiality may have been breached in these particular cases.

### **5.2.3 Voluntary participation**

Voluntary participation in research requires that researchers respect participants' acceptance or refusal to participate in the study, while guaranteeing the independence of further healthcare provision from this decision (WGEC, 2009). As previously mentioned, an information letter informed potential participants on the main features of the research.

The voluntary participation was reiterated through the participant information sheet and the consent form. Specific aspects such as the lack of influence on further healthcare provision by participation refusal and the possibility of withdrawal from the study up to two weeks after completion of the last research cycle were particularly highlighted. Lastly, compensation rewards or incentives were not given, thus preventing controversies over possible persuasion mechanisms on participants to be included in the study (WGEC, 2009).

#### **5.2.4 Harm avoidance**

Regarding patients and informal carers' involvement, study data collection conducted through interviews discussed subjects such as life worthiness, emotional discomfort and patient's loss of independence. Strategies planned to address these issues included the opportunity to terminate the data collection if the participant was too distressed and professional counselling service availability to all participants. These topics elicited minimal distress during participation and none of the planned strategies needed to be used during the interviews.

#### **5.2.5 Research independence**

The whole research was not influenced by the researcher's institution and the research independence within the same institution was guaranteed through the ethics approval process. Lancaster University sponsored the study as part of a PhD in Palliative Care.

### **5.3 Results**

This section is dedicated to the results from Phase I, which consisted in interviewing patients and informal carers on living with COPD. This first part of the study had an

informative purpose for the first CIG meeting. Therefore, the main results from Phase I are presented in this section and further integrated into the first action research cycle, which will be described in the following chapter on Phase II methods and results.

As previously discussed, the first phase of this research consisted in interviews with patients with advanced COPD (stages GOLD 3 and 4, Group D; GOLD, 2017) and informal carers. Five patients and five informal carers were interviewed from September 2016 to March 2017. An overview of participants' main demographic characteristics is shown in Table 5.2. Patients are identified as P and informal carers as IC.

**Table 5.2:** Main demographic characteristics of study participants

Participant	Patient/Informal carer	Gender	Age (years)
<b>Patients</b>			
P1	Patient (COPD GOLD 4)	Male	65
P2	Patient (COPD GOLD 3)	Female	63
P3	Patient (COPD GOLD 4)	Male	72
P4	Patient (COPD GOLD 3)	Female	76
P5	Patient (COPD GOLD 3)	Male	70
<b>Informal carers</b>			
IC1	Informal carer ( <i>wife of P1</i> )	Female	59
IC2	Informal carer (wife)	Female	76
IC3	Informal carer ( <i>wife of P5</i> )	Female	65
IC4	Informal carer (close friend)	Female	47
IC5	Informal carer (daughter)	Female	39

Seven females and three males participated in the study. The median age of participants was 65 years (range 36-76 years). Patients were older than informal carers. Patient and carers' dyads were present for participant P1 and IC1 and for participant P5 and IC3.

Informal carers were mainly family members, only one carer was a patient's close friend and neighbour (IC4). All interviews lasted between 35 and 45 minutes and were conducted on clinic premises. Three main themes were identified from the analysis: living day to day with COPD, psychosocial dimension of the disease and management of complex care. An overview of the identified themes and subthemes is listed in Appendix XII.

### **5.3.1 Living day to day with COPD**

Patients and informal carers described what it was like living day to day with advanced COPD or caring for a relative affected by the disease. Physical symptoms such as breathlessness, cough and fatigue were described and both patients and informal carers highlighted the impact these symptoms had on daily activities.

*“When I go out, I walk for about 50 meters to the bus station...and I am already out of breath...it is getting worse day by day” (P1).*

Informal carers are unable to sleep at night as they are frequently woken by their spouses.

*“He always coughs at night...and when he catches the flu...it is worse...it is difficult to sleep, even if we sleep in two separate bedrooms” (IC2).*

*“I am always awake at night, the least noise...because when he is short of breath it seems that he whistles...that's frightening...” (IC1).*

Daily life activities were limited and adapted to the progressive functional decline. Moreover, the need for frequent medications, such as inhalation therapy and long-term oxygen treatment further reduced patients' independence in daily living.

*“Grocery shopping has become a four hours ritual, since I need to do my inhalations first and then prepare the portable oxygen which I need to take with me...and the supermarket is only 300 meters away” (P3).*

Patients and informal carers also underlined that living with COPD meant they needed strategies to deal with the illness, to talk about it and to be aware of the overall implications the illness had on both patients and their families.

*“I try to find distractions in daily life and to enjoy myself as much as I can...I think my positive attitude helps me to face the difficulties with this respiratory problem” (P2).*

A sense of loss was described by both patients and carers in living day to day with COPD. Patients shared the loss of independence and issues of impairment as the disease progressed. They recalled all the daily life activities they were able to perform before disease progression in comparison with the limitations they currently experienced in daily life. Not only was physical impairment a topic, but they also described a reduced enjoyment in life due to an increased need for help, both from informal carers and healthcare professionals.

*“When I am feeling better, I make some plans...I want to go to the basement and do some work there...but it doesn't work...I need help and it is frustrating...” (P1).*

Dealing with the illness in daily life and being able to talk about it within the family and with healthcare professionals was important for both patients and carers. These aspects which were identified as subthemes in daily living with COPD were recognised as overlapping with the psychosocial dimension of the illness.

### 5.3.2 Psychosocial dimension of COPD

Patients and informal carers discussed the psychological dimension of COPD, in particular their emotions while living with or caring for a relative with COPD. Feelings of fault emerged among both patients and carers. Patients felt guilty and were ashamed of their smoking habit. Guilt was perceived by patients towards their families, especially towards spouses for the way in which the effects of living with the illness impacted more widely on the family/couple relationship.

*“I feel guilty because I realise that with my breathlessness I am limited with all my activities...I loved hiking in the mountains with my wife, but this is now impossible for us” (P5).*

This sense of guilt was openly discussed in relation to taking responsibility for acquiring the disease, nonetheless patients tried to implicate other causes for the illness, so that smoking was one of several factors concurring to the development of COPD.

*“A smoker knows that it is harmful...every excess is harmful, but also all fine particles in the air are harmful and there is nothing we can do about it” (P2).*

At the same time, informal carers blamed patients for their smoking habits leading to a “self-inflicted” disease, which influenced both the patients and family lives. Furthermore, informal carers blamed patients for their inability to stop this habit.

*“...but if he would stop smoking, he may be able to keep 40% of his lung function...but nothing, he keeps smoking...” (IC1).*

The latter aspect emerged especially in spouses who were formerly smokers and who were able to stop on their own. They felt their relative had a lack of commitment and willpower in stopping the habit.

*“...so I quit...well, we promised each other to stop, but...he didn't keep his promise...” (IC3).*

Patients were aware that carers blamed them for not being able to stop their habit and this increased the sense of guilt.

Furthermore, patients blamed healthcare professionals for feeling discriminated against because of their illness, which was described at different time points in their disease trajectory. They perceived that they were stigmatised because of their “addiction” and that COPD had a negative connotation among healthcare professionals because of the direct link between smoking and disease. Nonetheless, patients did not report low quality of care because of this sense of discrimination, but they perceived that healthcare professionals focused greatly on stopping their smoking habit and reiterated that during every visit, both planned and during exacerbations. Therefore, patients felt that issues they considered to be important from their perspective were not discussed with professional carers.

*“...because there is already a path...it is written “smoker” and you are branded...(P2).*

*“COPD has a negative feature...the same as for instance for AIDS...you don't know what it is but when you say AIDS you are already dead...” (P2).*

Feeling anxious was described as an important emotional aspect, both by patients and carers. Patients experienced anxiety in relationship with breathlessness, especially during an acute episode of shortness of breath or during an exacerbation of the disease. They perceived that both symptoms influenced each other further with the disease progression.

*“...because I already had dyspnea episodes and I was frightened the first time...after that I really felt anxious with every episode of even slight shortness of breath...”*  
(P3).

Moreover, patients and informal carers described their fears related to the disease itself and to the progressive physical decline. Fears of suffering and death were expressed by both patients and carers. Additionally, patients expressed their fear about what they could expect from the illness progression and about getting worse or being diagnosed with what they described as a “far more serious disease” such as cancer.

*“...I don't fight death, because it is useless to fight a thing which is already decided when you are born...it is fate...nonetheless I am afraid of suffering...pain, breathlessness...all these are frightening”* (P1)

Carers, particularly spouses, experienced a sense of loneliness and social isolation. They lived the illness together with their relatives and perceived the impairment as their own. Socialisation eventually became impossible in view of the declining health status of patients.

*“I have always been a person with lot of family and friends...now I feel lonely...he doesn't want anyone at home...”* (IC1).

Furthermore, carers perceived a loss of ability to care for their relatives. This was described as a permanent feeling of being inadequate to care for their spouse, father or close friend. They questioned their ability as a carer with further disease progression, increased symptom burden and physical impairment.

*“If she gets breathless, I am getting anxious and distressed...I really ask myself if I am the right person to look after her...” (IC4).*

This sense of being inadequate to care for patients with advanced COPD led to anxiety and emotional distress in informal carers. These feelings had an impact on daily management, thus increasing care complexity in advanced disease.

### **5.3.3 Management of complex care in COPD**

Patients and informal carers recognised that care was complex and could be fragmented which impacted their quality of life. They perceived the need to create a structured care network in which all healthcare professionals caring for patients were involved. According to their experiences this would allow a shared care plan through continuous communication and the integration of patients and relatives in decision making. Furthermore, carers expressed their belief in better care for their relatives through partial relief of the carer burden.

*“When everything got in place...it took some time...but when it got off...the care for my father...I felt relieved” (IC5).*

Patients and carers asked for transparency regarding diagnosis and its possible impact on daily living. Furthermore, patients experienced a feeling of insufficient understanding for their situation from several healthcare professionals, in particular

while discussing it with their respiratory physician. They expressed the need for more time during consultations in order to ask questions about the illness.

*“Well, knowing the people, what they have on their mind...I would like them to be understanding towards my situation” (P1).*

Moreover, patients and carers expressed their need for healthcare professionals to understand their multidimensional needs, while discussing disease management which integrated all aspects considered important by patients and their carers. It emerged from their experiences that not all healthcare professionals were “so open-minded” to take such a holistic approach in caring for patients with advanced COPD and their families.

Participants were specifically asked about palliative care and its role in the disease trajectory of patients with advanced COPD. Most of them had no knowledge of palliative care and the participants who were previously informed about palliative care gathered this information through relatives and friends who shared their experiences with palliative care services. None of the participants reported that healthcare services provided them with information about palliative care approaches in advanced COPD. When shown palliative care definition (WHO definition), they expressed that this was the type of care they believed should be provided for patients with advanced COPD. Holistic and multidimensional care was perceived to be important to support patients and their care network. Additionally, addressing social and financial related issues and promoting and respecting patients’ values and wishes was considered to be equally important. Both patients and carers emphasised lacking this type of care delivery in advanced COPD.

*“...maybe to teach her how to manage a situation...with breathlessness or anxiety, what to do and how...I think it could be really useful...” (IC4).*

*“I think palliative care should be involved in any care setting...at home especially...it gives you support in need and helps you to avoid suffering” (IC5).*

Sharing experiences with other people with COPD and their carers (defined as peers) was perceived as important for both patients and carers. Patients felt that they could possibly talk with peers about living with the illness and develop better coping strategies. At the same time, they expressed it was important to raise awareness amongst healthcare professionals about the lived experience in COPD from the patients' point of view.

*“...and then I met other people, with the same illness...one had a lung emphysema and a tumour...it was helpful to talk about our situation...you share your moments with them” (P3).*

Carers felt that sharing experiences with others living in a similar situation could help to improve their quality of care giving. The creation of support groups for informal carers was also raised by interviewees. Carers shared the view that such groups could be helpful for sharing practical advice on the availability of support for patients and families, but they could also create emotional bonds which may help to deal with the progressive decline of their relatives. They emphasised the need for healthcare professionals to initiate the development of such self-help group, which are lacking.

#### **5.4 Discussion and conclusion**

The findings reported in this chapter illustrate the experiences of patients with advanced COPD and of their informal carers along the disease trajectory. Some of the reported limitations related to disease progression, such as decline of daily life activities, sense of loss and social isolation, were previously described (Barnett, 2005; Panos, Krywkowski-Mohn, Sherman and Lach, 2013; Disler et al., 2014; Nakken et al., 2015; Iyer et al., 2019). However, in these interviews patients and informal carers described experiences which appear to be underreported in previously published studies (Lindqvist and Hallberg, 2010; Berger, Kapella and Larson, 2011; Halding, Heggdal and Wahl, 2011).

Patients expressed feelings of guilt and shame about their smoking habit with respect to their family. Being responsible for acquiring the disease was openly discussed during the interviews, but rarely acknowledged within the patient-carer relationship, even if there was a major impact on daily living from the disease for both patients and their informal carers. Conversely, carers blamed patients for their smoking habit and for the inability to quit. They reported that this “self-inflicted” disease led to a radical change in their lives, with a sense of loss of social activities and isolation. This important aspect needs to be deeply considered, as it could have a negative impact on the patient-carer relationship, which is essential for care delivery in this population (Nakken et al., 2015).

Patients reported the perception of stigma and discrimination by healthcare professionals because of their smoking habit. Ceasing to smoke was always addressed during specialist consultations and patients felt that time was lacking for discussions about other issues they considered to be important for their daily life. Nonetheless, patients were satisfied with the quality of care they received along the disease trajectory.

This contrasts with prior findings where patients perceived negative attitudes from healthcare professionals, especially if they did not manage to quit their smoking habit (Lindqvist and Hallberg, 2010). Improving communication skills on addressing smoking behaviour in COPD patients may reduce the perception of discrimination and strengthen the therapeutic relationship.

Management of complex care was identified as an important issue among patients and informal carers. The impact on carers of providing support for patients with advanced COPD was considered as important and challenging. Feeling inadequate to care for their relatives and questioning their ability as a carer with disease progression was well described by interviewed informal carers and is similarly reported in other long-term conditions, such as heart failure (Murray et al., 2002; Johnson, 2007). As emphasised by previous studies, better information about the disease and its impact on daily life was requested by both patients and carers (Hynes, Stokes and McCarron, 2012; Disler et al., 2014; Iyer et al., 2019). The fragmentation of care reported during the interviews could be addressed by the implementation of a structured care network with a clear leadership coordinating all services which provide care for a patient (Epiphaniou et al., 2014). Moreover, it could be important to respond to patients' and carers' suggestion to foster the development of self-help groups for this population, following neurodegenerative diseases' models. These groups could provide carers with practical information and help sharing the experience of disease progression. Furthermore, they may reduce the feeling of social isolation of both patients and informal carers (Hill, Vogiatzis and Burtin, 2013).

Awareness about palliative care and its role in the disease trajectory of patients with advanced COPD was lacking. None of the participants reported that healthcare services

provided them with information about palliative care, the ones who were informed gathered their knowledge through their social network. Nonetheless, as similarly reported in previous studies, they were receptive to components of palliative care integration, such as multidimensional care and promoting and respecting patients' values (Iyer et al., 2019). Palliative care services are designed to deliver multiprofessional care, while managing multidimensional complexity and they could play a role in the development of a care network for patients with advanced COPD (Fusi-Schmidhauser et al., 2018).

In conclusion, through these interviews it was possible to capture patients and informal carers' experiences in living with COPD. These findings informed the next phase of the study (Phase II), which was focused on developing new knowledge with healthcare professionals on how to integrate palliative care in advanced COPD. The following chapter will describe methods and results of phase two of the study.

## **CHAPTER 6: METHODS AND RESULTS PHASE II**

As outlined in the previous chapters, this research study was developed and conducted in two phases. Phase I focused on describing patients' and informal carers' perspective. The aim of this second study phase was to develop common knowledge on new ways to integrate palliative care provision in standard care for patients with advanced COPD through collaborative working methods. Central to Phase II was the establishment of a CIG with healthcare professionals working in the respiratory and palliative care field.

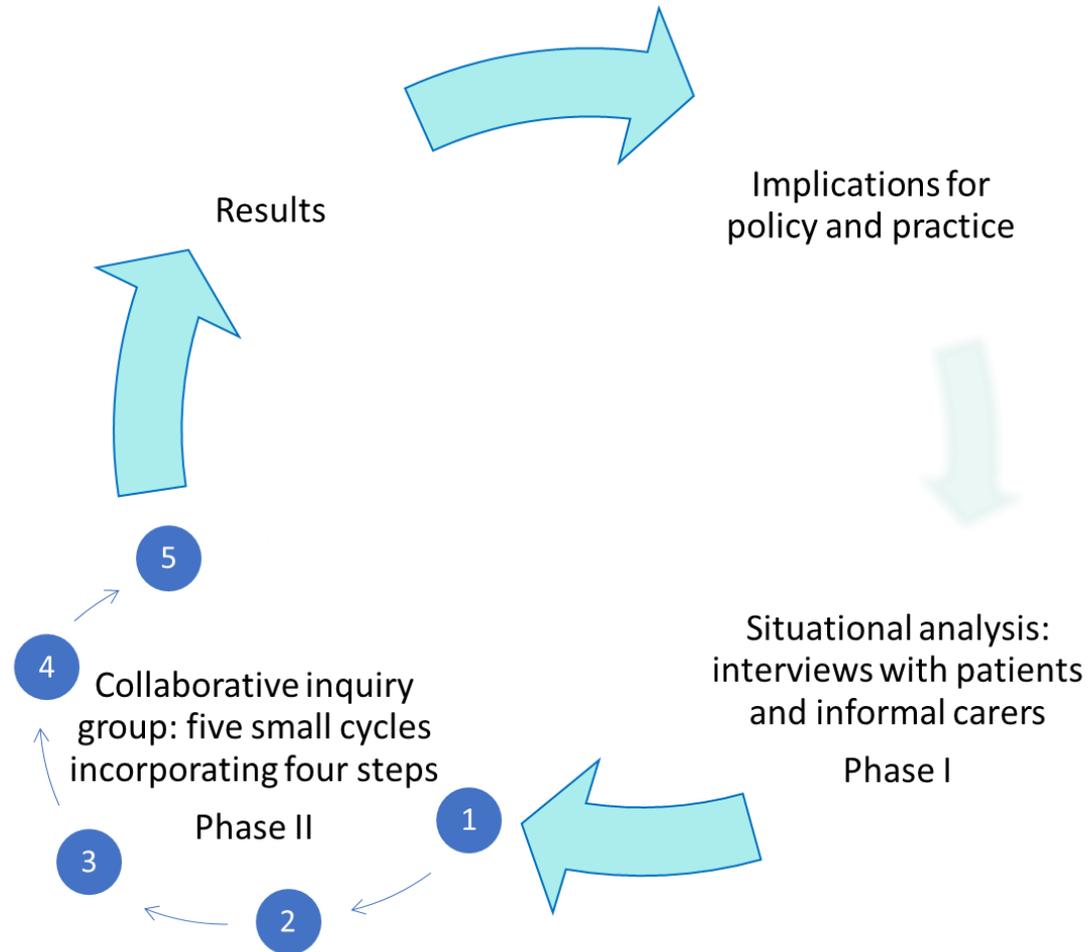
In this chapter the methods, including a detailed description on sampling, recruitment, data collection and data analysis, and findings of the second part (Phase II) of this study are outlined. Ethical aspects of this phase are also discussed, with particular attention to the chosen research methodology.

### **6.1 Methods**

#### **6.1.1 Study design**

Phase II was undertaken with a CIG of healthcare professionals working in respiratory and palliative care services over six action research cycles, which comprised an overarching cycle which held five small cycles, as depicted in Figure 6.1. All cycles shared the same structure and the same steps during each cycle were performed: action planning (situational analysis), acting, observing (evidence collection and analysis) and reflecting (process reviewing). The situational analysis in the overarching cycle gathered the results from all interviews with patients and informal carers (Phase I of this study). The second and third step of the overarching cycle (action performing, evidence collection and analysis) were conducted within the CIG through five small cycles incorporating four steps each, as depicted in Figure 6.2. The fourth step of each

small cycle led to the situational analysis and planning of the next cycle. The last step in the overarching cycle (process reviewing and reflection) corresponded to the results from all the preceding five cycles and informed the discussion chapter of this thesis.



**Figure 6.1:** Phase II study design



**Figure 6.2:** Model of each small cycle with a four-step process description

### **6.1.2 Recruitment and selection**

The study was conducted in a major public teaching hospital in Southern Switzerland, where both respiratory and palliative care services are available. Study participants were selected through purposive sampling. Healthcare professionals working for the respiratory care service and caring for people with advanced COPD, and professionals working for the Palliative and Supportive Care Clinic were eligible to participate. As previously described, healthcare professionals working for the respiratory care service were physicians, nurses and physiotherapists, and those working in the palliative care

field were physicians and nurses. A total of 17 professionals from the respiratory care service and 21 professionals from the Palliative and Supportive Care Clinic were eligible. Inclusion and exclusion criteria, as listed in Table 6.1 below, were applied during the process.

**Table 6.1:** Inclusion and exclusion criteria for healthcare professionals

Inclusion criteria professionals	Exclusion criteria professionals
<ul style="list-style-type: none"> <li>• Healthcare professionals caring for COPD or palliative care patients</li> <li>• Workplace in the respiratory care service or in the Palliative and Supportive Care Clinic</li> <li>• Fluent in Italian</li> <li>• Competent and willing to sign the informed consent sheet</li> </ul>	<ul style="list-style-type: none"> <li>• Working experience less than three years in either palliative care or respiratory medicine</li> </ul>

Potential participants were approached by the researcher via email. Recruitment was supported by a detailed information letter, which explained who was undertaking the research, what the aims were and what the research involved (including time requirements, potential risks and data handling in terms of confidentiality). The letter was e-mailed to all potential participants who met the inclusion criteria by the Palliative and Supportive Care Clinic central secretariat. Face-to-face appointments between the researcher and potential participants were offered to give them a chance to ask questions about the study: two people took up this opportunity. Healthcare professionals who declared an interest in participating, received a postage paid envelope, together with the participant information sheet and the consent form. Participants were given two weeks to consider whether to join the study. Email reminders were sent two and four weeks

after the initial invitation. The researcher met with participants at the first CIG meeting and gained informed, written consent before the meeting began.

### **6.1.3 Data collection**

Data collection followed a series of five action research cycles over a period of 16 months, from May 31<sup>st</sup> 2017 to September 27<sup>th</sup> 2018. Although the CIG had formally finished on September 27<sup>th</sup> 2018, three CIG participants later discussed their experience in collaborating in this research during individual face-to-face informal “conversations over coffee” (O’Reilly, 2009) with the researcher. The CIG meetings were conducted in a conference room on clinic premises during working hours, digitally recorded, anonymised and transferred to a password-protected computer.

Data was retrieved among different data sources and in different formats. Audio recordings, observations (field notes) and notes from a personal reflective journal represented data sources from the CIG meetings. Further data was collected through face-to-face conversations with three participants of the CIG after the completion of the fifth action research cycle. Demographic data, CIG meetings’ attendees for each session and all the results from Phase I of this study were also considered as data which informed the results of this second phase of the research. The data format was heterogeneous: audio material, transcribed verbatim, written notes, visual material such as power point presentations, diagrams, sketches, drawings and flowcharts. Each meeting was audio recorded, transcribed verbatim and analysed to form the data. An overview of data collection is listed in Table 6.2.

**Table 6.2:** Data collection for Phase II

Data sources	Who/What	How was data collected	Amount of data	Data formats
Interviews (Phase I)	Five patients with advanced COPD and five carers	Individual semi-structured interviews	10 interviews	Audio recordings Transcribed verbatim
Face-to-face conversations	Three CIG participants	“Conversations over coffee”	Three individual conversations	Written notes
Observations (field notes)	CIG meetings (seven participants)	Meetings’ data	About seven hours spread over 16 months	Audio recordings Transcribed verbatim Written notes Visual material: diagrams, sketches, drawings, flowcharts, power point presentations)
Reflective diary	Personal reflections and reflexivity	Mainly on paper and subsequently transcribed on password-secured PC by researcher	Word count: 8’000 words	Written notes

The data collected had different functions in the research process: it informed the CIG, it informed decisions about subsequent other data collection in all research cycles, guaranteeing the process flow among cycles, and it supported the process evaluation and outcomes for the overarching action research cycle. As previously discussed in the

methodology chapter, this research study aimed to be both informative and transformative. Data collected through patients' and carers' interviews informed the situational analysis for the overarching action research cycle, while explaining their experiences. The following cycles with the CIG explored theoretical and practical domains, leading to the development of a transformative model for palliative care integration in advanced COPD (Heron, 1996).

#### **6.1.4 Reflexivity**

Personal (first person inquiry) and group reflexivity (second person inquiry) was encouraged, the latter process through the principles of cooperative inquiry (Hynes, Coghlan and McCarron, 2012) as fundamentals of the research approach. Through first person inquiry I gained awareness and I reflected on my subjectivity, my positions and my motivations towards the research question and process unfolding during the action research cycles (Marshall, 2016). This helped to identify two levels of reflection: one happening during CIG meetings ("reflection in action") and the second one which occurred during data analysis of every single action research cycle ("reflection on action") (Schön, 1983).

#### **6.1.5 Data analysis**

Two different data analysis approaches were used (Titchen, 2000). Firstly, concurrent analysis during each small cycle (cycle one to five) was adopted to develop themes within the individual cycle, which informed the next cycle (Figure 6.2). This supported the research process and helped to further develop the next action research cycle. After every action performance, data collected in several different formats (audio and visual material, transcribed verbatim, written notes) was analysed using a thematic analysis

approach (Braun and Clarke, 2006). Field notes taken during all CIG meetings helped to triangulate data. Engagement with raw data, identification of initial codes and development of main themes were the steps in data analysis. All themes were translated to English and their connection was visually represented through use of a qualitative data analysis software (NVIVO<sup>®</sup>) package. A summary of preliminary themes and subthemes from the previous cycle was discussed at the beginning of the next CIG meeting, thus enabling participants to: 1) Discuss the possible themes from the previous cycle, 2) Generate new data during discussion on the themes, while shaping the new action to perform in the upcoming cycle.

Furthermore, a retrospective analysis following the cycle described in Figure 6.1 was performed at the end of the whole research process (Titchen, 2000). The starting point was the first situational analysis, where all the results from Phase I were discussed in the first CIG meeting and where all participants acknowledged the research question and the study methodology. All data collected in the situational analysis and in the following five action research cycles were analysed through thematic analysis to generate understanding about the whole research process, to inform the discussion and to answer the research question (Braun and Clarke, 2006).

#### **6.1.6 Data management plan**

Electronic data, visual material and data collected on paper were handled in the same manner as data collected in study Phase I. The data management plan is described in chapter five.

## **6.2 Ethical aspects**

As discussed in chapter five of this thesis, a duplicate ethical approval was obtained through Lancaster University and the Swiss Ethics Committee. Quality criteria, confidentiality and anonymity, voluntary participation, harm avoidance, research independence and research transparency (ESRC, 2015) were considered during the development and conduct of this second phase of the research, with particular attention to the chosen research methodology.

### **6.2.1 Quality criteria**

According to Reason (2006), the quality of an action research study may be evaluated through four criteria which address the fundamentals of this research methodology. Moreover, transparent process description and justification of all choices made during the research process are further indicators for quality in action research. Reason's quality criteria are described in the methodology section and their fulfilment during this research study is critically reviewed in the discussion chapter.

### **6.2.2 Confidentiality and anonymity**

Data were managed in accordance with both, the Swiss Federal Act on Data Protection and the UK Data Protection Act (Federal Council, 2019; UK Government, 1998). The procedure for confidentiality and anonymisation was described in chapter five, as it is the same for both study phases.

### **6.2.3 Voluntary participation**

Voluntary participation in research requires that researchers respect participants' acceptance or refusal to participate, while guaranteeing the independence of further

healthcare provision from this decision (WGEC, 2009). In this case, guaranteeing the independence of further healthcare provision may be interpreted as ensuring palliative care consultations for patients followed by a healthcare professional who refused to participate. Moreover, it entails the continuation of respectful professional relationships between the researcher and healthcare professionals who refused to participate.

The voluntary participation was reiterated through the participant information sheet and the consent form. Specific aspects such as the possibility of withdrawal from the study up to two weeks after completion of the last research cycle, were particularly highlighted. Lastly, compensation rewards or incentives were not given, thus preventing controversies over possible persuasion mechanisms on participants to be included in the study (WGEC, 2009).

#### **6.2.4 Harm avoidance**

Risks to subjects involved in this participatory action research were identified from the beginning of the study. Asymmetrical power relationships and subsequent difficulties in individuals voicing their own opinions and views needed to be addressed by responsiveness and reflexivity prior and during the research process (Casarett, 2010). External support via discussion with supervisors further addressed those sensitive issues. Potential harm to working relationships were also addressed among the CIG by openly discussing the issues between participants. Face-to-face conversations with three CIG members did not report any harm to professional relationships.

### **6.2.5 Research independence**

As described in chapter five, the whole study was not influenced by the researcher's institution and the research independence within the same institution was guaranteed through the ethics approval process.

## **6.3 Results Part A**

### **Action research cycles with the CIG: telling the story**

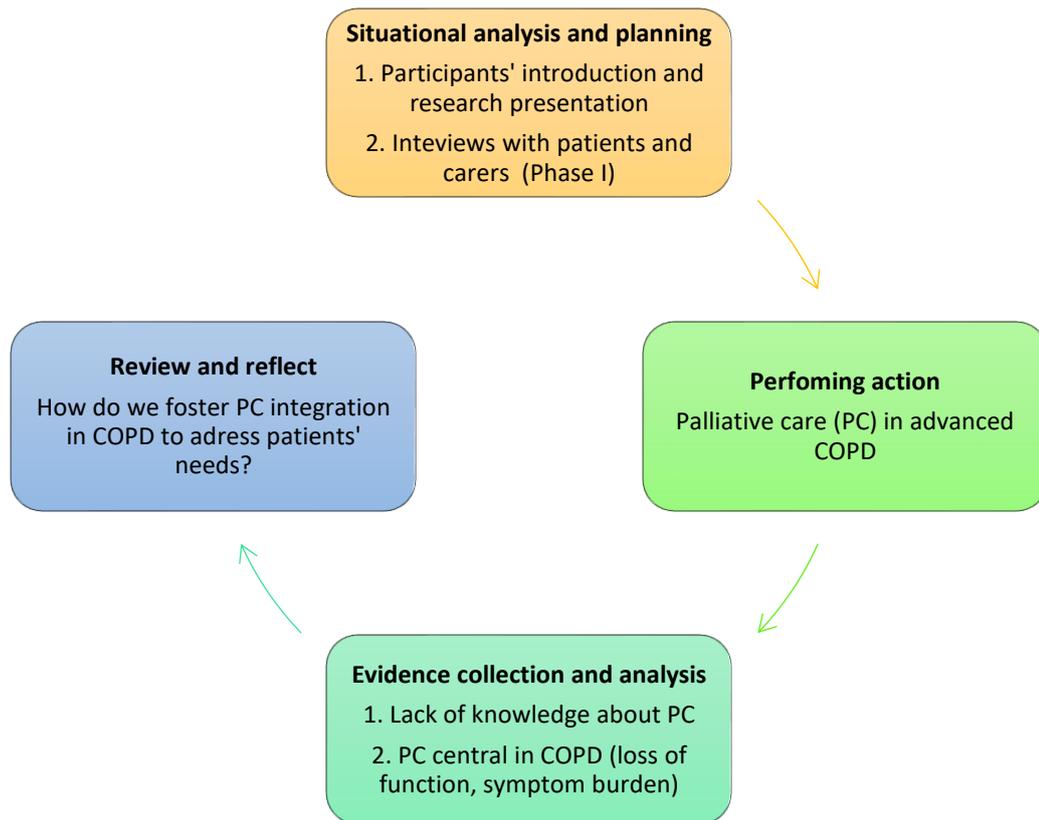
Five females and two males participated in the study. The median age of participants was 49 years (range 32-66 years). Five participants were physicians, one was a nurse and one a physiotherapist. All healthcare professionals had more than 10 years of clinical experience in their specific field (palliative or respiratory care). A higher level of detail could not be provided due to anonymity concerns. All meetings lasted about an hour and all participants attended the five meetings.

#### **6.3.1 Cycle one**

The first meeting was dedicated to introducing all the participants to the research through a short power point presentation and discussing the research methodology (Appendix XIII). All participants received a paper on action research 10 days prior to the first meeting (Baum, MacDougall and Smith, 2006). Particular attention was given to explain the ethical challenges of action research, especially considering all the existing hierarchical relationships and the possible power imbalance between the physicians in the group and other members coming from different professional backgrounds. Furthermore, the researcher dual role as a senior consultant and as researcher was highlighted and explained. After common discussion the group agreed

to attend the meetings in plainclothes, in order to avoid power imbalance through wearing a white coat within the physician group and between physicians and other healthcare professionals. Group interactions, especially the between physicians and the palliative care nurse, who was the youngest member of the CIG, were observed. The physicians acknowledged the palliative care nurse's professional skills in palliative care during the whole research process and mutual respect was established. All participants discussed the presented issues interactively and perceptions about members of the group being less active were not noted.

The second part of the first meeting focused on the situational analysis, which addressed reflections on definition and role of palliative care in general and in COPD in particular. These issues were introduced through the results from patients' and informal carers' interviews (Phase I of this study). Patients' and informal carers' citations were presented on cards, while the main themes identified from the interviews were depicted on a flip chart. Participants acknowledged the themes and were particularly interested in the aspect of stigmatisation and lack of knowledge about palliative care reported by both patients and informal carers. The group discussion focused on the role of palliative care in advanced COPD. All participants considered palliative care as central in healthcare provision for patients with advanced COPD. This was underlined by two aspects defining this patient population: the progressive decline of function during the disease trajectory and the available data from the literature that these patients often experience a severe symptom burden. This led to a reflection about how to foster palliative care provision in patients with advanced COPD, concluding the first cycle. A summary of cycle one is depicted in Figure 6.3.



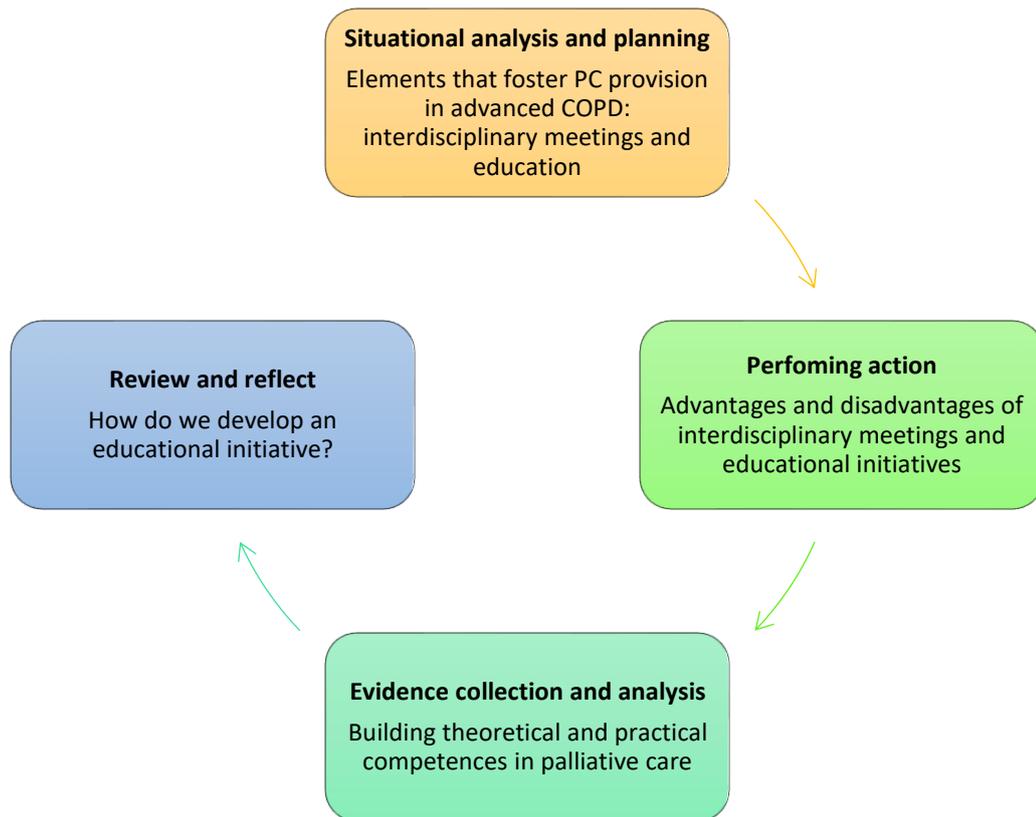
**Figure 6.3:** First action research cycle

### 6.3.2 Cycle two

The situational analysis of this second cycle focused on the individual reflection of each group participant about fostering palliative care provision in advanced COPD. The CIG proposed two elements that were considered as essential for a progressive integration of a palliative care approach in the disease trajectory of patients with advanced COPD. These elements were identified as collaborative interdisciplinary meetings and healthcare professionals' education. The group debated about the importance of creating a collaborative space where healthcare professionals could discuss all the aspects related to care provision for a particular patient, coordinate care delivery and prevent further care fragmentation. Different models from other care settings and diseases, such as oncology and neuro-degenerative diseases were identified and

discussed. The strengths of interdisciplinary meetings were identified as: 1) a systematic collaboration, 2) teaching opportunities, 3) building competences while learning from one another and 4) a structured, individualised and shared action plan for care provision in this patients' population. Reported weaknesses were time requirements, the interplay within hierarchical positions, breaking competences' boundaries and communication issues, such as discussing complex patients through teleconferencing.

The second element which was considered as essential in fostering palliative care integration in advanced COPD was to develop palliative care competencies in healthcare professionals working with these patients. Identifying palliative care needs, recognising the persistent functional decline, identifying care complexity and managing the multidimensionality of these patients were discussed as being fundamental in healthcare professionals' education. The group agreed on choosing the educational element as being the most important one to foster palliative care integration. The main justification for this choice was the importance for healthcare professionals to build their competences in palliative care within this particular patients' population in order to subsequently being able to discuss all issues related to patients' care with other professionals. A summary of cycle two is depicted in Figure 6.4.

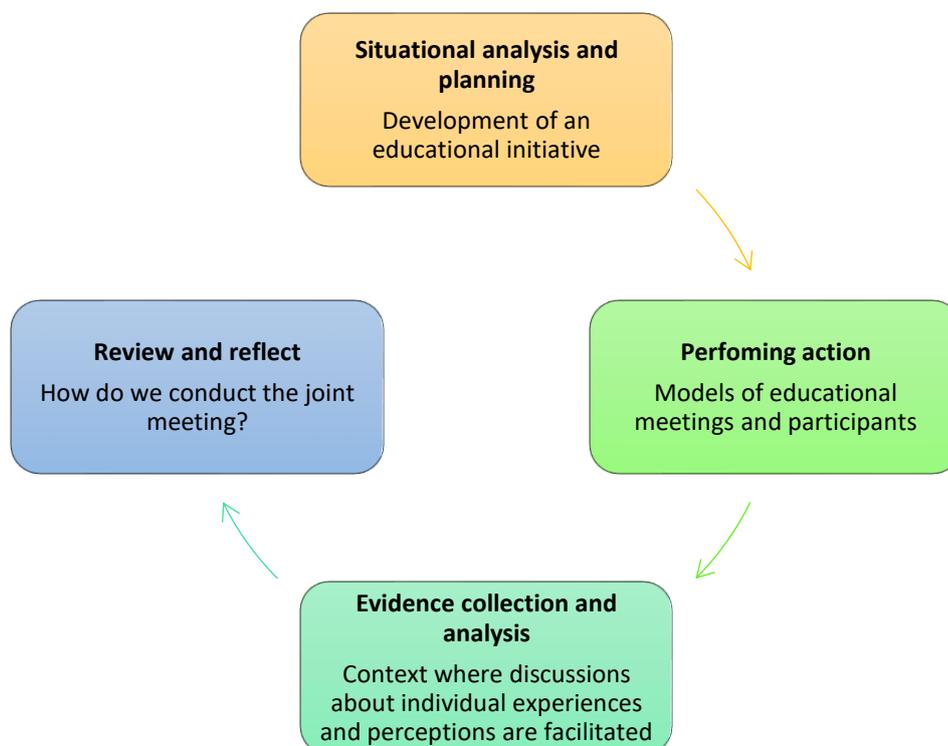


**Figure 6.4:** Second action research cycle

### 6.3.3 Cycle three

The group discussed how to organise an educational meeting for healthcare professionals caring for patients with advanced COPD. All participants agreed to involve professionals working for a partner organisation providing home support for patients with advanced COPD, including specialised nurses trained in home ventilation and social workers. Furthermore, members of hospital staff caring for inpatients with advanced COPD were also invited to attend the educational meeting. Different approaches for this meeting were proposed: a didactic lecture was excluded a priori as the group felt that this approach would not sufficiently allow the discussion about individual experiences and perceptions. The shared proposal was to organise a case discussion meeting about a patient who was known in all care settings (home care,

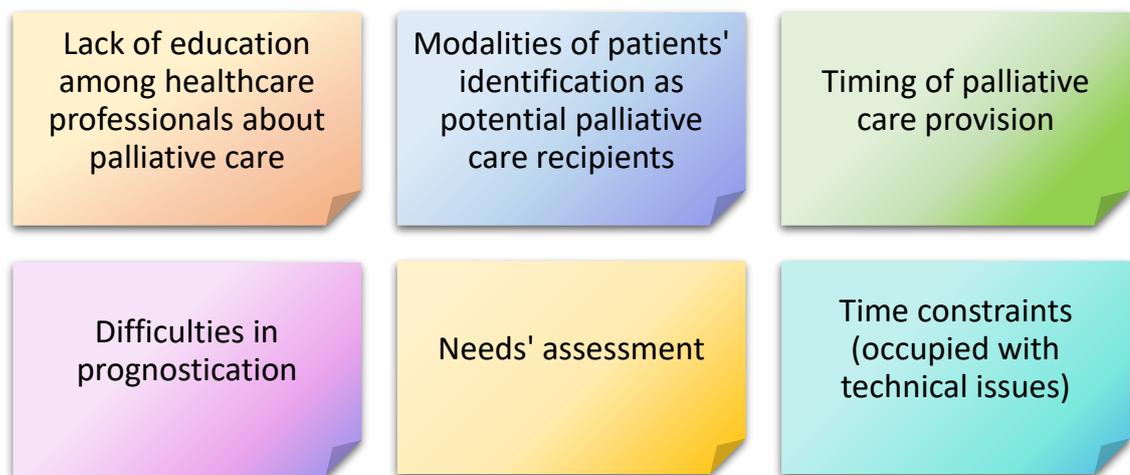
outpatient, hospital). The CIG selected the clinical case after an extensive discussion on advantages and disadvantages of building the educational meeting on a patient who was well-known by almost all healthcare professionals. The group felt that the clinical knowledge of the case might help to focus on perceptions and experiences rather than on technical issues. Furthermore, it was agreed that a shared knowledge of the case might facilitate discussions within the interdisciplinary group meeting. The case discussion was seen as a starting point to explore different aspects of palliative care provision and integration in advanced COPD. The CIG decided to open the joint meeting with a presentation introducing the topic and the clinical vignette and to eventually split the group in two, depending on the number of participants. Different CIG members would act as facilitators during the joint meeting. These reflections concluded the third cycle. An overview is depicted in Figure 6.5.



**Figure 6.5:** Third action research cycle

### 6.3.4 Cycle four

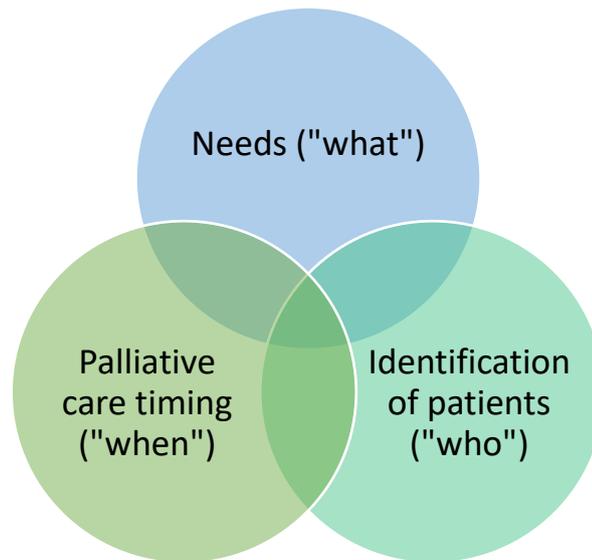
The fourth meeting was held after the joint educational meeting. Five nurses and one social worker from the partner organisation and four nurses from the hospital staff participated in the educational meeting. The group summarised and reviewed the development of the educational meeting, the interactions between the CIG members and the meetings' participants and the topics which were discussed. A description of the joint educational meeting is presented in Appendix XIV and a summary of the participants' reflection about barriers to palliative care integration in advanced COPD is presented in Figure 6.6.



**Figure 6.6:** Joint interdisciplinary meeting: barriers to palliative care integration in advanced COPD

Among all discussed issues, the CIG members highlighted two elements described as being modifiable barriers to palliative care integration in advanced COPD: difficulties

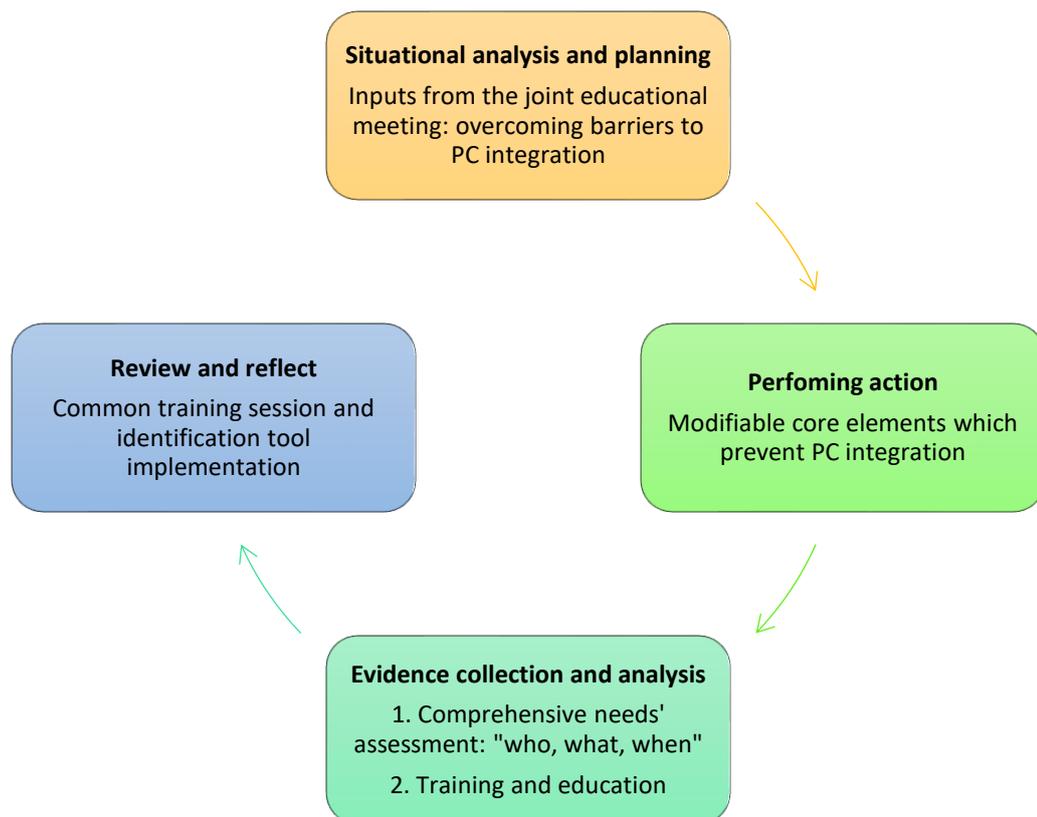
in performing comprehensive needs' assessment and lack of education and training in palliative care. The group defined as assessment not only the clinical evaluation of patients' needs (the "what") but also the question on how to identify them as palliative care recipients (the "who") and when to start palliative care provision (the "when"), as depicted in Figure 6.7.



**Figure 6.7:** Multidimensional assessment for palliative care recipients with advanced COPD

The group reflected on how to foster healthcare professionals' education and at the same time provide clinical elements of a palliative care approach within respiratory care consultations for patients with advanced COPD. The CIG agreed on proposing a dual intervention in the respiratory care service, combining an educational element with the practical aspect of implementing a patients' identification tool. The chosen tool is routinely used by the Palliative and Supportive Care Clinic and was developed after an extensive literature review and analysis of available prognostic tools, such as the Gold Standards Framework Proactive Identification Guidance (Gold Standards Framework, 2016). The CIG suggested a joint training meeting lasting about 30 minutes and held by

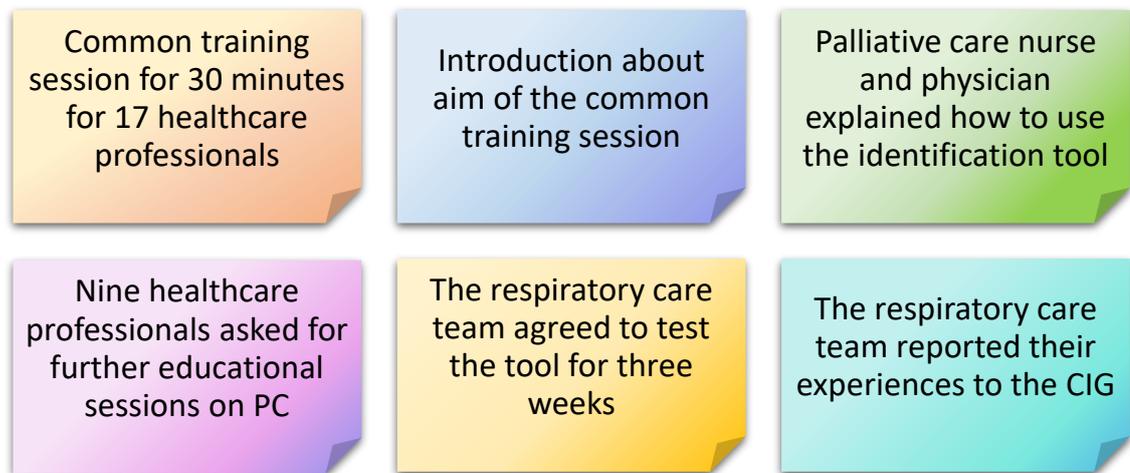
the palliative care team with compulsory attendance for the whole respiratory care service team. The session was scheduled four weeks prior to the next CIG meeting, in order to discuss the developments within the group during the following cycle. An overview of the fifth cycle is depicted in Figure 6.8.



**Figure 6.8:** Fourth action research cycle

### 6.3.6 Cycle five

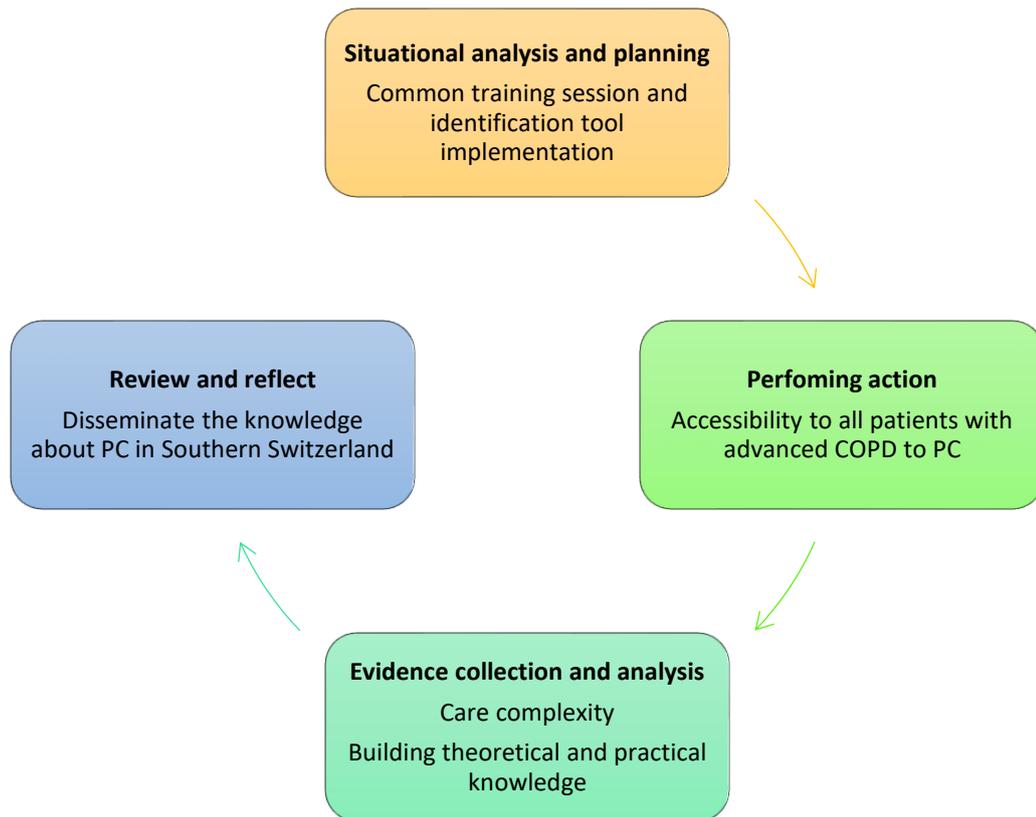
The participants focused on the evaluation of the common training session held for the respiratory care personnel by colleagues from the palliative care team. A summary of the training session and the topics discussed are depicted in Figure 6.9.



**Figure 6.9:** Common training session for respiratory care service personnel

The respiratory care team experiences in using the identification tool were part of the situational analysis of this cycle. The tool was simple, quick and easy to use and objectively confirmed a “gut feeling” about a declining trajectory in almost every patient with advanced COPD. The CIG agreed on the usefulness of the tool as a door opener for a palliative care approach, to be discussed within the team and with patients and their care network. Group members felt that accessibility to palliative care to all patients with advanced COPD should be granted across all public hospitals, where consultation services with specialised palliative care teams are available. They debated that identifying patients in need for a palliative care approach will expose healthcare professionals working in the respiratory care service to complexity which is not manageable without a specialised palliative care support. Furthermore, the tight collaboration with the palliative care team might help to build part of the needed theoretical and practical knowledge to care for these patients and their informal carers.

The reflections among the group lasted on the awareness that knowledge about the central role of palliative care in advanced COPD should be disseminated across all institutions in Southern Switzerland. The members felt that this action would overstep the boundaries of the research, since it would require the involvement of institutional stakeholders. Nonetheless, they expressed the importance of sharing the goal of knowledge dissemination about palliative care integration in advanced COPD with all respiratory care services in Southern Switzerland. Everyone agreed to conclude the action research cycles on September 27<sup>th</sup> 2018. The meeting ended with sharing the experience of being part of a CIG among all members. They pointed out the positive experience of “doing something new”, the relaxed atmosphere during meetings, the mutual respect and the appreciation of sharing knowledge with professionals from other fields. Even the difference between different professional epistemologies was perceived as a positive aspect and not as a barrier in group discussions. The major difficulty for all participants was time constraint, which needed to be overcome by attentive time management, especially by physicians. An overview of the last cycle is depicted in Figure 6.10.



**Figure 6.10:** Fifth action research cycle

### 6.3.7 “Conversations over coffee” with CIG participants

After the conclusion of data collection through CIG meetings on September 27<sup>th</sup> 2018, face-to-face informal appointments between the researcher and CIG members were offered to share their experience in participating in this research and were taken up by three from both palliative and respiratory care service. These “conversations over coffee” (O’Reilly, 2009) were not recorded and took place in a separate room of the hospital cafeteria during opening hours. The space and time offered for conversation sought to explore experiences about being part of a CIG, to discuss personal impressions not to be shared with others and to address potential issues of discomfort perceived during the meetings. All three CIG members separately agreed that this was a new experience which helped to better understand the point of view of healthcare

professionals working in a different field than theirs. Building knowledge together was both helpful and enriching for their personal clinical practice and for shaping new ways to provide a more holistic care for patients with advanced COPD, while addressing patients' needs and values. All three CIG members appreciated the spirit of mutual respect and esteem they perceived during all CIG meetings among participating healthcare professionals. They valued the easiness in finding common dates for all meetings through the Smartphone chat-app, which helped to avoid time-consuming electronic polls and mails within the group.

One member expressed an initial feeling of being “overwhelmed” by all the themes which came out during the first and the second cycle, especially in relationship with all the educational aspects discussed by the CIG. Nonetheless, the participant was able to explore all these issues within the group and valued the collaborative space which allowed this process. All three members expressed their engagement in supporting other healthcare professionals caring for patients with advanced COPD in changing their clinical practice through the establishment of working groups which might build knowledge together.

#### **6.4 Results Part B**

##### **Retrospective analysis of the cycles: what are we told in the story**

As previously discussed in the data analysis section, two different ways of data analysis were performed. Concurrent analysis was adopted during each small action research cycle to develop themes and inform the situational analysis of the next cycle. These results were summarised in the previous sections. Moreover, a retrospective analysis following the flow of the overarching cycle depicted in Figure 6.1 was performed at the

end of the entire research process. The last step in the overarching cycle (process review and reflection) corresponded to the results from all the preceding fifth cycles and informed the discussion chapter of this thesis. All the themes which were identified during this process are listed in Table 6.3.

**Table 6.3:** Main themes identified during retrospective analysis

Main themes	
<i>Multidimensional assessment</i>	Clinical assessment (patients' needs) Identification of palliative care patients Palliative care timing
<i>Healthcare professionals' education</i>	Theoretical knowledge of general palliative care approaches Shared practical knowledge Reflective practice
<i>Interdisciplinary team meetings</i>	
<i>Knowledge dissemination about palliative care in advanced COPD</i>	Local setting Regional setting

#### 6.4.1 Multidimensional assessment

According to Emanuel (2004), there are criteria which define integrated palliative care, as discussed in the literature review chapter. One of these criteria recommends a multidimensional assessment of patients and their care network. The multidimensionality is defined as physical, social, psychological and spiritual issues important to patients and their informal carers. From the first situational analysis (interviews with patients and carers) it emerged that understanding multidimensionality was paramount to address patients' holistic needs in a declining disease trajectory. The

extent of this assessment was long debated during the action research cycles and this topic repeatedly emerged during discussions.

*“We struggle with understanding what the real concerns of our patients are...besides breathlessness” (Pa1).*

*“How do we assess the whole picture and how do we include carers in this bigger picture?” (Pa4).*

*“We need to recognise that breathlessness is just the tip of the iceberg...” (Pa5).*

Other aspects such as palliative care timing and identification of potential palliative care recipients were considered as part of a holistic evaluation, as depicted in Figure 6.7.

Needs’ assessment was identified as being an important aspect of patients’ care. The reported expertise and confidence in evaluating physical symptoms diminished when healthcare professionals were asked to discuss issues related to the psychosocial and spiritual dimension. This perspective was also reported by patients and carers during their interviews, where they highlighted the difficulties in initiating conversations with healthcare professionals about “non-physical symptoms”. During the fifth action research cycle the CIG members acknowledged two different ways of enhancing a holistic needs’ assessment. Firstly, it was suggested that the use of simple evaluation tools, such as the Condensed Memorial Symptom Assessment Scale (Chang et al., 2004) or the Edmonton Symptom Assessment System (Bruera et al., 1991) might support healthcare professionals to address issues related to the psychosocial and spiritual dimension. These tools include questions about aspects other than just the physical ones. Secondly, it was recommended that healthcare professionals caring for patients with advanced COPD should increase their theoretical and practical competences in general

palliative care through education. The main thought behind this suggested approach was the awareness that trained staff would be able to: 1) Perform a basic assessment with advanced COPD patients and 2) Timely recognise care complexity requiring specialist palliative care involvement. Further reflections on healthcare professionals' training will be discussed in the following section.

The use of identification tools, such as the Gold Standards Framework Proactive Identification Guidance (Gold Standards Framework, 2016), the Supportive and Palliative Care Indicators Tool (SPICT) (The SPICT programme, 2017) and the SIAARTI Identification Guidance (SIAARTI, 2013) were considered as helpful for healthcare professionals caring for patients with advanced COPD to formally identify them as palliative care patients.

*“Having a simple tool to assist you in daily clinical practice is helpful to raise awareness about the disease trajectory...” (Pa3).*

Team discussions about how to deliver future care and how to approach needs' assessment might be fostered by formal patients' identification. The use of identification tool was considered by CIG members as one of the facilitating actions to introduce palliative care provision in advanced COPD.

*“With an identification tool you can also discuss with patients and families about having potential palliative care needs...” (Pa6).*

The debate about introducing identification tools led to the reflection about palliative care timing. According to the definitions of integrated palliative care (Emanuel, 2004), this timing should be declared and documented. Nonetheless, as discussed in the literature review chapter and debated within the CIG meetings, palliative care timing in

advanced COPD remains unclear (Crawford et al., 2012). Common clinical features about the disease trajectory in this population were identified and discussed. Starting long-term oxygen treatment and exacerbations requiring hospitalisations were viewed as indicators for a worsening prognosis and potential triggers for palliative care integration. They were considered as “steps of decline” almost every patient with advanced COPD will experience during the disease trajectory and they should be included in a holistic assessment. These elements were also seen in the literature, where these common features were defined as “milestones” which could be used to promote palliative care provision (Pinnock et al., 2011; Cawley et al., 2014; Landers et al., 2015).

In summary, the assessment which was considered as central for patients’ holistic care included a physical, psychosocial and spiritual needs’ evaluation, the identification of patients being potential palliative care recipients and the recognition of “steps of decline” which should trigger palliative care integration. All these elements are interconnected and present in structured theoretical and practical training for healthcare professionals, which represented the second main theme identified during data analysis.

#### **6.4.2 Healthcare professionals’ education**

Throughout the action research cycles, the theme about healthcare professionals’ education and training was central, a recurrent and common thread during the CIG meetings. Three different elements of education and training were identified and were considered as core components: theoretical knowledge about palliative care approaches, practical knowledge and experiences during practice.

#### **6.4.2.1 Theoretical knowledge about palliative care approaches**

Theoretical knowledge about palliative care approaches was identified as being an important element of healthcare professionals' education. Several aspects related to theoretical knowledge emerged during discussions. Differences in healthcare professionals' curricula during pre-graduate training prevent the establishment of a common theoretical ground. Pre-graduate medical school curricula include palliative care teaching, nonetheless if compared to pre-graduate nurses' training there is a clear imbalance in hours taught in medical versus nursing schools (Downar, 2017). Furthermore, post-graduate training in palliative care is often the nurses' prerogative. Physicians in the CIG debated that due to time constraints and lack of knowledge about post-graduate courses for healthcare professionals in palliative care, they would not attend those courses.

*“It is difficult to attend to all courses I am interested in...I will need a sabbatical to do all this training...” (Pa2).*

*“Palliative care lessons were never taught in our university curriculum” (Pa7).*

This knowledge imbalance was thought to foster a potential conflict within an interdisciplinary team in relationship to a better understanding of palliative care needs by the trained part of the team. Discussions and negotiations about future goals of care might be difficult because of a lacking common theoretical ground among healthcare professionals. Structured post-graduate short courses, which cover the theoretical knowledge gap about general palliative care, including elements of needs' assessment, prognostication and advance care planning were considered as a central part of healthcare professionals' training.

#### 6.4.2.2 Practical knowledge

The second element emerging as a core component of education and training in palliative care was practical knowledge. Practical knowledge was defined as competences and skills in performing a particular action which is important for clinical practice (Heron, 1992). Applying the theoretical backgrounds to daily clinical practice was seen as a fundamental skill to increase the quality of healthcare provision. The importance of building practical knowledge was underlined by the fact that real-life situations may differ from the theoretical viewpoints and that being in close contact with practice may deepen the understanding about how people learn to apply a certain skill and how they use it in real world situations (Katajavuori, Lindblom-Ylänne and Hirvonen, 2006). The CIG proposed educational initiatives to foster practical knowledge about palliative care within the respiratory care service. These initiatives included shared consultations (with a particular attention to how the palliative care team manages the practical aspects), brief periods of exchanging healthcare staff between the two services and practical knowledge transfer within different healthcare professional groups, such as nurses and physicians.

*“I think it would be useful to see how palliative care teams work with patients and how they approach difficult conversations...” (Pa3).*

Time constraints and lack of sufficient personnel were among the most debated barriers towards the proposed initiatives. Shared consultations were considered as the most effective way to gain mutual practical knowledge in a timely manner and with particular consideration of patients’ and informal carers’ needs. Furthermore, shared consultations would foster modalities of healthcare professionals working together in different ways,

thus supporting future models of interdisciplinarity (Sargeant, Loney and Murphy, 2008).

#### **6.4.2.3 Experiences during practice**

The third component of healthcare professionals' education was described as being based on experiences gained during clinical practice. This element of knowledge was clearly different to the one which relates to practical aspects of care provision. The group agreed that theoretical and practical knowledge need to be supported by ongoing opportunities for reflection about experiences encountered during care provision and that this reflection should foster the development of new ways of thinking about how care is provided by each healthcare professional and by the whole service. This reflective practice was recognised as being fundamental to support personal awareness about roles and relationships during care provision.

*“Reflecting on how we provide current care may help to discuss with others if we can improve what we are doing for our patients” (Pa4).*

Furthermore, this experiential knowledge was recognised as a resource in patients coping with uncertainty (Baillergeau and Duyvendak, 2016). Understanding their experiences and how they faced difficult situations may improve care provision by considering their point of view, while incorporating this knowledge in further reflective practices. The group assessed different proposals on how to support healthcare professionals in developing these attitudes towards clinical practice. The agreed on scheduled case discussions within the respiratory care service and participation of the palliative care team, with a stated focus on building competences and attitudes towards reflective practice.

### 6.4.3 Interdisciplinary team meetings

As previously discussed, patients with advanced COPD present with a high symptom burden and multidimensional needs. The management of care complexity requires an interdisciplinary approach, in order to have all professionals' competencies provided to patients and their carers. An interdisciplinary team approach involves participation, sharing of information and common goal setting within a group of healthcare professionals caring for a patient (Bokhour, 2006). The importance of developing the culture of interdisciplinary team meetings in advanced COPD was acknowledged during the research cycles. The fundamental element of an effective team work was considered to be ongoing communication within the team and between the single team members.

*“Building a communicative space to discuss patients and how we work together is important for better care delivery” (Pa1).*

*“We need to communicate as professionals and we need to do it as a team” (Pa6).*

This aspect was also described in literature as being a key facilitator for developing functioning interdisciplinary teams (Sargeant, Loney and Murphy, 2008; Xyrichis and Lowton, 2008; Youngwerth and Twaddle, 2011). Furthermore, the group considered other elements as being important in the development of an interdisciplinary team meeting: 1) Mutual respect and understanding of each members' professional role; 2) Creation of a collaborative space with dedicated and acknowledged time to discuss all aspects related to patients' care provision; 3) Common and shared knowledge about palliative and respiratory care delivery. Strengths and limitations of interdisciplinary

team meetings based on models from other healthcare settings, such as oncology and neurology (neuro-degenerative diseases) were discussed.

The main advantage of developing interdisciplinary team meetings for patients with advanced COPD was identified in a structured, individualised and shared action plan for care provision, with care fragmentation reduction. Furthermore, teaching opportunities and competence developing within the teams were seen as strengths for healthcare professionals. Several limitations were identified during discussions. Important time requirements and the interplay within hierarchical positions were among the most debated limitations of interdisciplinary team meetings. Moreover, breaking competencies' boundaries and organisational aspects, such as interacting and discussing complex patients through teleconferencing were seen as possible barriers for effective communication.

*“Participating in interdisciplinary meetings is very time consuming...I attend several meetings during the week and my agenda is greatly impacted by it” (Pa5).*

Interdisciplinary team meetings should also promote the involvement of primary care providers, such as general practitioners, nursing teams delivering care at home and other healthcare professionals (physiotherapist, social worker, psychologist among others) who support patients with advanced COPD at home.

*“I think it is important to involve all professionals involved in patients' care. This may foster a better understanding of choices made in different care settings and may help to share future care provision” (Pa7).*

Their involvement in these meetings was considered to be a difficult task, especially because of time and schedule constraints. Furthermore, it emerged that a lack of

knowledge about palliative care and its role in advanced COPD in primary care teams may prevent a structured and shared action plan for care provision. This would in turn lead to incompatible advance care planning between respiratory care service, supported by the palliative care team and the primary care team at home, with conflicting attitudes and communication with patients and their informal carers. Care fragmentation would be the real consequence of this approach. The development of joint interdisciplinary team meetings is thus dependent on a broad knowledge dissemination about palliative care integration in advanced COPD.

#### **6.4.4 Knowledge dissemination about palliative care in advanced COPD**

This research was conducted in a respiratory care service in the major teaching hospital in Southern Switzerland, where there was a good relationship with the palliative care team. The awareness about palliative care needs in patients with advanced COPD by both teams played an essential role in planning and conducting the research in this particular context. CIG participants underlined the importance of knowledge dissemination about palliative care in advanced COPD in local and regional settings.

##### **6.4.4.1 Local setting**

The respiratory care service is embedded in the major teaching hospital in Southern Switzerland. Patients living with life-limiting diseases were frequently seen as outpatients in different services and hospitalised in both, surgical and internal medicine wards. Subspecialties as neurology, nephrology and cardiology were also present. The CIG underlined the importance to disseminate the acquired knowledge to other services caring for patients with life-threatening diseases.

*“I think the cardiologists should gain more awareness about palliative care needs in their patients’ population” (Pa3).*

Knowledge dissemination about palliative care integration in advanced COPD was thought to foster collaborations across services, while sharing care plans with patients and their healthcare professionals. Furthermore, patients with advanced COPD often present multiple co-morbidities and are often referred to other specialists for diagnostic and therapeutic proposals. Palliative care patients’ identification skills acquired by professionals outside the respiratory care service was thought to prevent care approaches which are not individualised and agreed upon patients’ wishes and expectations, thus generating care fragmentation and controversies within care teams.

#### **6.4.4.2 Regional setting**

Public hospitals in Southern Switzerland are located across the canton. Respiratory care services are available in five out of seven public hospitals. Dissemination of knowledge about palliative care integration in advanced COPD was considered as essential to prevent care inequities in public hospitals where palliative care is provided. Patients followed in the local setting would benefit from these changes in practice, the others cared for in other locations would not gain access to an integrated care service, unless they changed their care setting. In order to guarantee accessibility to all patients with advanced COPD and foster collaboration within respiratory care services located in all public hospitals, groups members supported dissemination of the acquired knowledge and the practice changes to all heads of the local respiratory services. Common monthly conferences could offer the space to raise awareness on this important topic.

*“I believe we should organize a joint meeting with all respiratory care teams to inform them about our research” (Pa2).*

The evidence collected from the second phase of this study may be summarised through four themes which were discussed in this chapter: 1) Multidimensional assessment, patient’s needs, patient’s identification and palliative care timing; 2) Healthcare professionals’ education; 3) Service delivery through interdisciplinary team meetings and 4) Knowledge dissemination about palliative care in advanced COPD. These findings will inform the following discussion chapter, where implications for practice of this research will be presented and discussed.

## **CHAPTER 7: DISCUSSION**

In this chapter a short summary of the main findings from both research phases (phase I and phase II) is provided and these findings are related to the available literature on care integration. Synthesis and interpretation of the results on palliative care integration and service development for patient with advanced COPD in Southern Switzerland will be presented. Furthermore, the fundamentals of ToC as applied to palliative care integration and service development in Southern Switzerland will be illustrated. In the last section of this chapter future developments will be debated and study limitations will be acknowledged and critically discussed.

### **7.1 Summary of phase I and phase II results**

The understanding on essential elements for palliative care integration in advanced COPD are reiterated in this thesis. Furthermore, how these elements need to be developed and what key features each element should entail to foster the process of palliative care integration are discussed. Interviews with patients and informal carers represented phase I of this study, which was the first situational analysis informing the whole action research process (study phase II). Key findings were patients' feelings of guilt and shame about their smoking habits and carers blaming patients for their "self-inflicted" disease. The latter aspect needs to be particularly considered by healthcare professionals caring for these patients, as these feelings could negatively impact the patient-carer relationship, which is essential for care delivery in this population (Nakken et al., 2015). Furthermore, the perception of being stigmatised and discriminated by healthcare professionals because of their smoking habit needs to be addressed by improving professionals' communication skills, thus allowing a better focus on patients' priorities and wishes (Spence et al., 2009; Schroedl et al., 2014). Awareness

of palliative care and its role in the disease trajectory of patients with advanced COPD was lacking in patients and carers. Nevertheless, patients and carers were interested in key elements of palliative care, such as holistic care and personal priorities' and values' promotion (Iyer et al., 2019).

Findings from the CIG meetings (study phase II) are summarised in four main themes about the development of integrated palliative care in advanced COPD which were identified from the CIG meetings' analysis: 1) Multidimensional assessment, 2) Healthcare professionals' education, 3) Interdisciplinary team meetings and 4) Knowledge dissemination about palliative care in advanced COPD. These key themes, together with patients' and informal carers' experiences, helped to inform and develop a new model of integrated palliative care for patients with advanced COPD in the local research context.

## **7.2 Study results and available literature on palliative care integration**

In the background chapter, the definition of palliative care integration was discussed in-depth (InSup-C, 2014; van der Eerden et al., 2014; Siouta et al., 2016a) and represented the foundation for critical appraisal of studies included in the literature review. Palliative care integration in standard care was the focus of several published work in different care settings and for different life-limiting conditions (Burton and Payne, 2012; Bekelman et al., 2011; Nottelmann et al., 2019). Integrated palliative care criteria to assess care initiatives were defined by Emanuel et al. (2004) and were identifiable in several studies on integrated palliative care initiatives (Higginson et al., 2014, Gainza-Miranda et al., 2019; Nottelmann et al., 2019). Likewise, four of these integrated care criteria were identified in the action research process, where they were considered as key components for the development of a new integrated care model for patients with

advanced COPD. The relationship between the integrated care criteria and these key components is described in Table 7.1.

**Table 7.1:** Integrated care criteria and key components for new integrated care model

Integrated care criteria (Emanuel et al., 2004)	Key components of integrated care model
<b>Multidimensional assessment</b>	
<ul style="list-style-type: none"> <li>• Multidimensional assessment on patients' and their families</li> <li>• Setting the time for these assessments and when to repeat</li> <li>• Timing of palliative care integration</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical assessment (patients' needs)</li> <li>• Identification of palliative care patients</li> <li>• Palliative care timing</li> </ul>
<b>Healthcare professionals' education</b>	
	<ul style="list-style-type: none"> <li>• Theoretical knowledge of general palliative care approaches</li> <li>• Shared practical knowledge</li> <li>• Reflective practice</li> </ul>
<b>Interdisciplinary team meetings</b>	
<ul style="list-style-type: none"> <li>• Palliative care team involvement (interdisciplinary team, consultations, other services)</li> </ul>	<ul style="list-style-type: none"> <li>• General and specialist palliative care approaches</li> </ul>

Among further studies which aimed to understand how to integrate palliative care in the disease trajectory of patients with life-limiting conditions, the InSup-C research focused on patients, informal carers and healthcare professionals' experiences in care delivery in advanced disease (Hasselaar and Payne, 2016, p.2). This research analysed palliative care initiatives across Europe meeting integrated care criteria (Garralda et al., 2016; Siouta et al., 2016a; Van Beek et al., 2016). For this purpose, Ewert and

colleagues (2016) developed a taxonomy of integrated palliative care initiatives, which considered different aspects of care. The key elements identified by Ewert et al. (2016) are summarised as follows:

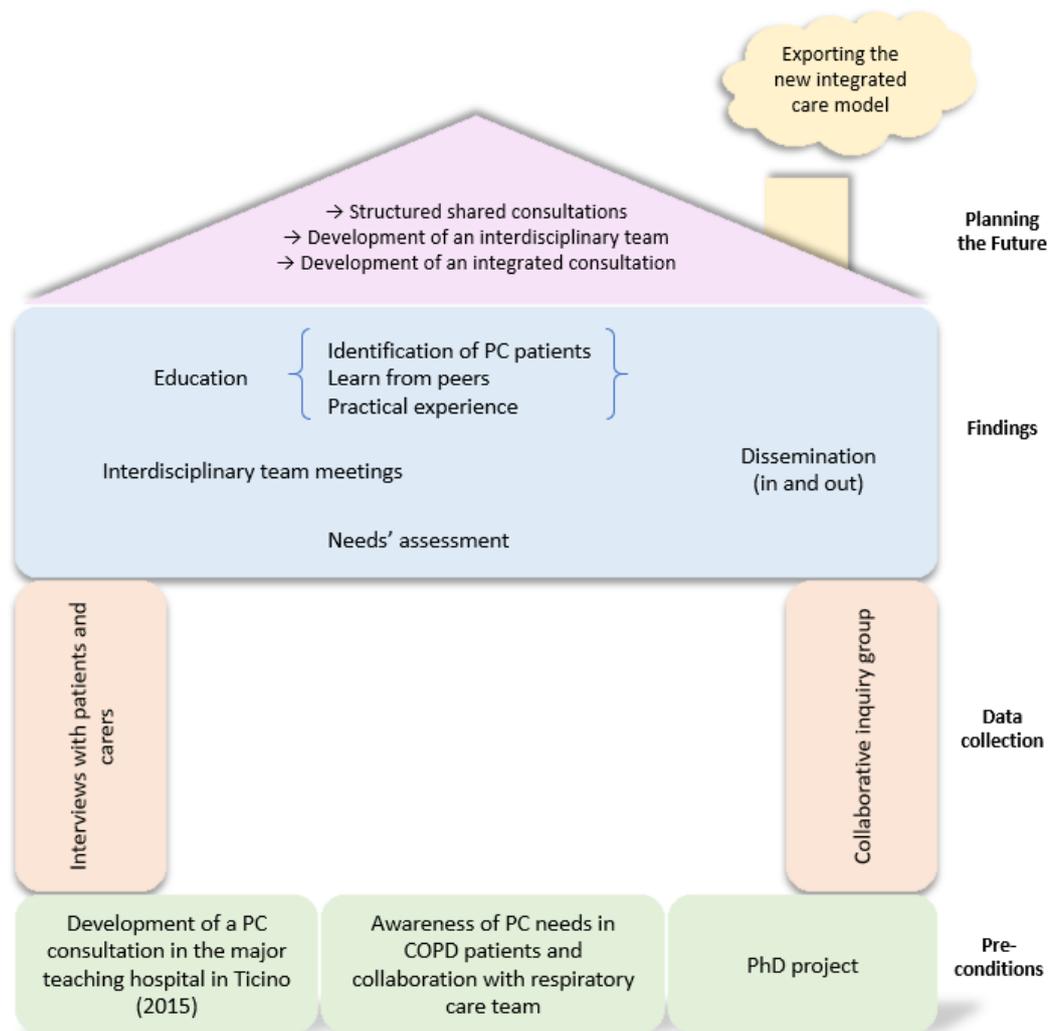
- 1) Type of life-limiting condition: cancer, chronic heart failure, COPD
- 2) Type of palliative care initiative: pathway, model, guideline
- 3) Level of care: primary, secondary, tertiary
- 4) Care setting: inpatient, homecare
- 5) Timing of intervention: early palliative care, concurrent with advanced disease, end-of-life care
- 6) Focus of intervention: patients' treatment, consultation, education/training
- 7) Modalities of collaborative working: network, protocol, team, case management
- 8) Key stakeholder: general practitioner, other healthcare professionals, palliative care specialist

This taxonomy of integrated palliative care initiatives may help to evaluate a new integrated palliative care model for advanced COPD and identify aspects which were not considered during the model development. The next sections of this chapter will illustrate how the new model of integrated palliative for patients with advanced COPD was developed and how the taxonomy may apply to this new care initiative.

### **7.3 Developing a new integrated palliative care model**

Ongoing palliative care consultations for inpatients were available in the local setting since 2015. As previously described in the background chapter, the role palliative care may play in the management of patients with advanced COPD was long recognised by the respiratory care team in the local research context. Collaborations between

respiratory and palliative care teams for hospitalised patients with advanced COPD were developed over many years. Several factors that facilitated such collaborations are described in literature and were paramount for the development of this action research study (Scheerens et al., 2018). Strong professional relationships within both teams, coordination of care delivered during hospital stays and shared discussions with patients about advance care planning were among several facilitating factors that supported the collaboration for hospitalised patients with advanced COPD. Nonetheless, as already illustrated, such modality of care delivery for outpatients was never implemented in a systematic manner in the local research setting. The question of understanding how to provide palliative care integration for this patient population was the fundamental aim of this study, as depicted in Figure 7.1. This drawing illustrates the research pre-conditions in the local context, the modalities of data collection, the main findings and the future developments of palliative care provision for patients with advanced COPD.



**Figure 7.1:** “The House” model representing the study and future developments

### 7.3.1 Key elements of the integrated care model

The starting point of this new integrated palliative care model for the local context was the assessment of needs. The identification of advanced COPD patients as palliative care recipients, the timing of palliative care provision in standard respiratory care and a holistic evaluation of patients’ needs were key features of this first component of the new model of care provision. Considering the assessment of needs as essential for the development of an integrated palliative care model is also confirmed by the literature

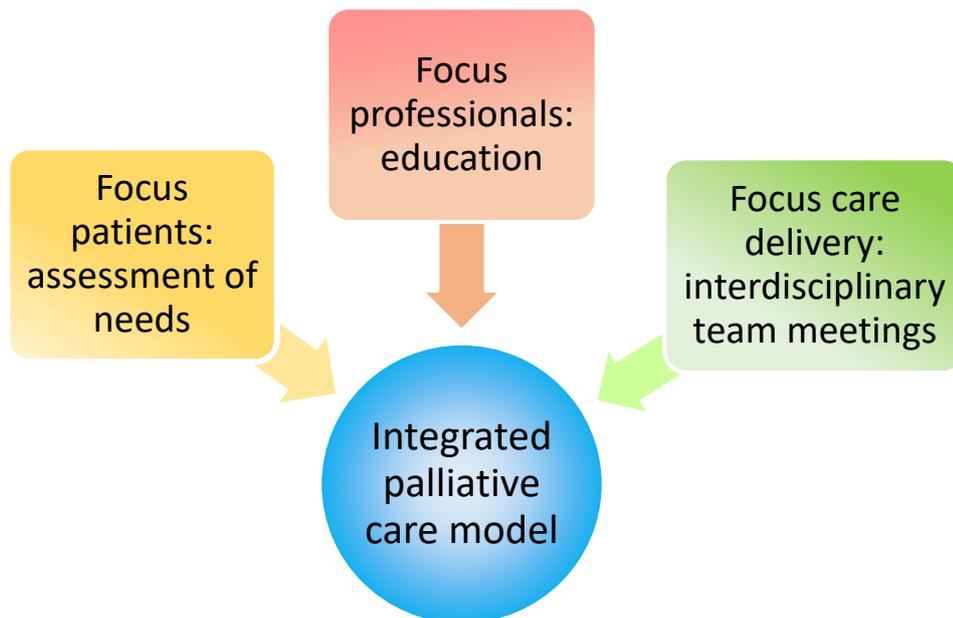
review of this thesis, where needs were identified as the first step of different modalities of palliative care provision, as depicted in Figure 3.2 (section 3.7) (Elkington et al., 2004; Cawley et al., 2014; Schroedl et al., 2014; Fusi-Schmidhauser et al., 2018). Furthermore, regularly performing a multidimensional assessment and establishing palliative care timing for potential recipients are among integrated care criteria according to Emanuel et al. (2004).

The second key component of the model of service delivery was healthcare professionals' education. Building theoretical knowledge on general palliative care approaches, developing skills and competences through shared consultations and fostering reflective practice among all professionals involved with care management of patients with advanced COPD were considered to be required elements of basic education. Healthcare professionals' education was considered as a fundamental element of palliative care integration in advanced COPD (Scheerens et al., 2018; Smallwood et al., 2018), even if not mentioned in Emanuel's et al. criteria (2004). Several examples of integrated care models focus on healthcare professionals' education as a facilitator in integrating palliative care in care management of patients with advanced COPD (Spence et al., 2009; Scheerens et al., 2018; Smallwood et al., 2018; Smallwood et al., 2018a). Educational interventions such as the development of communication skills and knowledge about palliative care delivery in different care settings were debated (Spence et al., 2009; Beernaert et al., 2013). Nonetheless, the evidence identified in this study about different levels of healthcare professionals' knowledge which are required to provide integrated palliative care for patients with advanced COPD is new and represents a pillar of the proposed integrated care model.

The third key component of this model of care integration focused on how care is delivered to patients with advanced COPD. The main element which was identified

from this action research study as being fundamental for integrated care provision was the implementation of interdisciplinary team meetings. Interdisciplinary team working was understood as integrating knowledge and competences from all healthcare professionals towards a common, patient-centred approach of care delivery (Wouters and Vanderhoven-Augustin, 2009). This is different to multidisciplinary, where collaborative work approaches among healthcare professionals with different competences and skills are practiced within discipline borders (Jessup, 2007). Although healthcare professionals' perceptions about the purpose and usefulness of multidisciplinary meetings for patients with advanced COPD were explored and participants agreed that these meetings were useful (Kruis et al., 2016), the evidence about the importance of interdisciplinary team meetings as a way to deliver care in advanced COPD is new.

The three key elements which needed to be included in the development of a new integrated care model for patients with advanced COPD are summarised in Figure 7.2. Each element focuses on different involved stakeholders and processes of integrated care: patients, healthcare professionals and service delivery. As previously discussed, these elements were also evidenced in the literature review, thus supporting the current findings and the development of this model. As already stated in the starting section of this chapter, this research demonstrates new evidence on how already known essential elements for palliative care integration, such as needs' assessment, educational initiatives and service delivery should be developed. In addition, this study identifies key features each element should include to foster the process of palliative care integration.



**Figure 7.2:** Key elements of the integrated palliative care model in advanced COPD

### **7.3.2 Mapping the new care model towards an integrated care taxonomy**

As aforementioned in the previous sections of this chapter, Ewert and colleagues (2016) developed a taxonomy of integrated palliative care initiatives which may help to evaluate new approaches of integrated palliative care. The model developing from this study was mapped towards this integrated care taxonomy, as depicted in Table 7.2.

**Table 7.2:** Integrated care model versus taxonomy of integrated care initiatives

Taxonomy of integrated care initiatives (Ewert et al., 2016)	New integrated care model for advanced COPD
<b>Type of life-limiting condition</b>	
<ul style="list-style-type: none"> <li>• Cancer, chronic heart failure, COPD</li> </ul>	<ul style="list-style-type: none"> <li>• COPD</li> </ul>
<b>Type of palliative care initiative</b>	
<ul style="list-style-type: none"> <li>• Pathway, model, guideline</li> </ul>	<ul style="list-style-type: none"> <li>• Model</li> </ul>
<b>Level of care</b>	
<ul style="list-style-type: none"> <li>• Primary, secondary, tertiary</li> </ul>	<ul style="list-style-type: none"> <li>• Secondary (tertiary)</li> </ul>
<b>Care setting</b>	
<ul style="list-style-type: none"> <li>• Inpatient, homecare</li> </ul>	<ul style="list-style-type: none"> <li>• Inpatient (respiratory care clinic)</li> </ul>
<b>Timing of intervention</b>	
<ul style="list-style-type: none"> <li>• Early palliative care, concurrent with advanced disease, end-of-life care</li> </ul>	<ul style="list-style-type: none"> <li>• Concurrent with advanced disease</li> </ul>
<b>Focus of intervention</b>	
<ul style="list-style-type: none"> <li>• Treatment, consultation, education and training</li> </ul>	<ul style="list-style-type: none"> <li>• Treatment, consultation, education and training</li> </ul>
<b>Modalities of collaborative working</b>	
<ul style="list-style-type: none"> <li>• Network, protocol, team, case management</li> </ul>	<ul style="list-style-type: none"> <li>• Team</li> </ul>
<b>Key stakeholder</b>	
<ul style="list-style-type: none"> <li>• General practitioner, other healthcare professionals, palliative care specialist</li> </ul>	<ul style="list-style-type: none"> <li>• Other healthcare professionals and palliative care specialist</li> </ul>

Type of life-limiting condition, type of initiative, care setting, timing of intervention and key stakeholder were clearly identifiable. The level of care was defined as secondary, but it may evolve toward a tertiary level of care as the hospital in which the

model was developed will become an academic training centre in the next years. Palliative care interventions covered all proposed foci from the taxonomy (treatment, consultation, training and education) and the modality of collaborative working was identified in a team work.

The element which distinguishes the integrated care taxonomy proposed by Ewert et al. (2016) and this new integrated care model is the definition of needs' assessment, both in terms of patients' needs (clinical assessment) and of healthcare professionals' needs (identification of palliative care recipients), as being essential for care integration. The starting point of this new care model was the multidimensional needs' assessment of patients identified as palliative care recipients. The same trigger for palliative care provision in advanced COPD was retrieved in the literature review of this thesis, where needs fostered different modalities of palliative care delivery (Figure 3.2, section 3.7). Furthermore, needs' assessment was also defined as an integrated care criterion by Emanuel et al. (2004).

This difference between the new developed integrated care model and the taxonomy proposed by Ewert et al. (2016) may be explainable through aspects such as the research setting and palliative care provision in daily clinical practice. The integrated care taxonomy was developed through an international consensus panel with healthcare professionals working in different disciplines (Ewert et al., 2016). This study was conducted in a specific hospital setting in Southern Switzerland, where care peculiarities and priorities inform patients' and carers' views on paramount elements of palliative care integration. These elements may differ from the one identified in international clinical and research settings. Moreover, established palliative care provision in daily clinical practice may lead to consider elements such as needs' assessment as an implied aspect of care management for patient with life-limiting

conditions. Nonetheless, the integrated palliative care taxonomy will be useful to map the further development of the new care intervention, especially in relationship to cantonal and possibly national dissemination (Ewert et al., 2016).

### **7.3.3 Potential barriers for integrated care model implementation**

Potential barriers that may prevent the implementation of this new integrated palliative care model need to be acknowledged and addressed. As with other integrated palliative care initiatives, the financial costs and benefits of this model are not foreseeable without testing the intervention (Epiphaniou et al., 2014; Kirkpatrick et al., 2014; Cassel et al., 2016). This uncertainty may lead to a challenging negotiation with institutional stakeholders, since more resources could be required in terms of financial support for educational programs and in terms of trained personnel. The latter aspect is particularly important, as both palliative and respiratory care team are lacking some professional roles that are essential for interdisciplinary care, such as a dietician and a social worker. Measuring the impact of the new care model on care indicators such as emergency department admissions and transfers to intensive care units will be of utmost importance to evaluate the potential financial benefits from a new care model implementation (Kirkpatrick et al., 2014; Cassel et al., 2016).

In addition, time constraints for healthcare professionals will need consideration, as they might prevent full participation in planned educational training. Lastly, organisational aspects will require particular attention, since shared consultations and interdisciplinary team meetings will need systematic planning that might be challenging since healthcare professionals will continue to work for different teams.

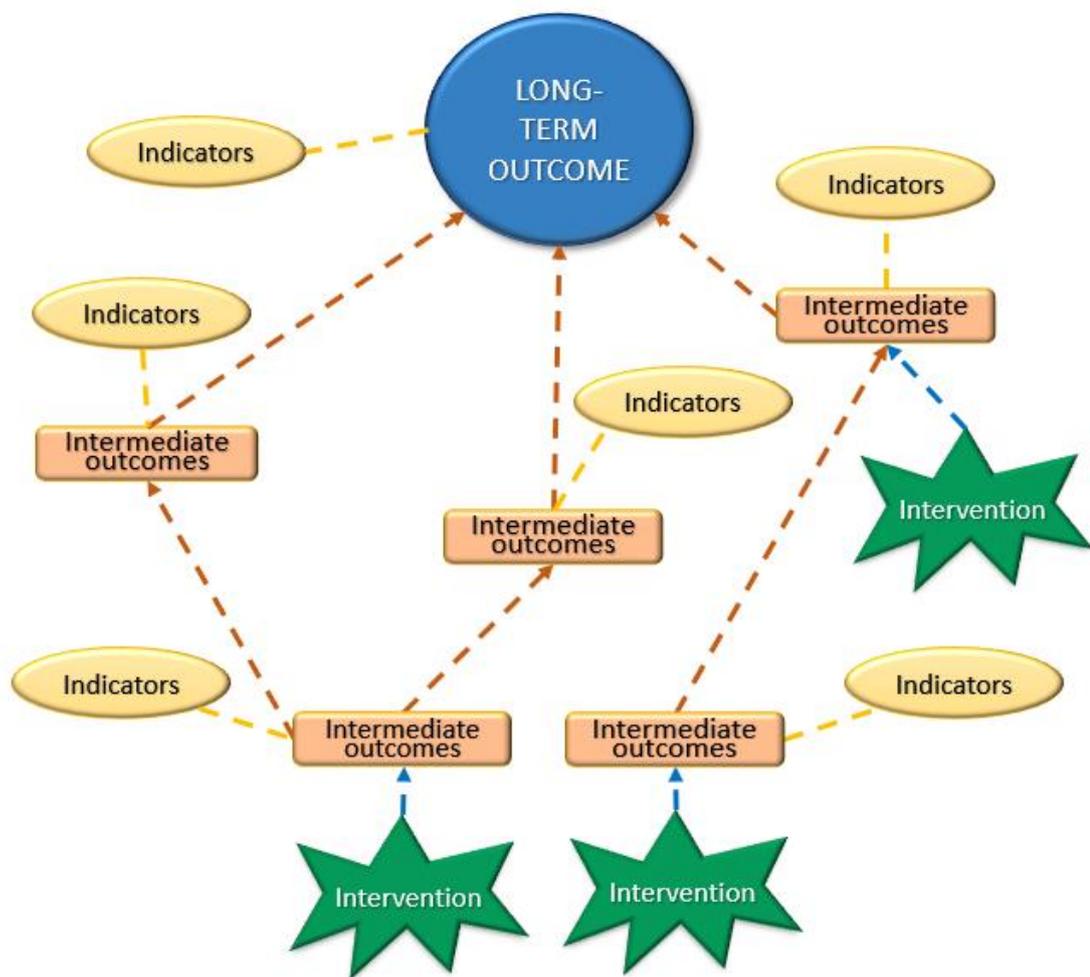
## **7.4 Theory of Change: organisational change and dissemination of the model**

### **7.4.1 Organisational change for the new integrated care model**

As previously discussed in the background chapter (section 2.11), the development and implementation of healthcare interventions can be theory-driven (Da Silva et al., 2014). A ToC approach explains how and why an initiative works through the measurement of pre-specified indicators on the pathway to impact, showing changes in care delivery compared to standard care (Anderson, 2005). The thesis literature review raised awareness about organisational changes that are necessary to develop integrated care. Further understanding about implementation of healthcare interventions and their evaluation in a specific context led to the inclusion of ToC as a theory to support the analysis and synthesis of themes identified during the CIG meetings. Moreover, ToC embedded in this action research encouraged reflections about the need to recognise different levels of an institution where changes may be facilitated or prevented (Apgar et al., 2017). To support a fundamental change in care delivery for patients with advanced COPD and foster palliative care integration, it is essential either to rethink the system where care is delivered or to adopt different models for care provision compared to the current situation (Hynes et al., 2015).

Key elements of a ToC approach (the “how and why”) were applied to understand how to further shape and develop the new integrated care model and to provide a framework for monitoring and promoting future evaluations. This provides stakeholders in other settings a process to follow for their implementation of a similar model, adapted to their healthcare service setting (Anderson, 2005). According to ToC, new care initiatives require clear definitions of steps which are essential to support their implementation towards a pre-defined long-term outcome (Da Silva et al., 2014). These essential steps

were identified through a ToC supported process of rethinking the themes that were defined in the CIG meetings as components of a pathway of change. Therefore, all the themes were linked with long-term and intermediate outcomes, interventions and indicators to evaluate the new integrated care model. This shift from themes identified in the CIG meetings towards a pathway of change helped to understand what is needed to further develop the implementation and broader dissemination of the integrated care model in advanced COPD. Figure 7.3 depicts all the previously described elements needed in a ToC approach and the following section will illustrate how the proposed model for integrated palliative care in patients with advanced COPD fits within a pathway of change (Anderson, 2005).



**Figure 7.3:** ToC approach for development and evaluation of care models

The elements of the pathway of change in relationship to the proposed integrated palliative care model are listed as follows:

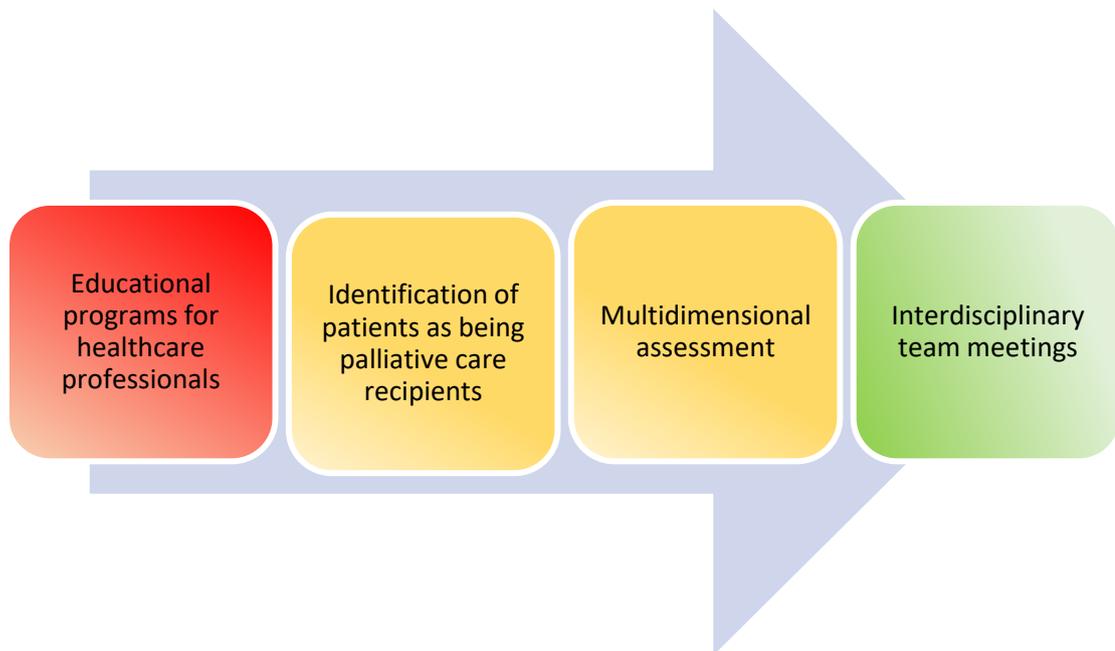
- 1) *Long-term outcome:* integrated palliative care cantonal model for advanced COPD
- 2) *Interventions:* educational training, choice and implementation of patient identification and needs' assessment tools, development of interdisciplinarity within caring teams

3) *Intermediate outcomes:*

- education: personnel is trained in palliative and respiratory care (acquiring theoretical, practical and experiential knowledge)
- needs' assessment: tools are used in daily clinical practice
- service delivery: interdisciplinary team meetings are regularly held

4) *Indicators:* they need to be discussed with key stakeholders in order to evaluate the integrated initiative (for example number of healthcare professionals who are trained, patients' and carers' satisfaction with care delivery, healthcare professionals' experiences with care model, economic impact)

This new model of care delivery requires important changes in how care is delivered. Furthermore, it is important to underline what the main potential barriers are prior to integrated care model implementation. Current service delivery might be described as a “Congress Practice Model”, where the respiratory care team refers patients for issues related to supportive care to different healthcare professionals, including palliative care physicians (Bruera and Hui, 2012). As debated in other studies, these referrals may increase fragmentation of care that is perceived as burdensome by patients and carers (Goodridge et al., 2009; Crawford et al., 2012). The proposed model will be delivered by the current teams, though moving beyond the “Congress Practice Model” to prevent care fragmentation, whilst seeking an integrated care provision. Based on the identified key elements of the new model with a focus on patients (multidimensional assessment), healthcare professionals (education) and service delivery (interdisciplinary team meetings), essential steps to cover were identified in order to implement integrated palliative care for patients with advanced COPD (Figure 7.4).



**Figure 7.4:** Essential steps for integrated palliative care model implementation for patients with advanced COPD

Healthcare professionals caring for patients with advanced COPD will benefit from specific training in both respiratory and palliative medicine. Acquiring theoretical and practical knowledge in both disciplines fosters acknowledgement of specific competences and improves understanding among healthcare professionals about different options proposed for care delivery (Smallwood et al., 2018a). This training will provide information about patients' identification and multidimensional assessment tools that will be used to: 1) identify patients requiring an integrated palliative care approach and 2) evaluate their multidimensional needs. Furthermore, theoretical knowledge will empower healthcare professionals in selecting appropriate identification and multidimensional needs' assessment tools for the local research setting as discussed during CIG meetings. The theoretical model envisages that patients

will be screened by the respiratory care team (including the rehabilitation department), by general practitioners who may select their patients for this integrated care model and by internal medicine ward staff during inpatients' consultations with planned follow-ups with the respiratory care team after discharge.

Members of both the palliative and respiratory care team will evaluate patients' multidimensional needs and elaborate a shared care plan, while discussing goals of care with patients and carers. Regular interdisciplinary meetings will further foster a patient-centred approach of care delivery, while considering patients' needs and wishes (Wouters and Vanderhoven-Augustin, 2009).

#### **7.4.2 Integrated care model dissemination on a cantonal level**

As illustrated earlier in the background chapter, palliative and respiratory care provision in Southern Switzerland is offered through both public and private institutions, while certified palliative care consultations are only delivered through the public healthcare system (Dipartimento Sanità e Socialità, 2015; Qualité Palliative, 2018). The findings described in the preceding chapter indicates that dissemination of knowledge about palliative care integration in advanced COPD is fundamental to grant accessibility to integrated care services, while preventing care inequities across public hospitals in Southern Switzerland, since local respiratory care services are independently managed (Ente Ospedaliero Cantonale, 2018). According to other integrated palliative care interventions, embedding palliative care within standard respiratory care delivery helps to reduce misconceptions that were reported in previously conducted studies about the role palliative care plays in advanced COPD (Hayle et al., 2013; Smallwood, 2018). Moreover, it is important to assess care delivery in local settings, in order to adapt integrated care provision to a specific context, while considering local and regional

peculiarities (WHO, 2016). Palliative and respiratory care teams in public hospitals in Southern Switzerland demonstrate different levels of interaction and collaboration. Availability and accessibility of palliative care teams, skills and competences of palliative care healthcare professionals in managing care for patients with advanced respiratory diseases and working relationships between respiratory and palliative care teams are among several issues that will need to be further evaluated (Partridge et al., 2009; den Herder-van der Eerden, 2017).

Although public respiratory care services in Southern Switzerland are independent entities, they are integrated in a wider care network with a common institutional and financial governance (Ente Ospedaliero Cantonale, 2018). Joint educational meetings and annual conferences are organised and common initiatives on the development of respiratory medicine in Southern Switzerland are shared. Moreover, some physicians consult in more than one outpatient clinic, thus experiencing different geographical and organisational working settings (Ente Ospedaliero Cantonale, 2019). In consideration of all these elements, the CIG members supported the dissemination of the developed knowledge about palliative care integration to all respiratory care teams in Southern Switzerland. This dissemination should raise awareness and foster collaboration across regional borders.

#### **7.4.2.1 “The how and the why” of a cantonal model dissemination**

As for the new integrated palliative care model itself, the cantonal dissemination requires clear definitions for how services will be delivered for patients with advanced COPD and why this new initiative will work for this specific patients’ population (Anderson, 2005). Therefore, stakeholders on a cantonal level will need to consider short- and long-term goals to achieve with this new modality of care provision (Blamey

and Mackenzie, 2007; De Silva et al., 2014). The specific local context will be of particular importance, as clinical, logistical and organisational peculiarities need to be addressed, in order to foster the implementation of the new integrated palliative care model (WHO, 2016). Key elements of integrated care which were identified in this study (multidimensional assessment, healthcare professionals' education and interdisciplinary team meetings) will require a tailoring to each local care setting. Moreover, it will be paramount to define the clinical governance of a cantonal model, as it should guarantee high-quality care provision for all patients with advanced COPD who access respiratory clinics across the canton (Western Australian Office on Quality and Safety in Health Care, 2001).

#### **7.4.2.2 The future plans for a cantonal integrated care model dissemination**

A joint meeting between the Palliative and Supportive Care Clinic, the Cantonal Rehabilitation Department and physicians of the local respiratory care services was fostered and organised by members of the CIG. The main goal was to share the findings from the action research study and to disseminate knowledge about palliative care integration in advanced COPD across local borders. This aspect was included in the institutional inquiry (third person inquiry) of this study (Hynes, 2013). Knowledge dissemination and discussions about a future initiative on care integration in all public respiratory care services was acknowledged as an important step for high-quality care delivery in this specific population. A joint statement about the willingness of future collaboration and care integration was delivered to the executive board of the cantonal health service (Ente Ospedaliero Cantonale, 2019). The executive board welcomed this initiative about a new model of care provision and supported the proposal to develop a pilot implementation plan to assess feasibility of the integrated care model, to evaluate

resource requirements in terms of specialised personnel, to organise healthcare professionals' training and to appraise the overall financial impact of this new model of care provision.

These elements can be incorporated in a ToC approach, where short-term goals (pilot implementation plan) are required to be achieved in order to drive a process of change which in turn aims at long-term outcomes (implementation of a new model of integrated palliative care in all respiratory care services in Southern Switzerland) (Anderson, 2005; Blamey and Mackenzie, 2007; De Silva et al., 2014; Breuer et al., 2016). The respiratory care service in the local research context was designated as the centre in which the development and implementation of this pilot will occur. The planning process has already started and the pilot implementation will start in January 2020. All aforementioned aspects will be evaluated and a detailed report will be delivered to the executive board of the cantonal health service after 12 months.

In conclusion, ToC will help to review the process which led to the development of this new integrated care model and will support model evaluations. At the same time ToC will inform the development of further studies testing the new model in a clinical context.

## **7.5 Research limitations and challenges**

Addressing limitations and challenges of this research was essential to contextualise the gathered evidence, while justifying all choices made during the research development and conduct (Puhan et al., 2012). Some of the limitations and barriers regarding the implementation of an integrated palliative care model for patients with advanced COPD on a local and cantonal level were already discussed in the previous sections. The

following discussion focuses on practical and methodological limitations and challenges which were encountered during the undertaking of the study.

### **7.5.1 First situational analysis: interviews with patients and informal carers**

In this section it is essential to highlight potential limitations of the first study phase (Phase I, interviews with patients and informal carers). The first potential limitation to consider is the small study sample (five patients and five informal carers). To prevent an incomplete insight on patients' and carers' experiences, interviews were conducted until data saturation was reached and further coding was not feasible. Data saturation was reached after nine interviews, the tenth confirmed the lack of new themes. The second limitation is related to the sampling method. Stratified purposive sampling could have led to a selection bias. This potential pitfall was addressed by medical chart recruitment by personnel not involved in the study. Lastly, interviews were conducted in a single service where local and regional peculiarities needed to be considered. Nonetheless, identified themes were also reported in previously published studies in broader contexts (Ek et al., 2011; Disler et al., 2014; Nakken et al., 2015).

### **7.5.2 Translation issues and interpretation of meanings**

As previously described, the first situational analysis involved interviews with patients and informal carers. Interviews were conducted and transcribed verbatim in Italian, as Italian is the main language in Southern Switzerland. Data analysis was performed in Italian, themes and subthemes were translated to English, as were patients' and carers' quotes. Translation may alter the meaning of concepts in themes and subthemes and the representation of textual data (quotes) (van Nes et al., 2010). Many narratives and metaphors were used by patients and carers during their interviews and these verbal

expressions are language-specific (Lakoff and Johnson, 1980). Different approaches were proposed to overcome barriers of translation and loss of in-depth meaning of collected data. Conducting interviews in the local language, employing professional translators to help with the findings' translation and leaving some quotes in the original language are among some proposed solutions to prevent loss of meaning (Smith, Chen and Liu, 2008; van Nes et al., 2010). In this study, data collection and analysis were performed in Italian, in order to capture the full extent of the quotes' meaning also in English, the translation of some of these particular expressions were discussed with a native speaker. Furthermore, the discussion with a native speaker on translation issues assisted in improving the use of English terms for defining the main themes.

### **7.5.3 The use of social media in action research cycles**

As previously reported in this thesis, a Smartphone chat-app was used to schedule all CIG meetings. The use of this chat-app helped to expedite scheduling and allowed each member to share their spontaneous thoughts with the group.

Despite the advantages of having a fast access to virtual platform which was accessible to all group members without time and location constraint, the group felt that text-based interactions were not helpful to create new knowledge. This aspect was also highlighted by Moore and colleagues (2015), while studying the interactions of online focus groups. Furthermore, issues about confidentiality, anonymity and potential breaking of both through voluntary or accidental data sharing within other Smartphone chat-app users prevented the use of this electronic media for data sharing even more. For all these reasons, the group decided to use the chat-app exclusively as a scheduling tool for CIG meetings.

#### **7.5.4 The role of the researcher**

As earlier debated in the theoretical and methodological chapter, practising action research within a practitioner's group with hierarchical relationships is challenging. The risk of developing asymmetrical relationships and thus preventing a truthful capture of all opinions and voices needs to be constantly assessed (Casarett, 2010). In addition, these hierarchical relationships were further challenged during the research conduct, as I was promoted to a senior consultant position within the palliative care and internal medicine department prior to the start of the CIG meetings. Therefore, the CIG presented a dual power imbalance: one between the researcher and the non-medical professionals (nurse, physiotherapist), the second between the researcher and her medical colleagues. The participants' age could also potentially create situations of asymmetrical relationships, especially due to the palliative care nurse's younger age.

These potential pitfalls were considered during the conduct of the research (sections 6.1.4 and 6.2.4). Continuous reflexivity and ongoing discussions about power relationships and sources of inequity were helpful to address potential study limitations (Grant, Nelson and Mitchell, 2008). In addition, the use of few practicalities, such as participants interacting by first name, creating an informal Smartphone chat-app to schedule all group meetings and attending meetings in plainclothes, thus avoiding white coats within the physician group, helped to overcome potential power imbalance. An example of this reflexivity process is depicted in Appendix XV.

As described in the previous paragraph, the researcher holds a senior consultant position in both palliative care and internal medicine departments. This aspect needs to be acknowledged, as it could open critique towards power relationships which may pressure the implementation of the new integrated care model. This research study was

facilitated because it built upon a pre-existing palliative care consultation service in the study setting since 2015. Good professional relationships and team work for patients with life-limiting conditions helped to raise awareness about the role of palliative care long before the researcher was promoted to her current clinical role. Furthermore, a common interdepartmental vision on shared clinical practice was developed to change care provision for patients with palliative care needs, resulting in the establishment of an integrated care ward in the internal medicine department (Ente Ospedaliero Cantonale, 2018). Assertive collaboration, common visions, empowerment, trust and participation were the key facilitating elements that fostered the development of this research study (Lovell, 1993). Healthcare professionals participating as CIG members shared the common goal to understand how to integrate palliative care provision for patients with advanced COPD in standard care.

Lastly, it is important to highlight the role the lead action researcher plays as facilitator in this particular setting (Grant, Nelson and Mitchell, 2008). As reported previously in the theoretical and methodological chapter, the lead action researcher was the person who was undertaking the PhD and therefore driving the study. This scenario challenges the concept of common research ownership as a fundamental element of action research, as it is only partially fulfilled in this research (Zuber-Skerritt, 2011). Prior to study commencement, it was important to explain to the CIG differences between this research and other action research studies in terms of ownership. This helped to maintain clarity and transparency about roles and expectations, which was fundamental for building trusted relationships within the CIG (Reason, 2002).

### **7.5.5 Researcher's learning and development**

This doctoral journey challenged many of my certainties, both as a professional and as a researcher. I started with a different research plan on how to answer the research question on palliative care integration in advanced COPD. A mixed-methods feasibility study seemed to be appropriate to collect data and gain knowledge to cover the gap in order to answer the research question. In the midst of the study protocol drafting, I read by chance a paper on participative research in healthcare and I think this was the turning point of my thesis (Hynes et al., 2015). I challenged my positivist background as a physician and I understood that I wanted to gain a different insight from this research to answer the question on how to integrate palliative care in advanced COPD.

Reflexivity in this context was essential to challenge my assumptions on how reality is perceived by others and to engage with participatory action research, both from a theoretical and methodological perspective. Exploring a new way to conduct a research, being a co-researcher with important stakeholders in the field of interest and learning to facilitate a CIG meeting were all tasks which I had to address in order to capture all the different aspects of this research. Furthermore, personal reflexivity was fundamental to understand how to conduct this research with high-quality standards and with rigour (Reason and Bradbury, 2008). I learned that different perspectives which were debated during the CIG meetings fostered data richness. The justification of all choices made during research planning and conducting was important to support this richness and to explain data analysis and synthesis, while underpinning the conclusions of this study.

My views as a researcher and as a professional were challenged and my thinking developed from a positivistic background towards critical social theory, being this the philosophical underpinning of this research.

### **7.5.6 Quality and rigour**

As earlier described, assessing quality and rigour in action research remains an open debate (McTaggart, 1994). Among different quality criteria which were proposed to establish high-quality action research (Waterman et al., 2001; Reason, 2006; Williamson et al., 2012), Reason's criteria were chosen to support quality and rigour of this action research study and are listed as follows: 1) Evaluation of worthwhile practical purposes, 2) Participative and democratic inquiry, 3) Inclusion of different forms of knowledge, and 4) Maintaining a continuum of research development over time.

The evaluation of worthwhile practical purposes was accomplished as palliative care integration was recognised in previous published literature and by main stakeholders in the local research context as a necessity for improved care provision in patients with advanced COPD (Smallwood et al., 2018a; Higginson et al., 2014). The participative and democratic inquiry was pursued during each CIG meeting. As debated in the earlier sections of this chapter, ongoing reflexivity and discussions about hierarchical and power relationships were useful to raise awareness about potential sources of inequities during the action research process (Reason and Bradbury, 2008). The new evidence which was identified in this study is founded on different forms of knowledge. Firstly, the knowledge collected during an extensive literature review on palliative care delivery and care integration in advanced COPD provided the gap of knowledge to cover through this research (Fusi-Schmidhauser et al., 2018). Secondly, interviews with patients and informal carers helped to illustrate their experiences and perceptions of living with a life-limiting condition, thus incorporating their voices in this study. Lastly, building knowledge through CIG meetings fostered the identification of key elements of the new

integrated palliative care model for patients with advanced COPD. The fourth and last criterion which define quality in action research according to Reason (2006) support a continuum of research development over time. This was achieved for the duration of this PhD and will be fostered through the integration of the integrated palliative care model in other care settings through regional, cantonal and possibly national dissemination. A summary of how the quality criteria according to Reason were addressed in this study is depicted in Table 7.3.

**Table 7.3:** Study quality criteria addressed in the study

Quality criteria (Reason, 2006)	How addressed in the study
<i>Addressing worthwhile practical purposes</i>	Palliative care integration in advanced COPD: <ol style="list-style-type: none"> <li>1. COPD represents a leading cause of morbidity and mortality worldwide</li> <li>2. High symptom burden and needs in advanced COPD</li> <li>3. Reduced accessibility to palliative care in COPD</li> </ol>
<i>Participative and democratic inquiry</i>	<ol style="list-style-type: none"> <li>1. Developing a communicative space</li> <li>2. Raising awareness about hierarchical relationships</li> <li>3. Building egalitarian relationships</li> <li>4. Encouraging participation and participants' empowerment</li> </ol>
<i>Different forms of knowledge</i>	<ol style="list-style-type: none"> <li>1. Experiential knowledge:               <ul style="list-style-type: none"> <li>- patients' and carers' experiences (interviews)</li> <li>- healthcare professionals' experiences (CIG)</li> </ul> </li> <li>2. Presentational knowledge:               <ul style="list-style-type: none"> <li>- development of a visual theoretical model of palliative care integration</li> </ul> </li> <li>3. Propositional knowledge:               <ul style="list-style-type: none"> <li>- theoretical background through literature review</li> </ul> </li> </ol>

	4. Practical knowledge: - six cycles of action and reflection
<i>Continuum of research development over time</i>	Development of participants and researcher understanding and skills in action research through the whole process

### 7.5.7 First, second and third person inquiry

As earlier debated in the theoretical and methodological perspective chapter, action research is conducted through three different entities: the researcher, the CIG and the institution which aims to promote a change in clinical practices (Torbert and Taylor, 2008). During the whole study, I reflected as lead action researcher on my motivations for developing and conducting this research study. It was important to reflect on my personal clinical practice and service provision for patients with advanced COPD and to recognise my personal views on this topic. This was helpful to gain awareness how other professionals might position themselves towards palliative care integration in advanced COPD, while acknowledging their interactions during the CIG meetings (Reason and Torbert, 2001). As a lead action researcher, I tried to identify two levels of reflection during the research process, through reflections on how the interactions within the CIG unfolded during the meetings (“reflection in action”) and thereafter how the process was developing (“reflection on action”) (Schön, 1983). Despite being these aspects challenging for a new action researcher, they helped to understand the action research process as a whole system of knowledge gathering.

The CIG interacted through interpersonal dialogues and discussions (Torbert and Taylor, 2008). Common knowledge development was fostered by the creation of a communicative space (Wicks and Reason, 2009). As a CIG, we supported the

preservation of this space, where all members had opportunities to acquire awareness about themselves and about their relationships with the group (Wicks and Reason, 2009). In order to preserve this space, CIG members gained awareness about the important distinction between their professional role and being a co-researcher in this action research study. This fostered ongoing interactions and discussions which led to common developed knowledge (Torbert and Taylor, 2008).

The dissemination of evidence about palliative care integration in advanced COPD to other regional care settings can be related to an institutional goal of this study. Furthermore, the development of a research network across regional boundaries may help to further disseminate the gained knowledge and may foster future common research (Hynes, 2013). This was achieved through a planned collaboration with correspondent palliative and respiratory care institutions located at the University Hospitals in Geneva. In addition, the researcher was invited to share the experience of leading an action research study within a building community of action researchers in the Canton Vaud (Fondation Pallium, 2019).

### **7.5.8 The development of shared reflexivity**

As described in the preceding paragraph, reflexivity was the mainstay of the CIG meetings, both as an individual process and on a group level through sharing and discussing among CIG members during all action research cycles. The practice of taking time to ponder the meaning of what happened during the action research cycles evolved during the research. The reflexivity process started on an individual-based perspective, which was shared and integrated in a broader context within the CIG. Furthermore, the dialogic and transformative nature of reflexivity acquired a new dimension through

common reflections on social processes within the group, defined as shared reflexivity (Widmer, Schippers and West, 2009).

The development of shared reflexivity requires key elements, such as questioning assumptions, shifting from an individual to a social perspective, considering power relations within the group and thinking about a broader context on an organisational level (Vince, 2002). According to Vince (2002, p.69), this common reflexivity promotes “the collective questioning of assumptions that underpin organising, revealing the power relations that inform organising, making them visible and therefore available for transformation”. This fosters a transition from an individual focus towards a common developed thinking and reflecting which may promote organisational changes in institutions (Kemmis, 1985; Vince, 2002).

Shared reflexivity supported the need for dissemination of the gained knowledge on a cantonal level. The common awareness about the importance of changing practices in care provision for patients with advanced COPD and challenge the way of current care delivery were fundamental for encouraging discussions about a future initiative on palliative care integration in all public respiratory care services in Southern Switzerland. Organising these reflections was essential, as it helped to develop common thinking about regional and institutional facilitators and barriers which may prevent an integration of palliative care delivery in standard care for patients with advanced COPD (Vince, 2002). These aspects, such as the specific local context, available resources in other public hospitals in Southern Switzerland and local organisational peculiarities need to be further considered and developed in order to disseminate and implement the new integrated care model (WHO, 2016).

## **7.6 Beyond the thesis: future research on the new care model**

Dissemination on a national level of the new integrated care model is an aim that goes beyond this thesis. Nonetheless, it is important to highlight that palliative and respiratory care institutions are interested in testing the new model for care delivery in advanced COPD. Stakeholders working in these institutions are part of the network which was created by the researcher and the CIG. As a palliative care physician, the researcher is involved in national working groups and due to her language knowledge (native Italian and German speaker and French speaker) was able to create connections with both the German and the French speaking palliative care institutions across Switzerland. Furthermore, her teaching activities for the Internal Medicine Department at the Master Course for Medical Students at the University of Geneva, helped to strengthen the links with colleagues from the Palliative Care and the Respiratory Care Department of the University Hospital in Geneva. Research studies within the Palliative Care Department in Geneva were focused on palliative care delivery in advanced COPD, in collaboration with the local respiratory care department (Janssens et al., 2019). Through invitations to research meetings and other conferences, information about ongoing projects, including findings from this study, were disseminated within both the Palliative and Supportive Care in Southern Switzerland and the corresponding institution in Geneva. The latter showed a particular interest in evaluating ways of translating the new initiative for care provision in advanced COPD, with palliative care integration.

According to the ToC process, it is essential to identify how and why an intervention work in a specific clinical context (De Silva et al., 2014). Furthermore, as previously discussed, it is important to set long-term goals which are obtained through a series of

pre-specified short- and medium-term outcomes (Breuer et al., 2016). The situation at the Geneva University Hospitals is characterised by the lack of a systematic palliative care provision for patients with advanced COPD. Therefore, the long-term goal of an integrated palliative care model needs to be achieved through intermediate outcomes, such as for instance knowledge dissemination and awareness of palliative care in advanced COPD and systematic collaboration for inpatients. Involvement of key stakeholders from the beginning of this transfer process is fundamental (Anderson, 2005; Breuer et al., 2016). A small working group involving these stakeholders may act as a driver for implementation. This working group needs to assess facilitating factors and barriers which potentially influence or prevent the new care model deployment (Breuer et al., 2016). In addition, contextual factors such as logistical and organisational aspects require consideration. Financial issues such as funding for educational programs for healthcare professionals and additional personnel resources for the new care model need to be pondered during this evaluation process. The last step is mapping of this process, which creates a framework for the development and the forthcoming evaluation of the new and contextually adapted integrated palliative care model (De Silva et al., 2014). Research on model testing in clinical practice and evaluating the implementation process may foster wider dissemination of the new care initiative across national palliative care institutions.

## **7.7 Conclusion**

In this chapter the in-depth analysis on how evidence from this research about palliative care integration for patients with advanced COPD informed the development of a new model of care provision in the local research setting was illustrated. Therewith, dissemination of this care model on a cantonal level was discussed and potential pitfalls

were identified. Research limitations and challenges were addressed, while justifying the choices made for the development and conduct of this research. Lastly, future research on model testing and implementation and dissemination in other palliative care institutions across Switzerland were presented.

In the final chapter of this thesis, implications for practice will be considered and recommendations for future research in this particular field will be suggested.

## **CHAPTER 8: CONCLUSION**

In the previous chapters, the research background and context were introduced and key issues such as integration of care, integrated palliative care and ToC were explained and debated (chapters one and two). The available knowledge on palliative care provision and integration in advanced COPD was systematically reviewed, while a model of palliative care delivery in advanced COPD was presented (chapter three). The theoretical underpinnings of this study and the choice of action research were discussed and justified (chapter four). Methods and findings of both research phases (I and II) were described, while the key elements of the new integrated care model were identified and discussed (chapter five and six). Synthesis and discussion of these findings and the original contribution to knowledge in integrated palliative care for patients with advanced COPD of this study were emphasised (chapter seven).

In the conclusive chapter of this thesis, the new evidence identified through the study will be reiterated. Furthermore, implications for practice resulting from this evidence will be considered and recommendations for future work in this field will be suggested.

### **8.1 Adding knowledge about palliative care integration in advanced COPD**

This research reiterates already known essential elements for palliative care integration in advanced COPD, such as holistic needs' assessment, educational initiatives and modalities of service delivery (Spence et al., 2009; Burgess et al., 2013; Siouta et al., 2016a; Duenk et al., 2017). The knowledge gap covered by this study addresses the identification of key features each essential element should include to allow and foster the process of palliative care integration in patients with advanced COPD. Firstly, multidimensional needs' assessment should consider three aspects, such as patients'

needs (the “what”), palliative care timing (“the when”) and identification of palliative care recipients (the “who”). Secondly, educational initiatives should promote different core components, such as theoretical knowledge (“to know”), practical knowledge (“to know how”) and experiential knowledge (“to know how to be”). Lastly, interdisciplinary team meetings should be a fundamental component of service provision in the integrated palliative care model for patients with advanced COPD.

This new evidence has implications for future practice in the management of patients with advanced COPD. The implications of these findings for practice and research are discussed next.

## **8.2 Implications for practice**

This study evidences how palliative care can be integrated in respiratory care services for patients with advanced COPD and what elements are essential to foster care integration. This research would not have been possible without a raised awareness among healthcare professionals working for the palliative and respiratory care service about the role palliative care might play in advanced COPD (Smallwood et al., 2018). This aspect is fundamental for promoting integrated care models into practice (Smallwood et al., 2018a). Supporting knowledge dissemination on this topic could mitigate pre-existing misconceptions about palliative care, such as being relevant only in end-of-life and oncological settings, thus increasing interest and initiatives towards palliative care integration in advanced COPD (Elkington et al., 2004; Ostgathe et al., 2011).

Healthcare professionals’ education was recognised as a pillar of this integrated care model. Fostering theoretical, practical and experiential knowledge is essential to

promote care integration in advanced COPD. Hence, institutions which are supporting change of care delivery for these patients are challenged to develop educational programmes for healthcare professionals working with advanced COPD patients and their families. Collaboration within educational networks may help to develop common programmes and define content and modalities of healthcare professionals' education in palliative care (Connolly and Charnley, 2015).

The new integrated palliative care model underlines the importance of working in an interdisciplinary manner. In comparison to the current model of practice ("Congress Practice Model"), an interdisciplinary approach will change how teams are interacting together. Interdisciplinarity requires integrating knowledge and competences from all involved healthcare professionals towards a common and patient-centred approach of care provision (Wouters and Vanderhoven-Augustin, 2009). Learning how to work together in an interdisciplinary way needs training and the use of individual and group reflective practice. This is a process which is time consuming and requires guidance from professionals who are used to working in and conducting interdisciplinary teams (Vyt, 2008).

Lastly, respiratory care services which are interested in implementing integrated care models should consider the impact of professional resources needed for palliative care delivery. The lack of available specialised healthcare professionals may prevent the implementation of an integrated care model (Partridge et al., 2009; Smallwood et al., 2018). Therefore, it is paramount to encourage healthcare professionals interested in working for integrated palliative care services to pursue educational programmes and develop competencies in this specific field.

### **8.3 Recommendations for future research**

In consideration of the new evidence presented in this thesis and the implications for practice discussed in the previous section, it is important to highlight areas of future research for this specific topic to be explored. Given the interest for the proposed model of palliative care integration in other Swiss care settings (for example Palliative and Respiratory Care Services, Geneva University Hospital), it is important for these services to understand how this model for palliative care provision may fit within existing institutions (WHO, 2016). Therewith, facilitators and barriers for implementation need to be explored and acknowledged during future service developments. In this context, a ToC approach may support both service development and subsequent evaluations, thus promoting process traceability and transparency (Anderson, 2005; De Silva et al., 2014).

Essential elements of integrated palliative care provision for patients with advanced COPD may be included in healthcare professionals' guidelines and frameworks, to inform and standardise to a certain point service delivery. Research on modalities of framework applications and the benefit on service provision and patients' outcomes of standardised practices may help to identify areas of improvement and adaptation to different contexts and settings. In addition, integrated palliative care models for patients with advanced COPD could benefit from future research on quality indicators for practice. These indicators may help to understand the "how and the why" of future care integration, while fostering high-quality care delivery.

Measuring clinical outcomes of integrated palliative care models in patients with advanced COPD may support this care approach within institutions. Evidence collection on reduction of emergency department accesses and days of hospitalisation,

reduction of intensive care unit transfers through increased advance care planning conversations with patients and overall cost reductions through less invasive treatments needs to be promoted (Kirkpatrick et al., 2014; Rucker et al., 2014; Cassel et al., 2016). At the same time, it is important to encourage future research on personnel resources' requirements of integrated palliative care models for patients with advanced COPD, thus promoting discussions within institutions about the development of recruitment programs for healthcare professionals working in specialised palliative care.

Lastly, in-depth research exploring patients', carers' and healthcare professionals' experiences within this model of palliative care integration should be promoted (Smallwood, 2019). Understanding the perspectives of end-users and of professionals working within and across services may foster quality improvement and ongoing model adaptation to changing needs. Moreover, perceptions of other care network partners, such as general practitioners, home care nurses and other professionals caring for patients with advanced COPD and their families should be explored. This may improve collaboration, reduce care fragmentation and address the wider care network needs in caring for this specific population.

#### **8.4 Conclusion**

A new developed integrated palliative care model in advanced COPD includes essential elements with a focus on patients, healthcare professionals and care delivery. Future research on service development, implementation processes and outcomes are deemed necessary to foster this care approach across all patients' settings.

## REFERENCES

- Adeloye, D., Chua, S., Lee, C., Basquill, C., Papan, A., Theodoratou, E., et al. (2015) Global and regional estimates of COPD prevalence: Systematic review and meta-analysis. *Journal of Global Health*, 5(2), 020415. Available at <https://doi.org/10.7189/jogh.05.020415> [Accessed 20 April 2019].
- Afonso, A.S.M., Verhamme, K.M.C., Sturkenboom, M.C.J.M. and Brusselle, G.G.O. (2011) COPD in the general population: Prevalence, incidence and survival. *Respiratory Medicine*, 105, 1872-1884.
- Aiken, L.S., Butner, J., Lockhart, C.A., Volk-Craft, B.E., Hamilton, G. and Williams, F.G. (2006) Outcome evaluation of a randomized trial of the PhoenixCare intervention: program of case management and coordinated care for the seriously chronically ill. *Journal of Palliative Medicine*, 9(1), 111-126.
- Anderson, A. (2005) *The Community Builder's Approach to Theory of Change. A Practical Guide to Theory Development*. New York: The Aspen Institute.
- Ando, H., Cousins, R. and Young, C. (2014) Achieving Saturation in Thematic Analysis: Development and Refinement of a Codebook. *Comprehensive Psychology*. Available at <https://doi.org/10.2466%2F03.CP.3.4> [Accessed 5 July 2019].
- Apgar, M.J., Allen, W., Albert, J., Douthwaite, B., Paz Ybarnegaray, R. and Lunda, J. (2017) Getting beneath the surface in program planning, monitoring and evaluation: Learning from use of participatory action research and theory of change in the CGIAR Research Program on Aquatic Agricultural Systems. *Action Research*, 15(1), 15-34.

Argyris, C. (2006) *Reasons and Rationalizations: The Limits of Organizational Knowledge*. Oxford: Oxford University Press.

Baillergeau, E. and Duyvendak, J.W. (2016) Experiential knowledge as a resource for coping with uncertainty: evidence and examples from the Netherlands. *Health, Risk and Society*, 18(7-8), 407-426.

Barnett, M. (2005) Chronic obstructive pulmonary disease: a phenomenological study of patients' experiences. *Journal of Clinical Nursing*, 14, 805-812.

Barrecheguren, M. and Miravittles, M. (2014) Assessment of symptoms in COPD: the importance of morning symptoms. *Hot Topics in Respiratory Medicine*, 9(27), 7-10.

Baum, F., MacDougall, C. and Smith, D. (2006) Participatory action research. *Journal of Epidemiology and Community Health*, 60(10), 854-857.

Beernaert, K., Cohen, J., Deliens, L., Devroey, D., Vanthomme, K., Pardon, K., et al. (2013) Referral to palliative care in COPD and other chronic diseases: A population-based study. *Respiratory Medicine*, 107(11), 1731-1739. Available at <https://doi.org/10.1016/j.rmed.2013.06.003> [Accessed 2 November 2016].

Bekelman, D.B., Nowels, C.T., Retrum, J.H., Allen, L.A., Shakar, S., Hutt, E., et al. (2011) Giving Voice to Patients' and Family Caregivers' Needs in Chronic Heart Failure: Implications for Palliative Care Programs. *Journal of Palliative Medicine*, 14(12), 1317-1324.

Berger, B.E., Kapella, M.C. and Larson, J.L. (2011) The Experience of Stigma in Chronic Obstructive Pulmonary Disease. *Western Journal of Nursing Research*, 33, 916-932.

- Bergold, J. and Thomas, S. (2012) Participatory Research Methods: A Methodological Approach in Motion. *Forum: Qualitative Social Research*, 13(1). Available at <http://www.qualitative-research.net/index.php/fqs/article/view/1801/3334> [Accessed 15 April 2019].
- Bettoncelli, G., Blasi, F., Brusasco, V., Centanni, S., Corrado, A., De Benedetto, F., et al. (2014) The clinical and integrated management of COPD. An official document of AIMAR (Interdisciplinary Association for Research in Lung Disease), AIPO (Italian Association of Hospital Pulmonologists), SIMER (Italian Society of Respiratory Medicine), SIMG (Italian Society of General Medicine). *Multidisciplinary Respiratory Medicine*, 9:25. Available at <https://doi.org/10.1186/2049-6958-9-25> [Accessed 2 November 2016].
- Beyea, S.C. and Nicoll, L.H. (1998) Writing an integrative review. *Association of periOperative Registered Nurses*, 67, 877-880.
- Blamey, A. and Mackenzie, M. (2007) Theories of Change and Realistic Evaluation: Peas in a Pod or Apples and Oranges? *Evaluation*, 13(4), 439-455.
- Bokhour, B. (2006) Communication in interdisciplinary team meetings: What are we talking about? *Journal of Interprofessional Care*, 20(4), 349-363.
- Boland, J.O.J., Ainscough, R. and Mahdi, H. (2014) Developing a service for patients with very severe chronic obstructive pulmonary disease (COPD) within resources. *BMJ Supportive and Palliative Care*, 4, 196-201.

Bove, D.G., Lavesen, M., Jellington, M.O., Bastrup-Madsen Marsaa, K. and Forsyth Herling, S. (2018) First year experiences with a palliative outpatients structure for patients with COPD: a qualitative study of health professionals' expectations and experiences. *BMC Palliative Care*, 17:113. Available at <https://doi.org/10.1186/s12904-018-0369-2> [Accessed 15 April 2019].

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Braun, V. and Clarke, V. (2013) *Successful qualitative research: a practical guide for beginners*. London: Sage Publications.

Braunwald, E., Fauci, A., Kasper, D.L., Hauser, S.L., Longo, D.L., & Jameson, J.L. (2001) *Harrison's Principle of Internal Medicine*, 15<sup>th</sup> ed. New York: McGraw-Hill Medical Publishing Division.

Breuer, E., Lee, L., De Silva, M. and Lund, C. (2016) Using theory of change to design and evaluate public health interventions: a systematic review. *Implementation Science*, 11:63. Available at <https://doi.org/10.1186/s13012-016-0422-6> [Accessed 20 April 2019].

Bruera, E., Kuehn, N., Miller, M.J., Selmsler, P. and Macmillan, K. (1991) The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *Journal of Palliative Care*, 7(2), 6-9.

Bruera, E. and Hui, D. (2012) Conceptual Models for Integrating Palliative Care at Cancer Centers. *Journal of Palliative Medicine*, 15(11), 1261-1269.

Buckingham, S., Kendall, M., Ferguson, S., MacNee, W., Sheik, A., White P., et al. (2015) HELPing older people with very severe chronic obstructive pulmonary disease (HELP-COPD): mixed-method feasibility pilot randomised controlled trial of a novel intervention. *NPJ Primary Care Respiratory Medicine*, 25: 15020. Available at <https://doi.org/10.1038/npjpcrm.2015.20> [Accessed 2 November 2016].

Burgess, T., Young, M., Crawford, G.B., Brooksbank, M.A. and Brown, M. (2013) Best-practice care for people with advanced chronic obstructive pulmonary disease: The potential role of a chronic obstructive pulmonary disease care co-ordinator. *Australian Health Review*, 37(4), 474-481.

Burton, C.R. and Payne, S. (2012) Integrating palliative care within acute stroke services: developing a programme theory of patient and family needs, preferences and staff perspectives. *BMC Palliative Care*, 11:22. Available at <http://www.biomedcentral.com/1472-684X/11/22> [Accessed 17 November 2017].

Buxton, K. L., Stone, R.A., Buckingham, R.J., Pursey, N.A. and Roberts, C.M. (2010) Current and planned palliative care service provision for chronic obstructive pulmonary disease patients in 239 UK hospital units: comparison with the gold standards framework. *Palliative Medicine*, 24(5), 480-485.

Carr, W. and Kemmis, S. (1986) *Becoming Critical: Education, Knowledge and Action Research*. London: The Falmer Press.

Carter, R., Tjep, B.L. and Tjep, R.E. (2008) The Emerging Chronic Obstructive Pulmonary Disease Epidemic. Clinical impact, Economic Burden, and Opportunities for Disease Management. *Disease Management and Health Outcomes*, 16(5), 275-284.

Casarett, D. (2010) Ethical Issues in Palliative Care Research. In Hanks, G., Cherry, N.I., Christakis, N.A., Fallon, M., Kaasa, S. and Portenoy, R.K. (eds.). *Oxford Textbook of Palliative Medicine*. 4<sup>th</sup> ed. Oxford: Oxford University Press (pp. 416-421).

Cassel, J., Kerr, K.M., McClish, D.K., Skoro, N., Johnson, S., Wanke, C., et al. (2016) Effect of a Home Based Palliative Care Program on Healthcare Use and Costs. *Journal of the American Geriatrics Society*, 64(11), 2288-2295.

Cawley, D., Billings, J., Oliver, D., Kendall, M., and Pinnock, H. (2014) Potential triggers for the holistic assessment of people with severe chronic obstructive pulmonary disease: analysis of multiperspective, serial qualitative interviews. *BMJ Supportive and Palliative Care*, 4(2), 152-160.

Centre de Soins Palliatifs et de Soins de Support (2019) *Mission du Centre de Soins Palliatifs et de Soins de Support*. Available at <https://www.hug-ge.ch/centre-soins-palliatifs> [Accessed 29 May 2019].

Chandler, D. and Torbert, B. (2003) Transforming Inquiry and Action. *Action Research*, 1, 133-152.

Chang, V.T., Hwang, S.S., Kasimis, B. and Thaler, H.T. (2004) Shorter Symptom Assessment Instruments: The Condensed Memorial Symptom Assessment Scale (CMSAS). *Cancer Investigation*, 22(4), 526-536.

Coghlan, D. and Brannick, T. (2010) *Doing Action Research in Your Own Organization*. 3<sup>rd</sup> ed. London: Sage Publications.

Committee on Diagnostic Standards for Nontuberculous Respiratory Diseases, American Thoracic Society (ATS) (1962) Definitions and classification of chronic bronchitis, asthma, and pulmonary emphysema. *American Review of Respiratory Disease*, 85, 762-769.

Connolly, M. and Charnley, K. (2015) Position Statement on Palliative Care Education on the Island of Ireland. *All Ireland Institute of Hospice and Palliative Care*. Available at <https://aiihpc.org/wp-content/uploads/2015/11/Palliative-Care-Education-Position-Statement-.pdf> [Accessed 10 June 2019].

Cooper, H.M. (1982) Scientific Guidelines for Conducting Integrative Research Reviews. *Review of Educational Research*, 52(2), 291-302.

Cooper, H.M. (1984) *The integrative research review: A systematic approach*. Beverly Hills, CA: Sage Publications.

Cooper, H.M. (1988) Organizing knowledge synthesis: A taxonomy of literature reviews. *Knowledge in Society*, 1, 104-126.

Cooper, H.M. (1998) *Synthesizing Research: A Guide for Literature Reviews*. 3<sup>rd</sup> ed. London: Sage Publications.

Crawford, G.B., Brooksbank, M.A., Brown, M., Burgess T.A. and Young, M. (2012) Unmet needs of people with end-stage chronic obstructive pulmonary disease: recommendations for change in Australia. *Internal Medicine Journal*, 43(2), 183-190.

Crawford, G.B., Burgess, T.A., Young, M., Brooksbank, M.A. and Brown, M. (2013) A patient-centred model of care incorporating a palliative approach: A framework to meet the needs of people with advanced COPD? *Progress in Palliative Care*, 21(5), 286-294.

Cunningham, J.B. (1993) *Action Research and Organizational Development*. Westport, CT: Praeger Publishers.

Curtis, J.R. (2008) Palliative and end-of-life care for patients with severe COPD. *European Respiratory Journal*, 32(3), 796-803.

Dalgaard, K.M., Bergenholtz, H., Espenhain Nielsen, M. and Timm, H. (2014) Early integration of palliative care in hospitals: A systematic review on methods, barriers, and outcome. *Palliative and Supportive Care*, 12, 495-513.

Davis, M.P., Strasser, F. and Cherny, N. (2015) How well is palliative care integrated into cancer care? A MASCC, ESMO, and EAPC Project. *Supportive Care Cancer*. Available at <https://doi.org/10.1007/s00520-015-2630-z> [Accessed 2 November 2016].

den Herder-van der Eerden, M., Ebenau, A., Payne, S., Preston, N., Radbruch, L., Linge-Dahl, L., et al. (2018) Integrated palliative care networks from the perspectives of patients: A cross-sectional explorative study in five European countries. *Palliative Medicine*, 32(6), 1103-1113.

Department of Health (2008) *End of Life Care Strategy*. Available at <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life> [Accessed 17 November 2017].

Department of Health (2010) *Supporting Australians to Live Well at the End of Life*.

Available at

<https://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2>

[FCA257BF000206168/\\$File/NationalPalliativeCareStrategy.pdf](https://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2_FCA257BF000206168/$File/NationalPalliativeCareStrategy.pdf) [Accessed 17

November 2017].

De Pietro, C., Camenzind, P., Sturny, I., Crivelli, L., Edwards-Garavoglia, S., Spranger, A., et al. (2015) Switzerland: Health System Review. *Health systems in transition*, 17(4), 1-288, xix.

De Silva, M.J., Breuer, E., Lee, L., Asher, L., Chowdhary, N., Lund, C. et al. (2014) Theory of Change: a theory-driven approach to enhance the Medical Research Council's framework for complex interventions. *Trials*, 15:267. Available at <https://doi.org/10.1186/1745-6215-15-267> [Accessed 20 April 2019].

Dickens, L. and Watkins, K. (1999) Action Research: Rethinking Lewin. *Management Learning*, 30:127. Available at <https://doi.org/10.1177/1350507699302002> [Accessed 15 April 2019].

Dipartimento Sanità e Socialità (2015) *Strategia cantonale di cure palliative*. Available at

[https://www4.ti.ch/fileadmin/DSS/DSP/UMC/malattie\\_infettive/Strategia\\_cantonale](https://www4.ti.ch/fileadmin/DSS/DSP/UMC/malattie_infettive/Strategia_cantonale)

[di\\_cure\\_palliative\\_versione\\_settembre\\_1\\_2015.pdf](https://www4.ti.ch/fileadmin/DSS/DSP/UMC/malattie_infettive/Strategia_cantonale_di_cure_palliative_versione_settembre_1_2015.pdf) [Accessed 17 November 2017].

Disler, R.T., Currow D.C., Phillips, J.L., Smith, T., Johnson, M.J. and Davidson, P.M. (2012) Interventions to support a palliative care approach in patients with chronic obstructive pulmonary disease: An integrative review. *International Journal of Nursing Studies*, 49, 1443-1458.

Disler, R.T., Green, A., Lockett, T., Newton, P.J., Inglis, S., Currow, D.C. et al. (2014) Experience of advanced chronic obstructive pulmonary disease: metasynthesis of qualitative research. *Journal of Pain and Symptom Management*, 48, 1182-1199.

Downar, J. (2018) Resources for Educating, Training, and Mentoring All Physicians Providing Palliative Care. *Journal of Palliative Medicine*, 21(S1). Available at <https://doi.org/10.1089/jpm.2017.0396> [Accessed 21 April 2019].

Duenk, R.G., Heijdra, Y., Verhangen, S.C., Dekhuijzen, R.P., Vissers, K.C. and Engels, Y. (2014) PROLONG: a cluster controlled trial to examine identification of patients with COPD with poor prognosis and implementation of proactive palliative care. *BMC Pulmonary Medicine*, 14:54. Available at <https://doi.org/10.1186/1471-2466-14-54> [Accessed 2 November 2016].

Duenk, R.G., Verhagen, C., Dekhuijzen, P.N.R., Vissers, K.C.P., Engels, Y. and Heijdra, Y. (2017) The view of pulmonologists on palliative care for patients with COPD: A survey study. *International Journal of COPD*, 12, 299-311.

Dundar, Y. and Fleeman, N. (2014) Developing My Search Strategy and Applying Inclusion Criteria. In Boland, A., Cherry, M.G. and Dickson, R. (eds.), *Doing a systematic Review*. London: SAGE Publications (pp. 35-59).

Economic and Social Research Council (ESRC) (2015) *ESRC Framework for research ethics*. Available at [http://www.esrc.ac.uk/\\_images/framework-for-research-ethics\\_tcm8-33470.pdf](http://www.esrc.ac.uk/_images/framework-for-research-ethics_tcm8-33470.pdf) [Accessed 10 December 2015].

Ek, K., Sahlberg-Blom, E., Andershed, B. and Ternestedt, B.M. (2011) Struggling to retain living space: patients' stories about living with advanced chronic obstructive pulmonary disease. *Journal of Advanced Nursing*, 67, 1480-1490.

Elkington, H., White, P., Addington-Hall, J., Higgs, R. and Pettinari, C. (2004). The last year of life of COPD: a qualitative study of symptoms and services. *Respiratory Medicine*, 98(5), 439-445.

Emanuel, L., Alexander, C., Arnold, R.M., Bernstein, R., Dart, R., Dellasantina, C., et al. (2004) Integrating palliative care into disease management guidelines. *Journal of Palliative Medicine*, 7(6), 774-783.

Ente Ospedaliero Cantonale (2018) *Rapporto annuale 2017*. Available at <https://www.eoc.ch/dms/site-eoc/documenti/documenti/Comunicazione/RA17/Rapporto-annuale-2017/Rapporto%20annuale%202017.pdf> [Accessed 3 April 2019].

Ente Ospedaliero Cantonale (2019) *Ospedali e Istituti*. Available at <https://www.eoc.ch/Ospedali-e-Istituti.html> [Accessed 3 April 2019].

Epiphaniou, E., Shipman, C., Harding, R., Mason, B., Murray, S.A.A., Higginson, I.J., et al. (2014) Coordination of end-of-life care for patients with lung cancer and those with advanced COPD: are there transferable lessons? A longitudinal qualitative study. *Primary Care Respiratory Journal*, 23(1), 46-51.

Ewert, B., Hodiament, F., van Wijngaarden, J., Payne, S., Groot, M., Hasselaar, J. et al. (2016) Building a taxonomy of integrated palliative care initiatives: results from a focus group. *BMJ Supportive and Palliative Care*, 6, 14-20.

Federal Council (2018) *Federal Law*. Available at <https://www.admin.ch/gov/en/start/federal-law/classified-compilation.html> [Accessed 2 March 2019].

Federal Council (2019) *Federal Act on Data Protection*. Available at <https://www.admin.ch/opc/en/classified-compilation/19920153/index.html> [Accessed 20 April 2019].

Federal Department of Foreign Affairs (2014) *Discover Switzerland*. Available at <https://www.eda.admin.ch/aboutswitzerland/en/home.html> [Accessed 2 March 2019].

Federal Office for Public Health (2013) *Palliative Care Strategy*. Available at <http://www.bag.admin.ch/themen/gesundheitspolitik/13764/index.html?lang=en> [Accessed 17 November 2017].

Federal Office for Public Health (2018) *Health Insurance: The Essentials in Brief*. Available at <https://www.bag.admin.ch/bag/en/home/versicherungen/krankenversicherung/krankenversicherung-das-wichtigste-in-kuerze.html> [Accessed 17 October 2018].

Federal Statistical Office (2018) *Look for statistics: Population*. Available at <https://www.bfs.admin.ch/bfs/en/home/statistics/population.html> [Accessed 2 March 2019].

Fondation Pallium (2019) *Projets de recherche*. Available at <http://pallium.ch> [Accessed 4 June 2019].

Froggatt, K. (2013) Demonstrating quality and rigour in action research: peer education for end-of-life care. In Hockley, J., Froggatt, K. and Heimerl, K. *Participatory Research in Palliative Care: Actions and Reflections*. Oxford: Oxford University Press (pp. 149-159).

Fusi-Schmidhauser, T., Riglietti, A., Froggatt, K. and Preston, N. (2018) Palliative care provision for patients with advanced chronic obstructive pulmonary disease: A systematic integrative literature review. *COPD*, 5(6), 600-611.

Gainza-Miranda, D., Sanz-Peces, E.M., Alonso-Babarro, A., Varela-Cerdeira, M., Prados-Sanchez, C., Vega-Aleman, G., et al. (2019) Breaking Barriers: Prospective Study of a Cohort of Advanced Chronic Obstructive Pulmonary Disease Patients To Describe Their Survival and End-of-Life Palliative Care Requirements. *Journal of Palliative Medicine*, 22(3), 290-296.

Ganong, L.H. (1987) Integrative reviews of nursing research. *Research in Nursing and Health*, 10, 1-11.

Gardiner, C., Gott, M., Payne, S., Small, N., Barnes, S., Halpin, D., et al. (2010). Exploring the care needs of patients with advanced COPD: An overview of the literature. *Respiratory Medicine*, 104(2), 159-165.

Garralda, E., Hasselaar, J., Carrasco, J.M., Van Beek, K., Siouta, N., Csikos, A., et al. (2016) Integrated palliative care in the Spanish context: a systematic review of the literature. *BMC Palliative care*, 15,1:1. Available at <https://doi.org/10.1186/s12904-016-0120-9> [Accessed 6 July 2019].

Gershon, A.S., Warner, L., Cascagnette, P., Victor, J.C. and To, T. (2011) Lifetime risk of developing chronic obstructive pulmonary disease: a longitudinal population study. *The Lancet*, 378, 991-996.

Gesundheits- und Fürsorgedirektion des Kantons Bern (2013) *Konzept für die Palliative Versorgung im Kanton Bern*. Available at [https://www.gef.be.ch/gef/de/index/gesundheit/gesundheit/palliativecare.assetref/dam/documents/GEF/SPA/de/Palliativecare/Konzept\\_palliativeVersorgung\\_d\\_20140108.pdf](https://www.gef.be.ch/gef/de/index/gesundheit/gesundheit/palliativecare.assetref/dam/documents/GEF/SPA/de/Palliativecare/Konzept_palliativeVersorgung_d_20140108.pdf) [Accessed 10 February 2017].

Global Initiative For Chronic Obstructive Lung Disease (GOLD) (2017) *Global Strategy for the Diagnosis, Management and Prevention of COPD*. Available at <http://goldcopd.org/gold-2017-global-strategy-diagnosis-management-prevention-copd> [Accessed 10 February 2017].

Gold Standards Framework (2016) *The GSF Prognostic Indicator Guidance*. Available at <http://www.goldstandardsframework.org.uk/cd-content/uploads/files/PIG/NEW%20PIG%20-%20%20%2020.1.17%20KT%20vs17.pdf> [Accessed 10 February 2017].

Gomes B., Calanzani, N., Curiale, V., McCrone, P. and Higginson, I.J. (2013) Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Systematic Reviews*, 6(6): CD007760. Available at <https://doi.org/10.1002/14651858.CD007760.pub2> [Accessed 2 June 2016].

Gómez-Batiste, X., Martínez-Munõz, M., Blay, C., Amblàs, J., Vila, L., Costa, X., et al. (2017) Utility of the NECPAL CCOMS-ICO© tool and the Surprise Question as screening tools for early palliative care and to predict mortality in patients with advanced chronic conditions: A cohort study. *Palliative Medicine*, 31, 754-763.

Goodridge, D.M., Marciniuk, D.D., Brooks, D., van Dam, A., Hutchinson, S., Bailey, P., et al. (2009) End-of-life care for persons with advanced chronic obstructive pulmonary disease: report of a national interdisciplinary consensus meeting. *Canadian Respiratory Journal*, 16(5), e51–e53. Available at <https://doi.org/10.1155/2009/987616> [Accessed 2 June 2016].

Gott, M., Gardiner, C., Small, N., Payne, S., Seamark, D., Barnes, S., et al. (2009) Barriers to advance care planning in chronic obstructive pulmonary disease. *Palliative Medicine*, 23, 642-648.

Grant, J., Nelson, G. and Mitchell, T. (2008) Negotiating Challenges of Participatory Action Research: Relationships, Power, Participation, Change and Credibility. In Reason, P. and Bradbury, H. (2008) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. 2<sup>nd</sup> ed. London: SAGE Publications (pp. 589-601).

Greenwood, J. (1994) Action Research: A Few Details, A Caution and Something New. *Journal of Advanced Nursing*, 20, 13-18.

Greer, J.A., Jackson, V.A., Meier, D.E and Temel, J.S. (2013) Early integration of palliative care services with standard oncology care for patients with advanced cancer. *CA: A Cancer Journal for Clinicians*, 63, (5), 349-363.

Gröne, O. and Garcia-Barbero, M. (2001) Integrated care. A position paper of the WHO European office for integrated health care services. *International Journal of Integrated Care*. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1525335/pdf/ijic2001-200121.pdf> [Accessed 17 November 2017].

Guba, E.G. and Lincoln, Y.S. (1994) Competing Paradigms in Qualitative Research. In Denzin, N.K. and Lincoln, Y.S. (eds.) *The Handbook of Qualitative Research*. London: SAGE Publications (pp. 105-117).

Gwyther, L., Brennan, F. and Harding, R. (2009) Advancing Palliative Care as a Human Right. *Journal of Pain and Symptom Management*, 38(5), 767-774.

Habermas, J. (1981) *Theorie des kommunikativen Handelns*. Frankfurt am Main: Suhrkamp Verlag.

Halbert, R.J., Natoli, J.L., Gano A., Badamgarav, E., Buist, A.S. and Mannino, D.M. (2006) Global burden of COPD: systematic review and meta-analysis. *European Respiratory Journal*, 28, 523-532.

Halding, A.G., Heggdal, K. and Wahl, A. (2011) Experiences of self-blame and stigmatisation for self-infliction among individuals living with COPD. *Scandinavian Journal of Caring Sciences*, 25, 100-107.

Hardin, K.A., Meyers, F. and Louie, S. (2008) Integrating Palliative Care in Severe Chronic Obstructive Lung Disease. *COPD*, 5, 207-220.

Hasselaar J., and Payne, S. (Eds.) (2016) *Integrated palliative care*. Nijmegen, the Netherlands: Radboud University Medical Center.

Haute Autorité de Santé (2014) *Guide du parcours de soins: bronchopneumopathie chronique obstructive*. Available at <https://www.has-sante.fr/portail> [Accessed 24 June 2016].

Hawker, S., Payne, S., Kerr, C., Hardey M. and Powell J. (2002) Appraising the Evidence: Reviewing Disparate Data Systematically. *Qualitative Health Research*, 12(9), 1284-1299.

Hayle, C., Coventry, P.A., Gomm, S. and Caress, A. (2013). Understanding the experience of patients with chronic obstructive pulmonary disease who access specialist palliative care: A qualitative study. *Palliative Medicine*, 27(9), 861-868.

Heron, J. (1992) *Feeling and personhood: Psychology in another key*. Newbury Park, CA: SAGE Publications

Heron, J. (1996) *Co-operative Inquiry: Research into the Human Condition*. Thousand Oaks, CA: SAGE Publications.

Higginson, I.J., Bausewein, C., Reilly, C.C., Gao, W., Gysels, M., Dzingina, M., et al. (2014) An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *The Lancet Respiratory Medicine*, 2(12), 979-987.

Hill, K., Vogiatzis, I. and Burtin, C. (2013) The importance of components of pulmonary rehabilitation, other than exercise training, in COPD. *European Respiratory Review*, 22, 405-413.

Hockley, J. (2013) Critical theory and action research. In Hockley, J., Froggatt, K. and Heimerl, K. *Participatory Research in Palliative Care: Actions and Reflections*. Oxford: Oxford University Press.

Horkheimer, M. and Adorno, T.W. (2013) *Dialektik der Aufklärung*. 21<sup>st</sup> ed. Berlin: Fischer Verlag.

Horton, R., Rucker, G., Dale, A., Young, J., Hernandez, P. and Sinuff, T. (2013). Implementing a Palliative Care Trial in Advanced COPD: A Feasibility Assessment (The COPD IMPACT Study). *Journal of Palliative Medicine*, 16(1), 67-73.

Hughes, I. (2008) Action Research in Healthcare. In Reason, P. and Bradbury, H. (2008) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. 2<sup>nd</sup> ed. London: SAGE Publications (pp. 381-393).

Hurst, S.A., Zellweger, U., Bosshard, G., Bopp, M., for the Swiss Medical End-of-Life Decisions Study Group (2018) Medical end-of-life practices in Swiss cultural regions: a death certificate study. *BMC Medicine* 16:54. Available at <https://doi.org/10.1186/s12916-018-1043-5> [Accessed 17 April 2019].

Hynes, G., Coghlan, D. and McCarron, M. (2012) Participation as a multi-voiced process: Action research in the acute hospital environment. *Action Research*, 10(3), 293-312.

Hynes, G., Stokes, A. and McCarron, M. (2012) Informal care-giving in advanced chronic obstructive pulmonary disease: lay knowledge and experience. *Journal of Clinical Nursing*, 21, 1068-1077.

Hynes, G. (2013) First, second, and third person inquiry. In Hockley, J., Froggatt, K. and Heimerl, K. *Participatory Research in Palliative Care: Actions and Reflections*. Oxford: Oxford University Press.

Hynes, G., Kavanagh, F., Hogan, C., Ryan, K., Rogers, L., Brosnan, J., et al. (2015). Understanding the challenges of palliative care in everyday clinical practice: an example from a COPD action research project. *Nursing Inquiry*, 22(3), 249-260.

InSuP-C Integrated Palliative Care An EU Framework 7 Programme (2016) Available at <http://www.insup-c.eu> [Accessed 3 January 2018].

Iyer, A.S., Dionne-Odom, N.J., Ford, S.M., Crump Tims, S.L., Sockwell, E.D., Ivankova, N.V. et al. (2019) A Formative Evaluation of Patient and Family Caregiver Perspectives on Early Palliative Care in COPD across Disease Severity. *Annals ATS*. Available at <https://doi.org/10.1513/AnnalsATS.201902-112OC> [Accessed 22 May 2019].

Janssens, J.-P., Weber, C., Herrmann, F.R., Cantero, C., Pessina, A., Matis, C., et al. (2019) Can Early Introduction of Palliative Care Limit Intensive Care, Emergency and Hospital Admissions in Patients with Severe Chronic Obstructive Pulmonary Disease? A Pilot Randomized Study. *Respiration*, 97, 406-415.

Jessup, R.L. (2007) Interdisciplinary versus multidisciplinary care teams: do we understand the difference? *Australian Health Review*, 31(3), 330-331.

Johnson, C., Paul, C., Girgis, A., Adams, J. and Currow, D.C. (2011) Australian General Practitioners' and Oncology Specialists' Perceptions of Barriers and Facilitators of Access to Specialist Palliative Care Services. *Journal of Palliative Medicine*, 14(4), 429-435.

Johnson, M.J. (2007) Management of end stage cardiac failure. *Postgraduate Medicine Journal*, 83, 395-401.

Katajavuori, N., Lindblom-Ylänne, S. and Hirvonen, J. (2006) The significance of practical training in linking theoretical studies with practice. *Higher Education*, 51, 439-464.

Kauhl, B., Maier, W., Schweikart, J., Keste, A. and Moskwyn, M. (2018) Who is where at risk for Chronic Obstructive Pulmonary Disease? A spatial epidemiological analysis of health insurance claims for COPD in Northeastern Germany. PLoS One. Available at <https://doi.org/10.1371/journal.pone.0190865> [Accessed 27 August 2019].

Kemmis, S. (1985) Action Research and the Politics of Reflection. In Boud, D., Keogh, R., and Walker, D. (Eds). *Reflection: Turning Experience into Learning*. London: Kogan Page.

Kemmis, S. (2001) Exploring the Relevance of Critical Theory for Action Research: Emancipatory Action Research in The Footsteps Of Jürgen Habermas. In Reason, P. and Bradbury, H. (2001) *Handbook of Action Research: Participative Inquiry and Practice*. 1<sup>st</sup> ed. London: SAGE Publications (pp. 91-103).

Kemmis, S. and McTaggart, R. (1988) *The Action Research Planner*. Deakin: Deakin University Press.

Kemmis, S. and McTaggart, R. (2005) Participatory Action Research: Communicative Action and the Public Sphere. In Denzin, N. and Lincoln, Y. *The Sage Handbook of Qualitative Research*. 3<sup>rd</sup> ed. London: SAGE Publications.

Kincheloe, J.L. and McLaren, P.L. (1994) Rethinking Critical Theory and Qualitative Research. In Denzin, N.K. and Lincoln, Y.S. *Handbook of Qualitative Research*. London: SAGE Publications (pp. 138-157).

Kirkpatrick D.P., Dransfield, M.T., Wells, J.M., Tucker, R., Leach, L., Henry, M. (2014) Improving The Care Of Patients With COPD Using An Integrated Practice Unit. *American Journal of Respiratory and Critical Care Medicine*, 189, A3028.

Kodner, D.L. and Spreeuwenberg, C. (2002) Integrated care: meaning, logic, applications, and implications - a discussion paper. *International Journal of Integrated Care*, 2. Available at <http://www.ijic.org> [Accessed 17 November 2017].

Koshy, V. (2005) *Action Research for Improving Practice: a Practical Guide*. London: SAGE Publications.

Koshy, E., Koshy, V. and Waterman, H. (2011) *Action Research in Healthcare*. London: SAGE Publications.

Kruis, A.L., Smidt, N., Assendelft, W.J.J., Gussekloo, J., Boland, M.R.S., Rutten-van Mülken, M., et al. (2013) Integrated disease management interventions for patients with chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, 10. Available at <https://doi.org/10.1002/14651858.CD009437.pub2> [Accessed 10 December 2017].

Kruis, A.L., Soljak, M., Chavannes, N.H. and Elking, S.L. (2016) COPD Multidisciplinary Team Meetings in the United Kingdom: Health Care Professionals' Perceptions of Aim and Structure. *COPD*, 13, 639-641.

Lakoff, G. and Johnson, M. (1980) *Metaphors we live by*. Chicago: The University of Chicago Press.

Lancaster University Library (2019) Referencing Guides. Available at <https://www.lancaster.ac.uk/library/how-to/reference/referencing-guides/> [Accessed 27 July 2019].

Landers, A., Wiseman, R., Pitama, S. and Beckert, L. (2015) Patient perceptions of severe COPD and transitions towards death: a qualitative study identifying milestones and developing key opportunities. *NPJ Primary Care Respiratory Medicine* 25, 15043. Available at <https://doi.org/10.1038/npjpcrm.2015.43> [Accessed 10 December 2017].

Lanken, P.N., Terry, P.B., DeLisser, H.M., Fahy, B.F., Hansen-Flaschen, J., Heffner, J.E., et al. (2008) An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. *American Journal of Respiratory and Critical Care Medicine*, 177(8), 912-927.

Leonardo, Z. (2004) Critical Social Theory and Transformative Knowledge: The Functions of Criticism in Quality Education. *Educational Researcher*, 33(6), 11-18.

Lincoln, Y.S and Guba, E.G. (1985) *Naturalistic Inquiry*. Newbury Park, CA: SAGE Publications.

Lindqvist, G. and Hallberg, L.R.M. (2010) “Feelings of Guilt due to Self-inflicted Disease”: A Grounded Theory of Suffering from Chronic Obstructive Pulmonary Disease (COPD). *Journal of Health Psychology*, 15, 456-466.

Lingard, L.A., McDougall, A., Schulz, V., Shadd, J., Marshall, D., Strachan, P.H., et al. (2013) Understanding Palliative Care on the Heart Failure Care Team: An Innovative Research Methodology. *Journal of Pain and Symptom Management*, 45, (5), 901-911.

Loewenson, R., Laurell, A.C., Hogstedt, C., D’Ambruoso, L. and Shroff Z. (2014) *Participatory Action Research in Health Systems. A Methods Reader*. Available at <http://www.equinetafrica.org/bibl/docs/PAR%20Methods%20Reader2014%20for%20web.pdf> [Accessed 20 December 2017].

Løkke, A., Lange, P., Scharling, H., Fabricius, P. and Vestbo, J. (2006) Developing COPD: a 25 year follow up study of the general population. *Thorax*, 61, 935-939.

Lovell, R.J. (1993) Power and the project manager. *International Journal of Project Management*, 11(2), 73-78.

Luckett, T., Phillips, J., Agar, M., Virdun, C., Green, A. and Davidson, P.M. (2014) Elements of effective palliative care models: a rapid review. *BMC Health Services Research* 14:136. Available at <http://www.biomedcentral.com/1472-6963/14/136> [Accessed 17 November 2017].

MacDonald, C. (2012) Understanding Participatory Action Research: A Qualitative Research Methodology Option. *Canadian Journal of Action Research*, 13(2), 34-50.

MacPherson, A., Walshe, C., O'Donnell, V. and Vyas, A. (2012) The views of patients with severe obstructive pulmonary disease on advance care planning: A qualitative study. *Palliative Medicine*, 27, 265-272.

Marshall, J. (2016) *First Person Action Research: Living Life as Inquiry*. Croydon UK: SAGE Publications.

Mast, K.R., Salama, M., Silverman, G.K. and Arnold, R.M. (2004) End-of-life content in treatment guidelines for life-limiting diseases. *Journal of Palliative Medicine*, 7(6), 754-773.

McIlfatrick, S. (2007) Assessing palliative care needs: views of patients, informal carers and healthcare professionals. *Journal of Advanced Nursing*, 57, (1), 77-86.

McTaggart, R. (1991) Principles for participatory action research. *Adult Education Quarterly*, 41(3), 168-187.

McTaggart, R. (1994) Participatory Action Research: issues in theory and practice. *Educational Action Research*, 2(3), 313-337.

Methley, A.M., Campbell, S., Chew-Graham, C., McNally, R and Cheraghi-Sohi, S. (2014) PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews. *BMC Health Services Research*, 14:579. Available at <https://doi.org/10.1186/s12913-014-0579-0> [Accessed 17 November 2017].

Ministry of Health (2001) The New Zealand Palliative Care Strategy. Available at <http://www.health.govt.nz/publication/new-zealand-palliative-care-strategy> [Accessed 17 November 2017].

Miravittles, M., Soler-Cataluña, J.J., Calle, M., Molina, J., Almagro, P., Quintano, J.A., et al. (2012) Guía Española de la EPOC (GesEPOC). Tratamiento farmacológico de la EPOC estable. *Archivos de Bronconeumología*, 48(7), 247-257.

Montes de Oca, M., López Varela, M.V., Acuña, A., Schiavi, E., Rey, M.A., Jardim, J., et al. (2015) Guía Latinoamericana de EPOC - 2014, Basada en Evidencia (LatinEPOC - 2014). *Respirar*, 7(3), 1-43.

Moore, T., McKee, K. and McLoughlin, P. (2015) Online focus groups and qualitative research in the social sciences: their merits and limitations in a study of housing and youth. *People, Place and Policy*, 9(1), 17-28.

Mousing C.A., Timm, H., Kirkevold, M. and Lomborg, K. (2014) Patients with COPD wish to discuss palliative care with health professionals. *European Respiratory Journal*, 44(Suppl. 58), 1410.

Murray, S.A., Boyd, K., Kendall, M., Worth, A., Benton, T.F. and Clausen, H. (2002) Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *British Medical Journal*, 325, 929-932.

Murray, S.A., Kendall, M., Boyd, K. and Sheikh, A. (2005) Illness trajectories and palliative care. *British Medical Journal*, 330, 1007-1011.

Nakken, N., Janssen, D.J.A., van den Bogaart, E.H.A. Wouters, E.F.M., Franssen, F.M.E., Vercoulen, J.H. (2015) Informal caregivers of patients with COPD: Home Sweet Home? *European Respiratory Review*, 24, 498-504.

National Institute of Clinical Excellence. National Health System (2010) *NICE clinical guideline 101: Management of chronic obstructive pulmonary disease in adults in primary and secondary care*. Available at <http://www.nice.org.uk/nicemedia/live/13029/49397/49397.pdf> [Accessed 10 February 2017].

NHS Quality Improvement Scotland (2010) *Chronic Obstructive Pulmonary Disease Services*. Available at [www.nhshealthquality.org](http://www.nhshealthquality.org) [Accessed 10 February 2017)].

Nijboer, C., Triemstra, M., Tempelaar, R., Mulder, M., Anderman, R. and van den Bos, G.A. (2000) Patterns of caregiver experiences among partners of cancer patients. *Gerontologist*, 40(6), 738-746.

Nottelmann, L., Jensen, L.H., Vejilgaard, T.B. and Groenvold, M. (2019) A new model of early, integrated palliative care: palliative rehabilitation for newly diagnosed patients with non-resectable cancer. *Supportive Care Cancer*, 27(9). Available at <https://doi.org/10.1007/s00520-018-4629-8> [Accessed 8 July 2019].

Nurmatov, U., Buckingham, S., Kendall, M., Murray, S.A., White, P., Sheikh, A., et al. (2012) Effectiveness of Holistic Interventions for People with Severe Chronic Obstructive Pulmonary Disease: Systematic Review of Controlled Clinical Trials. *PLoS ONE*, 7(10), e46433. Available at <https://doi.org/10.1371/journal.pone.0046433> [Accessed 10 February 2017)].

O'Donnell, D.E., Ora, J., Webb, K.A., Laveneziana, P. and Jensen, D. (2009) Mechanisms of activity-related dyspnea in pulmonary diseases. *Respiratory Physiology and Neurobiology*, 167, 116-132.

O'Reilly, K. (2009) *Key concepts in ethnography*. Thousand Oaks, CA: SAGE Publications.

Organisation for Economic Cooperation and Development (2018) Health at a Glance: Europe 2018-State of Health in the EU Cycle. Available at [https://doi.org/10.1787/health\\_glance\\_eur-2018-en](https://doi.org/10.1787/health_glance_eur-2018-en) [Accessed 12 April 2019].

Ostgathe, C., Alt-Epping, B., Golla, H., Gaertner, J., Lindena, G., Radbruch, L., et al. on behalf of the Hospice and Palliative Care Evaluation (HOPE) Working Group (2011) Non-cancer patients in specialized palliative care in Germany: What are the problems? *Palliative Medicine*, 25(2), 148-152.

Palliative CH (2019) Fachgesellschaft für Palliative Care. Available at <https://www.palliative.ch/de/ueber-uns/fachgesellschaft> [Accessed 29 May 2019].

Pandolfi, P., Zanasi, A., Musti, M.A., Stivanello, E., Pisani, L., Angelini, S., et al. (2015) Socio-Economic and Clinical Factors as Predictors of Disease Evolution and Acute Events in COPD Patients. *PLoS One*. Available at <https://doi.org/10.1371/journal.pone.0135116> [Accessed 27 August 2019].

Panos, R.J., Krywkowski-Mohn, S.M., Sherman, S.N. and Lach, L.A. (2013) Patient Reported Determinants of Health: A Qualitative Analysis of Veterans with Chronic Obstructive Pulmonary Disease. *COPD*, 10, 333-347.

Parkin, P. (2009) *Managing change in healthcare using action research*. London: Plaggrave.

Partridge, M.R., Khatri, A., Sutton, L., Welham, S. and Ahmedzai, S.H. (2009) Palliative care services for those with chronic lung disease. *Chronic Respiratory Disease*, 6, 13-17.

Philip, J., Gold., M., Brand, C., Douglass, J., Miller, B. and Sundararajan, V. (2012) Negotiating hope with chronic obstructive pulmonary disease patients: a qualitative study of patients and healthcare professionals. *Internal Medicine Journal*, 42(7), 816-822.

Philip, J., Lowe, A., Gold, M., Brand, C., Miller, B., Douglass, J., et al. (2012a) Palliative care for patients with chronic obstructive pulmonary disease: Exploring the landscape. *Internal Medicine Journal*, 42(9), 1053-1057.

Philip, J., Gold., M., Brand, C., Miller, B., Douglass, J. and Sundararajan, V. (2014) Facilitating change and adaptation: The experiences of current and bereaved carers of patients with severe chronic obstructive pulmonary disease. *Journal of Palliative Medicine*, 17(4), 421-427.

Philip, J., Crawford, G., Brand, C., Gold, M., Miller, B., Hudson, P., et al. (2018) A conceptual model: Redesigning how we provide palliative care for patients with chronic obstructive pulmonary disease. *Palliative and Supportive Care*, 16, 452-460.

Pinnock, H., Kendall, M., Murray, S.A., Worth, A., Levack, P., Porter, M., et al. (2011) Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *British Medical Journal*, 342, d142. Available at <https://doi.org/10.1136/bmj.d142> [Accessed 12 September 2016].

Polit, D.F. and Beck, C.T. (2004) *Nursing Research: Principles and Methods*. 7<sup>th</sup> ed. Philadelphia: JB Lippincott Co.

Princeton, D.M. (2015) The Critical Theoretical Perspectives and the Health Care System. *Review of Arts and Humanities*, 4(1), 72-79.

Puhan, M.A., Akl, E.A., Bryant, D., Xie, F., Apolone, G. and ter Riet, G. (2012) Discussing study limitations in reports of biomedical studies-the need for more transparency. *Health and Quality of Life Outcomes*, 10:23. Available at <https://doi.org/10.1186/1477-7525-10-23> [Accessed 28 May 2019].

Qualité Palliative (2018) *Zertifizierte Institutionen Qualitätspalliative*. Available at <https://www.qualitepalliative.ch/das-label/zertifizierteinstitutionen/?L=0> [Accessed 12 April 2019].

Raghavan, N., Webb, K., Amornputtisathaporn, N. and O'Donnel, D.E. (2011) Recent advances in pharmacotherapy for dyspnea in COPD. *Current Opinion in Pharmacology*, 11, 204-210.

Reason, P. (2002) The Practice of Co-operative Inquiry. *Systemic Practice and Action Research*, 15(3), 169-176.

Reason, P. (2006) Choice and Quality in Action Research Practice. *Journal of Management Inquiry*, 15(2), 187-203.

Reason, P. and Bradbury, H. (2008) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. 2<sup>nd</sup> ed. London: SAGE Publications.

Reason, P. and Torbert, W.R. (2001) The Action Turn: Toward a Transformational Social Science. *Concepts and Transformation*, 6, 1-37.

Reishtein, J.L. (2005) Relationship Between Symptoms and Functional Performance in COPD. *Research in Nursing and Health*, 28, 39-47.

Roberts, G. and Dick, B. (2003) Emancipatory design choices for action research practitioners. *Journal of Community and Applied Social Psychology*, 13, 486-495.

Rocker, G. M. and Verma J.Y. (2014). INSPIRED' COPD Outreach Program: Doing the Right Things Right. *Clinical & Investigative Medicine*, 37(5), E311-E319.

Rolfe, G., Freshwate, D. and Jasper, M. (2001) *Critical Reflection for Nursing and the Helping Professions: A User's Guide*. London: Palgrave Macmillan.

Romieu, I. and Trenga, C. (2001) Diet and obstructive lung diseases. *Epidemiology Review*, 23(2), 268-287.

Rosenthal, R. and Blanck, P.D. (1993) Science and Ethics in Conducting, Analyzing, and Reporting Social Science Research: Implications for Social Scientists, Judges, and Lawyers. *Indiana Law Journal*, 68(4). Available at: <http://www.repository.law.indiana.edu/ilj/vol68/iss4/9> [Accessed 5 July 2019].

Rush, B., Hertz, P., Bond, A., McDermid, R.C. and Celi, L.A. (2017) Use of Palliative Care in Patients With End-Stage COPD and Receiving Home Oxygen: National Trends and Barriers to Care in the United States. *Chest*, 151(1), 41-46.

Russell, C.L. (2005) An overview of the integrative research review. *Progress in transplantation*, 15(1), 8-13. Available at <https://doi.org/10.7182/prtr.15.1.0n13660r26g725kj> [Accessed 4 July 2016].

Sargeant, J., Loney, E. and Murphy, G. (2008) Effective interprofessional teams: “Contact is not enough” to build a team. *Journal of Continuing Education in the Health Professions*, 28(4), 228-234.

Scheerens, C., Deliens, L., Van Belle, S., Joos, G., Pype, P. and Chambaere, K. (2018) “A palliative end-stage COPD patient does not exist”: a qualitative study of barriers to and facilitators for early integration of palliative home care for end-stage COPD. *NPJ Primary Care Respiratory Medicine*, 28:23. Available at <https://doi.org/10.1038/s41533-018-0091-9> [Accessed 15 April 2019].

Schön, D.A. (1983) *The Reflective Practitioner*. New York: Basic Books.

Schroedl, C., Yount, S., Szmuiłowicz, E., Rosenberg, S.R. and Kalhan, R. (2014) Outpatient palliative care for chronic obstructive pulmonary disease: a case series. *Journal of Palliative Medicine*, 17(11), 1256-1261.

Seamark, D.A., Seamark, C.J. and Halpin, D.M.G. (2007) Palliative care in chronic obstructive pulmonary disease: a review for clinicians. *Journal of the Royal Society of Medicine*, 100, 225-233.

Shin, J. and Temel, J. (2013) Integrating palliative care: when and how? *Current Opinion in Pulmonary Medicine*, 19(4), 344-349.

Singer, A., Goebel, J., Kim, Y., Dy, S., Ahluwalia, S., Clifford, M., et al. (2016) Populations and Interventions for Palliative and End-of-Life Care: A Systematic Review. *Journal of Palliative Medicine*, 19(9), 995-1008.

Siouta, N., van Beek K., Preston, N., Hasselaar, J., Hughes, S., Payne, S., et al. (2016) Towards integration of palliative care in patients with chronic heart failure and chronic obstructive pulmonary disease: a systematic literature review of European guidelines and pathways. *BMC Palliative Care*, 15: 18. Available at <https://doi.org/10.1186/s12904-016-0089-4> [Accessed 13 May 2017].

Siouta, N., van Beek K., van der Eerden, M.E., Preston, N., Hasselaar, J.G., Hughes, S., et al. (2016a). Integrated palliative care in Europe: a qualitative systematic literature review of empirically-tested models in cancer and chronic disease. *BMC Palliative Care*, 15: 56. Available at <https://doi.org/10.1186/s12904-016-0130-7> [Accessed 13 May 2017].

Smallwood, N., Currow, D., Booth, S., Spathis, A., Irving, L. and Philip, J. (2018) Attitudes to specialist palliative care and advance care planning in people with COPD: a multi-national survey of palliative and respiratory medicine specialists. *BMC Palliative Care*, 17:115. Available at <https://doi.org/10.1186/s12904-018-0371-8> [Accessed 15 April 2019].

Smallwood, N., Thompson, M., Warrender-Sparkes, M., Eastman, P., Le. B., Irving, L., et al. (2018a) Integrated respiratory and palliative care may improve outcomes in advanced lung disease. *European Respiratory Journal Open Research*, 4:00102. Available at <https://doi.org/10.1183/23120541.00102-2017> [Accessed 15 April 2019].

Smallwood, N., Moran, T., Thompson, M., Eastman, P., Le. B. and Philip, J. (2019) Integrated respiratory and palliative care leads to high level of satisfaction: a survey of patients and carers. *BMC Palliative Care*, 18:7. Available at <https://doi.org/10.1186/s12904-019-0390-0> [Accessed 15 April 2019].

Smith, H.J, Chen, J. and Liu, X. (2008) Language and rigour in qualitative research: Problems and principles in analysing data collected in Mandarin. *BMC Medical Research Methodology*, 8:44. Available at <http://www.biomedcentral.com/1471-2288/8/44> [Accessed 15 May 2019]

Società Italiana di Anestesia, analgesia, rianimazione e terapia intensiva (2013) Grandi insufficienze d'organo "End Stage": Cure intensive o cure palliative? "Documento condiviso" per una pianificazione delle scelte di cura. Available at <http://www.siaarti.it/News/grandi-insufficienze-organo-end-stage-cure-intensive-o-cure-palliative.aspx> [Accessed 17 November 2017].

Société de Pneumologie de Langue Française (2010) Recommendations de la Société de Pneumologie de Langue Française sur la prise en charge de la BPCO. *Revue des Maladies Respiratoires*, 27, Supplément 1.

Sorenson, H.M. (2013) Improving end-of-life care for patients with chronic obstructive pulmonary disease. *Therapeutic Advances in Respiratory Disease*, 7(6), 320-326.

Spence, A., Hasson, F., Waldron, M., Kernohan, W.G., McLaughlin, D., Watson, B., et al. (2009) Professionals delivering palliative care to people with COPD: qualitative study. *Palliative Medicine*, 23(2), 126-131.

The SPICT Programme (2019) *Supportive and Palliative Care Indicators Tool™*. Available at <http://www.spict.org.uk/the-spict> [Accessed 12 May 2019].

Stoecker, R. (1999) Are Academics Irrelevant? Roles for Scholars in Participatory Research. *American Behavioral Scientist*, 42(5), 840-854.

Strang, S., Ekberg-Jansson, A., Strang, P. and Larsson, L. (2013) Palliative care in COPD-web survey in Sweden highlights the current situation for a vulnerable group of patients. *Upsala Journal of Medical Sciences*, 118, 181-186.

Swiss Ethics Committees (2015) *Swiss Ethics Committees on research involving humans*. Available at <http://www.swissethics.ch/index.html> [Accessed 8 December 2015].

Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., et al (2010) Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *New England Journal of Medicine*, 363, 733-742.

Titchen, A. (2000) *Professional craft knowledge in patient-centred nursing and the facilitation of its development*. DPhil Thesis, Linacre College. Kidlington, UK: Ashdale Press.

Torbert, W.R. and Taylor, S.S. (2008) Action Inquiry: Interweaving Multiple Qualities of Attention for Timely Action. In Reason, P. and Bradbury, H. (2008) *The Sage Handbook of Action Research: Participative Inquiry and Practice*. 2<sup>nd</sup> ed. London: SAGE Publications (pp. 239-251).

Torraco, R.J. (2005) Writing Integrative Literature Reviews: Guidelines and Examples. *Human Resource Development Review*, 4(3), 356-367.

UK Government (1998) *Data Protection Act 1998*. Available at <http://www.legislation.gov.uk/ukpga/1998/29/data.pdf> [Accessed 10 December 2015].

Valentijn, P.P., Boesveld, I.C., van der Klauw, D.M., Ruwaard, D., Struijs, J.N., Molema, J.J.W., et al. (2015) Towards a taxonomy for integrated care: a mixed-methods study. *International Journal of Integrated Care*, 15:e003. Available at <https://doi.org/10.5334.ijic.1513> [Accessed 8 July 2019].

Valters, G. (2015) *Theories of Change: Time for a radical approach to learning in development*. London: Overseas Development Institute. Available at <https://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/9835.pdf> [Accessed 8 July 2019].

Van Beek, K., Siouta, N., Preston, N., Hasselaar, J., Hughes, S., Payne, S., et al. (2016) To what degree is palliative care integrated in guidelines and pathways for adult cancer patients in Europe: a systematic literature review. *BMC Palliative care*, 15,1:1. Available at <https://doi.org/10.1186/s12904-016-0100> [Accessed 6 July 2019].

Van der Eerden, M., Csikos, A., Busa, C., Hughes, S., Radbruch, L., Menten J., et al. (2014) Experiences of patients, family and professional caregivers with Integrated Palliative Care in Europe: protocol for an international , multicenter, prospective, mixed method study. *BMC Palliative Care*, 13.52. Available at <http://www.biomedcentral.com/1472-684X/13/52> [Accessed 30 October 2018].

Van der Klauw, D., Molema, H., Grooten, L. and Vrijhoef, H. (2014) Identification of mechanism enabling integrated care for patients with chronic diseases: a literature review. *International Journal of Integrated Care*, 14. Available at <http://www.ijic.org> [Accessed 5 January 2017].

Van der Linden, B.A., Spreeuwenberg, C. and Schrijvers, A.J.P. (2001) Integration of health care in the Netherlands: the development of transmural care. *Health Policy*, 55(2), 111-120.

van Nes, F., Abma, T., Jonsson, H. and Deeg, D. (2010) Language differences in qualitative research: is meaning lost in translation? *European Journal of Ageing*, 7, 313-316.

Vejlgaard, T. and Addigton-Hall, J. (2005) Attitudes of Danish doctors and nurses to palliative and terminal care. *Palliative Medicine*, 19(2), 119-127.

Vince, R. (2002) Organizing Reflection. *Management Learning*, 33(1), 63-78.

Vogel, I. (2012) Review of the use of “Theory of Change” in international development. *UK Department for International Development (DFID)*. Available at [http://www.theoryofchange.org/pdf/DFID\\_ToC\\_Review\\_VogelV7.pdf](http://www.theoryofchange.org/pdf/DFID_ToC_Review_VogelV7.pdf) [Accessed 10 May 2019].

Vogelmeier, C., Buhl, R., Criée, C.P., Gillissen, A., Kardos, P., Köhler, D., et al. (2007) Leitlinie der Deutschen Atemwegsliga und der Deutschen Gesellschaft für Pneumologie und Beatmungsmedizin zur Diagnostik und Therapie von Patienten mit chronisch obstruktiver Bronchitis und Lungenemphysem (COPD). *Pneumologie*, 61, e1-e40. Available at <https://doi.org/10.1055/s-2007-959200> [Accessed 10 August 2016].

Vyt, A. (2008) Interprofessional and transdisciplinary teamwork in health care. *Diabetes/Metabolism Research and Reviews*, 24, Suppl 1:S106-109. Available at <https://doi.org/10.1022/dmrr.835> [Accessed 10 June 2019].

Waterman, H., Tillen, D., Dickson, R. and de Koning, K. (2001) Action research: a systematic review and guidance for assessment. *Health Technology Assessment*, 5(23), iii-157.

Weingaertner, V., Scheve, C., Gerdes, V., Schwarz-Eywill, M., Prenzel, R., Bausewein, C., et al. (2014) Breathlessness, Functional Status, Distress, and Palliative Care Needs Over Time in Patients With Advanced Chronic Obstructive Pulmonary Disease or Lung Cancer: A Cohort Study. *Journal of Pain and Symptom Management*, 48(4), 569-581.

Weiss, C.H. (1995). Nothing As Practical As Good Theory: Exploring Theory-Based Evaluation for Comprehensive Community Initiatives For Children And Families. In Connell J.P., Kubisch, A.C., Schorr, L.B. and Weiss, C.H. (eds.). *New Approaches to Evaluating Community Initiatives Volume 1, Concepts, Methods and Contexts*. Washington, DC: The Aspen Institute (pp. 65-92).

Western Australian Office on Quality and Safety in Health Care (2001) *Introduction to clinical governance: A background paper. Information Series No. 11*. Available at [http://www.ressma.com/Documentation/BIBLIO/GOUVERNANCE/Introduction to Clinical Governance.pdf](http://www.ressma.com/Documentation/BIBLIO/GOUVERNANCE/Introduction_to_Clinical_Governance.pdf) [Accessed 12 May 2019].

White, P. and Lynch, M. (2013) Palliative interventions and acute respiratory care in Ireland. In Hockley, J., Froggatt, K. and Heimerl, K. *Participatory Research in Palliative Care: Actions and Reflections*. Oxford: Oxford University Press.

Whitehead, J. and McNiff, J. (2006) *Action Research: Living Theory*. London: SAGE Publications.

Whittemore, R., Chase, S.K. and Mandle, C.L. (2001) Validity in Qualitative Research. *Qualitative Health Research*, 11(4), 522-537.

Whittemore, R. and Knafk, K. (2005) The integrative review: updated methodology. *Journal of Advanced Nursing*, 52(5), 546-553.

Whyte, W.F. (1991) *Participatory action research*. Thousand Oaks, CA: SAGE Publications.

Wicks, P.G. and Reason, P. (2009) Initiating Action Research. *Action Research*, 7, 243-262.

Widmer, P.S., Schippers, M.C. and West, M.A. (2009) Recent Developments in Reflexivity Research: A Review. *Psychology of Everyday Activity*, 2(2), 2-11.

Williamson, G.R., Bellman, L. and Webster, J. (2012) *Action Research for Nursing and Healthcare*. London: SAGE Publications.

Working Group of the Swiss Ethical Committees for Research with Human Subjects (WGEC) (2009) *Research with Human Subjects: A manual for general practice*. Available at [http://www.samw.ch/dms/en/Publications/Statements/e\\_Leitfaden\\_Forschung\\_def.pdf](http://www.samw.ch/dms/en/Publications/Statements/e_Leitfaden_Forschung_def.pdf) [Accessed 6 December 2015].

World Health Organization (2013) *Palliative care*. Available at <http://www.who.int/cancer/palliative/en> [Accessed 17 November 2017].

World Health Organization (2014) *Burden of COPD*. Available at <http://www.who.int/respiratory/copd/burden/en> [Accessed 17 November 2017].

World Health Organization (2015) *People-centred and integrated health services: an overview of the evidence*. Available at [https://apps.who.int/iris/bitstream/handle/10665/155004/WHO\\_HIS\\_SDS\\_2015.7\\_eng.pdf?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/155004/WHO_HIS_SDS_2015.7_eng.pdf?sequence=1) [Accessed 11

November 2018].

World Health Organization (2016) *Integrated care models: an overview*. Available at [http://www.euro.who.int/\\_data/assets/pdf\\_file/0005/322475/Integrated-care-models-overview.pdf](http://www.euro.who.int/_data/assets/pdf_file/0005/322475/Integrated-care-models-overview.pdf) [Accessed 19 May 2019].

World Health Organization (2017) *Noncommunicable diseases and their risk factors*. Available at <http://www.who.int/ncds/management/palliative-care/en/> [Accessed 11 November 2018].

Wouters, E.F.M and Vanderhoven-Augustin, I.M.L. (2009) Importance of integrated care for the chronic obstructive pulmonary disease patient. *Therapy*, 6(6), 831-835.

Xyrichis, A. and Lowton, K. (2008) What fosters or prevents interprofessional teamworking in primary and community care? A literature review. *International Journal of Nursing Studies*, 45, 140-153.

Yach, D., Hawkes, C., Gould, C.L. and Hofmann, K.J. (2004) The Global Burden of Chronic Diseases. *JAMA*, 291(21), 2616-2622.

Youngwerth, J. and Twaddle, M.L. (2011) Cultures of Interdisciplinary Teams: How to Foster Good Dynamics. *Journal of Palliative Medicine*, 14(5), 650-654.

Zuber-Skerritt, O. (2011) *Action Leadership: Towards a Participatory Paradigm*. London: Springer.

## APPENDICES

### APPENDIX I. Search terms used for database search

Population	Palliative care	Service provision	Setting of care
COPD [MeSH term]	Palliative care [MeSH term]	Integration	Hospital [MeSH term]
Chronic obstructive pulmonary disease [MeSH term]	Palliative medicine [MeSH term]	Integrated care/treatment*/intervention*/management/ approach*/model*/therap*	Hospitalization [MeSH term]/ Hospitalisation [MeSH term]
Chronic obstructive pulmonary disorder*	Life-threatening disease*/condition*/illness*	Coordination	
Chronic obstructive lung disease [MeSH term]	Life-limiting disease*/condition*/illness*	Coordinated care/treatment*/intervention*/management/ approach*/model*/therap*	Hospital unit [MeSH term]
Chronic obstructive lung disorder*	Advanced disease*/condition*/illness*		
Chronic obstructive airway disease [MeSH term]	End-stage disease*/condition*/illness*	Multidisciplinarity	Inpatient service*/unit*/ clinic*/program*/centre*/ center*
Chronic obstructive airway disorder*	Terminal disease*/condition*/illness*	Multidisciplinary care/treatment*/intervention*/ management/ approach*/model*/therap*	
Non-malignant respiratory disease*/disorder*	Supportive care [MeSH term]	Interdisciplinarity	Outpatient service*/ unit*/program*/centre*/ center*/clinic [MeSH term]
Emphysema [MeSH term]	Terminal care [MeSH term]	Interdisciplinary care [MeSH term]/treatment*/ intervention*/ management/ approach*/model*/therap*	
Pulmonary emphysema [MeSH term]	End-of-life care [MeSH term]		
Lung emphysema	Last year of life	Collaboration	Homecare/Home care [MeSH term]/Homehealth/ Home health [MeSH term]
Chronic bronchitis [MeSH term]	Life's end	Collaborative care/treatment*/intervention*/ management/ approach*/model*/therap*	
	Terminally ill [MeSH term]	Patient focused care/treatment*/intervention*/ management/ approach*/model*/therap*	Daycare/Day treatment Day care [MeSH term]
		Patient centered care [MeSH term] or centred care/ treatment*/intervention*/ management/ approach*/model*/therap*	Community-based care Hospice [MeSH term]

## APPENDIX II. Systematic reviews searched for relevant papers

Authors	Year	Country	Context	Aims	Study design	Sample
<b>Daalgard et al.</b>	2014	USA, Canada, Australia, New Zealand, EU	Hospital	1) To early identify palliative trajectories of life-threatening diseases and 2) To identify preconditions for early integration of general PC (palliative care) in hospitals	Systematic review (both experimental and non-experimental designs)	44 included papers
<b>Disler et al.</b>	2012	Countries not defined	All care settings	To review interventions used to support palliative approach in patients with COPD	Integrative review	118 included papers
<b>Gardiner et al.</b>	2010	Countries not defined	All care settings	To explore evidence that supports, or otherwise, the value of a systematic PC approach in COPD	Systematic review (not comprehensive)	15 included papers
<b>Kruis et al.</b>	2013	Countries not defined	All care settings	To evaluate the effects of integrated disease management programs or interventions in people with COPD on health-related QoL, exercise tolerance and number of exacerbations	Systematic review for randomised controlled trials (RCTs) and cluster RCTs with meta-analysis	26 included papers
<b>Mast et al.</b>	2004	USA	All care settings	To assess the degree to which end-of-life care is integrated into nationally developed guidelines for life-limiting diseases	Systematic compendia review	91 guidelines (12 for COPD)
<b>Nurmatov et al.</b>	2012	USA, Australia, Thailand	All care settings	To assess the effectiveness of interventions designed to deliver holistic care for people with advanced COPD	Systematic review with RCTs, quasi-RCTs and controlled clinical trials	3 included papers
<b>Singer et al.</b>	2016	USA, Western Europe, Israel, Canada, Australia, New Zealand	All care settings	1) To identify individuals appropriate for PC and 2) To identify elements of health service effective in achieving better outcomes for patients, carers, and the healthcare system	Systematic review and narrative synthesis	124 included randomised controlled trials (19 studies with COPD patients)
<b>Siouta et al.</b>	2016	Europe	All care settings	To obtain an overview of the current level of PC integration in advanced COPD/ CHF in Europe	Systematic review and narrative synthesis	19 included papers (17 guidelines and 2 pathways)

### APPENDIX III. National and international guidelines searched for empirical evidence

<b>Authors</b>	<b>Year</b>	<b>Country</b>	<b>Aim</b>
<b>Bettoncelli et al.</b>	2014	Italy	To establish Italian national guidelines for the management of COPD
<b>GOLD</b>	2017	International	To establish worldwide guidelines for the management of COPD
<b>Lanken et al.</b>	2008	USA	To establish US national guidelines for the management of COPD
<b>Miravittles et al.</b>	2012	Spain	To establish Spanish national guidelines for the management of COPD
<b>NHS</b>	2010	UK (Scotland)	To establish Scottish regional guidelines for the management of COPD
<b>NICE</b>	2010	UK	To establish UK national guidelines for the management of COPD
<b>Montes de Oca et al.</b>	2015	Latin America	To establish international guidelines (Latin America) for the management of COPD
<b>SPLF</b>	2010	French-speaking countries	To establish French-speaking countries' guidelines for the management of COPD
<b>Vogelmeier et al.</b>	2007	Germany	To establish German national guidelines for the management of COPD

#### APPENDIX IV. Trial registers and dissertation databases

<b>Source</b>	<b>Search date</b>	<b>Context</b>	<b>Retrieved studies</b>
<a href="http://www.ClinicalTrials.gov">www.ClinicalTrials.gov</a>	20 February 2017	Trial database	None
<a href="http://www.who.int/trialsearch">www.who.int/trialsearch</a>	20 February 2017	Trial database	None
<a href="http://www.greylit.org">www.greylit.org</a>	22 February 2017	Grey literature database	None
<a href="http://www.proquest.co.uk">www.proquest.co.uk</a>	23 February 2017	Dissertation and master theses database	None
<a href="https://oatd.org">https://oatd.org</a>	24 February 2017	Dissertation and master theses database	One thesis in Swedish
<a href="http://www.ndltd.org">http://www.ndltd.org</a>	26 February 2017	Dissertation and master theses database	None

**APPENDIX V.** Sample completed data extraction form for included studies

<b>Extraction items</b>	<b>Description</b>
Authors, year of publication and title	Landers A et al. (2015) Patient perceptions of severe COPD and transitions towards death: a qualitative study identifying milestones and developing key opportunities
Source	Primary Care Respiratory Medicine
Country	New Zealand
Study language	English
Research question	How do patients understand a palliative approach to care?
Aims of the study	To explore the experiences of patients with advanced COPD after a life-threatening event, focusing on EOL issues
Palliative care definition	WHO definition
Definition of care integration	Not applicable to paper
Ethics	Nurse Maude Ethical Advisory Group and Southern Health and Disability Ethics Committee, URB/12/02/012/A05)
Study methodology	Grounded theory
Study setting	Home care
Recruitment approach	Senior respiratory registrar identified patients who had required NIV and approached them 1-2 days before planned discharge
Participant characteristics	Patients with a diagnosis of COPD admitted to respiratory specialist services at Canterbury District Health Board for NIV
Data collection methods	Semi-structured interviews
Data analysis approach	Grounded theory
Findings/key themes identified in the study	<ul style="list-style-type: none"> <li>• Loss of recreation</li> <li>• Care in home environment</li> <li>• Episodes of acute care as milestone</li> <li>• Long-term oxygen requirements as turning point</li> <li>• Panic attacks</li> <li>• Difficulty with self-care</li> </ul>
Authors explanation of findings/key themes	<ul style="list-style-type: none"> <li>• Patients do not see themselves as dying but living with illness</li> <li>• Identification of milestones of decline</li> <li>• Transition of illness often involves more than one event</li> </ul>
Recommendations made by authors	Milestones may identify patients in need of PC
Quality Assessment	35

## APPENDIX VI. Characteristics of studies included in the integrative review

<b>Authors Year Country</b>	<b>Context</b>	<b>Palliative care definition</b>	<b>Aims</b>	<b>Study design</b>	<b>Sample</b>	<b>Quality assessment</b>
<b>Aiken et al.</b> 2006 USA	Home care	Multidisciplinary team Advance care planning Symptom relief End-of-life (EOL) discussions	To document outcomes on self-management, preparation for EOL, physical and mental functioning and emergency department (ED) visits of a coordinated PC program	Randomised controlled trial	100 patients (33 with COPD) in intervention group, 90 controls (28 with COPD)	33
<b>Bove et al.</b> 2018 Denmark	Outpatient service	Not mentioned	To explore healthcare professionals' expectations of novel nurse-led palliative care outpatients' structure	Qualitative study through focus groups and interviews, interpretive description	3 respiratory care physicians, 7 respiratory nurses and 2 community care nurses	31
<b>Beernaert et al.</b> 2013 Belgium	General practitioners (GP) practices	Not mentioned	To describe how patients with different life-limiting illnesses differ in terms of frequency and timing of referral to PC	Retrospective, population-based study	2405 registered deaths of which 111 from COPD	35
<b>Buckingham et al.</b> 2015 UK	Home care	Not mentioned	To identify and address holistic care needs of people with advanced COPD through a novel nurse-led intervention	Mixed-methods feasibility pilot trial	32 patients with COPD	33
<b>Burgess et al.</b> 2013 Australia	Public/private primary and specialist care	Not mentioned	1) To explore service availability and accessibility for people with advanced COPD and their carers and 2) To assess the role of a care-coordinator	Qualitative study through focus groups and interviews	8 GP, 6 respiratory nurses, 8 PC nurses and social workers, 4 respiratory physicians, 8 community care nurses, 30 people from COPD community support group, 20 people from hospital respiratory team, 2 representatives from carer support group and 2 community service providers	34

<b>Authors Year Country</b>	<b>Context</b>	<b>Palliative care definition</b>	<b>Aims</b>	<b>Study design</b>	<b>Sample</b>	
<b>Buxton et al.</b> 2010 UK	Hospital	Not mentioned	To assess current and planned PC service delivery for COPD in comparison with Gold Standard Framework	Web-based survey (national audit)	239 respiratory units in UK	31
<b>Cassel et al.</b> 2016 USA	Community setting	Multidisciplinary team	To evaluate the nonclinical outcomes of a proactive PC program	Observational, retrospective study using propensity-based matching	370 patients (66 with COPD) in intervention group, 1075 controls (111 with COPD)	32
<b>Cawley et al.</b> 2014 UK	Primary/secondary care	Not mentioned	To identify events which potentially could act as triggers for PC provision	Qualitative in-depth interviews	21 patients, 13 informal carers, 18 professionals	36
<b>Crawford et al.</b> 2012 Australia	Urban hospital and rural clinic	Not mentioned	1) To explore the needs of people with end-stage COPD in South Australia and 2) To develop recommendations for a model of care	Qualitative multi-perspective approach (interviews, focus groups, group sessions and expert panel)	15 patients and 8 carers for interviews; 13 professionals for expert panel; 34 professionals for focus group and 20 people from consumer support as group session	35
<b>den Herder-van der Eerden</b> 2018 Europe	All care setting	Multidisciplinary team Care provision independent from illness	1) To explore patients' perspective on composition and quality of care of integrated PC initiatives and 2) To explore patients' perceived integration between professionals and its association with care satisfaction	Cross-sectional explorative study	157 patients (39 with COPD)	36
<b>Duenk et al.</b> 2017 Netherlands	Hospital	WHO definition	To explore the view of respiratory care physicians on PC in general, for COPD patients and on organization of PC	National study survey	256 respiratory care physicians covering 85.9% of the hospital organisations in the Netherlands	35
<b>Elkington et al.</b> 2004 UK	All care settings	Not mentioned	1) To assess symptoms experienced and their impact on patient's lives in the last year of life of COPD and 2) To assess access to healthcare service	Qualitative in-depths interviews	25 carers of COPD patients who had died in the preceding 3-9 months	34

<b>Authors Year Country</b>	<b>Context</b>	<b>Palliative care definition</b>	<b>Aims</b>	<b>Study design</b>	<b>Sample</b>	
<b>Epiphaniou et al.</b> 2014 UK	Teaching hospital and home care	Optimise quality of life Provide holistic care	To explore patients' experience of care coordination in patients with life- threatening diseases such as lung cancer and COPD	Longitudinal qualitative interview study	18 patients (7 with COPD); total of 38 interviews (14 with COPD patients)	33
<b>Gainza-Miranda et al.</b> 2019 Spain	Home care	Not mentioned	1) To analyse survival of patients followed by PC home care team and 2) To describe EOL needs and processes	Prospective observational study	60 patients with COPD	31
<b>Goodridge et al.</b> 2009 Canada	All care settings	Initiating dialogue and EOL planning Anticipating the need for EOL Advanced care planning Optimising interdisciplinary team care Selecting interventions for patients with COPD	To discuss the applicability, development and monitoring of indicators measuring the quality of end-of-life care for individuals with advanced COPD	Consensus meeting (Delphi process)	15 professionals, patients and informal carers (not defined)	31
<b>Hayle et al.</b> 2013 UK	In- and outpatients	Not mentioned	To evaluate the experiences of patients with COPD who accessed specialized PC	Semi-structured interviews through hermeneutic phenomenological approach	8 patients with COPD	36
<b>Higginson et al.</b> 2014 UK	Outpatients	Symptom control Multidimensionality Multidisciplinary team	To assess effectiveness of early PC integrated with respiratory services for patients with advanced disease and refractory breathlessness	Randomised controlled trial	53 patients (29 with COPD) in intervention group, 52 patients (28 with COPD) in standard care	36

<b>Authors Year Country</b>	<b>Context</b>	<b>Palliative care definition</b>	<b>Aims</b>	<b>Study design</b>	<b>Sample</b>	
<b>Horton et al.</b> 2013 Canada	Home care	Assessment of symptoms Understanding of illness Goals of care Multidimensional treatment Individualized treatment plan	1) To determine the feasibility of implementing a customised home-based palliative care service for patients and carers living with advanced COPD and 2) To measure outcomes of such services	Single-centre cohort longitudinal observational study	30 patients with COPD and 18 carers	32
<b>Hynes et al.</b> 2015 Ireland	Hospital (both urban and rural services)	WHO definition Improve quality of life Multidimensionality More than EOL	To explore the conflict between acute care and PC, bringing into question the feasibility of embedding PC principles in acute care environment in COPD	Two-phased action research study	Phase I: interview with 26 patients Phase II: co-operative inquiry group (6 nurses from respiratory and PC team)	35
<b>Kirkpatrick et al.</b> 2014 USA	Hospital/home- based	Not mentioned	To evaluate reduction of 30-days readmission rate for acute COPD exacerbations with Integrated Practice Unit	Pre-/post-intervention observational study	110 patients pre-intervention, 114 patients post-intervention	Not available (conference abstract)
<b>Landers et al.</b> 2015 New Zealand	Home care	Focus on quality of life	To explore the experience of patients with advanced COPD after a life-threatening event, with a focus on EOL issues	Grounded theory guided interviews	15 patients with advanced COPD	35
<b>Partridge et al.</b> 2009 UK	Hospital	Not mentioned	1) To elucidate availability and access to specialist palliative care services, 2) To identify availability of non-invasive ventilation within specialist PC services, 3) To determine the existence or otherwise of formal policies for EOL in chronic lung diseases and 4) To seek respiratory physicians' view on specialised PC services for their patients	Survey	107 respiratory care physicians	30

<b>Authors Year Country</b>	<b>Context</b>	<b>Palliative care definition</b>	<b>Aims</b>	<b>Study design</b>	<b>Sample</b>	
<b>Pinnock et al.</b> 2011 UK	Primary and secondary care	Not mentioned	To understand the perspectives of people with advanced COPD, their informal carers and professionals	Longitudinal qualitative study	21 patients, 13 informal carers, 18 professionals	36
<b>Philip et al.</b> 2018 Australia	All care settings	Not mentioned	To develop a model of palliative care provision for COPD patients and their informal carers	Consensus meeting within a mixed-method study	8 professionals	31
<b>Rocker et al.</b> 2014 Canada	Home care	Not mentioned	To evaluate the effect of a supportive program of individualized care for patients and families on ED visits, hospital admissions and hospital stays	Pre-/post-intervention observational study	93 patients pre-intervention and post-intervention	30
<b>Rush et al.</b> 2017 USA	Hospital	Not mentioned	To investigate the use of PC in hospitalized patients with end-stage COPD requiring home oxygen	Retrospective nationwide cohort	181'689 patients with COPD	34
<b>Scheerens et al.</b> 2018 Belgium	Home care	WHO definition	To identify facilitators and barriers from the perspective of GP and community nurses for early integration of PC in standard home care	Focus group interviews	28 GP and 28 community nurses	32
<b>Schroedl et al.</b> 2014 USA	Outpatients in PC clinic	Not mentioned	To describe an outpatient PC program for patients with COPD	Retrospective case series	36 patients with COPD	31
<b>Smallwood et al.</b> 2018 Australia and New Zealand	All care settings	Not mentioned	To explore the approaches of respiratory and palliative care specialists to PC and advance care planning in advanced COPD	Survey	177 respiratory care physicians, 263 palliative care physicians	32

<b>Authors Year Country</b>	<b>Context</b>	<b>Palliative care definition</b>	<b>Aims</b>	<b>Study design</b>	<b>Sample</b>	
<b>Smallwood et al.</b> 2018a Australia	Outpatient clinic and home care	WHO definition	Outcomes of novel integrated respiratory and PC service	Single-group observational cohort study	142 patients with COPD	32
<b>Smallwood et al.</b> 2019 Australia	Outpatient clinic and home care	WHO definition	To explore patients' and carers' experiences of integrated care	Survey through questionnaires	64 patients with COPD and 24 carers	33
<b>Spence et al.</b> 2009 UK	Acute and community care settings	Not mentioned	1) To determine whether professionals felt patients had PC needs and 2) To explore barriers faced by professionals in delivering PC to patients with COPD	Qualitative approach through interviews and focus groups	23 health and social care professionals	33
<b>Strang et al.</b> 2013 Sweden	All care settings	WHO definition	To explore the perceptions of respiratory physicians in relationship to medical and organizational aspects of PC in COPD	Web-survey	93 respiratory care physicians	31

**APPENDIX VII.** Recruitment letter patients (translated version in English)



Health &  
Medicine

Lancaster  
University



**Date**

Name  
Address

Dear Mrs/Mr....

My name is Tanja Fusi-Schmidhauser and I am a PhD student at the Division of Health at Lancaster University, UK. I am writing to invite you to participate in my research study about integration of palliative care provision in the treatment of patients with advanced COPD (chronic bronchitis, emphysema).

A review of your medical records suggests you might be eligible to participate in this study. I obtained your contact information from the respiratory clinic. Participation will require to complete a 30 minutes interview with the investigator (Tanja Fusi-Schmidhauser). The interview will take place prior or after a regular consultation at the respiratory clinic in Lugano.

If you may be interested in participating in this study or have questions, please call at [+41918119372](tel:+41918119372) or e-mail me at [t.fusi@lancaster.ac.uk](mailto:t.fusi@lancaster.ac.uk). No one will call you about the study unless you call first (through telephone or email).

Participating in this study is voluntary. It won't affect your treatment at the respiratory clinic if you decide not to call about the study or decide not to participate.

Sincerely,  
Tanja Fusi-Schmidhauser, MD

**APPENDIX VIII.** Information sheet and consent form for patients/carers (Italian)



Health &  
Medicine



**A) Modello versione breve**

Versione breve del documento informativo sullo studio	Dettagli pagina
<b>Sviluppo di un approccio collaborativo per l'integrazione di cure palliative nella presa in carico di pazienti ambulatoriali con broncopneumopatia cronico-ostruttiva (BPCO) severa: uno studio secondo ricerca-azione (action research) (IOSI-PAL-012)</b>	
<p><b>Invito a partecipare allo studio</b></p> <p>Con il presente documento La invitiamo a partecipare al nostro studio concernente l'integrazione delle cure palliative nella presa in carico dei pazienti con una broncopneumopatia cronico-ostruttiva severa. Lei soffre di una malattia polmonare (bronchite cronica, enfisema) o è stato identificata/o da un paziente con broncopneumopatia cronico-ostruttiva (bronchite cronica, enfisema) quale familiare/amico che provvede alla presa in carico domiciliare del paziente stesso. Per tale ragione Le inviamo il presente documento informativo sullo studio.</p>	
<p><b>Scopo dello studio</b></p> <p>Questo studio si propone di valutare le modalità di introduzione di un supporto palliativo in contemporanea alle cure abituali erogate dai professionisti della salute in pazienti affetti da BPCO (bronchite cronica, enfisema) severa.</p>	4
<p><b>Informazioni generali sullo studio</b></p> <p>Questo studio prevede:</p> <p>Un'intervista della durata di 30 minuti con la persona che conduce la ricerca. Verranno poste delle domande aperte sul vissuto personale della malattia (o della malattia del proprio caro), sui sintomi che sono presenti e sulle aspettative della presa in carico attuale e futura della propria malattia (o della malattia del proprio caro).</p>	4-5
<p><b>Benefici e rischi connessi allo studio</b></p> <p>La partecipazione a questo studio non presenta vantaggi particolari per il partecipante.</p>	5-6

<p>Non vi sono rischi previsti con la partecipazione a questo studio. Tuttavia, se dovesse avvertire un disagio emozionale a seguito della partecipazione, è invitato ad informare il responsabile della ricerca.</p>	
<p><b>Diritti dei partecipanti allo studio</b></p> <p>La Sua partecipazione a questo studio è volontaria. La mancata partecipazione non modifica in alcun modo l'assistenza medica che Le viene al momento prestata (o quella prestata al Suo caro). Se ora decide di partecipare, potrà comunque ritirarsi in qualsiasi momento dallo studio senza addurre alcuna motivazione.</p> <p>Lo studio prevede la rilevazione di dati medici e/o personali sulla Sua persona. Non saranno inoltre raccolti ulteriori dati che La riguardano, fermo restando l'utilizzazione di quelli eventualmente già raccolti per determinare, senza alterarli, i risultati della ricerca.</p>	5
<p><b>Obblighi dei partecipanti allo studio</b></p> <p>Se decide di partecipare verrà intervistato lo stesso giorno di una consultazione abituale presso l'ambulatorio di pneumologia per una durata di 30 minuti.</p>	5
<p><b>Trattamento dei dati dei partecipanti</b></p> <p>Rispettiamo tutte le disposizioni legislative in materia di protezione dei dati. I Suoi dati sono utilizzati solo nel quadro dello studio in questione. L'intervista verrà condotta nella struttura ospedaliera durante l'orario lavorativo, verrà registrata digitalmente, anonimizzata e trasferita su un computer protetto da password. Tutte le persone coinvolte sono tenute al rispetto del segreto professionale. I Suoi dati personali, in particolari quelli relativi al Suo stato generale se paziente, vengono trattati solo per fini di questo studio. L'elenco aggiornato dei responsabili che gestiscono i Suoi dati è disponibile e su Sua richiesta, il medico che la seguirà potrà fornirglielo.</p>	6-7
<p><b>Significato del consenso</b></p> <p>A complemento della presente versione breve, le pagine seguenti contengono informazioni approfondite, che costituiscono parte integrante del documento informativo. Sottoscrivendo la dichiarazione di consenso, accetta i contenuti dell'intero documento.</p>	3-7
<p><b>Contatti di riferimento</b></p> <p>Ha la facoltà di porre domande in qualsiasi momento.</p> <p>Nome: Fusi-Schmidhauser Tanja</p> <p>Funzione: Capoclinica Cure Palliative IOSI-EOC</p> <p>Indirizzo/numero di telefono:</p> <p>IOSI-EOC Ospedale San Giovanni</p> <p>6500 Bellinzona</p> <p>Tel. +41 (0) 91 811 93 72</p> <p>Fax + 41 (0) 91 811 90 44</p>	7

## B) Modello versione lunga

Indice	Pagina x di x
1 Selezione dei partecipanti allo studio	3-4 di 9
2 Scopo dello studio	4 di 9
3 Informazioni generali sullo studio	4-5 di 9
4 Svolgimento dello studio per i partecipanti (Interruzione dello studio da parte dei ricercatori)	5 di 9
5 Diritti dei partecipanti	5 di 9
6 Obblighi dei partecipanti	5 di 9
7 Benefici per i partecipanti	5 di 9
8 Rischi e inconvenienti	6 di 9
9 Opzionale: altri metodi di trattamento	6 di 9
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16 Persona/e di contatto	7 di 9

### **Sviluppo di un approccio collaborativo per l'integrazione di cure palliative nella presa in carico di pazienti ambulatoriali con broncopneumopatia cronico-ostruttiva (BPCO) severa: uno studio secondo ricerca-azione (action research) (IOSI-PAL-012)**

**Promotore:** Servizio Cure Palliative (IOSI)

Gentile partecipante,

siamo professionisti di cure palliative, attivi nell' ente ospedaliero, al domicilio e presso altre strutture specializzate e Le proponiamo la partecipazione al seguente studio.

#### **1. Selezione dei partecipanti allo studio**

La partecipazione è aperta alle persone che soffrono di broncopneumopatia cronico-ostruttiva (bronchite cronica, enfisema) severa o che sono state identificate dai pazienti come responsabili della presa in carico domiciliare del paziente stesso. Lo studio si propone di valutare le modalità di introduzione di un supporto palliativo in contemporanea alle cure abituali erogate dai professionisti della salute in pazienti affetti da broncopneumopatia cronico-ostruttiva (bronchite cronica, enfisema) severa.

Per essere incluso nello studio il partecipante deve:

- avere un'età superiore ai 18 anni
- avere una diagnosi formale (spirometria) e documentata di BPCO severa o essere identificato dai pazienti con BPCO come familiare/amico che provvede alla presa in carico domiciliare del paziente
- essere seguito presso il servizio di pneumologia dell'Ospedale Regionale di Lugano
- essere capace ad esprimersi in italiano in modo scorrevole
- essere disposto a firmare il consenso informato

Sono invece escluse dalla partecipazione le persone che:

- non possono recarsi alle consultazioni ambulatoriali
- sono ospedalizzate
- che sono già seguite dai servizi di cure palliative ambulatoriali e/o domiciliari
- che soffrono di una malattia oncologica

## **2. Scopo dello studio**

Questo studio ha lo scopo di comprendere come integrare un supporto palliativo nei pazienti ambulatoriali con broncopneumopatia cronico-ostruttiva (bronchite cronica, enfisema) severa.

Le cure palliative permettono di migliorare la qualità di vita dei pazienti affetti da malattie croniche come la BPCO, controllando in modo adeguato i sintomi fisici e supportando il paziente e la famiglia nella presa in carico. Nello stesso tempo si possono inserire nelle cure abituali che vengono prescritte dagli operatori sanitari (tra i quali il medico di famiglia, lo specialista pneumologo, il fisioterapista, l'infermiere domiciliare).

Costituiscono obiettivi specifici:

1. Rivedere le pratiche correnti dell'erogazione di cure palliative nei pazienti con BPCO severa
2. Esplorare facilitatori e barriere per l'erogazione e l'integrazione delle cure palliative nella BPCO severa
3. Valutare le differenti modalità di cure palliative integrate nella BPCO severa
4. Comprendere le modalità di lavoro interprofessionale in cure palliative e nella BPCO

## **3. Informazioni generali sullo studio**

Lo studio a Lei proposto si svolge in Ticino. I pazienti ed i curanti informali vengono seguiti dall'ambulatorio di pneumologia dell'Ospedale Regionale di Lugano. Partecipare a questo studio non comporterà per Lei o per il Suo caro un trattamento diverso da quello già in atto o previsto dai Suoi curanti. Lo studio durerà diciotto mesi dal momento del suo inizio, previsto per luglio 2016. Si prevede di intervistare da cinque a otto pazienti e da cinque a otto curanti informali (famigliari/amici). Successivamente verranno coinvolti gli operatori sanitari che

proseguiranno lo studio fino a sua conclusione. I risultati definitivi dello studio saranno disponibili dopo circa un anno.

Questo studio si svolge nel rispetto della legislazione Svizzera e delle direttive in vigore a livello internazionale. È stato esaminato ed approvato dalla competente commissione etica cantonale.

Una descrizione di questo studio si può trovare anche alla pagina Internet dell'Ufficio Federale della Sanità Pubblica: [www.kofam.ch](http://www.kofam.ch).

#### **4. Svolgimento dello studio per i partecipanti**

La Sua partecipazione allo studio avrà una durata di un giorno (giorno dell'intervista).

Se decide di partecipare allo studio, verrà intervistato lo stesso giorno di una consultazione abituale (o di una consultazione abituale del Suo caro) presso l'ambulatorio di pneumologia dell'Ospedale Regionale di Lugano. L'intervista avrà la durata di 30 minuti e verrà svolta dalla persona che conduce la ricerca. Verranno poste delle domande aperte sul vissuto personale della malattia, (o della malattia del proprio caro), sui sintomi che sono presenti e sulle aspettative della presa in carico attuale e futura della propria malattia (o della malattia del proprio caro).

Non sono previsti esami invasivi nè ulteriori appuntamenti inerenti lo studio.

#### **5. Diritti dei partecipanti**

La partecipazione a questo studio è un atto esclusivamente dovuto alla Sua volontà. Nessuno può in alcun modo costringerla o persuaderla a parteciparvi. Il trattamento medico in corso (o quello del Suo caro) non è in alcun modo influenzato dalla Sua mancata partecipazione allo studio. Se non intende partecipare allo studio, non dovrà addurre alcuna motivazione. Se decide di partecipare, può revocare la Sua decisione in qualsiasi momento. Anche in questo caso non dovrà in alcun modo motivare la Sua decisione.

Può porre in ogni momento tutte le domande che desidera in merito allo studio. A tale scopo La preghiamo di rivolgersi alla persona indicata alla fine del presente documento informativo.

#### **6. Obblighi dei partecipanti**

Se decide di partecipare allo studio, dovrà attenersi ad alcune regole a beneficio della Sua sicurezza e della Sua salute. Da parte nostra faremo il possibile per sostenerla. In qualità di partecipante allo studio è tenuto a:

- essere intervistato per una durata di 30 minuti dalla persona che conduce la ricerca
- segnalare l'insorgenza di disagio emozionale a seguito della partecipazione al responsabile della ricerca

Il mancato rispetto degli obblighi qui descritti potrebbe comportare la perdita del diritto di adire le vie legali.

## 7. Benefici per i partecipanti

La partecipazione a questo studio non presenta vantaggi particolari per il partecipante. I risultati possono rivelarsi importanti per altre persone colpite dalla stessa condizione.

La partecipazione allo studio è gratuita.

## 8. Rischi e inconvenienti

Non vi sono rischi previsti con la partecipazione a questo studio. Tuttavia, se dovesse avvertire un disagio emozionale a seguito della partecipazione, è invitato ad informare il responsabile della ricerca.

## 9. Altri metodi di trattamento

La Sua partecipazione allo studio non è obbligatoria. Se non partecipa, questo non pregiudicherà in alcun modo l'assistenza che riceverà in seguito presso questa istituzione (o l'assistenza fornita al Suo caro).

## 10. Risultati dello studio

Non è prevista un'informazione a me od ai miei medici circa i risultati, ma potrò richiedere (fin da ora) di essere informato circa i risultati di questo studio.

Lei può scegliere tra le possibilità seguenti (segnare la scelta con una X):

- Desidero essere informato/a dei risultati
- Desidero non essere informato/a dei risultati
- Desidero che i risultati siano comunicati a una persona di mia scelta (P. es. parenti, medico curante ecc.)

Nome, contatto: \_\_\_\_\_

## 11. Confidenzialità dei dati

Nell'ambito di questo studio clinico saranno raccolti dati personali e medici sulla Sua persona. Questi dati saranno codificati. Codificare significa che tutti i dati che potrebbero identificarla (p. es. nome, data di nascita ecc.) sono sostituiti da un codice, che impedisce a chiunque non ne sia a conoscenza di risalire alla Sua persona. All'interno del Servizio Cure Palliative e dei responsabili del progetto presso l'università di Lancaster, i dati possono essere consultati anche in forma non codificata da persone autorizzate e chiaramente designate. Il codice di decodifica rimane sempre all'interno dell'istituzione.

È possibile che lo svolgimento dello studio sia sottoposto a verifica. La verifica può essere effettuata dalle autorità che hanno precedentemente controllato ed approvato lo studio. Questa istituzione s'impegna affinché le regole siano rispettate e la Sua sicurezza non sia messa in pericolo. Il responsabile dello studio dovrà eventualmente mettere a disposizione i Suoi dati personali e medici ai fini di tali controlli.

Tutte le persone coinvolte a qualsiasi titolo nello studio sono tenute all'assoluta confidenzialità. Il Suo nome non sarà pubblicato in rapporti o pubblicazioni, in forma stampata o su Internet.

Per il rispetto delle direttive nazionali ed internazionali in materia di protezione dei dati è responsabile il promotore in Svizzera.

## 12. Ulteriore impiego di materiale e dati

Se lo desidera, può ritirarsi dallo studio in qualsiasi momento. Per non invalidare il valore dell'intero studio, i dati personali e medici rilevati fino a quel momento saranno comunque valutati.

I Suoi dati saranno poi anonimizzati, vale a dire che il Suo nome non apparirà più su di essi in modo definitivo. Nessuno avrà modo di risalire alla provenienza dei dati.

L'eventuale ulteriore impiego dei dati sanitari personali in **Svizzera o all'estero** è disciplinato, a seconda della forma e del tipo, dagli articoli 28-32 ORUm (cfr. relativi modelli su [www.swissethics.ch](http://www.swissethics.ch))

## 13. Indennità per i partecipanti allo studio

Per la partecipazione a questo studio clinico non Le sarà versata alcuna indennità.

## 14. Copertura dei danni

Questo progetto di ricerca rientra nella categoria A. Le misure previste la raccolta di dati personali comportano soltanto rischi e incomodi minimi, ragione per cui non è prevista un'assicurazione specifica.

Se ha subito un danno, si rivolga al responsabile dello studio o all'organo di consulenza sotto indicato.

## 15. Finanziamento dello studio

Lo studio è finanziato, per quello che concerne le spese inerenti al Comitato etico, dal *Servizio di Cure Palliative, IOSI-EOC, Ospedale San Giovanni, 6500 Bellinzona*.

## 16. Persona/e di contatto

In caso di dubbi, timori o emergenze che dovessero insorgere durante o dopo lo studio, può rivolgersi in ogni momento a una delle persone di contatto indicate di seguito.

Responsabile dello studio: Fusi-Schmidhauser Tanja

Indirizzo: IOSI-EOC Ospedale San Giovanni, 6500 Bellinzona

Telefono: +41 (0) 91 811 93 72

Fax: + 41 (0) 91 811 90 44

Organo di consulenza

Se desidera rivolgersi a un organo indipendente esterno allo studio, può rivolgersi a:

\*Ufficio del Farmacista cantonale

tel. 091 816.59.41

e-mail: [dss-ufc@ti.ch](mailto:dss-ufc@ti.ch)

Tale organo non ha alcun legame con i ricercatori addetti allo studio. Il Suo caso sarà trattato in modo assolutamente confidenziale.

### C) Modello *dichiarazione di consenso*

#### Dichiarazione di consenso scritta per la partecipazione a uno studio

- Legga attentamente il presente formulario.
- Non esiti a porre domande se qualcosa non Le è chiaro o se desidera una spiegazione.

<b>Numero dello studio:</b> (presso la commissione d'etica competente)	<b>IOSI-PAL-012</b>
<b>Titolo dello studio:</b>	<b>Sviluppo di un approccio collaborativo per l'integrazione di cure palliative nella presa in carico di pazienti ambulatoriali con broncopneumopatia cronico-ostruttiva (BPCO) severa: uno studio secondo ricerca-azione (action research)</b>
<b>Istituzione responsabile (promotore):</b> (indirizzo completo)	Servizio Cure Palliative
<b>Luogo dello studio:</b>	Ambulatorio pneumologia Ospedale Regionale di Lugano
<b>Responsabile dello studio:</b> (cognome e nome in stampatello)	Fusi-Schmidhauser Tanja
<b>Partecipante:</b> (cognome e nome in stampatello) Data di nascita:	<input type="checkbox"/> donna <input type="checkbox"/> uomo

- Sono stato/a informato/a dal medico o infermiere sottoscritto oralmente e per scritto in merito allo scopo, allo svolgimento dello studio la valutazione delle modalità di introduzione di un supporto palliativo in contemporanea alle cure abituali erogate dai professionisti della salute in pazienti affetti da BPCO (bronchite cronica, enfisema) severa.
- Alle mie domande relative alla partecipazione a questo studio è stata data risposta in modo soddisfacente. Posso conservare il documento informativo scritto sullo studio 04.03.2016/versione 2 (due parti) e ricevo una copia della mia dichiarazione di consenso scritta. Accetto il contenuto del documento informativo scritto fornito in relazione allo studio sopra menzionato.
- Partecipo allo studio volontariamente. Posso revocare il mio consenso in ogni momento e senza addurre alcuna motivazione; ciò non comporterà svantaggi per il mio ulteriore trattamento medico (o quello del mio caro).
- Ho avuto tempo a sufficienza per prendere la mia decisione.
- Sono d'accordo che il mio medico curante venga informato della mia partecipazione allo studio.

Sì  No

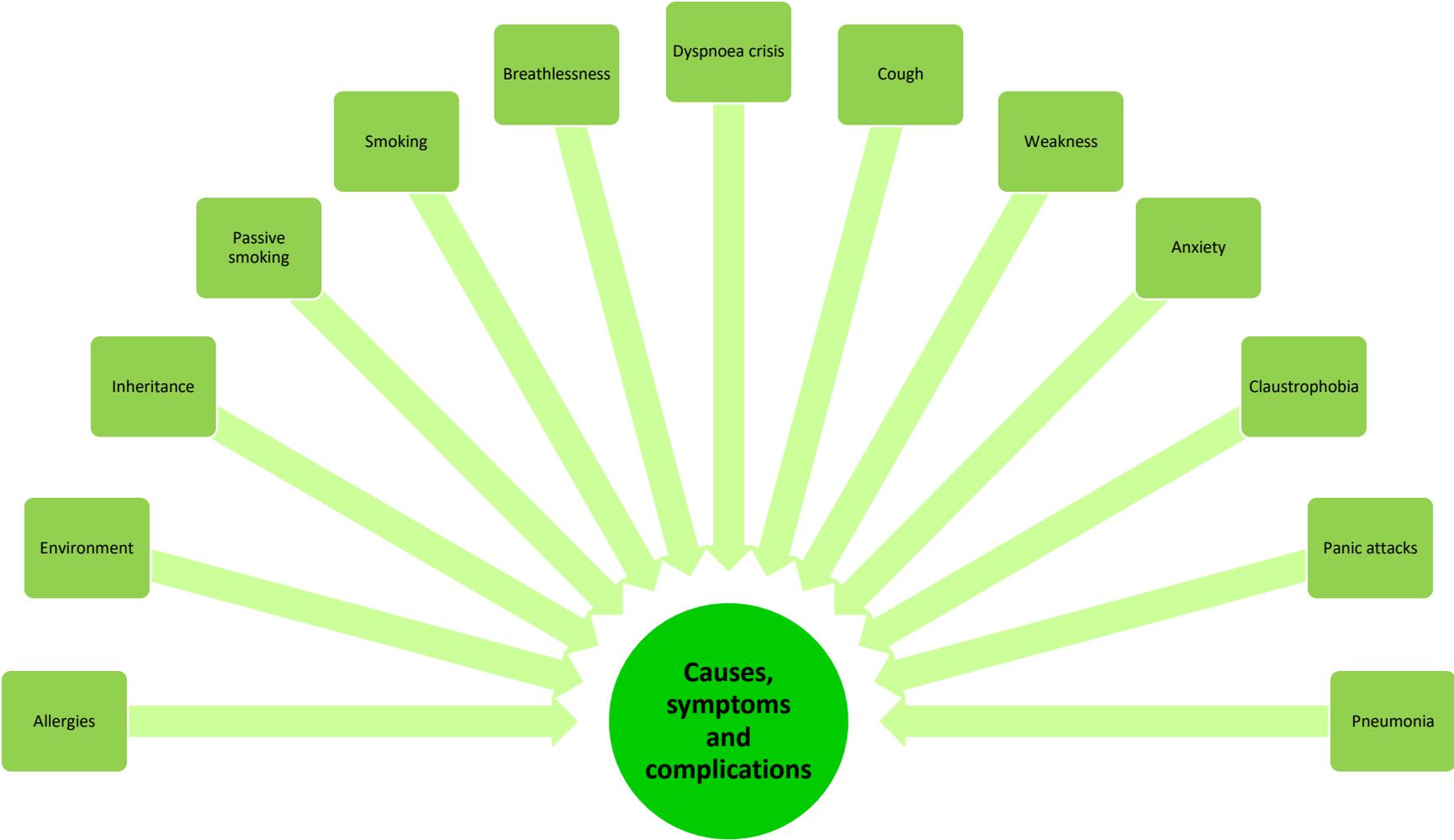
- In caso di reperti casuali desidero:
  - essere informato/a in ogni caso
  - non essere informato/a
  - lasciare la decisione alla persona indicata di seguito:  
.....
- So che i miei dati personali saranno trasmessi solo in forma codificata per scopi di ricerca. Acconsento al fatto che gli specialisti competenti del committente dello studio, delle autorità e del comitato etico cantonale possano accedere ai miei dati originali a fini di esame e controllo, tuttavia in stretta osservanza della confidenzialità.
- Sono consapevole della necessità di rispettare gli obblighi menzionati nel documento informativo durante lo studio. A beneficio della mia salute il responsabile può escludermi in ogni momento dallo studio.

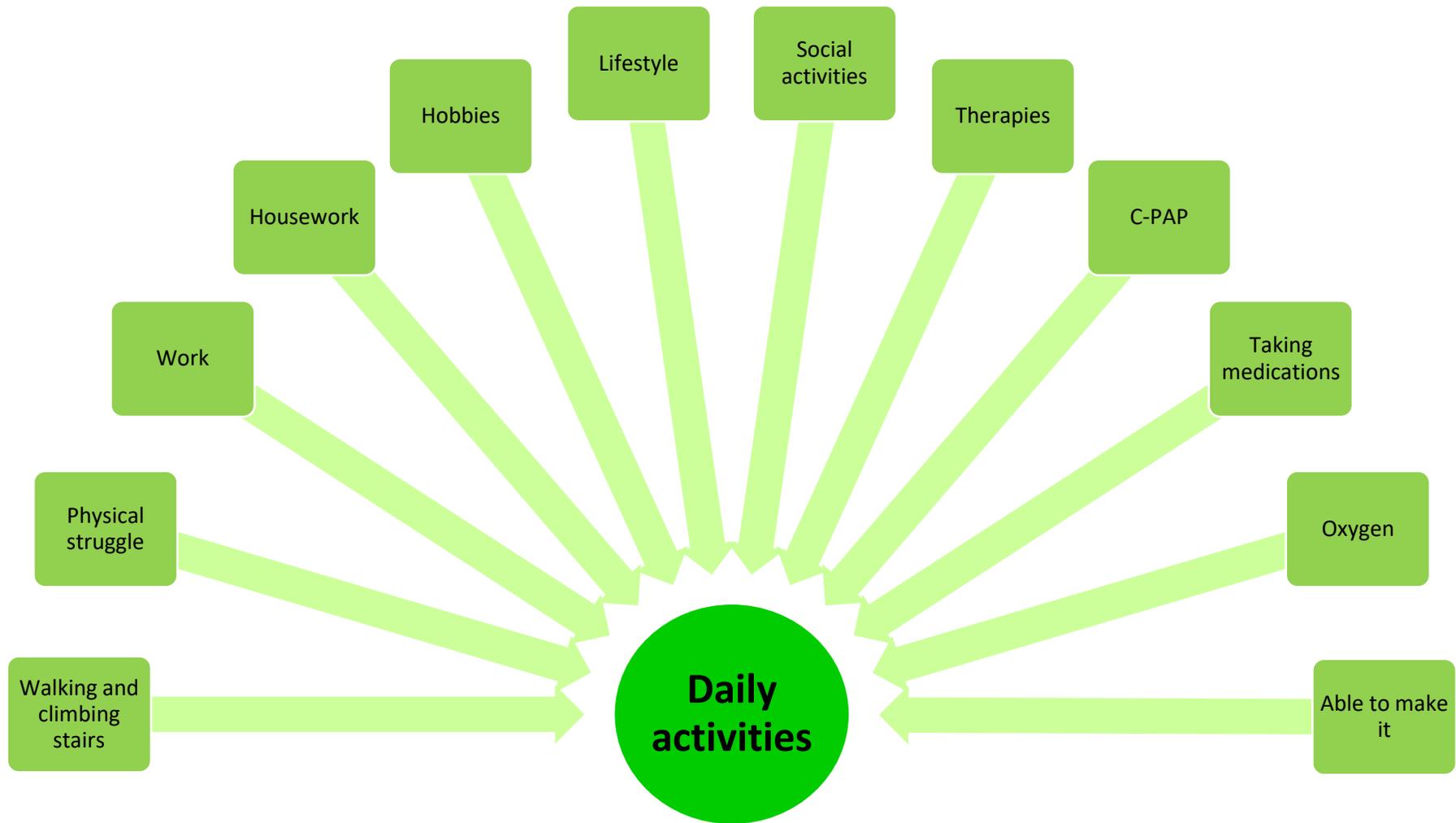
Luogo e data	Firma del/della partecipante allo studio
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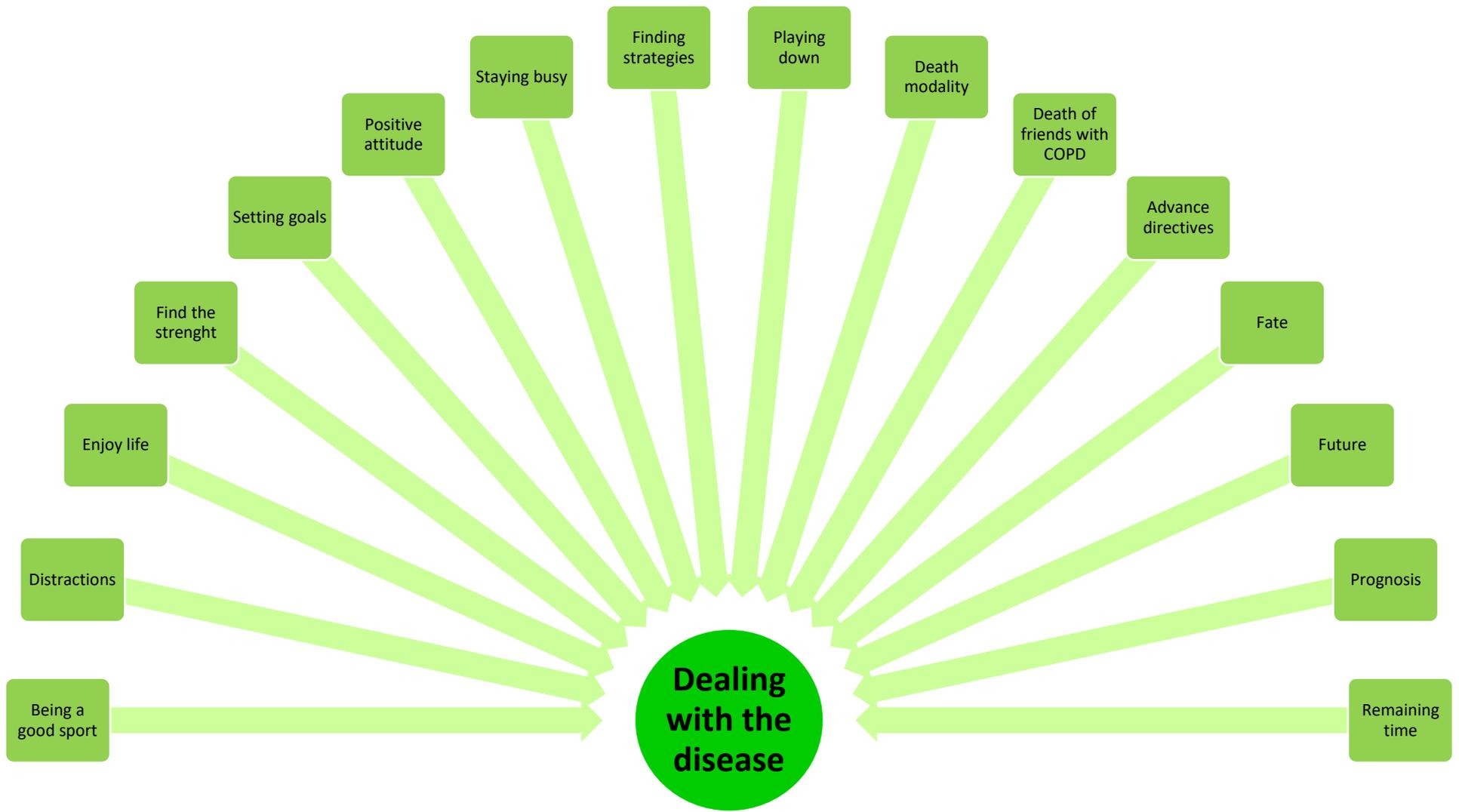
**Dichiarazione dello sperimentatore:** dichiaro di aver spiegato al/alla partecipante in questione la natura, l'importanza e la portata dello studio. Garantisco di adempiere gli obblighi inerenti a questo studio secondo il diritto vigente. Se in qualsiasi momento dello studio dovessi venire a conoscenza di aspetti che potrebbero influenzare la disponibilità del/della paziente a partecipare allo studio, provvederò a informarlo/a immediatamente.

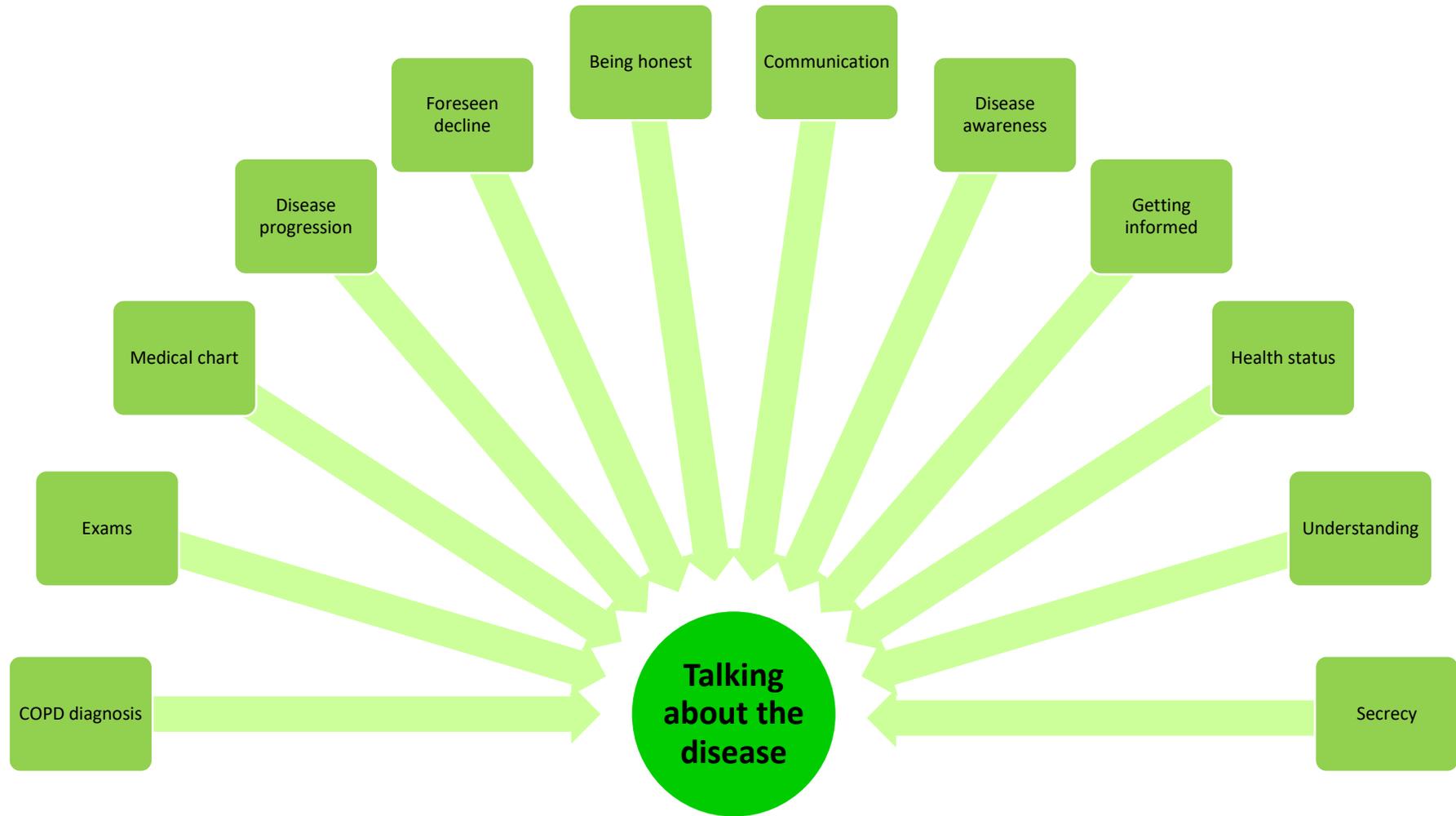
Luogo e data	Firma dello sperimentatore
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**APPENDIX IX.** Coding sample and identified subthemes









## APPENDIX X. Swiss ethics committee consent for research

telefono	c/o Ufficio di sanità Via Orico 5 091 814 30 57	Repubblica e Cantone Ticino
fax	091 814 44 47	
http	www.ti.ch/CE	
Funzionario incaricato	<b>Gutacker</b>	<b>Comitato etico cantonale 6501 Bellinzona</b>
telefono	091 814 30 57	Dr. med. Tanja Fusi-Schmidhauser
e-mail	michaela.gutacker@ti.ch	IOSI, Cure Palliative Ospedale San Giovanni 6500 Bellinzona

Bellinzona  
13.04.2016



Ns. riferimento

Vs. riferimento

### Decisione del Comitato etico del Canton Ticino

Numero Studio\*: **Rif. CE 3044 BASEC 2016-00361**

\*Per favore riportare Rif. CE in tutta la corrispondenza futura

#### Titolo dello studio:

**The development of collaborative palliative care integration in respiratory medicine consultations for adult outpatients with advanced chronic obstructive pulmonary disease (COPD): An action research study**

**Sperimentatrice principale** (responsabile principale nel settore di competenza del Comitato etico) e **promotrice del progetto**

Titolo, Nome, Cognome: Dr. med. Tanja Fusi

Funzione: Capoclinica cure palliative

Indirizzo: Ospedale San Giovanni, 6500 Bellinzona

Il Comitato etico ha fondato la sua valutazione sulla documentazione elencata:

nell'allegata lista di documenti (checklist) data 12.04.2016

nella lettera di accompagnamento del

prima valutazione

rivalutazione

#### I. Il comitato etico decide in

procedura normale

procedura semplificata

procedura presidenziale

## II. Decisione

**Lo studio viene autorizzato**

Questo significa che: la ricerca può essere effettuata nel rispetto delle condizioni quadro del protocollo di studio sottomesso e nel rispetto delle basi legali applicabili.

Autorizzazioni di progetti di ricerca clinica delle categorie B e C sono accettati a condizione che

1. eventuali carenze constatate dall'autorità federale (Swissmedic/UFSP/UFAM) non richiedano modifiche alla documentazione valutata dal comitato etico e che
2. sia stata ottenuta l'autorizzazione delle autorità federali (Swissmedic/UFSP/UFAM)

**Lo studio viene autorizzato ma è vincolato da requisiti vincolanti**

Questo significa che: la ricerca può essere iniziata nel rispetto delle condizioni quadro del protocollo di studio sottomesso e nel rispetto delle basi legali applicabili. Le condizioni sono da soddisfare nelle tempistiche adeguate. La documentazione rielaborata viene valutata in procedura presidenziale.

Condizioni:

**Attualmente lo studio non può ancora essere autorizzato**

Questo significa che: la ricerca non può ancora essere iniziata. Siete pregati di rispondere alle domande e soddisfare le condizioni elencate nella tabella allegata e di risottomettere la documentazione rielaborata. È necessaria una valutazione successiva da parte del Comitato etico.

Motivazioni:

**Lo studio non può essere autorizzato**

Questo significa che: la ricerca non può essere effettuata nella forma attuale. È possibile una nuova sottomissione.

Motivazioni:

**Non entrata in materia**

Questo significa che: il Comitato etico non è legalmente competente per l'autorizzazione. È possibile che sia responsabile un altro ente, oppure che la sperimentazione possa essere effettuata senza autorizzazione.

Motivazioni:

## III. Tipologia

**Il progetto è una sperimentazione clinica secondo OSRUm:**

- con agenti terapeutici
- con dispositivi medici
- con espanti standardizzati
- terapia genica
- con organismi geneticamente modificati o patogeni
- trapianti
- altre sperimentazioni cliniche secondo OSRUm cap.4
- riclassificazione in altra categoria secondo OSRUm, articolo 71 cpv 3
- con agenti che possono emettere radiazioni ionizzanti o sorgenti radioattive

Categoria: A B C

**Il progetto è un progetto di ricerca secondo ORUm:**



- ricerca con persone, Categoria: A B
- riclassificazione in altra categoria secondo ORUm Art. 48 cpv. 2, Cat.: A B
- Progetti di ricerca con materiale biologico e dati sanitari personali
- Ricerca su persone decedute
- Ricerca su embrioni e feti provenienti da interruzioni di gravidanza e da aborti spontanei, compresi i nati morti

**Riutilizzo di materiale biologico o dati sanitari in assenza di consenso (Art. 34 LRUm, Art. 37-40 ORUm):**

- a. scopo dell'utilizzo:
- b. descrizione del materiale biologico o dei dati sanitari:
- c. persone autorizzate all'utilizzo:
- d. persone autorizzate alla ricezione del materiale o dei dati:

**IV. Rimedi di diritto:**

Contro la presente decisione è dato **ricorso entro 15 giorni** da questa notifica; l'atto di ricorso deve essere indirizzato al Comitato etico cantonale che lo trasmetterà in seguito al Consiglio di Stato.

**V. Comunicazione al richiedente; con copia a**

- Promotore
- Swissmedic
- UFSP
- Comitati etici locali (studi multicentrici), unicamente email
- Altri: Dr.ssa Manuela Sarti (solo email)

**VI. Composizione del Comitato etico**

Il Comitato etico si è riunito il 22.03.2016 nella composizione riportata qui di seguito (in ottemperanza all'art. 5, Org-LRUm): **vedi allegato**

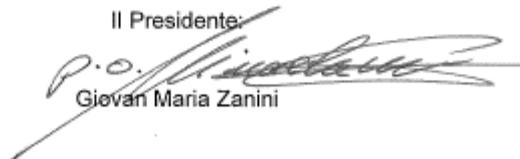
**VII. Tassa: fr. 300.-**

La polizza di versamento sarà inviata separatamente dal Centro sistemi informativi all'indirizzo da voi indicato.

Con i migliori saluti.

PER IL COMITATO ETICO CANTONALE

Il Presidente:

  
Giovan Maria Zanini

**APPENDIX XI.** Lancaster ethics committee consent for research



Applicant: Tanja Fusi  
Supervisor:  
Department: Health Research  
FHMREC Reference: FHMREC15099

19 July 2016

Dear Tanja

**Re: The development of collaborative palliative care integration in respiratory medicine consultations for adult outpatients with advanced chronic obstructive pulmonary disease (COPD): an action research study.**

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Diane Hopkins (01542 592838 [fhmresearchsupport@lancaster.ac.uk](mailto:fhmresearchsupport@lancaster.ac.uk)) if you have any queries or require further information.

Yours sincerely,

A handwritten signature in black ink that reads "Diane Hopkins".

Dr Diane Hopkins  
Research Development Officer

CC Ethics@Lancaster; Professor Roger Pickup (Chair, FHMREC)

**APPENDIX XII.** Themes and subthemes from interviews with patients/informal carers

<b>Subthemes</b>	<b>Main themes</b>
Causes, symptoms and complications	<b>Living day to day with COPD</b>
Daily activities	
Dealing with the disease	
Talking about the disease	
Guilt/Blame	<b>Psychosocial dimension of COPD</b>
Stigma	
Fear	
Loss	
Care network	<b>Management of complex care in COPD</b>
Healthcare professionals	
Type of desired care provision	
Getting help	

**APPENDIX XIII.** Sample of first CIG meeting data



...a volte mi faccio proprio schifo...

...c'è scritto "fumatore" e tu sei già bollato...



...io per esempio non ho paura di morire...

...diciamo sapere a cosa si va incontro...



...per me è finita e per lui pure. Prima sì, andavamo...

...che può morire durante il sonno, che «si perde di aria»...

Famigliare	Tema	Paziente
Crisi di dispnea	Sintomo fisico	Dispnea
La malattia è stata causata dal proprio caro, il paziente è responsabile per l'isolamento sociale della coppia	Vergogna, colpa	Per il fumo, verso i propri cari
Isolamento sociale della coppia	Perdita di indipendenza	Attività della vita quotidiana
	Discriminazione da parte dei curanti	Malattia causata dal fumo
Attualmente non disponibile	Importanza di approccio multiprofessionale	Attualmente non disponibile
Condivisione delle esperienze permette di migliorare la presa in carico	Importanza di condivisione delle esperienze con altri pazienti/parenti	Condivisione delle esperienze permette di aumentare l'attenzione sul problema

#### **APPENDIX XIV.** Summary of joint educational meeting (23.01.18)

All seven participants attended the joint educational meeting with healthcare professionals from a partner organisation providing home support for patients with advanced COPD and with hospital staff. All participants had previously been informed about the meeting context and development. A total of nine nurses (four working in hospital and five providing home support) and one social worker from the partner organisation participated in the joint educational meeting. The meeting was held on clinic premises and lasted about 90 minutes. I introduced the topic (palliative care integration in advanced COPD) and presented the clinical vignette. The CIG decided to split the participants in two smaller groups to allow broader space for discussions. Therefore, three CIG members were added to each group and one of them acted as facilitator during discussions. The researcher alternatively observed the ongoing actions within both groups. The case discussion within both groups led to a broader reflection on the role of palliative care in advanced COPD. Participants highlighted their awareness about the declining performance status and high symptom burden recorded in this population. Furthermore, they acknowledged COPD as being a life-limiting illness with emerging patients' and informal carers' needs. Both groups suggested that several factors were responsible for the lack of palliative care integration in advanced COPD. The researcher observed the interactions within both groups and between the CIG members acting as facilitators and the rest of the interdisciplinary group. Role and profession distinctions were avoided by wearing non work clothes. Age differences among participants did not prevent active interaction and hierarchical relationships, especially within hospital staff were openly discussed by facilitators prior to discussion within both groups and were not observed during the meeting.

**APPENDIX XV.** Reflexivity in CIG meeting (05.09.17, second CIG meeting)

*Context:* discussion about interdisciplinary meetings as key elements of palliative care integration in advanced COPD

The palliative care physician (senior registrar) was reflecting on barriers for interdisciplinary meetings, such as the interplay with hierarchical positions, especially within the palliative care setting. I reflected on my role in previous interdisciplinary meetings, both as a resident and senior registrar and I could not recall experiences of power imbalance and hierarchical constraints. Nonetheless, I tried to reflect on how the colleague and other CIG members reported their experiences, while challenging my perceptions and worldview related to this particular topic. Sharing my thoughts and reflections with the other CIG members helped to focus on different aspects of interplay with hierarchical positions within interdisciplinary meetings.