

# **Developing end-of-life care at a Portuguese nursing home through participatory action research**

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**MD, MSc Gerontology, MSc Palliative Care**

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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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research

**Abstract**

Background: Nursing homes are places where older people live and often die but little is known about the needs of those who care for them, in Portugal.

Aim: to identify the needs of nursing home staff when caring for older people at the end of life; to understand the cultural nuances of providing care at the end-of-life in nursing homes; to develop, with nursing home staff, a culturally appropriate programme that meets their needs; and to plan for future development.

Methods: Participatory Action Research was used to identify needs and to develop interventions, designed by the staff themselves, aimed at improving care. Up to ten nursing home staff participated in a six-cycle research process, with data collected, analysed, and used in sequential plan-act-reflect steps.

Findings: The silence that surrounds a resident's death has a severe impact on the lives of those who survive him/her. Lacking competencies in grief management, and with no emotional and relational space to express grief emotions, staff strive to manage their loss, while trying to support other residents. Acknowledging the existence of death and its impact on nursing home life made the invisibility of death and mourning visible, and interventions possible, providing closure to all.

Conclusion: The impact of death and dying on nursing home life needs to be recognised. If adequately supported, nursing home staff can develop strategies to manage grief and mourning, to improve their knowledge of the residents' needs and wishes, improve communication among staff, and ultimately improve care.

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I dedicate this Thesis:

To my parents and grand-parents, *in memoriam*

To Mariana and Gary, my two loves

I, Cristina Galvão, declare that this thesis entitled **Developing end-of-life care at a Portuguese nursing home through participatory action research** has a total of 39,445 words in length, exclusive of the title page, table of contents, list of tables and figures, abstract, appendices, and references.

## **Chapter 1 – Background and Context**

This chapter will present and evaluate the challenges of caring for an ageing population and its need for palliative and end-of-life care, in particular in nursing home context. It introduces the research questions, aims and objectives, and the thesis structure and overview, followed by my positioning in the research process and knowledge construction. The chapter concludes presenting the research setting and giving an overview of care homes in the Portuguese context.

### **1.1 An ageing population**

Demography shows ageing as a worldwide phenomenon, to which international organizations have called attention (United Nations, 2019). A decrease in birth rates, an increase in life expectancy and the ageing of the “baby boom” generation (those born between 1946 and 1964, and who will be older than 65 years old in 2030) contribute to this scenario (Carone & Costello, 2006; WHO, 2015).

By 2050 the proportion of the population older than 60 years will increase and the number of people aged eighty and over (“the oldest old”) is expected to increase even more (Bloom et al., 2011; Gomes et al., 2012). Several challenges and opportunities (at biological, social and cultural levels) arise with the population increasingly ageing. At a biological level, there is a need to promote strategies that allow people to reach a final stage of life with maximum physical and mental capacity and wellbeing; this will allow older people to live longer and more healthily, enjoy life more and, at the same time, use the accumulated expertise to their benefit and that of society. This leads to the need to reorganise not just the labour market, but social security services as well; healthcare systems and services will need reorganisation in search of greater efficiency and adapted care. By living longer, older people will not only need more healthcare, but differentiated care as well; this implies the need to adapt society to provide care at home for as long as possible, and, at the same time, to create skilled nursing homes to care for the frailer and more dependent. At a cultural level, giving older persons reasons to live with dignity is an important challenge. There is also a need to develop health and social care, namely end-of-life and palliative care, that ensures respect for the cultural and spiritual values of the elderly (Caldwell et al., 2008; Sander et al., 2015).

Culturally appropriate care respects culture, a “set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs” (UNESCO,

2001, p.1). It involves the healthcare professional's self-awareness of his/her own cultural identity, and understanding of the cultural background of those entrusted to them, which is not always the case. Culturally appropriate care implies respect for the self and for the other, adapting care to the culture of the patient (Black, 2008). Culturally appropriate care is thus an ongoing exercise in learning, in which healthcare professionals constantly learn how to care for patients from distinct cultures. However, Williamson and Harrison (2010) call attention to a broader concept of culture and care, where the patient's position in society explains his/her health condition; it sees caring, without respecting the cultural background of the patient, as potentially being an unbalanced power relationship, and culturally appropriate care as a relationship that empowers the patient. Caring for, in a culturally competent way, is thus a balanced relationship, empowering the carer and the cared for.

Due to older people's increased health and social care needs (European Commission, 2019), there are concerns about how to ensure access to adequate comprehensive and culturally appropriate healthcare (WHO, 2015). Defining new guidelines or national policies that respect the patients' cultural beliefs and practices was deemed fundamental to improving quality of life, and quality of care (Hines-Martin et al., 2019). However, as mentioned earlier, when healthcare professionals are not fully aware of their and the patient's cultural identity, an increased dependency on care could increase the patient's suffering at the end-of-life.

It is this increased dependency on care that arrives with older age, and the lack of informal home care support, that contribute to older people making the decision to move to care homes (be they residential or nursing homes) (Canadian Institute for Health Information, 2011; Figueiredo et al., 2017; Kehusmaa et al., 2012; WHO, 2015). Moving to a nursing home occurs at older ages, with advanced disease (such as progressive disability, frailty, multiple chronic diseases, organ failure, cancer, advanced dementia, or a gradual deterioration until death), with increasing dependency for the basic activities of daily living, or when physical and/or cognitive functions decline (Barclay et al., 2014; Brown & Abdelhafiz, 2011; Froggatt et al., 2011; Froggatt & Payne, 2006; Gill et al., 2010; Lini et al., 2016; Seymour et al., 2011). Even if not terminally ill at admission, about a quarter of residents will ultimately die in nursing homes (Balance of Care Group & National Audit Office, 2008).

## **1.2 Palliative and end-of-life care for an older population**

To address the complex needs of frail nursing homes residents, international organizations have advocated the development of services that respect older persons' values, choices, rights and

dignity, committing to introducing a holistic perspective into care, based on older persons' needs (WHO, 2015). Nursing and care homes – residential institutions, where personal, nursing and medical care is provided twenty-four hours a day, throughout the year (Froggatt et al., 2013) - are places where frail older people live the last months or years of their lives and eventually die (Calanzani et al., 2014); the need to provide the most appropriate care for this elderly population, led to the development of recommendations on the availability of palliative and end-of-life care (Radbruch et al., 2009). Palliative care is “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (Froggatt et al., 2013, p.12). End-of-life care for seniors is “an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions” (Froggatt et al., 2013, p.13); although recently defined as “comprehensive care for dying patients in the last few hours, days or weeks of life” (Payne et al., 2022, p.6) this thesis uses the concept of care in the last year of life (Froggatt & Payne, 2006). A commitment to change (Froggatt et al., 2013), the support of management and external palliative care specialists (Lo et al., 2010), and staff education and training (Kinley et al., 2011a; Stillman et al., 2005), can, at a nursing home level, contribute to the improvement of end-of-life care provision.

However, research has shown that inequalities in the provision of palliative and end-of-life care exist (World Palliative Care Alliance, 2014). The development of palliative and end-of-life care differs from country to country, but accessibility to this type of care can be different within the same country as well (Hawley, 2017; Lynch et al., 2010). Access to palliative and end-of-life care is usually easier for cancer patients, while chronic non-cancer patients with palliative needs are less likely to be referred to these services, even in countries where palliative care is well developed. Disparities also exist between urban and rural areas; in the latter, this type of resource is usually scarce and more difficult to access. The lack of sufficient professionals to meet the population needs is a reality, particularly in rural areas. Basic palliative care knowledge and skills are not uniform in all healthcare professionals, leading some patients to experiencing greater difficulty in obtaining adequate care. Nursing and medical pre-graduate training in palliative care is not available in every country.

Access to essential drugs, especially opioids, is not equal in all countries, the most developed ones included; the existence of bureaucratic obstacles, the fact that drugs can only be prescribed by some specialists and not by all doctors, and drug availability in pharmacies, constitute

important barriers to adequate symptom control. Unwillingness of healthcare professionals to refer patients for palliative care support, or the reluctance of patients (and families) to be referred to those services, has also been mentioned as preventing people's access to the most appropriate care. A lack of coordination of care among different medical specialities has also been reported, hindering the provision of care for those in need. In several countries, there is a lack of funding for palliative care development and provision, as well as for research and education (Lynch et al., 2010).

Locally, cultural issues can also contribute to hindering access to this type of care (Hines-Martin et al., 2019). Different cultural backgrounds, or discord between the patient or the relatives' cultural beliefs and practices, can lead to increased suffering. Moreover, in southern Europe, there is a reluctance to discuss end-of-life issues by the patient and family (Aboitiz, 2012), while family requests for nondisclosure regarding prognosis are common (Meñaca et al., 2012). In their literature review of research in Italy, Spain and Portugal, Meñaca et al. (2012) found eighty-one papers with information regarding diagnostic and prognostic disclosure and advanced directives: partial disclosure of diagnosis persisted at the same level between 1994 and 2009 in Spain and Italy, with less information provided on prognosis than on diagnosis, and with significant differences within Italy. However, a trend for full disclosure was found in both countries, with some papers describing intermediate positions. Only two studies undertaken in Portugal were found (1999 and 2005). These addressed diagnostic awareness and desire for diagnostic information: both were from the same city (Porto) and both had higher values than the Italian and Spanish studies. There were differences in doctors' attitudes towards advance directives: while no papers were found on the Portuguese situation, Spanish doctors considered advance directives positive, while Italian doctors knew very little about the topic. However, recently, two studies have been published. In one study, focusing on the awareness and attitudes of Portuguese adults towards advance care directives (ACD), with mainly women and healthcare professional participants, it was found that, although 73% of the participants knew about ACD, only 2% had provided one (Laranjeira et al., 2021). The other study revealed the low ACD compliance of the Portuguese, with only 29,000 ACD for an adult population of about 9 million inhabitants (Macedo, 2020).

A lack of education and training of health professionals on palliative and end-of-life care makes care delivery challenging (Lynch et al., 2010; Meñaca et al., 2012). This is reported to be the most common barrier to palliative care development in Western Europe; as a result, few professionals enter the palliative care speciality, resulting in a shortage of these professionals relative to the countries' needs. Lack of research in palliative care, limited knowledge of opioids

for pain control, and a deterioration of the quality of care provided, have also been linked to the lack of education and training in several European countries (Lynch et al., 2010). Still, in their literature review of end-of-life care in southern Europe, Meñaca et al. (2012) note that Spanish doctors demand more training in end-of-life care in areas such as psychosocial and emotional topics, and symptom control. In Portugal, some of the problems referred to by Lynch et al. (2010) as barriers to access to palliative care or to adequate symptom control (a lack of opioids and their high cost) do not exist anymore. Portuguese patients nowadays have access to opioids at a minimal cost, and there are no bureaucracies in their prescription. However, the political will to implement palliative care is still variable and dependent on government support, and palliative care services, and hospital and community palliative care teams are not adequately distributed in the country.

### **1.3 End-of-life care and nursing homes**

With an expected increase in the world's ageing population, there is a growing demand for education and training in palliative and end-of-life care (WHO, 2011), in particular for healthcare and related professionals (Suzman & Beard, 2011; United Nations Population Fund (UNFPA) & HelpAge International, 2012). Research shows that nursing homes are important places of care for older adults, and that improving end-of-life care in nursing homes is possible through the implementation of programmes that lead to the appropriate recognition and management of residents' needs (Anstey et al., 2016; Boogaard et al., 2018; Froggatt, 2000; Hall et al., 2011; Hockley et al., 2010; Kinley et al., 2011, 2014). Identification and integration of the cultural aspects of end-of-life care (family, religious background, relationships, values, practices) is also being advocated (Crawley et al., 2002; Gysels et al., 2012; Meñaca et al., 2012).

Older people's death trajectories are different, but they are usually preceded by a period of functional, and sometimes mental decline, diverse co-morbidities and complex care needs (Gill et al., 2010). When living in long-term care institutions, older people have the right to have their choices respected and their symptoms relieved and prevented where possible (Age-Platform, 2010; Davies & Higginson, 2004). The need for adequate and culturally-adapted education and training in end-of-life and palliative care, as a way to improve older people's care has been underlined (Age-Platform, 2010; Davies & Higginson, 2004). The importance of an end-of-life care approach, provided by trained formal carers, independently of the person's age, based on the patient's needs and with respect for the patient's rights, has also been emphasised (Age-Platform, 2010; Davies & Higginson, 2004), with the EAPC recommending that it should also be



provided at nursing homes and other assisted living facilities (Froggatt et al., 2013; Radbruch et al., 2009).

Improvement of nursing home care at the end-of-life proves challenging, with frequent sustainability issues (Reitinger et al., 2013). Rigorous and robust research into end-of-life care in nursing homes is needed, as well as the generation of evidence that can be immediately applied, to contribute to service improvement (Bennett et al., 2010; Bolmsjo, 2008; Parker, 2014). The support of nursing home management and of palliative care specialists, as well as a commitment to change, are fundamental to improving care provision (Froggatt et al., 2013; Lo et al., 2010). The EAPC Taskforce (2013) recognized that contexts are different and that there are cultural differences in the provision of end-of-life care within nursing homes across Europe (Reitinger et al., 2013).

Research into the needs of nursing home staff when caring for older residents at the end-of-life has mainly been undertaken in northern Europe and north America (Bolt et al., 2019; Seymour et al., 2011; Whittaker et al., 2006), while little is known about the problem in south European countries. Katz et al. (2001) researched the support needs of English nursing home staff, residents and relatives when a resident dies. Staff need practical support to care for dying residents, and emotional support to cope with their grief. The needs expressed by the staff were not always the same as those mentioned by the managers. Residents' support needs were rarely met before a resident's death, although support improved after the death. Relatives' needs (practical and emotional) were often not met. A literature review on nursing home staff in providing palliative care for residents with dementia found two types of staff needs. At a direct-care level, staff referred to a need for improved communication (verbal and non-verbal), and support to identify and address comfort, behaviour and symptom control. Education and training, support for nursing home staff, and organisational change were the needs identified at a non-direct care (institutional and job) level (Bolt et al., 2019). Organisational improvement and reorganisation, as well as increased staff support and education, in order to improve end-of-life care and to prevent staff burnout were mentioned by other authors in Canada (Marcella & Kelley, 2015; Pott et al., 2020). Research in Japan found that staff needed more education to improve end-of-life care; round-the-clock medical and nursing support, knowledge of symptom control and psychological support, plus improved levels of staffing were other needs mentioned (Hirakawa et al., 2009). Improvement in staff attitudes towards end-of-life care was achieved in Spanish nursing homes, through a complex intervention (the NUHELP programme) developed between nursing home staff, and palliative care and primary care professionals (Mota-Romero et al., 2021). In Portugal, to my knowledge, within the care home domain, there is an absence

of research focusing on the needs of nursing home staff when caring for older residents at the end-of-life.

#### **1.4 Research questions, aims and objectives**

This study was guided by the following research question: “How can a culturally appropriate organisational programme for nursing home staff be developed to care for older people at the end of life?” The aim of the research was to develop a culturally appropriate organisational programme, using participatory research methodology. Its purpose was to listen to the voices of nursing home staff, hear about their needs when caring for older residents at the end-of-life, and develop the organisational programme with them.

Six objectives were defined to meet the research aim:

1. To identify the needs (including learning, management, emotional support) of nursing home staff when caring for older people at the end of life
2. To understand the cultural nuances of providing care at the end-of-life in nursing homes
3. To develop, with nursing home staff, a culturally appropriate programme that meets their needs
4. To deliver and run the programme
5. To understand the challenges faced by the participants
6. To develop plans for future development work

#### **1.5 My voice**

I have almost forty years’ experience working as a doctor, half of which have been in palliative care. I have developed palliative care provision in the region where I was born and live in Portugal, and have worked as a full-time palliative care doctor and medical coordinator of my team for about fourteen years, providing care in the community integrated within the Portuguese National Health Service (SNS). As the team expanded its working area (to about 6000Km<sup>2</sup>), community/at home palliative care began to be available 24 hours-a-day; but there was no support for nursing home residents. My concerns regarding the care provided at end-of-life in those facilities were shared with the team, leading to a pioneering decision in 2011 to

offer advice and support to nursing homes at the same level as in the community. Education and training, decision-making, access to medicines, out-of-hours support and advice for staff, residents and families were the main areas covered. However, huge differences exist among different nursing homes, and the support has been provided on-demand, without knowing exactly what the real needs of the nursing homes are. A decision to research this area, to contribute to narrowing the knowledge gap regarding the needs of nursing home staff when caring for older residents at the end-of-life, was taken.

I am aware of the influence of my previous experience, assumptions and beliefs on my work, as well as on the research process. Reflexivity, as an important element of participatory action research, will be demonstrated throughout the thesis, through transparency, and the use of first-person language, where relevant. Reflection on my personal and professional ontological and epistemological beliefs began prior to this research, but intensified in the first steps of this study. The need to continuously be aware of the influence my own philosophical stance would have on the research process became clear.

I recognise that who I am and the way I approach reality and perceive knowledge has been modelled through time; I also recognize my part (the conscious and the sub-conscious) in accepting or discarding knowledge in what has become my system of beliefs (worldviews) and ultimately knowledge (epistemology) (Hofer, 2000). I acknowledge that my own life experiences, as well as my worldviews and epistemology, shaped the practice of the research, and influenced the choice of the research methodology and methods, data analysis and conclusions (Creswell, 2013; Malterud, 2001). From here I state:

- I am a white, middle-aged, middle-class woman graduating almost forty years ago as a physician, who had the opportunity to continue my studies to a high level. University studies allowed me to develop critical thinking skills and to integrate reflection into practice (Majumder et al., 2019; Mann et al., 2009), and increased my awareness of my “privileged position to access and produce knowledge, as well as control interpretation of knowledge” (Demos & Lemelle Jr., 2006, p.7) and of the power issues this brings to social interactions and to research.
- As a medical professional, I have dealt with different patients, families and contexts: each one has brought its own meaning to the health/disease arena. With them, because of them, I felt the need to think and reflect on my own practice and the way(s) I have acquired and managed knowledge (Ingrassia, 2013).

- As a palliative care doctor, I have noticed how my patients' and their families' life histories shape the way they approach death, and the way they live life until the end: there is no single way to live these realities, either as actors in one's own history, or as caregivers that bring their own experiences and perspectives to the caring scene. They have contributed strongly to my personal growth, as well as to my continuously discovering and rediscovering meaning in life (Sinclair, 2011).
- As a physician I have a special interest in older people's health and well-being and in end-of-life care. I work in community palliative care, independently of the place where the person lives (home, long-term care or nursing home). While at home, a patient can have one or more carers, but at a nursing home is usually cared for by different professionals. Regarding nursing homes, research shows that many of the residents will ultimately die there (Calanzani et al., 2014) and that to manage their end-of-life care needs there is an increasing demand for support staff (Carneiro et al., 2012; Hall et al., 2011; WHO, 2011), which led me to research end-of-life care in the nursing home context.
- As a "becoming researcher" I learned from my teachers, supervisors, and my fellow students, as well as from the obstacles, errors and successes of the research journey: each situation and every day were different from the previous ones, and shaped my personal development and ultimately the research itself (Attia & Edge, 2017).
- Being a non-English speaker (Portuguese is my mother tongue), I have struggled not only with my own difficulties in writing in academic English, but also with translation across languages, needing to be constantly aware of how to not lose the meaning of words or cultural language subtleties, as well as of how to prevent bias (Temple & Young, 2004).

In every situation and in the relationships established during my life (some more than others), I learned. These brought their own ontological and epistemological perspectives (complementary or antagonistic) (Moon et al., 2019; Pitard, 2017), contributing to the way I recognize, connect to, and comprehend knowledge (Hofer, 2000), to the way I learn and work (Billett, 2009), and ultimately to the development of my own self (Mosselson, 2010). Research is thus shaped by my personal epistemology, itself contributing to the way I see myself and approach the world, and eventually research (Lu & Hodge, 2019). In summary, research is not only constantly influenced by my own worldviews, dynamic per se, but also influences the manner in which I, as a researcher, create knowledge.

## **1.6 The research setting**

The research took place in a nursing home located in a small city inland in the south of Portugal. It is directed by a community of catholic nuns, with a forty-bed capacity. Several factors formed the basis of the choice to carry out the study at this institution: its proximity to my residence was one of them. Being a community palliative care doctor, I have contact with all the nursing homes in the zone. In a 100 Km radius, there was no nursing home that had not yet had professional visits from me. Considering this, a decision was made to conduct the research at this nursing home, mainly because of the institution's willingness to participate in the research to improve care, along with the staff voicing the difficulties they had in caring for the residents at the end-of-life, and their desire to improve that care. Conscious of the difficulties (but also of the benefits) of being an insider undertaking research at the institution, several factors were taken into consideration, which are discussed in the Ethics chapter, among them the decision to not provide care at the nursing home while the research was ongoing.

## **1.7 Care homes and the Portuguese context**

With a population of 10 million inhabitants, and 2.2 million of these aged 65 and over (21.8%), Portugal is the country with the seventh highest ageing rate in the world and the third in the European Union (Eurostat, 2015; INE, 2019; United Nations Department of Economic and Social Affairs, 2013). By 2030, it is expected that this proportion will have risen to about 27%, making Portugal the country with the third highest ageing rate in the world, only behind Japan and Italy (United Nations Department of Economic and Social Affairs, 2019). The old-age dependency ratio (the ratio of older dependent people (aged 65 or above) to the working-age population (aged 15-64 years old)) is projected to rise from 32.9% (2017) (Pordata, 2019) to 65.8% by 2050 (Eurostat, 2019). The dependency (WHO, 2015), progressive chronic illness and the frailty (Murray et al., 2005) associated with ageing, along with a lack of home support with care (Atkinson & Marlier, 2010; Carneiro et al., 2012) contribute to nursing home admissions. More than 90,000 older people, 50% of whom are 90 years or older, live in Portuguese care homes facilities (GEP-MTSSS, 2019).

Different care home facilities can be found (see Table 1: ERPI typologies). Assisted living residencies, called "residências assistidas", are very scarce and owned by the private for-profit sector; they provide accommodation, in individual apartments or villas, for individuals or older couples. Collective residential structures for older people, called officially "Estruturas Residenciais para Pessoas Idosas – ERPI" (in English Residencies for Older People) are generally

referred to as “Lar”, the former designation (Portaria n.º 67/2012 de 21 de Março, 2012). Owned by organizations in the public and private sector (79% non-profit), they provide temporary or permanent housing in single or collective bedrooms, along with personal care with the basic and instrumental activities of daily living, as well as nursing and medical care, based on the residents’ needs. Residential structures that provide just long-term basic social care are unavailable (GEP-MTSSS, 2019; Joël et al., 2010).

Table 1: ERPI typologies

	Accommodation	Common Designation	Ownership	Services Provided	Number	Total (Approximately)
ERPI	Collective Housing with Bedrooms	"Lar"	Welfare Organisations (79% Non-profit Org) - Private Sector - Public Sector	Basic care Nursing care Medical care	?	2 500
	Individual Apartments / Villas	Residencias Assistidas	Private sector (for profit)	Psycological care	? (very few)	

Supported by a change in legislation, between 2000 and 2014, not only did the number of nursing homes increase (to 59% more), but also the general quality of facilities and care improved (Carneiro et al., 2012; Portaria n.º 67/2012 de 21 de Março, 2012; Resolução da Assembleia da República n.º 93/2018, 2018). Overseen by Social Security services, nursing homes were required to follow the published best practice manual rules (Instituto da Segurança Social, n.d., 2005), with an emphasis on active ageing and social integration; the document makes no recommendations regarding end-of-life care (Portaria n.º 67/2012 de 21 de Março, 2012). No data is available on the quality control of the nursing homes.

Research, mainly Masters theses and case studies, generally points to high levels of client satisfaction with the care received (Diogo, 2016; Pereira, 2016); however, comments have been made on lack of privacy, low food quality, inadequate care from aides, and risk to mobility (Diogo, 2016; Martins, 2015; Pereira, S. 2016; Pereira, V. 2013). Despite the efforts made in the last decade to improve Portuguese nursing homes, several problems continue to characterize these organizations: poor quality of space and care, low professionalization of staff, lack of staff qualifications and high staff turnover (Carneiro, 2012).

Legislation defines the number of nurses per facility/residents (one per forty), but neither states the required number of working hours, nor requires the support of geriatric or palliative care nurse specialists (Portaria n.º 67/2012 de 21 de Março, 2012). Regarding medical services, no

specifications exist either: a contract with a general practitioner that visits the facility once or twice a week is the usual practice.

Although palliative care has been officially sanctioned by governmental initiatives, as part of the national network for integrated continuous care (Decreto-Lei N° 101/2006, 2006), access to palliative care continues to be problematic for older people living in nursing homes. Very few of the existing community palliative care teams provide support to nursing home residents (Cardoso, 2014; Gomes et al., 2013), and access to the scarce palliative care units and beds is slow and hindered by bureaucracy (Entidade Reguladora da Saúde, 2015). In Portuguese society, death is seen as a failure (Cruz & Nunes, 2016), resulting in an emphasis on curative treatments even at the end-of-life, together with defensive medicine and medical futility (Gomes-Pedro et al., 2001; Teixeira et al., 2012). Communication problems regarding end-of-life care decisions have been reported; discussing the proximity of death is socially considered as taboo, and a lack of palliative care education makes decisions about end-of-life care difficult (Oliveira, 2008; Pacheco, 2004; Silva, 2017). There is a need to improve the basic skills of nursing home staff in older people's care, and the development of in-service training programmes has been suggested as a way to improve professional competencies when caring for older persons in Portugal (Carneiro et al., 2012). However, no evidence exists on the educational needs of Portuguese nursing home staff, when providing end-of-life care for older residents, or the support they need to better provide their care.

## **1.8 Thesis structure and overview**

The thesis comprises five chapters, the present Introduction (Chapter 1) and four others, as discussed below.

### Chapter 1: Introduction

The introductory chapter presents the challenges faced by nursing homes when providing end-of-life care and provides an overview of the resident population of nursing homes. It discusses inequalities in accessibility and provision of care, and introduces some international recommendations to improve care. The chapter concludes with a brief overview of the Portuguese context, and summarises nursing home data and palliative care development in the country.

### Chapter 2: Literature review

This chapter identifies what interventions aimed at improving end-of-life care have been implemented in nursing homes, and what resources are required to sustain them. A narrative synthesis approach was used, allowing for a detailed clarification of the issue under research. The literature review findings support the theoretical framework and methodological approach of this thesis.

### Chapter 3: Methodology and Methods

The methodological approach used in this research study is described in this chapter, along with the epistemological and ontological perspectives that underpin the research. The choice of a Participatory Action Research (PAR) approach is outlined and data collection and analysis detailed. Ethical considerations are described, and research quality and rigour discussed.

### Chapter 4: Findings

Research took place within six PAR Cycles. In Cycle 1, nursing home staff were recruited and data collection took place. In Cycle 2, the interview results were appraised by the staff who consented to participate and interventions aimed at improving end-of-life care designed. In Cycle 3, the implementation of the interventions began. Cycle 4 comprised the phase where the interventions continued to be developed without my support, due to unforeseeable events that will be described later. In Cycle 5, the interventions were evaluated. Cycle 6 describes the planning of future interventions. Research findings will be summarised.

### Chapter 5: Discussion and Conclusions

In this chapter, the research findings will be discussed in relationship to the research questions, and compared and contrasted with previous research. Research strengths and limitations will be presented, and the research knowledge implications for future policy, research and practice will be evaluated.

## **1.9 Summary**

Although considerable literature exists on interventions aimed to improve end-of-life care in nursing homes, in particular in Anglo-Saxon countries, many gaps in knowledge in this area exist in southern European countries, particularly in the Portuguese context. These include: a lack of knowledge of nursing home staff needs when caring for older residents at the end-of-life; the impact of cultural values on the provision of care; the interventions developed in nursing homes to address these needs; and what is needed to maintain the interventions. This research has



been designed to address these gaps, at the same time as, with a participant methodology, supporting and empowering the nursing home staff. Beyond the research, it was intended that the staff were given their own voice, thus allowing their experience and concerns to contribute to knowledge development.

The next chapters will address the interventions aimed at improving the end-of-life care implemented in nursing homes, and the needs of nursing home staff when caring for older residents at the end of life.

## **Chapter 2 – Literature review**

### **2.1 Background**

A decrease in birth rates and higher life expectancy has led to the world population ageing (Albers et al., 2012). It is estimated that people will live longer and die at older age. This trend is likely to continue through the middle of the 21<sup>st</sup> century (Gomes et al., 2012). Old age can bring dependency, comorbidities, chronicity, more complex symptoms and increased healthcare needs, contributing to older people's frailty (Bowman et al., 2004; Estabrooks et al., 2015). The lack of availability of informal carers (persons, usually with familiar bonds who, in a non-professional, unpaid capacity, give regular and ongoing assistance to elderly people) (Beesley, 2006) contribute to older peoples' seclusion, raising concerns on care provision, particularly of the very old ( $\geq 85$  years old) (Kinley et al., 2014; Sarmiento et al., 2016; Seymour et al., 2011), as they become frailer and more dependent on care.

A move to a nursing home, an institutional setting where personal and nursing care is provided 24 hours a day, all year long (Froggatt et al., 2013), is one of the options in the last years of life (Davies & Higginson, 2004; Froggatt, 2001). Residents in nursing homes are mostly very old persons, with poor health, multimorbidity and frailty, which contribute to the suffering of the residents and families and negatively impact their quality of life (Davies & Higginson, 2004; Estabrooks et al., 2015; WHO, 2011).

A palliative care approach, provided on an as needed basis and independently of the place of care (WHO, 2017; World Palliative Care Alliance, 2014), has been advocated to improve standards of care (Badger et al., 2007, 2012; Cartwright, 2002; Froggatt & Payne, 2006; Hockley et al., 2010). Support and care for frail older people with life-limiting conditions in the last years of their lives, should follow an active, sensitive and compassionate approach (end-of-life care for seniors), that prevents and relieves suffering (Froggatt et al., 2013). Independently of the place of care, the need for quality end-of-life care has been advocated (Gomes et al., 2012). Nursing homes, as places where older people live the last phase of their lives, should be pivotal in providing high quality end-of-life care.

Although death and dying are present in care homes, research has shown the existence of facilitators and barriers to end-of-life care provision (Beck et al., 2014; Casey et al., 2011; Ersek & Wilson, 2003; Fryer et al., 2016; Jenull & Brunner, 2008; Miller et al., 2015; Phillips et al., 2008). Different initiatives to promote organizational change that drives the improvement of care (interventions) have been undertaken all over the world to address this problem. There is evidence on the different interventions developed in nursing homes aimed at improving end-of-

life care (Froggatt et al., 2006; Hockley et al., 2010). These frequently address heterogeneous and complex interventions, such as staff education, symptom control, care improvement, advanced care planning and care pathways implementation (Froggatt et al., 2006; Lorenz et al., 2008). Although research has shown that palliative care services have become more widely available within nursing homes, literature also shows that concerns exist on the sustainability of interventions implemented at nursing homes to improve end-of-life care (Anstey et al., 2016; Finucane et al., 2013; Kinley et al., 2011b).

Thus, a literature review was undertaken, aimed to systematically identify the existing evidence on the nursing homes interventions used to improve end-of-life care, and the resources needed to sustain them, using a narrative synthesis approach. The literature review addressed the following research question: What interventions have been used to improve end-of-life care in nursing homes, and what resources are needed to sustain them?

## **2.2 Methods**

This section reports on the methods used in this literature review.

### **2.2.1 Type of literature review**

Following a narrative synthesis approach (Popay et al., 2006), a systematic literature review was undertaken of the different interventions developed in nursing homes aiming at improving end-of-life care, and identifying the resources needed to sustain them. The literature review process involved the following stages: research question formulation, relevant articles' location and selection (literature search strategy), data extraction and analysis, and findings interpretation.

To understand what nursing homes interventions were developed required the analysis of both qualitative and quantitative papers. A narrative synthesis approach allows the combination of different types of papers, based on different methodologies, through the analysis of relationships and comparison within and between studies, contributing to a broad perspective on the topic (Barnett-Page & Thomas, 2009; Lucas et al., 2007; Popay et al., 2006). With a narrative synthesis approach, study characteristics (the context, contrasts, and similarities) are integrated and summarized (Barnett-Page & Thomas, 2009), in an iterative process that brings together a comprehensive explanation of the phenomenon in study (Popay et al., 2006).

### **2.2.2 Literature search strategy**

The research question asked, informed the search for relevant papers. A SPICE (setting, perspective, intervention, comparison, evaluation) framework has been used to structure the research question and to define the inclusion and exclusion criteria.

Setting: interventions conducted in nursing homes (as defined earlier);

Perspective/Population: residents, families and nursing home staff viewpoints were considered;

Interventions: interventions aimed to improve care in the last months, weeks or days of life (end-of-life care, as defined earlier) were included;

Comparison: not applicable;

Evaluation: resources needed to sustain end-of-life care interventions conducted at the nursing homes.

As part of the literature search strategy, search terms were defined, and database searches were performed.

### **2.2.3 Search strategy**

Six electronic databases were systematically searched: three North American primary sources general databases (PubMed, PsycInfo and Web of Science); one European database (EMBASE); one database of nursing primary sources (CINAHL) and one Latin American general database of primary sources (LILACS). The Medline search strategy is presented in Appendix 1; the same search strategy was adapted to each different database, with slight adjustments to their search criteria. The search was undertaken between September and December 2017 and repeated at 2020, after being subjected to refinement, with a date limit of the years 2000-2019.

A hand search of relevant palliative care journals (Palliative Medicine, European Journal of Palliative Care, Journal of Hospice and Palliative Nursing, International Journal of Palliative Nursing, Palliative and Supportive Care, Journal of Palliative and Supportive Care, BMC Palliative Care), as well as Spanish, Portuguese and Brazilian palliative care journals (Medicina Paliativa, Revista Cuidados Paliativos, Revista Brasileira de Cuidados Paliativos) published between 2000 and 2019 was also done. A hand search of the references of included papers was performed, to identify additional relevant citations. Titles were screened and abstracts were read to identify potentially relevant papers. To facilitate the referencing process and to allow duplicate detection and removal, results were exported to Mendeley Desktop. Full texts of eligible studies were retrieved, and the review taken forward. When clarification on data was needed, the papers' authors were contacted. The full-text articles that were excluded, were entered a

different table where reasons for exclusion were registered (Appendix 2). A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart is included in the review to show the flow of the screening process and the number of papers at each stage.

### 2.2.4 Search terms

Descriptors and key-words identification was performed, and MeSH (Medical Subject Headings) and DeCS (Health Sciences Descriptors) analysed for inclusion, with adaptation to the specifics of each database searched. According to each searched database indexing system rules key-words were changed and quotation marks, truncation and wildcards (?/\*/\$) were used to broaden the searches. To link and make interact free text and MeSH terms Boolean operators (AND/NOT/OR) were used. A combination of search terms was used.

Search terms relating to End-of-life care were combined with terms describing Older Persons, Interventions and Nursing Homes (Table 2).

Table 2: Search terms

<b>TOPIC 1: End of Life Care</b>	<b>TOPIC 2: Older Person</b>	<b>TOPIC 3: Interventions</b>	<b>TOPIC 4: Nursing Homes</b>
(MH "Terminal Care") (MH "Palliative Care") (MH "Long-Term Care ")	(MH "Aged+")		(MH "Homes for the Aged") (MH "Nursing Homes ")
"End of life care" "Palliative Care" Terminal Dying Death "Advanced Disease"	"Old* Person" Elderly Geriatric* OAP Pensioner* "Senior Citizen*" Aged	Intervention* Treatment* Therap* Program* Strateg* Training Facilitation "Role Modelling" "Needs Assessment*"	"Nursing Home*" "Residential Care" "Retirement Home"

### 2.2.5 Inclusion and exclusion criteria

Papers that addressed the topic interventions conducted in nursing homes were retained and submitted to the inclusion and exclusion criteria (Table 3).

Table 3: Inclusion and exclusion criteria

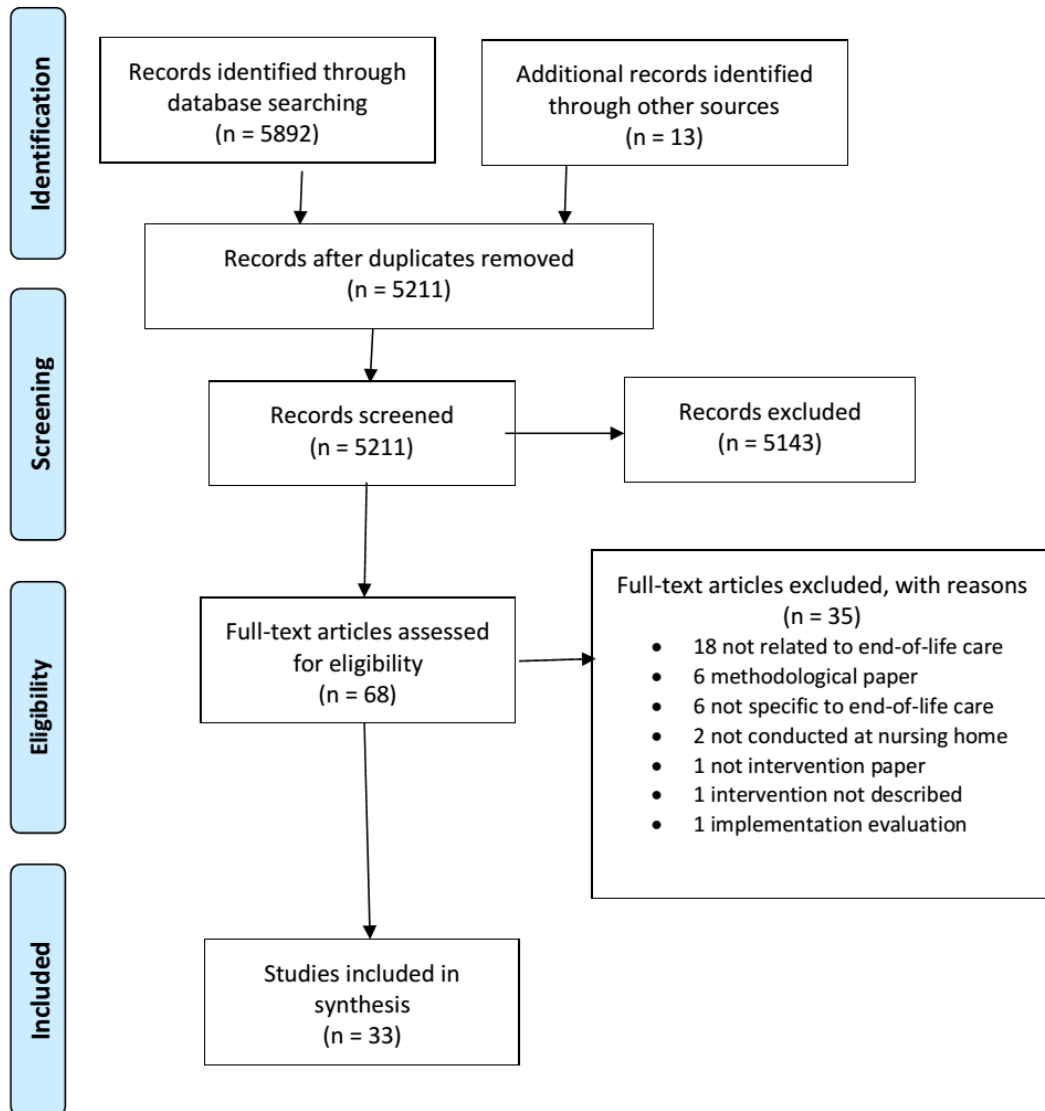
Inclusion criteria	Exclusion criteria
papers published in peer-reviewed journals	papers published in non-peer reviewed journals
papers published between 2000-2019	written in other languages than the ones mentioned in the inclusion criteria
English, Portuguese, Spanish and French	editorials, expert opinions, guidelines, grey literature, letters to the editor, newspaper articles, reviews and research protocols
research and practice development papers	without full text access
full text available	interventions conducted in other supported care living arrangements
interventions conducted in nursing homes	interventions were aimed to improve quality of care but were not related to end-of-life care
interventions aimed to improve end-of-life care	
interventions aimed to improve care provided to residents 65 years old or older	interventions aimed to improve care provided to residents, any age, when data could not be disaggregated
residents, families and staff viewpoints were considered	

Exclusion criteria included papers written in other languages than English, French, Portuguese or Spanish; although with capacity to read and understand Italian and Catalan, my fluency is not enough to feel comfortable to review papers in those two languages. Also excluded were papers with interventions aimed to improve the quality of care, but not specifically geared to older residents or to end-of-life care. According to the eligibility criteria, titles and abstracts of identified papers were screened for their relevance. If in doubt when reading the abstract, references were conditionally accepted.

### 2.2.6 Study selection

The searches generated 5892 potentially relevant articles. After duplicates were removed, the titles and abstracts were screened, resulting in 55 papers. Five further records were retrieved

through the search of relevant palliative care journals, while the hand search of the references of accepted papers retrieved a further eight new records, resulting in a total of sixty-eight potential papers that met the eligibility criteria of the review. These papers were accessed and submitted to a full review: thirty-five papers did not meet the eligibility criteria, leaving 33 papers for the review (Figure 1).



(Adapted from: Moher et al., 2009)

Figure 1: The PRISMA flowchart

### 2.2.7 Data extraction

An adapted data extraction tool (Appendix 3) was developed, with guidance from the Cochrane “Checklist of items to consider in data collection or extraction” (Julian & Higgins, 2011). Selected papers were assessed, and data collected, extracted systematically and transferred to the adapted data extraction tool. Data extracted included general information (author(s), title, year of publication, journal of publication, country, language, aims of the paper, palliative care/end-of-life care definition), and information on the interventions (general description of the intervention, aims, study design, sample, coordinating role, timescale intervention and follow-up), the evaluation tools (data collection, data analysis), the results (outcomes, facilitators, barriers) and the resources (sustainability). Findings were tabulated for differences and similarities’ analysis between studies.

### **2.2.8 Quality appraisal**

Selected papers were appraised using the Hawker et al. quality appraisal tool (2002) (Appendix 4). This nine criteria (abstract, introduction, method, sampling, analysis, ethics and bias, results, transferability and implications) quality assessment scale has good inter-rater reliability and grades the quality of assessed papers, allowing the use of qualitative studies in systematic reviews (Flemming & McInnes, 2011; Hawker et al., 2002). Each criterion, scoring between 4 (good) and 1 (very poor) point, has its own descriptors, contributing to appraisal transparency. According to the defined protocol, papers were appraised, resulting in a total score of methodological quality for each study, with a minimum possible score of 9 and a maximum of 36 points. A score of 36 was judged as high quality, between 28 and 35 good quality, between 19 and 27 fair quality and 18 or lower poor quality. No guidance has been provided by Hawker et al. (2012) on the lowest score acceptable for studies inclusion. A cut-off score of 19 has been used previously by other authors when using the same methodological quality appraisal tool (Flemming & McInnes, 2011).

Heterogeneity characterised the papers quality (Appendix 5). According to Hawker et al. (2002) eleven articles were graded “good”, and twenty-two were graded “fair”. Only a third of the papers presented a well-structured abstract and an unequivocal account of the study, with most of them providing most but not all information. Since the paper selection involves the titles and abstracts evaluation, fair quality could have led to the initial exclusion of fundamental papers. Most of the papers were rated as good (n= 17) or fair (n=16) relatively to findings presentation, allowing to a good understanding of the results obtained; however, more diversity existed when evaluating the importance of the findings for policy and practice, leaving a gap in this area.



### 2.2.9 Data synthesis and analysis

To understand which nursing homes’ interventions worked, required the analysis and synthesis of both qualitative and quantitative studies. Anticipating that the papers selected for this review would be heterogeneous, a narrative synthesis approach was chosen, allowing the combination of different and heterogeneous types of papers, based on different methodologies, through the analysis of relationships and comparison within and between studies, and contributed to a broader perspective on the topic (Barnett-Page & Thomas, 2009; Campbell et al., 2018; Lucas et al., 2007; Snilstveit et al., 2012; Popay et al., 2006). Themes generated from the data were analysed: concordance or divergence among findings was highlighted before an aggregative narrative synthesis of data was performed.

### 2.3 Results

After a thorough overview of the included papers, the results of the systematic review will be discussed, according to the two points of the research question, namely which interventions intended to improve end-of-life care were used, and which were the resources contributing to sustain them. Study characteristics, design, definitions, sample size, participants and type of interventions will be presented. Four themes were identified: the heterogeneity of the interventions; different strategies to implement the interventions; education (and training) as the most used strategy; facilitation is key to implement change.

A table with a summary of the interventions is presented in Appendix 6.

**2.3.1 Study characteristics:** The thirty-three studies identified were published between 2003 and 2019, with more than 50% conducted in the United Kingdom (UK) (Table 4).

Table 4: Selected papers per country and year of publication

UK (n=19)	Non- UK	
Hockley et al., 2005	<b>Australia</b>	Phillips et al., 2008
Hanson et al., 2005		Chapman et al., 2018
Waldron et al., 2008	<b>Canada</b>	Verreault et al., 2018
Heals, 2008		
Badger et al., 2009	<b>China</b>	Chan and Pang, 2010
Hockley et al., 2010		
Hall et al., 2011	<b>Ireland</b>	Cornally et al., 2015
Hewison et al., 2011		
Badger et al., 2012	<b>Norway</b>	Aasmul et al., 2018
Livingston et al., 2013		
	<b>Sweden</b>	Beck et al, 2012

UK (n=19)	Non- UK	
Finucane et al., 2013 Kinley et al., 2014 Farrington, 2014 Hockley, 2014 Baron et al., 2015 O'Brien et al., 2016 Hockley and Kinley, 2016 Moore et al., 2017 Little et al., 2019		Beck et al., 2014 Bökberg et al., 2019
	<b>The Netherlands</b>	Brännström et al., 2016 Boogaard et al., 2018
	<b>USA</b>	Keay et al., 2003 Levy et al., 2008 Wen et al., 2012

**2.3.2 Design:** a range of research designs were used, both quantitative (n=21), qualitative (n=8) and mixed methods (n=4) (Table 5). The study design was mentioned in twenty papers; of the thirteen papers where it was not mentioned, six could be classified as case studies (Beck et al., 2012; Finucane et al., 2013; Hall et al., 2011; Heals, 2008; Waldron et al., 2008; Wen et al., 2012), three as a before-after study (Baron et al., 2015; Bökberg et al., 2019; Little et al., 2019) and the others a cohort study (Hockley & Kinley, 2016), a case control study (Hanson et al., 2005), a quasi-experimental design (Levy et al., 2008), and an exploratory study (Hockley et al., 2010).

Table 5: Selected papers research design

Quantitative (n=21)	Qualitative (n=8)	Mixed methods (n=4)
Keay et al., 2003 Hanson et al., 2005 Levy et al., 2008 Waldron et al., 2008 Heals, 2008 Badger et al., 2009 Chan and Pang, 2010 Hockley et al., 2010 Wen et al., 2012 Finucane et al., 2013 Kinley et al., 2014 Beck et al., 2014 Baron et al., 2015 Brännström et al., 2016 Hockley and Kinley, 2016 Aasmul et al., 2018 Boogaard et al., 2018 Chapman et al., 2018 Verreault et al., 2018 Bökberg et al., 2019 Little et al., 2019	Hockley et al., 2005 Phillips et al., 2008 Hall et al., 2011 Hewison et al., 2011 Beck et al., 2012 Hockley, 2014 Cornally et al., 2015 O'Brien et al., 2016	Badger et al., 2012 Livingston et al., 2013 Farrington, 2014 Moore et al., 2017

A before-after study design was used by all the mixed-methods research papers. Hockley et al. (2005) describe an intervention where mixed-methods were used, but the paper reports just the qualitative analysis.

**2.3.3 Definitions:** although reporting on interventions aimed to improve end-of-life care, only one paper presents a definition of end-of-life care (Farrington, 2014); four papers define palliative care (Beck et al., 2012; Beck et al., 2014; Hockley et al., 2005; Waldron et al., 2008), and one mentions the WHO definition of palliative care without presenting it (Bökberg et al., 2019).

**2.3.4 Sample size:** ranged from one nursing home (Farrington, 2014; Levy et al., 2008; Little et al., 2019; Livingston et al., 2013) to ninety-five nursing homes (Badger et al., 2012). However, while Badger et al. (2012) refers that of the ninety-five nursing homes that participated in the first phase of GSFCH programme, only ten had been selected, as case studies, for evaluation, Hockley and Kinley (2016) report that up to 76 nursing homes participated in the GSFCH programme, along the seven years quality improvement initiative.

**2.3.5 Participants:** although staff, relatives and residents were included in the 33 interventions, resident outcomes were often indirectly assessed, through records' audit or through staff or family members surveys. Only three papers describe interventions in which residents took part (Aasmul et al., 2018; Chan & Pang, 2010; Hall et al., 2011), while five others describe staff educational interventions, in which the outcomes were evaluated through the resident's records, questionnaires or interviews with relatives or staff (Aasmul et al., 2018; Chapman et al., 2018; Little et al., 2019; Livingston et al., 2013; Verreault et al., 2018).

Fourteen papers refer staff as participants, although not defining their professions. Managers, nurses, and care aides, as well as doctors, took part in the interventions. Only one intervention was specifically addressed to doctors who provided care to the facilities (Keay et al., 2003). Manager numbers varied from four (Beck et al., 2014) to thirty (Badger et al., 2012), but it is not clear when the manager is a nurse or another professional. One hundred and fifteen nurses (Aasmul et al., 2018) and between nine (Hall et al., 2011; Phillips et al., 2008) to two-hundred and eighty care aides (Bökberg et al., 2019) took part in the interventions.

## **2.4 Type of Interventions**

The literature review revealed a large diversity in the type of nursing home intervention and programme evaluation. Most of the papers do not distinguish between the intervention and the

research objectives. Many papers do not mention the intervention implementation dates. An educational component was present in all but one intervention (Chan & Pang, 2010). Besides education, two more strategies were used in the interventions: advance care planning and integrating a palliative care team in the nursing home. While in some nursing homes staff lacked previous training in palliative care, in others at least basic training existed before the intervention.

Multicomponent interventions encompassed organizational change, symptom control of and communication with residents at the end-of-life and their families. They included the use of the Gold Standards Framework for Care Homes (GSFCH) programme, advance care planning (the COSMOS trial, the MAPP programme, the “Let me Talk”, the “Let me Decide”, and the “Advance Care Wishes” programmes), or study circles (discussions about texts and participants experiences, as well as workshops to discuss suggestions of facility change).

Two sets of papers refer to the same intervention each: Badger et al. (2009, 2012) and Beck et al. (2012) and Beck et al. (2014). The 2009 Badger et al. paper evaluates the impact of phase 2 GSFCH introduction on nursing homes end-of-life care, using a pre–post survey design, while the 2012 paper evaluates its impact on nursing home staff collaboration with other health professionals, using survey methods and qualitative case studies. Conversely, the Beck 2012 paper describes the influence an intervention using a palliative care approach had in care aides work, while the 2014 one describes its effects on care provision and climate. The first used semi-structured individual interviews to collect data, while the second one employed questionnaire before, immediately after the intervention, and six-month later.

Four papers describe interventions related to end-of-life care of residents with dementia, where different strategies were used. One of the papers reports of an audit and feedback strategy, where bereaved relatives rated their satisfaction with care and comfort at the end of the residents’ life, after which results were discussed in the nursing home team meetings and improvement strategies proposed (Boogaard et al., 2018). Another one, focused in improving the quality of care and the quality of dying (symptom control and comfort), combined a multidimensional intervention (encompassing pain monitoring, regular mouth care and communication with relatives about end-of-life care) with a facilitator to support change in the institution (Verreault et al., 2018). A third intervention approached advance care planning (Livingston et al., 2013), while Moore et al. (2017) intervention covered both staff education and training, with a residents’ person-centred evaluation.

Several interventions were related to advance care planning, either integrated in multicomponent interventions, like the GSFCH (Aasmul et al., 2018; Badger et al., 2009, 2012; Baron et al., 2015; Finucane et al., 2013; Hall et al., 2011; Hockley & Kinley, 2016; Keay et al., 2003), the COSMOS trial (Aasmul et al., 2018) or the MAPP programme (Levy et al., 2008), or in programmes addressing end-of-life wishes communication, like the “Let me decide” (Cornally et al., 2015) or the “Let me talk” (Chan & Pang, 2010) programmes. Only three interventions had a direct contact with the residents: the “Let me talk” used a storytelling approach where the residents were stimulated to travel through their past, linking it with the present and project themselves into the future, while in a second one the residents participated in the intervention intended to improve communication between the residents, relatives and staff (Aasmul et al., 2018), and in the third the residents were interviewed to evaluate the perceived benefits of the programme implementation (Hall et al., 2011). The remaining papers on interventions with at least a component on advance care directives just reported on the residents’ files audit. One paper reported on an intervention implementing a palliative care team in each nursing home (Hanson et al., 2005).

Twenty-four papers refer to the presence of an intervention coordinator/facilitator (Aasmul et al., 2018; Badger et al., 2009; Badger et al., 2012; Baron et al., 2015; Beck et al., 2012; Beck et al., 2014; Chan & Pang, 2010; Chapman et al., 2018; Farrington, 2014; Finucane et al., 2013; Hanson et al., 2005; Heals, 2008; Hewison et al., 2011; Hockley, 2014; Hockley et al., 2010; Hockley & Kinley, 2016; Kinley et al., 2014; Levy et al., 2008; Little et al., 2019; Moore et al., 2017; O’Brien et al., 2016a; Phillips et al., 2008; Verreault et al., 2018; Waldron et al., 2008). Some interventions used internal facilitators (nursing home staff, who received extra-training, and supported the intervention implementation) (Aasmul et al., 2018; Hanson et al., 2005; Phillips et al., 2008; Verreault et al., 2018).

One paper describes the introduction of an early warning tool (the Significant 7) to assist with the recognition and care improvement of the residents whose clinical situation begins to deteriorate (Little et al., 2019). Two papers report on the use of high-facilitation strategies to implement the GSFCH in nursing homes: both promoted staff intensive training, one with two or three facilitator visits a month, in an eighteen-month programme (Hockley et al., 2010), while the other promoted ongoing training, role modelling and every six months introductory courses for new staff (Kinley et al., 2014). One paper reports on the use of reflective debriefing groups after the residents’ death, as a way to learn with previous experiences and to feel supported in grief (Hockley, 2014). Only one intervention used a blended (facilitated workshop and e-learning) strategy, the ABC palliative care course, for staff (other than nurses and doctors) that

provide end-of-life care (Farrington, 2014); however, Wen et al. (2012) reports an educational intervention where the lectures were videorecorded, allowing staff not able to be present to follow-up on lessons later.

The duration of the interventions varied between half-a-day (Keay et al., 2003) and two years (Cornally et al., 2015; Hockley & Kinley, 2016), but more than half of the papers did not mention the intervention timescale. Intervention follow-up occurred from six weeks (Little et al., 2019) to five years after its end (Hockley & Kinley, 2016); however, twenty-two papers do not mention the follow-up period or when the last evaluation was done.

## **2.5 Outcomes**

The most frequently measured outcomes were residents' care and symptom control. Different tools were employed: residents' files record audit, semi-structured interviews or questionnaires (staff, relatives), and focus groups (staff). The papers evaluate nursing home practices to improve symptom control and comfort at the end-of-life, emergency services visits and hospitalisations, palliative care and/or hospice referrals, staff distress or confidence in providing end-of-life care, and relatives satisfaction with the care provided.

**2.5.1 Nursing home practices:** several papers refer improvements in communication: with residents (Beck et al., 2014), between residents and families (Chan & Pang, 2010), between staff and relatives (Beck et al., 2012; Aasmul et al., 2018), among staff (Beck et al., 2012; O'Brien et al., 2016b), with GPs (Badger et al., 2012; Hall et al., 2011). Improvements were related to increased staff confidence, in-depth discussions on end-of-life care, better relevant communication, end-of-life multidisciplinary planning, and discussing advanced directives. Communication improvement enabled to discuss end-of-life care in advance (Hanson et al., 2005), preventing conflict and the need to make decisions in crisis (Cornally et al., 2015). The intervention presented by Wen et al. (2012) promoted the discussion of residents' goals of care with their relatives, documenting advance care planning and promoting the respect for different cultures or religious beliefs. However, it was recognised that although the interventions improved communication with GPs, there were still problems in obtaining GP support (Hall et al., 2011; Hockley et al., 2005) and anticipatory medication (Badger et al., 2012; Hall et al., 2011). Problems with communication inside the nursing homes also existed, with Beck et al. (2014) referring difficulties in articulating work between the care aides and the nurses, Beck et al. (2012) referring a perceived lack of supportive leadership, and Farrington (2014) reporting that care aides felt that nurses control made difficult to implement change.

Symptom improvement was also mentioned as a result of the interventions, namely nausea and dyspnoea (Brännström et al., 2016), and pain, dyspnoea and other uncomfortable symptoms at the end-of life (Keay et al., 2003). Also improved were pain assessment (Hanson et al., 2005; Wen et al., 2012) and management (Moore et al., 2017; Wen et al., 2012). Hanson et al. (2005) state that although non-pharmacologic pain treatment improved, there was no change in pain medication use. In the Brännström et al. (2016) intervention, fatigue and sleepiness increased. The existence of care protocols, to improve the quality of care and the quality of dying, was also mentioned (Badger et al., 2009).

**2.5.2 Emergency services visits and hospitalisations:** there was mixed evidence regarding the impact of interventions on hospital admissions and deaths. A reduction of hospital admissions, inappropriate deaths at the hospital, and lengths of stay (Hockley et al., 2010) were described. Rates of hospitalisation did not change (Chapman et al., 2018), while death rates at the hospital reduced (Chapman et al., 2018; Hockley et al., 2010) or increased (Finucane et al., 2013).

**2.5.3 Palliative care and/or hospice referrals:** two papers report improvement in hospice enrolment (Hanson et al., 2005) or referral to a palliative care team (Levy et al., 2008). However, Levy et al. (2008) mention that the mean of days in hospice or palliative care had no significant improvement.

**2.5.4 Advance care planning:** pathways were also used in the last days of life to support staff when providing care at the end-of-life (Aasmul et al., 2018; Finucane et al., 2013; Hockley et al., 2010; Hockley & Kinley, 2016; Keay et al., 2003; Levy et al., 2008; Livingston et al., 2013; Moore et al., 2017; O'Brien et al., 2016b). Other studies mention the existence of improved documentation (Heals, 2008), documented preferred place of death (Chapman et al., 2018), and do not resuscitate (DNR) orders (Finucane et al., 2013; Hockley et al., 2010; Hockley & Kinley, 2016; Kinley et al., 2014; Levy et al., 2008; Livingston et al., 2013). However, Kinley et al. (2014) showed no significant difference in registered DNR orders between intervention and control group.

**2.5.5 Staff distress or confidence in providing end-of-life care:** several papers focused on staff confidence in providing end-of-life care (Farrington, 2014; Hall et al., 2011; Heals, 2008; Hockley et al., 2005; Little et al., 2019; Livingston et al., 2013; O'Brien et al., 2016b; Phillips et al., 2008). The interventions gave staff more knowledge and improved their confidence in talking with residents, families and the GPs (Heals, 2008), dealing with multidisciplinary teams (O'Brien et al., 2016b), and in promoting end-of-life planning and implementing advanced care (Livingston et al., 2013).

One intervention showed positive results in improving staff distress when caring for older residents; however, its effect did not last long, as showed by a follow-up at nine months (Aasmul et al., 2018).

**2.5.6 Family perception of residents’ care:** seven interventions evaluated relatives’ satisfaction with care, with different results. Livingston et al. (2013) and Moore et al. (2017) referred that relatives noticed improved symptom control, with the first stressing the importance the relatives gave to feeling supported when making decisions. Two papers evaluated satisfaction with quality of care (Moore et al., 2017; Verreault et al., 2018) and quality of dying (Verreault et al., 2018), with improvements after the intervention. Improvement in nausea and dyspnoea, but not in pain control, were mentioned by Brännström et al. (2016). The Boogaard et al. (2018) feedback intervention showed no improvement on perceived quality of care and quality of dying, while Aasmul et al. (2018) refers improved communication between relatives and nurses, but not with the nursing home doctor.

## 2.6 Initiation of change – facilitators and barriers

This section report on the strategies used to facilitate change and the barriers identified to effectively initiate it.

### 2.6.1 Facilitators

The papers reported several strategies to ensure successful initiation of change. The importance of external support (from local hospices, community palliative care teams or specialist nurses) through the use of an intervention facilitator was highlighted. Motivation to change and the use of adapted training strategies were also emphasised. The presence of a facilitator and the existence of institutional (internal) support to bring about change (Table 6) were also valued.

Table 6: end-of-life care improvement interventions facilitators

External support	Internal facilitator	Motivation to change	Use of adapted training strategies	Internal support
Hanson et al., 2005 Heals, 2008 Waldron et al., 2008 Chan and Pang, 2010 Hockley et al., 2010	Phillips et al., 2008 O’Brien et al., 2016 Aasmul et al., 2018 Verreault et al., 2018	Keay et al., 2003 Hanson et al., 2005 Levy et al., 2008 Phillips et al., 2008 Waldron et al., 2008 Badger et al., 2009 Farrington, 2014 Kinley et al., 2014	Heals, 2008 Hewison et al., 2011 Badger et al., 2012 Wen et al., 2012 Farrington, 2014 Kinley et al., 2014 Baron et al., 2015	Keay et al., 2003 Chan and Pang, 2010 Hockley et al., 2010 Finucane et al., 2013 Hockley, 2014



<b>External support</b>	<b>Internal facilitator</b>	<b>Motivation to change</b>	<b>Use of adapted training strategies</b>	<b>Internal support</b>
Hall et al., 2011 Hewison et al., 2011 Badger et al., 2009 Badger et al., 2012 Beck et al., 2012 Wen et al., 2012 Finucane et al., 2013 Beck et al., 2014 Farrington, 2014 Hockley, 2014 Kinley et al., 2014 Baron et al., 2015 Hockley and Kinley, 2016 O'Brien et al., 2016 Moore et al., 2017 Chapman et al., 2018 Little et al., 2019		Moore et al., 2017 Little et al., 2019	Cornally et al., 2015 O'Brien et al., 2016 Moore et al., 2017 Chapman et al., 2018 Little et al., 2019	Moore et al., 2017 Bökberg et al., 2019

Facilitators were part of external teams that developed the interventions (GSFCH, or the “Let me decide” programmes, ABC course), or selected nursing home staff who received extra-training to enable them to replicate the educational sessions, or to support the institutions where they worked. Several papers did not specify the existence of a facilitator (Bökberg et al., 2019; Boogaard et al., 2018; Brännström et al., 2016; Cornally et al., 2015; Hockley et al., 2005; Keay et al., 2003; Levy et al., 2008; Livingston et al., 2013).

In some papers the use of an internal or external facilitator is not clear. Brännström, who does not mention a facilitator, met regularly with the nursing home manager and nurses, while implementing the intervention (Brännström et al., 2016). Others, like Hall et al. (2011), who do

not mention facilitators, evaluate the perceived benefits and barriers to the implementation of the GSFCH; however, the GSFCH intervention use facilitators in its implementation strategy.

The existence of internal support, from management or nurses, was described as facilitating the interventions implementation and change. Likewise, to ensure successful implementation several papers mention that nursing homes have to be motivated, without which the intervention will fail. Another important aspect is the use of adapted training strategies, that promote staff adherence to training and improve learning. Besides educational sessions (lectures, workshops), the interventions used e-learning (Farrington, 2014), role-play and case-study discussions (Baron et al., 2015), educational material for relatives and residents (Cornally et al., 2015), newsletters for staff (Heals, 2008), or training updates (O'Brien et al., 2016).

### **2.6.2 Barriers**

Staff and time constraints, and often difficult relationships with doctors, were the main barriers named in successfully completing and integrating the intervention in the nursing home culture of care (Table 7).

Table 7: Barriers for intervention implementation

		<b>Barriers</b>	<b>References</b>	
<b>Time constraints</b>		time management	Waldron et al., 2008 Hall et al., 2011	
		to attend training	Hewison et al., 2011 Hockley, 2014 Moore et al., 2017	
		to implement the intervention	Cornally et al., 2015 O'Brien et al., 2016 Bökberg et al., 2019	
		to discuss problems or share experiences	Farrington, 2014	
<b>Staff constraints</b>		ineffective leadership	Hanson et al., 2005	
		difficulties to attend training and problems with continuity of care	lack of trained staff Hockley and Kinley, 2016	
	staff turnover		need to substitute staff	Heals, 2008 Hockley, 2014 O'Brien et al., 2016
			staff or management turnover	Hockley et al., 2010 Baron et al., 2015
			residents' hospital deaths	Finucane et al., 2013
			capacity to identify frail residents close to death	Finucane et al., 2013
			intervention implementation	O'Brien et al., 2016
			intervention evaluation	Baron et al., 2015 Bökberg et al., 2019
<b>Difficult relationships with doctors</b>		lack of involvement of doctors	Keay et al., 2003 Hockley et al., 2005 Cornally et al., 2015 Aasmul et al., 2018	
		difficult relationships	Hall et al., 2011 Badger et al., 2012	
		difficulties in accessing GPs	Badger et al., 2009	
		difficulties in accessing GPs in out-of-hours service	Badger et al., 2012	
		timely referral of very frail residents to palliative care services	Levy et al., 2008	

Time constraints were a major problem. General concerns of time management by the nursing homes were raised, with an impact on staff availability to participate in training or in interventions aimed at nursing home change, implementing change, caring for residents, and communicating with them and relatives.

Problems with staff retention and recruitment were also mentioned. Ineffective leadership, and staff or management turnover, were seen as a hinderance to change, while the lack of trained staff, or the need to substitute staff, made it difficult to attend training, while affecting continuity of care. Staff turnover was also mentioned as causing problems in identifying frail residents close to death, contributing to inappropriate hospital referrals at the near-death stages, and therefore increasing the number of hospital deaths. Furthermore, staff turnover interfered with intervention implementation and evaluation. Despite the staff-related constraints already mentioned, the research undertaken by Heals (2008) found that staff turnover can be positive, as new staff can be trained, while those who leave to other nursing homes can potentially raise the level of care in new places of employment.

The delayed referral of older residents to palliative care or hospice services, jeopardizing the access to fundamental care, was also seen as a barrier. As well, access to doctors or end-of-life medications were seen as problematic, in particular if needed out-of-hours, hindering the quality of care.

## **2.7 Sustaining the interventions**

Intervention sustainability is the capability of an institution to maintain, without external support, the intended benefits after the end of an intervention (Rabin et al., 2008). Most of the papers do not provide information on which resources are needed to sustain interventions. Only two papers specifically address sustainability (Hockley et al., 2010; Hockley & Kinley, 2016), while six other briefly mention the subject (Aasmul et al., 2018; Beck et al., 2014; Finucane et al., 2013; Hockley, 2014; Hockley et al., 2005; O'Brien et al., 2016a). An analysis of how sustaining the interventions was considered identified four main themes: support; reflective thinking; ongoing learning and funding.

**2.7.1 Support:** sustaining nursing homes change, and improving end-of-life care, needs ongoing support, stable management, and commitment to change. External ongoing support (from local hospices or palliative care nurse specialists) and the appointment of nursing home champions seem to be key to change and to the sustainability of change (Aasmul et al., 2018; Finucane et al., 2013; Hockley et al., 2005; Hockley & Kinley, 2016). Peer support from nursing homes that had completed the programme (Hockley et al., 2005; O'Brien et al., 2016a) was also seen as a way to improve sustainability. However, management turnover, with possible different policy developments or intervention commitments (Finucane et al., 2013), as well as different viewpoints between staff and management (Hockley et al., 2010), can hinder sustainability and

the development of a different culture of care. Continuous and long-term in-depth support for those nursing homes where the programme's values are not yet embedded in the home's culture, seem to be crucial to sustain change (Beck et al., 2014; Hockley et al., 2005; O'Brien et al., 2016a).

**2.7.2 Reflective thinking:** audit, critical thinking and the use of reflective debriefing groups after residents' death were ways to improve learning and practice, central to support change. Audit seem to be an important component of nursing homes interventions to promote quality end-of-life care. Audit data analysis and feedback to nursing home management and staff, followed by critical reflective thinking on data (Aasmul et al., 2018; Boogaard et al., 2018; Hockley, 2014; Hockley & Kinley, 2016; Verreault et al., 2018), can contribute to reshape the interventions, to improve documentation on end-of-life care delivery and to bring about change (Hockley & Kinley, 2016), in a cycle of continuous improvement. Reflective debriefing groups after a residents' death also promote staff's critical, reflective thinking about their own feelings and practice (Hockley, 2014), as a way to improve self-learning on end-of-life care, and to increase nursing home culture of care.

**2.7.3 Ongoing learning:** as a mechanism to support change, training of regular and new staff seems essential to integrate end-of-life care into the nursing home care culture (Hockley et al., 2010). Suggestions of a specific induction programme for new staff have been made (O'Brien et al., 2016a), while a long-term sustainability programme developed into a monthly run "introduction to palliative care day" for all staff (Hockley & Kinley, 2016, p. 477).

**2.7.4 Funding:** Hockley et al. (2010) and Hockley and Kinley (2016) emphasise that the maintenance of nursing homes end-of-life care cultural change is not possible without costs. The ongoing support needed to maintain the results achieved through nursing homes intervention programmes have costs: concerns have been raised about funds to support nursing homes, after the interventions finished (Hockley & Kinley, 2016). Hockley and Kinley (2016) and O'Brien et al. (2016) also argue for the cost of sustainability being anticipated.

## **2.8 Discussion**

The need to improve nursing home end-of-life care has been recognised, with the Covid-19 pandemic in particular calling attention to the challenges posed in this context (Lapid et al., 2020). This review aimed to identify nursing homes interventions developed to improve end-of-life care, and the resources needed to sustain them. The literature review focused on nursing

homes, excluding other important places of care, such as hospitals and old peoples' homes. Although a Latino-American database (LILACS) was included in the search strategy, no results on the topic were found: this may be related to a lack of development of end-of-life care research in nursing homes in Latin-American countries.

It is not clear which end-of-life care definition was used in the interventions, as almost no definitions were provided. As end-of-life care can have different meanings (Froggatt et al., 2006), not knowing which one was used was problematic from the analysis viewpoint; however, as highlighted by Froggatt and Payne (2006), if the main objective is to provide a continuum of high-quality care from admission to a nursing home (or even before) to after the resident's death, this can also be positive.

The included studies were characterized by variable methodological quality; data were incomplete or poorly described, methods and data collection were not clearly presented, reasons for staff or nursing home selection were unclear, staff functions were not detailed, the importance of the findings for policy and practice was vague. In addition to the intervention, other reasons may have contributed to the change, but were not searched for or disclosed. Institutional change has thus been attributed to the intervention; however, only three randomised controlled trials (RCT) were included, with a third of the studies using an uncontrolled before-after design.

The majority of the papers in this research used quantitative methods. However, research has highlighted a need for more qualitative research on residents' experiences on end-of-life care (Greenwood et al., 2018). Qualitative methods are deemed effective in obtaining in-depth and clear data on social and personal experiences, and a deeper understanding of the complexities surrounding the end-of-life, contributing to improve knowledge and inform policy-decision making (Gonella et al., 2021). In a search for more robust evidence, RCT have been used more in nursing and social sciences. However, only three RCT were included in the review, with the majority of the other interventions using a pre- and post-intervention comparison design. Two studies used action research, a methodology adequate to obtain evidence and overcome some research barriers in this setting (like differences in professional experience or skills, and staff turnover) (Iida et al., 2021).

Although some interventions seem to improve communication with GPs, several studies mention difficulties in communication or in obtaining support, even after the intervention was implemented; however, only two interventions included doctors, and just one was specifically designed for them. The importance of anticipatory end-of-life care decisions is known, as the

role of healthcare staff in discussions with patients and relatives. However, research shows that end-of-life care issues were discussed less frequently by doctors with nursing home residents in Belgium, than with hospital patients (Evans et al., 2014). The papers report research in countries where palliative and end-of-life care are well developed and exist since a few decades; it is possible then that the doctors have training in this area and do not feel a need to improve it. If papers from south-European countries were retrieved, possibly the results would have been different. The doctors' alleged lack of time, that some of the papers report as an excuse or a reason to not participate in the interventions, were also found by other authors (Sharp et al., 2013). It is also possible that doctors were not integrated in the interventions because they were not part of the nursing home staff, an aspect with possible implications for the practice and organization of these institutions.

The interventions improved nursing homes practices, namely early detection of residents with palliative needs, documentation on symptom assessment and control, communication about the residents' end-of-life care wishes and goals of care. Communication between staff and residents (or relatives) on end-of-life issues was described as difficult, with perceived improvement after the interventions. Quality end-of-life care relies on good communication between all the stakeholders, allowing older residents to define and plan ahead the last phase of their lives, avoiding the pain of crisis decisions; to achieve this objective, communication skills improvement has been advocated for nursing home staff, contributing to meet the residents' goals of care (Bennett et al., 2021) and ultimately to improve them (Payne et al., 2018), as highlighted by several papers in this literature review.

Most of the papers report on improvements from a staff viewpoint, and showed little or heterogeneous evidence of the interventions effect on symptom control, relatives' care evaluation or advance care planning. Two of the three cluster RCT showed no improvement in end-of-life care outcomes or its continuation at a nine-month follow-up evaluation, while the third one showed no significant effect. Of the four interventions addressing residents with dementia, one found no evidence of improvement, while the remaining three showed improvements in documentation on end-of-life care wishes and relatives care evaluation.

Nursing home staff development through education was an important component of almost all interventions (Froggatt et al., 2006). Research shows a need for education and training, tailored to the context and staff needs, although education alone does not change practice (Bui et al., 2020; Collingridge Moore et al., 2020). Concerns have been raised that nursing homes' residents should be heard and preferences fulfilled (Froggatt & Payne, 2006); the Chan and Pang

intervention (2010), aimed to give voice to nursing home residents' wishes, being the only intervention that had no educational component, a noteworthy exception. As most of the interventions ultimately have the goal of improving residents' end-of-life experiences, there is a need for the development of interventions that allow stakeholders to express their views. There are recommendations in research for the inclusion of residents and relatives. Effective integration of residents in research is possible, in particular when participatory action research is used (Backhouse et al., 2016; Higginson et al., 2013).

Several papers report on resident outcomes, mainly evaluating advance care planning or cardiopulmonary resuscitation documentation, crisis admission to hospital or place of death. Some evaluated the intervention effect on symptom control (Brännström et al., 2016; Hanson et al., 2005; Heals, 2008; Keay et al., 2003; Moore et al., 2017; Verreault et al., 2018); however, only one intervention was directed to prevention (Little et al., 2019), and none of the papers describe interventions aimed at supporting staff, the relatives or even the other residents when one of them dies.

Notwithstanding the use of online technology and high-facilitation have been advocated as resources to incorporate new knowledge in practice, to sustain institutional change, only one intervention used these strategies (Farrington, 2014; Iida et al., 2021). Given the increased and generalised use of new technologies in the Covid-19 era, this is probably an area that will soon see great development.

Due to its nature and differences in social contexts, implementation time of the interventions varied among studies, already highlighted by other authors (Damschroder et al., 2009; van Riet Paap et al., 2015). The introduction of interventions (multicomponent, care pathways, others) to improve end-of-life care through the organizational change process seem to be fundamental to support staff (Chan & Webster, 2011; Kinley et al., 2018; Seymour et al., 2011), but are not enough to sustain change by themselves (McConnell et al., 2013).

Despite the rigour of the search strategy few had data on the resources needed to maintain change. Sustaining an intervention is a complex and dynamic process (Buchanan et al., 2005; Burnes, 2017) that implies that at a nursing home level, achieved change becomes embedded in the culture of care, through continued effort (Martin et al., 2012). Few papers discuss the topic of sustaining the interventions. Of the eight papers that address intervention sustainability, a note of interest is that Hockley was co-authors of four (Hockley et al., 2005; Hockley et al., 2010; Hockley & Kinley, 2016; Kinley et al., 2014), in three as first author. Maintaining change achieved by the intervention is an important but apparently neglected



aspect in the nursing home context. In this review follow-up was mentioned in just a third of the interventions, after a year or less, with one exception. The four main themes related to sustaining the interventions identified in this review (support, reflective thinking, ongoing learning and funding) were also emphasized by other authors (Colón-Emeric et al., 2016; Hoben et al., 2021). Recent research also highlighted the need for considering to address interventions' sustainability during, and not just after, their implementation (Devi et al., 2022).

The literature review covers twenty years, from 2000 to 2019. More papers on intervention in nursing homes, aimed at improving end-of-life care, have been published from 2020 on; some will be used in the Discussion chapter, allowing for more contrast and comparison in this area.

In summary, although multiple interventions were carried out, there was mixed evidence in suggesting that nursing homes end-of-life care improved after the interventions' implementation. Moreover, sustaining the interventions is still a disregarded aspect which clearly needs attention.

## **2.9 Strengths and limitations**

A strength of this review is the inclusion of a broad range of electronic databases, as well as the manual search for other studies, over twenty years. The use of a long list of multiple search terms might have contributed to the large number of papers found; the search of relevant palliative care journals and the hand search of the references accepted generated a small number of papers, indicating good sensitivity, another strength of the review.

In terms of limitations, one reviewer conducted the synthesis, allowing opportunities for error and limited objectiveness. It is not possible to guarantee that relevant papers were not missed, despite the search strategy identifying many papers. Searches were conducted between 2000 through the end of 2019. It is possible that other relevant papers have been published before or since, limiting the information on the review theme. The selection criteria excluded papers written in languages other than English, French, Spanish and Portuguese.

Despite having performed a comprehensive search strategy it is possible not all published data on the literature review subject were identified. No papers published in Portuguese or Spanish were found, despite LILACS database was searched. With the exception of the Chan and Pang, (2010) paper, the interventions took place in a limited number of western countries, which prevents the generalizability of the findings due to the diversity of care contexts. The papers' heterogeneity made the information synthetization challenging, although the narrative

synthesis approach was used. Research design was not mentioned in many papers, with just one paper providing a definition of end-of-life care (Farrington, 2014). Heterogeneity characterizes the type and duration of the interventions, as well as the resources needed to sustain change, making comparison difficult. Data are scarce on intervention sustainability resources, becoming unclear when other factors could contribute to sustain change besides the ones found: future research is needed to address this knowledge gap.

## **2.10 Implications for future research, policy and practice**

Research has shown that with the world population growing older, with multiple health problems, ongoing adaptation is needed for health and social care. Nursing homes are the place where a considerable part of this population lives the last months or years of their lives, and eventually dies. The quality of care provided is varied. Providing the nursing homes with conditions that allow older people to live with the most effective care and with dignity until the end, implicates a serious effort to change care, at a local and global level. Research on this process of change and its implementation is fundamental to improving the care provided. Since nursing home characteristics are very different from country to country, and sometimes from region to region within the same country, there is a need to find methodologies that allow for a deeper, comprehensive and global view, and to promote more effective interventions, whose effects stay on in time.

This review has identified limited robust research evidence on nursing homes interventions to improve end-of-life care. It has identified a need for research that values those who work and those who live in nursing homes, and to promote sustainable changes. It is essential to hear the stakeholders and staff's voices, promote consistent but flexible training and education, create a culture of ongoing reflection and learning, and guaranty ongoing support: all these are areas where research is needed. Further qualitative and quantitative research on nursing homes interventions aimed to improve end-of-life care and on the resources needed to sustain change is therefore warranted.

## **2.11 Conclusions**

The papers included in this literature review refer to several different interventions whose aim was to improve end-of-life care in nursing homes. Those interventions were geared to different nursing homes' professionals, or to improve structure, process and outcome data. Although the

papers' heterogeneity limits the generalization of conclusions, it is reasonable to say that sustaining the interventions is not possible without costs, and that these should be anticipated and taken into consideration, when planning interventions to improve end-of-life care. Reflective thinking, continuous learning, and ongoing internal and external support are needed to sustain change and to integrate end-of-life care into the nursing homes' care culture.

## **Chapter 3 – Methodology and Methods**

Since its beginning this research sought to work with nursing home staff, contributing to their empowerment, and to improve knowledge and care. Methodology refers to the research framework and methods to the tools or techniques used to undertake this research. A Participatory Action Research (PAR) methodology was chosen to achieve the research objectives.

### **3.1 Methodology**

This section introduces the methodology chosen to achieve the objectives of this research.

#### **3.1.1 Introduction**

In this chapter a description of the research, its objectives and its philosophical perspectives will be presented, as well as the way data collection and analysis were performed through the research cycles. The aim of this research was to develop a culturally appropriate organizational programme to prepare nursing home staff to care for older people at the end-of-life. The research question was “How can a culturally appropriate organizational programme for nursing home staff be developed to care for older people at the end-of-life?”.

The research objectives were:

1. to identify the needs (including learning, management, emotional support) of nursing home staff when caring for older people at the end of life;
2. to understand the cultural nuances of providing care at the end-of-life in nursing homes;
3. to develop with nursing home staff a culturally appropriate programme that meets their needs; to deliver and run the programme; to evaluate the impact on staff practice after the programme implementation and to draw up plans for future development work.

A Participatory Action Research (PAR) methodology was chosen to achieve the research objectives, which will be discussed below, along with a description of the philosophical positioning of the research.

#### **3.1.2 Philosophical perspectives**

The choice of a methodological approach is influenced by the researcher's worldviews (the way the researcher perceives reality), as well as by his/hers philosophical reflection process (Bendixen & Rule, 2004; Pansiri, 2009). The researcher's adopted paradigm (values, beliefs and standards) enlightens knowledge creation: reality can be seen as objective (knowledge as a conceptual representation of external reality) or subjective (knowledge as a personal achievement) and the approach taken to the research process is based on this paradigm. The choice of paradigm regulates understanding of the nature of reality (ontology), the criteria used to judge the validity of created knowledge (epistemology), and the strategies, procedures and techniques used for data collection and analysis (methodology and methods) (Scotland, 2012). Assumed philosophical paradigms or worldviews (a broad set of values and beliefs that mould the way an individual interprets and interacts with the world), the nature of the research question and the problem under investigation, as well as personal positioning, shape the way research is conducted (Berryman, 2019; Denzin & Lincoln, 2017). Research design is thus shaped by the researcher's multifaceted, complex and context-bound understanding of the nature of reality (ontology) and knowledge (epistemology) (Bunniss & Kelly, 2010; Mclachlan & Garcia, 2015; Petty et al., 2012; Schraw, 2013).

Knowledge is, then, socially and culturally constructed from different personal meanings through a dynamic process in which the experience of reality, learning and knowledge is different and equal from person to person (Coghlan & Brydon-Miller, 2014; Schraw, 2013; Scotland, 2012). The quest for knowledge brings research and participation together, intertwining them as a consequence of the researcher's adopted ontological and epistemological assumptions regarding knowledge creation (Mantoura & Potvin, 2012).

Researchers emphasise the importance of choosing the most appropriate methodology to address the research issue (Bryman, 2012b; Offredy & Vickers, 2010; Spencer, 2008). Literature shows that research conceptualization and its direction is influenced by the researcher's adopted paradigm and that every paradigm creates important information (Bunniss & Kelly, 2010). The research paradigm (a broad system of practice and thought correlations that characterise the essence of inquiry) guided the selection of the research methodology. The context of the research (the nursing home) and the nature of the research question (how), as well as my own values, guided the choice of the approach (Berryman, 2019; Darlaston-Jones, 2007; Hammersley & Atkinson, 2007). Three major dimensions were encompassed and intrinsically associated with the research process: the nature of reality (ontology) and knowledge (epistemology) and the philosophy behind the research process (methodology) (Lincoln & Guba, 2000).

### 3.1.2.1 Ontology and Epistemology

Ontology is concerned with the form and nature of reality, epistemology refers to the nature of knowledge and the approach to knowledge and learning, while methodology exposes the rationale for the way research should proceed (Berryman, 2019; Creswell, 2014; Jackson, 2013). Depending on the ontological and epistemological philosophies assumed, reality(ies) and truth(s) are perceived and experienced in different ways in the context of the research. Reality is either unique and independent of human perceptions and interpretations (positivist) or multiple, relational, co-created and context bound (interpretivist). The first approach aims to find cause and effect, which leads to quantifiable research questions (how, why) - researchers seek objectivity and stay detached from participants. The latter pursues understanding, explanation and meaning, leading to qualitative questions (how, what) - research takes place in a context, with the close cooperation of the participants in the research process (Berryman, 2019; Creswell, 2013, 2014; Loewenson et al., 2014). Furthermore, Bryman (2012) highlights that in social research, reality (ontology) can be either objective and independent of the researcher (objectivism) or a result of social interactions (constructionism). Reality (what exists – ontology) and the way to know it (epistemology) are thus intertwined, as reality can be known through knowledge progress.

Knowledge generation was possible through cooperation between researcher (myself) and participants (nursing home staff), a wish to co-learn, a desire to exchange expertise, to share decision-making power, and consent to mutually control the research process. Co-learning is a process of mutual learning and, by analogy with Brantmeier (2013), power deconstruction. Co-learning encompasses the researcher's own assumption of not knowing everything, contributing to power sharing and to the participants' empowerment, leading to a participatory commitment that generates knowledge. I saw myself not as a detached observer, but as a co-researcher with the participants, themselves holders of experiential knowledge, therefore with a unique and genuine view of their own problems. I recognised the nursing home reality as being complex and multifaceted, brought forward by the different views of different participants. Generating new and socially constructed knowledge was possible through the interaction between the participants and myself in the specific context of this nursing home, bridging the gap between theory and practice. Stating this, I recognise the interpretivist paradigm as the methodological choice for answering this research's questions.

My ontological and epistemological stances and my philosophical reflection process (Bendixen & Rule, 2004; Pansiri, 2009), in parallel with the participants' experiential knowledge and desire for social change, genuine cooperation and mutual desire to share knowledge, to co-learn, and to bring about change, led to the choice of a PAR approach (Viswanathan et al., 2004).

### **3.1.3 Participatory Action Research**

The philosophical premise underlying PAR is compatible with the postmodern tradition in which multiple realities are acknowledged but objectivity is unachievable, and in which research contributes to the generation of change (Charles & Ward, 2007; Kelly et al., 2015). PAR has been defined in different research sectors, and used in different contexts (health, agriculture, education, climate change, mining, tourism). As a result, distinct definitions and meanings can be ascribed to it. It is "research which involves all relevant parties in actively examining together current action (which they experience as problematic) in order to change and improve it (...) by critically reflecting on the historical, political, cultural, economic, geographic and other contexts which make sense of it" (Wadsworth, 1998, p.10). It is "problem-focused or context-specific research centred on a particular problem involving all participants" (Anderson & McFarlane, 2014, p.97), a democratic process that subsequently culminates in the development of pragmatic knowledge (Ospina et al., 2008), "privilege[ing] the experiences and perspectives of a given community in defining and resolving community problems" (Christensen et al., 2019, p.28).

More than a research methodology, PAR is a process that raises awareness of social inconsistencies and sees reflection as key to the process of personal empowerment and social change (Freire, 2000). Participant collaboration is key to their empowerment (Fals Borda, 2005; MacDonald, 2012). Participants are no longer "research subjects": research is conducted *by* or *with*, not *on* or *for* participants, who are therefore considered co-researchers (Swantz, 2008), community members actively engaged in data collection and analysis as well as in bringing about change. A process of encouraging the participants to share their experiences was used in the current research; this was done by valuing their insider knowledge, stimulating their collaboration in data collection and their interpretation of data meanings, sharing research leadership in different research moments and co-constructing research findings (Martin et al., 2019; Pope, 2020). In this systematic enquiry process, knowledge was co-created by the researcher (myself) and the co-researchers (nursing home staff) in a transformative and

empowering process that strengthened a sense of community and conscientization, leading to action and ultimately to change (Kemmis & McTaggart, 2005; Shani et al., 2012; Young, 2006).

Charles and Ward (2007) call attention to the existence of PAR different main characteristics, as highlighted by distinct authors. Its participatory orientation, cooperative community involvement, co-learning practice, community skills development, participant empowerment, and reaching a research-action equilibrium constitute the core principles of PAR (Minkler & Wallerstein, 2008). Bunniss and Kelly (2010) name it an “iterative research design” (p.361), which Kelley and McKee (2013, p. 42-43) see as consisting of “identifying a problem; planning a change; acting and observing the process and consequences of the change; reflecting on these processes and consequences; and re-planning, acting, observing and reflecting (repeating the cycle)”. Reason and Bradbury (2008) also emphasise participation, collaboration, co-learning and the research-action balance, but add research democratisation (resulting from equalisation of the relationship between researcher and participants, and co-ownership of the research process and the knowledge generated), flexibility (through dialogue and reflective cycles of planning-action-observation-reflection) and action-change agreed by all participants.

The reflection process at the heart of this methodology contributes to change in participants’ worldviews, as well as to co-learning and to a broadening of knowledge and theory (epistemology) (Bjørn & Boulus, 2011). This “extended epistemology” (Heron & Reason, 2008), where knowledge drives action, is explicit in the PAR cycles of search-reflection-action (Marshall & Rossman, 2006), which aim to continuously develop knowledge and promote change through shared reflection and scrutiny (Koch et al., 2002). It is this interaction between self and collective reflexivity that enables PAR to realize the complexities of a particular situation or context, engage with those contexts and improve them through ongoing collaboration between researcher and co-researchers (Baum et al., 2006). Community change is thus the result of all the research participants partnerships (Minkler & Wallerstein, 2008).

Using PAR I was seeking understanding and improvement (Bradbury, 2015). Knowledge creation was based in the participants’ values, experiences and contexts (interpretive paradigm), rather than in evidence collected by me (positivist paradigm) (Malterud, 2016). Accepting that the research would be marked by my own values (Hammersley & Atkinson, 1983), I was rejecting a neutral stance to research (Janesick, 1994) and affirming reality as being socially constructed (Miller & Nowacek, 2018). Research decentralization (from a more orthodox, positivist social science research perspective) was achieved through the particular anchoring of PAR in a local context – the nursing home (Marshall & Rossman, 2006). Listening to community voices,



experiences and information were exchanged, which contributed to the building of themes and to the establishment of common meanings. PAR pursues social change using the Action Research methodology: in this study, cycles of action-reflection created “experiential learning” (Genat, 2009, p.103), in a research process that paid attention to context and generated contextualized knowledge.

Using this approach, this research study aimed to: meet the participants’ needs and seek change through participation, reflecting the practicality of the approach; use a reflexive practice and transparency in the process of knowledge generation, reflecting the participatory worldview of the approach; promote participants’ collaboration to the extent of their capabilities, interests and priorities, reflecting the collaborative nature of the approach (Kindon et al., 2007). Knowledge, obtained from multiple and diverse sources, was, then, community-rooted and continuously constructed through a communicative process that valued a compromise between listening, learning and changing (Mullett, 2015; Taylor & Pettit, 2007). My own previous knowledge of the nursing home and of some of the participants contributed to knowledge construction, which created a need for a serious reflection on how I positioned myself relatively to the research, the setting and the participants.

#### **3.1.4 The insider-outsider duality**

Researcher’s positionality, in particular when using a PAR methodology, due to the close relationships established between the researcher and the participants, is key to research quality (Herr & Anderson, 2012). As I had grown up and still lived in the same small town as most of the participants, I shared a cultural background with them, so I could be seen as an insider; being a doctor, however, and in this case, a researcher, I had a different educational background, positioning me as an outsider. Besides this, having visited patients as a palliative care doctor at the nursing home and discussed their clinical situation with some of the staff, I could consider myself, and be seen by the participants, to be an insider. However, doors closed, I knew little about the inner life of the nursing home, so positioned myself, and could be seen as, an outsider. As an insider I had more readily access to staff, and could argue that I could present a more authentic image of the cultural aspects of the institution. In contrast, my descriptions and analysis could be biased by my previous knowledge, and some more intimate aspects of the caring tasks staff undertook, or their feelings, could be hidden from me during the interviews or meetings. Although I had the power of “methodological knowledge”, the interviewees had the power of providers of the “information shared” (Merriam et al., 2001). As such, while balancing

between insider and outsider positions (an 'inbetweener', as Milligan (2016) referred to it), I had to be constantly aware of power differentials and negotiate them. Israel et al. (2008) emphasise that as all participants in PAR are invited to contribute to all research phases, power is shared in a fair and earnest way. Yet, although a PAR approach was chosen, I am aware that, due to the PhD constraints, the participants did not participate in all research phases, and that different results may have been achieved if that had been possible.

I wanted the research to benefit the facility where it would take place, bridging the knowledge-practice gap that frequently is attributed to research implementation (De Brún et al., 2016). My epistemological stance influenced the research process: the participants' voices were heard and their knowledge valued, co-learning took place, research and action proceeded together and that drove change (Jacobs, 2010; Khan et al., 2013; Sommer, 2009). An ongoing process of reflection brought research from cycle to cycle, bringing about new themes and contributing to the enhancement of practice (Hockley et al., 2013).

## **3.2 Methods**

This section report on the breadth of methods used to inform this research.

### **3.2.1 Context**

This research took place on a nursing home (henceforth referred to as 'nursing home' or Lar) located in a small city inland in the south of Portugal. The institution is nine years old, is directed by a community of catholic nuns, and has a forty-bed capacity. Several factors were at the basis of the choice to carry out the study at this institution: its proximity to the researcher's place of residence was one of them. Being a community palliative care doctor, I have contact with all the nursing homes in the zone (an area of 6,000 Km<sup>2</sup>). In a 100-Km radius there was no nursing home that had not yet received a professional visit from me. A decision was made to conduct the research at this Lar, namely for the institution's willingness to participate in the research to improve care, along with the staff's stated difficulties in caring for residents at the end-of-life, and their desire to improve that care. Conscious of the difficulties (but also of the benefits) of being an insider carrying out research at the institution, several considerations were taken into account (and are discussed in the Ethics section) and the decision to not provide care at the Lar while research was ongoing was made.

### **3.2.2 Sampling strategy**

A purposive opportunistic sampling approach was undertaken, with the aim of selecting participants with personal and experiential knowledge of the research subject, who were able to provide useful, rich, in-depth information in answers to the research question(s) (Bryman, 2012; Creswell, 2013; Whitehead & Whitehead, 2016).

Participants were self-selected staff members who care for older people at the end-of-life. It was expected that a professionally diverse group would bring distinct experiences and perspectives, and contribute to knowledge production concordant and consistent with reality (Mantoura & Potvin, 2012). No consensus on the minimum sample size exists and no advantages seem to be obtained from the number or the length of researchers' and participants' interactions (Creswell, 2013; Onwuegbuzie & Leech, 2007; Whitehead & Whitehead, 2016). The following inclusion and exclusion criteria were used:

Inclusion criteria:

- staff aged eighteen or over;
- staff who had worked at the nursing home for a minimum of six months;
- staff who worked directly with older residents (in the roles of manager, doctor, nurses, care aides, social worker, receptionist, psychologist, physiotherapist, and activities coordinator); and
- staff who spoke Portuguese.

Exclusion criteria:

- staff aged under eighteen; and
- staff working in the facility with no direct care contact with residents.

Invitation letters were sent to the participants' work address by mail, in the recruitment phase of Cycle 1, Cycle 2 and Cycle 5 (see Appendices 7-9). The letter presented and described the study, explained what would be expected from the participants and requested the return of a form in which participants provided their name and contact telephone for the scheduling of an interview. Self-addressed stamped envelopes to return the forms were provided.

### **3.2.3 Ethical issues**

Ethical issues were covered in accordance with Portuguese law on clinical research (Lei nº21/2014) and personal data protection (Lei Nº67/98, 1998). The Research Ethics Guidebook and the Framework for Research Ethics (2015), published by the Economic and Social Research

Council (ERSC), also guided the ethical issues related to this research. The Portuguese law on clinical research states that participants' rights "prevail over the interests of science and society" and that clinical studies must be conducted "in strict compliance with the principle of human person dignity and its fundamental rights" (Lei N° 21/2014, 2014, p.2452).

**3.2.3.1 Ethics review boards approvals:** Throughout this thesis, the theoretical foundations of the study design have been presented. The quality and integrity of this thesis are ensured through the research design. Approval from the Portuguese Data Protection Authority was granted with the reference 7234/2017. Approval from the Portuguese competent Ethical Commission (Lei N° 21/2014, 2014) – Comissão de Ética para a Investigação Clínica/National Ethics Committee for Clinical Research (CEIC) - was requested and granted with the reference 2017-RP11-01. The Faculty of Health and Medicine Research Ethics Committee (FHMREC) reviewed the research proposal before the beginning of the study, and approval was granted with the reference FHMREC17005. After the 2019-2020 intercalation, a few amendments to the research project were submitted to CEIC and approval granted with the reference PPF 2020\_EO\_08\_(2017\_EO\_06). The FHMREC reviewed the amendment to this research project, and approval was granted with the reference FHMREC20038 (02/12/2020).

**3.2.3.2 Information:** Residents and their families were informed about the research through a poster that was placed in the nursing home entrance (see Appendix 10). Participation was voluntary and those interested were provided with a full information sheet prior to the interviews and cycle 2 meetings (Silverman, 2013) (see Appendices 11-13). Before beginning the interviews, participants were informed in detail about the research study and given time to ask questions. Participants were informed that participation was voluntary, that the interview could be stopped at their request at any time if they did not wish to continue, and that they had the right to ask for the destruction of the information provided up until the moment when the interview stopped. Information was also provided on their right to withdraw from the research project at any moment (Koshy et al., 2011) without giving a reason and without detriment to themselves.

In addition to the right to withdraw from the study, once the interview had been completed, participants had two weeks to ask for data to be withdrawn from the study. Participants were also informed that when participating in group meetings, it would not be possible to exclude individual data once the session had commenced, if a decision to withdraw was made. Participants were informed that, based on Portuguese law and best ethical practices, no monetary incentives would be provided (Lei N° 21/2014, 2014). Information was given on the

participants' different roles, these being, at the same time, those of research participant and co-researcher.

**3.2.3.3 Anonymity and confidentiality:** Participants' anonymity was guaranteed by the researcher both internally (at the institution) and externally (during dissemination of the results). Anonymised direct quotations from the interviews were used in the reports or publications based on the study, in presentations at future conferences, and for future training events and resources. Anonymous data may also be shared and used by me for further analysis in the future. The confidentiality of the interviews and group meetings was guaranteed by me. Group meetings were held with no more than ten participants at a time. At the beginning of each group meeting, the need for confidentiality was reiterated and continuously negotiated.

Interviews were conducted with each participant individually. The typed version of the interviews was made anonymous by removing any identifying information, including participants' names. Participants were provided with a copy of the audiotaped interviews and corrections were requested. Critical comments on the research design and the research conduct were welcomed and research was redirected according to what participants said. All personal data is confidential and was kept separately from interview responses. Some limits to confidentiality existed: if, during the interview or meetings, a participant voiced anything that made me think that she, or someone else, was at significant risk of harm, confidentiality would have been broken and the research supervisors at Lancaster University informed. Confidential data was not and will not be communicated to the facility owner, unless agreed among all participants, and only after anonymization and in such a manner that research participants cannot be identified.

**3.2.3.4 Participant consent:** An informed consent form was provided before the beginning of the interviews in Cycles 1 and 5 (see Appendices 14-15) and Cycle 2 meetings (Appendix 16) and participants were invited to read and sign it; no interview or meeting took place before an informed consent form had been signed (Kelley & McKee, 2013; Koshy et al., 2011; Sheldon & Sargeant, 2014; Silverman, 2013). A signed copy was returned to the participant.

**3.2.3.5 Security:** Data was treated according to the Portuguese law of personal data protection (Lei N°67/98, 1998). No other information besides gender, time working in the nursing home and occupation was collected at the beginning of the interviews. Interviews were audiotaped and notes on non-verbal language were taken immediately after the interviews and the meetings. Before being transferred to a password-protected computer, interviews and group meeting records were securely stored in a safe-box accessible only to me, with the respective

hand notes. Audio-records were kept at my house in a safe-box and will be destroyed by me after the completion of the research project in accordance with ethical approval (Silverman, 2013). As soon as possible, they were transferred by me to a password-protected laptop computer, and transcribed, alongside the hand notes; immediately afterwards, they were deleted from the recorder. Data were anonymized and encrypted. Hard copies of transcripts were also kept in a safe-box. Data, including hard copies of interview transcripts, are kept securely in the safe-box for ten years and at the end of this period, they will be destroyed.

**3.2.3.6 Harm prevention:** No major harm was expected to occur to participants. However, Bellman (2013), points to the risk of participants feeling pressured to participate or being manipulated: this was prevented through showing openness to the co-researchers' ideas, giving feed-back, ensuring same-level relationships through shared decisions, pursuing common goals and bringing action to the centre of the research (Bellman, 2013). The risk of discomfort or psychological distress when talking about sensitive issues existed: participants were informed that interviews could be temporarily stopped or ended at any moment if they so wanted. If needed, support from a psychologist external to the institution was available, and participants were informed about access to her in the Participant Information Sheet (Appendix 11) and at the beginning of the interviews and meetings.

Although the expected risk of harm for me was low, I worked in relative isolation, as interviews were held privately with the participants (Braun & Clarke, 2013a; Silverman, 2013). Following Lancaster University recommendations and best practices policies on lone working, and The Research Ethics Guidebook, interviews took place in a neighbouring building owned by the nursing home, outside working hours, by prior appointment with the participant. Verbal and non-verbal clues to any potential aggression were considered by me and the interview place would have been abandoned if needed; debriefing with a third party (a psychologist, but not the same one as for the participants) was available, without breaking confidentiality, if the sensitive nature of the data collected upset me.

**3.2.3.7 Positioning:** Being a member of the local community palliative care team, I had worked sporadically as a consultant palliative care doctor at the nursing home, discussing patients' clinical cases with the nursing home nurse, so I could be seen as an insider. However, I am not paid by the institution where the research took place, as I am a public health service professional, at public expense. Whilst the research was being carried out, I did not work as a palliative care consultant at the facility.

No grants were awarded for this research project and it is endorsed by the Lancaster University as PhD research.

#### **3.2.4 Data collection methods**

Data collection occurred on different occasions, and several methods of data collection were used, comprising interviews, group meetings, field notes following interviews and meetings, and a reflective diary.

A semi-structured individual interview method was chosen for its potential for collecting sensitive data, for its capacity to generate valuable and thick data, for its convenience with small samples, and for the flexibility it offers to introduce other questions to address unexpected aspects derived from the participants' answers (Birks et al., 2007; Braun & Clarke, 2013d; Creswell, 2012; DiCicco-Bloom & Crabtree, 2006; Koshy et al., 2011). Prior to commencing the research interviews, a pilot interview was conducted with a psychologist that works in a palliative care team, but not in the nursing home, allowing for improvements in the interviewing techniques and refinements to the interviewing style. So as not to interfere with the service, interviews took place outside working hours, subject to participants' availability and willingness. Participants' organizational needs were explored in face-to-face audiotaped interviews, with conversation directed by a few pre-determined guiding questions that covered particular areas of interest (Petty et al., 2012b), giving the participants leeway to openly express themselves (McNamara, 2017). Participants shaped the interview content, which contributed to a greater depth of data being obtained (Vandenberg & Hall, 2011). Interviews took place between November and December 2017, with a last interview, due to the participant personal motifs in September 2018 (Cycle 1), and in January 2021 (Cycle 5).

Group meetings took place with no more than ten participants present. They contributed in gaining an in-depth understanding of the relationship between the nursing home staff and of the way they interacted in solving problems (Cyr, 2016; Gill et al., 2008). It was not just a method for data collection but also a working tool, called action group meetings in this thesis. The group meetings were scheduled according to the participants availability, had a pre-set but still flexible agenda, and were audio-taped.

Field notes were handwritten, as preliminary annotations, immediately after the interviews and meetings, documenting participants' nonverbal cues and my own thoughts and feelings, and supplemented later on, when transcribing the interviews and aside of the interview transcripts (Mulhall, 2003). Field notes are a qualitative research method that offer insight into places, behaviours, sensations and emotions (Fetters & Rubinstein, 2019; Maharaj, 2016; Wolfinger,

2002), contextualize interview data (Fetters & Rubinstein, 2019), provide a systematic approach to data (Deggs & Hernandez, 2018) and help in data analysis (Phillippi & Lauderdale, 2018). My field notes contributed to enhancing the depth and the context of the findings and to strengthening research rigour (Phillippi & Lauderdale, 2018; Fetters & Rubinstein, 2019). Immediately after one of the first interviews I wrote, “The way Maria talks about the last days of Mrs. X’s life, and how this time allowed staff to say goodbye, makes a contrast with the sudden death of Mr. B, and the extreme anguish staff continue to feel. Being able to care for a resident until the end seems to provide not only comfort but also facilitate closure. To pay attention to in the next interviews”.

The reflective diary was a tool in which I maintained a constant dialogue with myself, bringing to a conscious level my own subjective role in the research process (Darawsheh, 2014; Pitard, 2017), my relationship with the participants and data (Berger, 2015; Freshwater & Avis, 2004), and my own recognition as participant in the social world being studied (Muhallim, 2019; Palaganas et al., 2017). In this introspective process, I became aware of the role of subjectivity in the research process and of my own input in the co-construction of meanings (Palaganas et al., 2017).

### **3.2.5 Data collection instruments**

Previously prepared semi-structured, face-to-face interviews were used in order to achieve an in-depth understanding of the needs of the nursing home staff when caring for older people at the end of life (Appendix 17) and to evaluate the interventions (Appendix 18). During the interviews, the participants were asked about their experience in caring for older residents at the end-of-life, the organisation of the facility, communication with the residents, and their perceived needs for support, education, and training. The interview protocol, with a few guiding questions designed to cover the most important research areas (Bryman, 2012c; Koshy et al., 2011), was prepared in advance and submitted for ethical approval. Following the interview protocol, key topics were addressed according to the flow of the conversation. Interview questions were asked in a flexible order, according to the direction of the participants’ discourse, and, when necessary, were followed by supplemental questions that explored further the participants’ experiences and perspectives.

Interviews and group meetings were recorded using a hand-held digital recording device (Philips Voice Tracer®). The audio recordings were revisited on the same day as they were recorded, and further notes, if any, added.

### **3.2.6 Participants**



Ten participants accepted the invitation and consented for Cycle 1: two nurses, two care aides, the social worker, the manager, the receptionist, the occupational therapist, the physiotherapist, and the activities coordinator.

After the second recruitment phase, eight of the ten participants in Cycle 1 (two nurses, a care aide, a physiotherapist, an activities coordinator, a social worker, a receptionist and the manager) that participated in the interviews accepted the invitation and consented for Cycle 2 and the following one.

Six participants (physiotherapist, manager, receptionist, one care aide, two nurses) who consented for Cycle 5 were interviewed.

### **3.2.7 Data processing**

Before beginning the interviews the participants were asked to choose a pseudonym to protect their identity when quotes were presented (Saunders et al., 2015; Surmiak, 2018). Interview and meetings records were transcribed verbatim by me within 48 hours after the interviews took place, after which they were anonymised and encrypted. Anonymised copies were delivered by hand and in a sealed envelope to participants: no one chose to withdraw any part of the text or asked for any changes. Three interviews were partially translated in order to facilitate the guidance and support of my academic supervisors.

Transcripts were checked against the original recordings for accuracy and then subjected to analysis, using a thematic analysis framework. An inductive latent approach was used, allowing data to determine the themes and exploring its meanings and assumptions. Thematic analysis follows a six-step process: familiarization with the data, the generation of initial codes, the search for themes, the reviewing of potential themes, the definition and naming of themes, and the production of the report (Braun & Clarke, 2012). Interview transcripts were read and re-read, the first time while the audio recordings were being played, to capture the essence of the data ("data immersion" in the words of Braun and Clarke (2006)), to identify patterns and topics, and to become familiar with it (familiarization). In parallel with transcript-reading, annotations were made partly in order to insert the field-notes written down in a notebook immediately after the interviews had taken place, as well as to call attention to specific text sections that could become codes (thereby generating initial codes) (see Appendix 19). The most relevant text sections were highlighted with different colours, corresponding to the different codes. Interview transcripts were constantly compared and contrasted with the field notes and with data from my reflective diary. Transcripts were re-read until no more codes could be found. To illustrate the codes, direct quotations were selected from the transcripts, and organised in tables (see

Appendix 21). Codes and quotations were then aggregated (Appendix 20) based on similarity of patterns (sub-themes) in an iterative process which moved between the transcripts, the codes, and the research questions; these were then grouped in clusters (themes) representative of the data (searching for themes).

### **3.2.8 Data analysis**

The initial intention was to analyse the data using computer assisted qualitative data analysis software (CAQDAS). NVivo 12<sup>®</sup> was chosen for its suitability to thematic analysis (Zamawe, 2015) and, considering my limited computer skills, for its apparent simplicity in use. Research is a decision-making process in which choices have to be made: after several attempts to try to understand NVivo 12<sup>®</sup> functioning and to begin using it, the decision was made to use manual analysis. A number of factors led to this decision: my limited computer skills; the time and effort needed to learn how to efficiently use CAQDAS (St John & Johnson, 2000); the recognition that CAQDAS assists with (Braun & Clarke, 2013a) but does not perform the analysis or the final report (Carvajal, 2002); and the risks of CAQDAS misuse, namely not thoroughly using research methods (Jones & Diment, 2010).

Through the research cycles, concurrent and retrospective analysis was carried out. Retrospective analysis was conducted through thematic analysis of the interview transcripts, following the thematic analysis method described by Braun and Clarke (2012). Considered in qualitative analysis as a method and a tool (Braun & Clarke, 2013b), thematic analysis is a flexible, structured analysis suitable to participatory approaches, that aims to find patterns that are relevant to the research question and to evaluate its significance (Braun & Clarke, 2013b; Nowell et al., 2017). According to Payne (2007), it is appropriate to analyse small data sets when semi-structured interviews are used and descriptive narratives summarize the situation researched. Through a bottom-up approach (from data to knowledge), themes inductively emerged from the data (Braun & Clarke, 2013b) in an active process of pattern identification and organisation into meaningful themes, this assisting in the construction of knowledge (Bazeley, 2014a).

Topic repetitions were systematically organized into themes (Bryman, 2012a). Themes were subsequently analysed to check for consistency or contradictions in the codes (and quotes) within the theme (reviewing potential themes). The process was repeated as many times as necessary, going back and forth between the codes (and corresponding quotations) and the themes, until all relevant data was coded and consistent themes established. Themes were subsequently named and described, to make a coherent account in line with the research

question (defining and naming themes). Results were written up in an account that, with the aid of the quotes, created a detailed report of the research journey and the findings (producing the report).

Simultaneously, a pool of data entered into concurrent analysis: data gathered during the interviews and meetings, alongside my continuous reflection in the field notes and the diary, and the equal, ongoing reflections and suggestions of the co-researchers with reference to the themes presented, and/or the development of action.

### 3.2.9 Enhancing trustworthiness

I have followed the Lincoln and Guba (1986) criteria aimed to meet trustworthiness, systematically selecting the most relevant approaches to this research. Attempting to conduct a trustworthy thematic analysis, the analytical procedures (adapted from Nowell et al. (2017)) described below (Table 8) were followed:

Table 8: The criteria used to ensure trustworthiness

<b>Rigour criteria</b>	<b>Concept</b> (adapted from Nowell et al., 2017)	<b>Strategies applied to achieve rigour</b>
Credibility	Results are accurate and trustworthy (according to the participants)	<ul style="list-style-type: none"> <li>- Testing the semi-structured interviews protocol using a pilot interview</li> <li>- Taking field notes and registering non-verbal data immediately after the interviews</li> <li>- Giving interview transcripts to the participants for their comments</li> <li>- Soliciting co-researchers' comments on the themes emerging from data</li> </ul>
Dependability	The research process is coherent and clearly illustrated	<ul style="list-style-type: none"> <li>- Providing a thorough description of the research methods</li> <li>- Creating an audit trail (describing decisions made) throughout the entire research process</li> </ul>

<b>Rigour criteria</b>	<b>Concept</b> (adapted from Nowell et al., 2017)	<b>Strategies applied to achieve rigour</b>
		- Measuring coding accuracy; re-doing the coding of the first set of interviews one year later
Confirmability	Researcher's accounts and conclusions are generated from the data	- Maintaining a reflective diary through the research process
Transferability	Research generalizability	- Accurately describing the context where the research took place

In PAR, data analysis is an iterative process, occurring in partnership with the researcher and the participants as co-researchers, in a dynamic process that brings about change (Hockley & Froggatt, 2006). An audit trail was created, contributing to research transparency and reliability (Moravcsik, 2014; Tuval-Mashiach, 2017). Co-researchers' contributions (reflections on data, ideas, suggestions), as well as my reflective diary, contributed to continuously improving the transparency and reliability of the data analysis throughout the research process (Bazeley, 2014b; Braun & Clarke, 2013c). Data analysis, performed through this iterative process between the data and myself/co-researchers' partnership, contributed to the accuracy of the research process and to its progress, and, overall, to research quality (Bunniss & Kelly, 2010; Kelley & McKee, 2013; Noble & Smith, 2015; Tuval-Mashiach, 2017).

### **3.3 The research cycles**

The intention was to collect the data in three cycles. However, as the research developed, more cycles were identified, and the final count was six cycles. Figure 2 depicts an overview of the process and purpose of the six cycles and includes the timing of the research (including two periods of intercalation where data collection had to be halted).

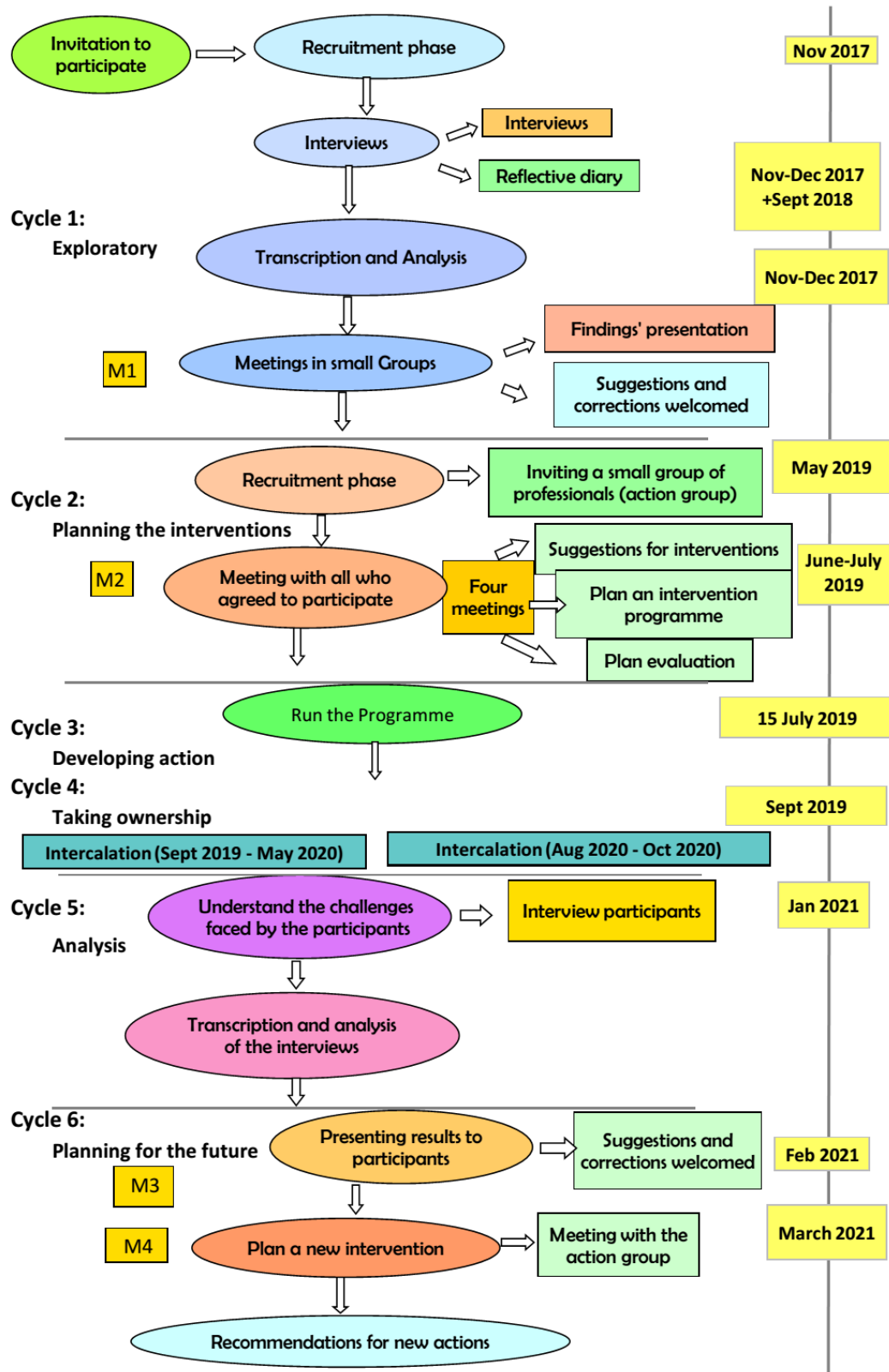


Figure 2: The six cycles of research

**3.3.1 Cycle 1:** the focus in this cycle was to understand the needs of nursing home staff when caring for older residents at the end-of-life.

Nursing home staff was invited to participate, after which interviews took place in a room on a neighbouring building, owned by the nursing home organization. Just before beginning to record the interview, the research objectives and interview rules were explained to participants, and time given for questions about the research process. Two identical consent forms, covering participation in the interview and in the following group meetings, were signed by me and each participant (Albala et al., 2010; Manti & Licari, 2018), one being kept by me and the other returned to the participant. Participants' consent to record the interview was also sought (Al-Yateem, 2012) and given by all, after which the interview began.

After all the interviews were transcript and analysed, a synopsis was presented to the participants, who agreed to meet in a small group (M1). No corrections to the results were made, and neither did the participants suggest any improvements; some suggestions on how to use the findings from the interviews to improve end-of-life care at the nursing home were, however, expressed, but an agreement was reached to postpone further decisions to a next meeting.

**3.3.2 Cycle 2:** the focus in this cycle was the development of an organizational intervention programme, aimed at improving end-of-life care at the nursing home.

After the second recruitment phase, eight of the ten participants in the interviews accepted the invitation to form part of an action group that would define and run one or more organized interventions. With the limitations imposed by research, within the scope of the PhD, the nursing home staff slowly evolved from being collaborative (and passive) interview and meeting participants, to having a voice in the research, with an active role in data analysis during the meetings, contributing with new data, planning the interventions, collaboratively engaging in preparing the interventions, and continuing their implementation through the research cycles. From then on, research was conducted *with* the participants, who, as reminded by Swantz (2008), therefore became co-researchers. We met four times to prepare and develop the organizational intervention programme. Not every co-researcher was present at all the meetings, due to personal reasons or holidays. Informed consent was signed before the four meetings (M2) were held (see Appendix 22).

Meeting 1 (18/6/2019): one care aide, two nurses, the activities coordinator, the manager, the social worker, the receptionist, and the physiotherapist were present. Ground rules were discussed, confidentiality issues negotiated and a reflection on M1 results made. In this and the following meetings, the co-researchers expressed their own perspectives and interpretations,

presented their experiences and stories, interrelated and discussed data significance, creating new insights into the research topics, and in this way contributing to data analysis. All together, we co-constructed understandings, and co-learned while performing the research.

Meeting 2 (19/06/2019): one care aide, two nurses, the activities coordinator, the manager, the social worker, and the receptionist were present. The co-researchers and I continued to reflect on the results and prioritize the most important issues. Decisions on who was going to do what were made and roles were distributed.

Meeting 3 (3/7/2019): two nurses, the activities coordinator, and the receptionist were present. Decisions on which practice changes could take place were made. They had to be feasible and to have visible results in a group-defined, six-month timeframe. As these interventions and work methodology had never been used before in the nursing home, the co-researchers expressed concerns regarding their ability to plan, enact and evaluate a great number of interventions at the same time. Five interventions were unanimously accepted, and planning started. Decisions were made and accepted that the planning of the interventions, performed by the action group, would continue during the week, while I would analyse thematically the meetings record and bring the results to the next meeting.

Meeting 4 (10/07/2019): one care aide, two nurses, the activities coordinator, the manager, and the receptionist were present. Results of the analysis of the records of the meetings were discussed. The co-researchers in charge of further developing each intervention informed the group about planning progress and explained decisions made. Further improvements and the implementation strategy were discussed. A decision was made to begin the interventions on the 15 July (the first Monday after this meeting), and to hold periodic meetings to monitor the progress of the programme. We all reflected on the planning process and what had been achieved so far.

**3.3.3 Cycle 3:** the focus in this cycle was developing action through the implementation of the interventions.

The programme implementation started on the chosen day, and ran as planned for two months (July-August 2019). Two meetings took place (17 and 24 July 2019). The ongoing programme was analysed and a few issues addressed (for example, rescheduling a “Resident’s Life Celebration” due to family constraints; the need to clarify terms in the “Resident’s File” form). Further details on the implementation of the interventions were discussed among all the participants, and progress evaluated. Each intervention was fine-tuned and details discussed by

all. Cooperation, both among the nursing home staff in general and among the people in the group was fundamental to the outcome of the interventions.

**3.3.4 Cycle 4:** the focus in this cycle was to continue to develop the interventions without the researcher.

This cycle spans between the beginning of September 2019 and the end of October 2020. This was an unforeseen and unusual cycle. Due to unanticipated events (my own sudden health problems), I had to enter into a nine-month period of intercalation (September 2019 – May 2020), followed by two months where I prepared for a new ethical approval and three more months of intercalation (August – October 2020). The participants made me aware of the group's unanimous decision to continue to run the programme and to develop the areas that had been decided upon during the Cycle 2 meetings (M2). Considering that the interventions had been decided on by the action group, and that they were integrated into the daily life of the nursing home, the co-researchers determined that there was no way to stop them, and that they had to continue independently.

Participation, power and research ownership issues can be raised. Taking the initiative to mobilize themselves, participants took on a project they considered theirs (Pretty, 1995), exerting autonomy and collaboration in their own way. In this way, a shift in the power dynamics occurred, with power redistributed and necessarily shared. As stated by Areljung et al. (2021), in participatory research, power is shared between researcher and co-researchers, but only the co-researchers' "development of confidence in their roles" (p.464) contributed to their sense of research ownership and to them feeling empowered to take the implementation of the interventions into their own hands. These exceptional circumstances led not only to the need to adapt the research process, but influenced the knowledge created (Jootun et al., 2009; Loewenson et al., 2014; Smith, 2006). I resumed research after the second Intercalation time, and after a second ethics approval (for readjustments in the research project, namely in the objectives and timetable).

**3.3.5 Cycle 5:** the focus in this cycle was on the evaluation of the interventions.

The same participants were invited to a second interview through an invitation letter (see Appendix 9). At the beginning of 2021, when nursing homes were under strict pandemic rules, interviews took place in the same building as they had in Cycle 1. Full PPE were used during the interviews. Co-researchers were asked about their experience in developing and running the interventions, the challenges faced during my intercalation and Covid-19 pandemic, and about



suggestions for new interventions. Following the same procedures previously described, the interviews were audiotaped and transcribed, and the transcriptions analysed.

**3.3.6 Cycle 6:** the focus in this cycle was on planning for the future. Two meetings were held.

Meeting 1 (19/2/2021): The findings from the analysis of the interviews were presented and discussed with five co-researchers (the physiotherapist was on sick leave). Due to the pandemic and its constraints, only one intervention (on Hydration) was fully maintained, although adapted, while the other interventions had been suspended (totally suspended: the Farewell Table and the Resident's Life Celebration; partially suspended: the Resident's File), with the co-researchers reinforcing the need to resume them as soon as possible. With regard to planning for the future, the different suggestions that came from the Cycle 5 interviews were discussed.

Meeting 2 (8/3/2021): The same participants as in the previous meeting were present. Resuming two of the interventions (the Farewell Table and the Resident's Life Celebration) was considered a priority. Additionally, the highest priority new interventions - education (mouth care and feeding in the last days/hours of life) and advance care planning - were defined. The different preparatory tasks were divided between the co-researchers. These tasks included: with regard to education- defining what is important to talk about, organising the sequence of care and the take-home messages, finding images; and with regard to ACP - creating a meeting plan, a checklist and a final agreement form. My assistance with finding adequate bibliographical references to support the implementation of the interventions was requested. The tasks assigned to each of the co-researchers were outlined and a new meeting scheduled to continue to develop the new interventions, depending on the participants' shifts and data availability.

### **3.4 Summary**

This chapter described the research paradigm, my own epistemological and ontological positioning, and their influence in the approach to the research. PAR was chosen for this research for its capacity to generate contextualized knowledge and social change through cycles of action-reflection. The research was based on the participants' voices, valuing their knowledge and expertise in their particular field. The chapter described the setting, the sampling strategy, the ethical issues related to this research, the data collection methods and instruments, the participants, data processing and data analysis. Using thematic analysis, data interpretation led to the definition of several themes, that allow a broader view on nursing home staff needs when caring for older residents at the end-of-life. The ways to enhance trustworthiness were outlined,

after which the research cycles were described. The next chapter reports the findings identified when using this methodological approach.

## Chapter 4 – Findings

Chapter three presented the methodology and methods of this research, and described how the six cycles of PAR developed in practice. The aim of this chapter is to present each cycle in detail, including the characteristics of the participants, the purpose of the cycle, the data associated with the cycle, and the findings. Figure 3 depicts an overview of the process of Action- Reflection- Planning during the six cycles.

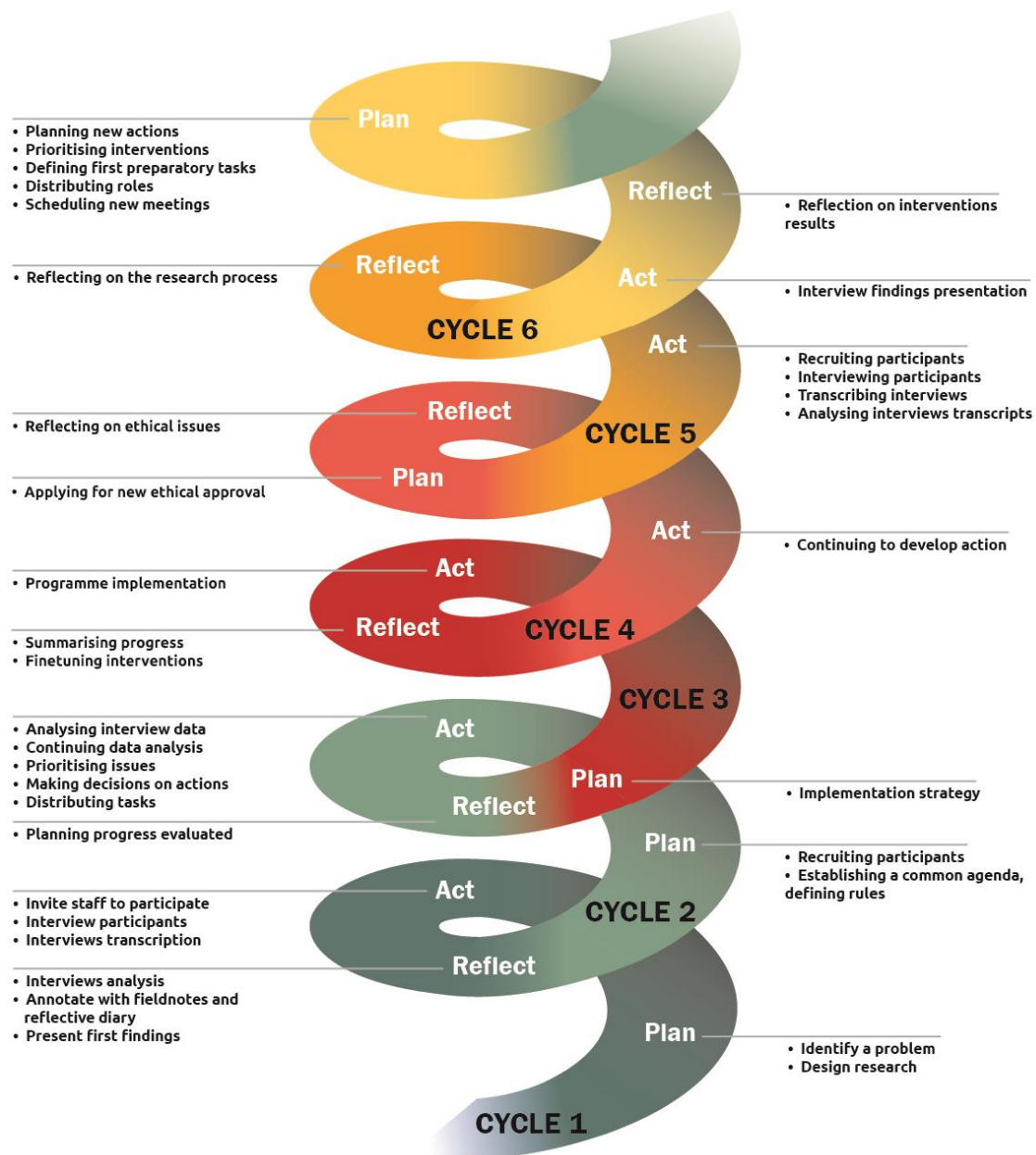


Figure 3: The research cycles

#### 4.1 Cycle 1

Cycle 1 relates to the exploratory research phase, when data was collected from interviews and my personal reflective diary.

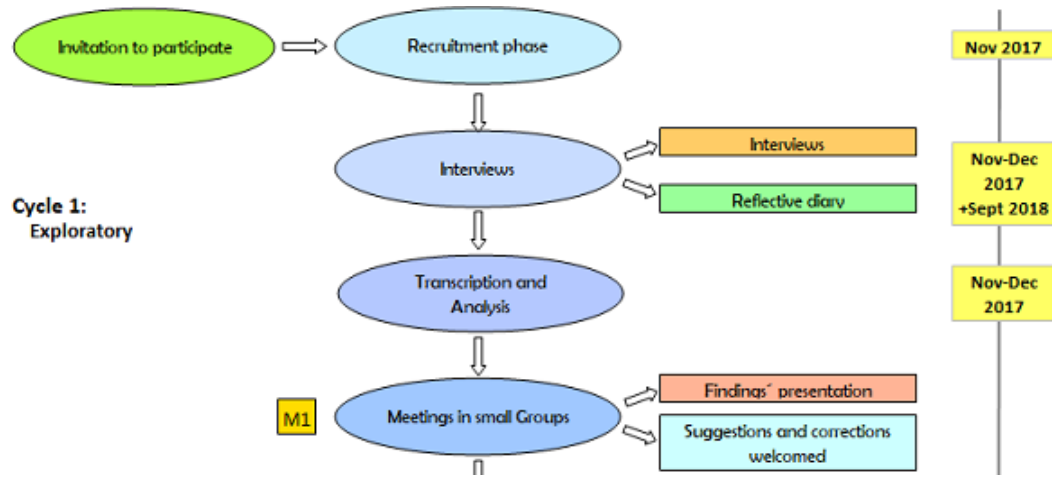


Figure 4: Cycle 1

Ten nursing home staff consented to participate in Cycle 1 and were interviewed. Interviews lasted between 42 and 68 minutes. Participant profession and time worked at the facility are presented in table 9:

Table 9: Participants’ characteristics

Professional Role	Time worked at the nursing home
Physiotherapist	1.5 years
Manager	4 years
Nurse	11 months
Receptionist	1.5 years
Occupational therapist	1.5 years
Activities coordinator	2 years
Care aide	4 years
Care aide	2.5 years
Social worker	4 years
Nurse	3 years

Interviews were transcribed and analysed following the Braun and Clarke (2012) thematic analysis method. Codes and themes were reorganised several times as the analysis continued, enabling data re-interpretation and the generation of seven themes, through an inductive approach: i) Nursing homes are undervalued; ii) “There is no book to teach us” - education and training; iii) Care at the end of life; iv) Death is hidden; v) No time to mourn; vi) “I think all of us can contribute to change”. An overarching theme vii) The complexities of caring for people at the end of life, brings together the first six themes.

#### 4.1.1 Nursing homes are undervalued

Nursing home staff believed that their work in nursing homes was not valued, regardless of profession, despite them being places where older and frail people live, and often die. Compared to similar positions in hospitals, working in a nursing home is seen by society as inferior, creating a stigma that the lack of education and professionalisation accentuates:

*“And then I think that our society does not look very favourably on those working in nursing homes, it is not only the care aides, it is really everything” (Matilde).*

The care aides, who provide care 24 hours a day, were seen as fundamental; however, it was noted that they did not value their work or themselves, contributing to staff discomfort and turnover:

*“I think when people work at a nursing home, they think it is an unworthy job. (...) If there was a bigger communication among staff, maybe it would be easier to organize the work, but that communication had to be sincere” (Luísa).*

Likewise, a need to speak openly about situations that cause discomfort among the staff (schedules, days-off, tasks distribution, and training) was verbalized. As a high interdependency exists between people and positions, the prevention of conflict, let alone disputes, becomes more difficult.

Latent or manifest conflict (suspicion, questioning, relatives directly calling an ambulance) was reported when families and staff, particularly the nursing home health care team, disagreed about care goals, or crisis referrals to hospital emergency services. Effective and proactive communication with families, as well as an anticipatory definition of care goals, were often lacking:

*“Families can... can and should be included in... in the definition of the care plan and of what is planned, in the definition of what needs to be done” (Teresa).*

Unrealistic expectations of families, especially those with low or no presence in the life of the nursing home, about the residents' rehabilitation, were also mentioned:

*“Families, they don't accept the changes that come with age, and sometimes they expect results that are not possible to achieve. Expectations are often very unrealistic” (Sofia).*

When the care wishes for the resident's last days of life were not recorded and agreed upon in written form, they often came as a surprise or are contradicted by family, which led to the resident's transfer to a hospital in the last days or hours of life, as a result of family demands:

*"The residents are not really removed, but let's say, they do not belong to us, but they are taken from us, may be... They are taken from a place of warmth, their place of comfort, to a corridor of the hospital, to finish there the last... the last moments of life"* (Lurdes).

A different organisation of nursing home work, clear communication among the care aides and between them, other staff and management, and education and training were also identified as having the potential to contribute to improvements in some of the problematic areas.

#### **4.1.2 "There is no book to teach us" - education and training**

Recognising that end-of-life care is an area where improvement is needed, education and training were pointed to as ways of maintaining and improving competencies, and ultimately, care. Concerns were raised about there being no special competencies, particularly in care for older people or end-of-life care, being required to open a nursing home. Training is scarce or non-existent, contributing to concerns regarding the specificity of the care to be provided. Still, caring for frail older residents at the end of life, is a demanding task that requires skills that especially the non-technical staff (cooks, cleaners, and, in particular, care aides) are less likely to have:

*"Working in a nursing home, taking care of older people, fundamentally such frail people, requires knowledge and requires skills that we cannot guarantee afterwards with the level of training, with the level of skills that care aides have today"* (Teresa).

Education was seen as needing to be applicable to every-day practice, with attention paid to every detail. Followed by the daily support and monitoring of the technical team (nurses, physiotherapist, occupational therapist), education should be regularly repeated to train new staff and to correct practice flaws

*"Even those who have been trained should repeat, value, call attention again"* (Ana).

As the residents are all different, and their care needs are equally diverse, continuous and practical education was seen as valuable:

*“Every resident has his/her own life history and specificities. (...) Training is essential to better care for them” (Lurdes).*

*“We can say that all areas are important, but the ones they learn more easily are the practical ones... Doing. Those are the areas they learn better” (Teresa).*

A willingness to learn is desirable so that training can produce behavioural and attitudinal changes, but not all professionals have this, and some of the interviewees saw no benefit in continuous education.

Less qualified staff have no access to previous training and do not see skills acquisition or improvement as a priority. As was also remarked, a lack of education can contribute to resistance to additional training, and in-service training was considered difficult to achieve due to some staff reluctance:

*“Care aides do not have the same availability to this type of activities. We are talking of a population, of a professional group that has very little education, very little schooling, frequently with little schooling. They are people that have no ambition in terms of education, they do not have a tradition, a past in education, at all. They do not have that will to do courses or training to improve their practice, to improve their professional practice, that doesn't exist” (Teresa).*

When resistance or lack of motivation exists, to change daily routines and improve care becomes challenging and jeopardizes team work, leading to communication disruption and to potentially decreasing the quality of the end-of-life care for residents:

*“And the team is all the staff, we all have an important role to fulfil, it is fundamental, and if we all collaborate and work as a team the resident has quality” (Ana).*

#### **4.1.3 Care at the end-of-life**

To provide the most adequate care, nursing home staff are seen as being in need of having certain competencies, such as interpersonal and communication skills, the capacity to work in a team, compassion, respect for confidentiality, cultural awareness and respect for ethical principles, these enabling them to assist older people in daily care activities. This is not, however, the case in Portuguese culture. Care aides, who support residents' day and night, have no prior training, unless they have previously worked in similar institutions:

*“Care aides have no formal education; they had no education to be here. Education is provided during daily activities” (Teresa).*

Among the technical staff, the reality is not very different either, since no specific training for working in nursing homes exist. This reality, and the constraints it causes, is mentioned by many of the participants.

The nursing home struggled to provide end-of-life care for its residents, which would be impossible without external support, namely from the local palliative care team:

*“It is... thanks to that team we have been able to care until the end, because without them, we could not care” (Lurdes).*

Understaffing (due to staff turnover, illness or recruitment issues), has a tendency to endanger standards of care, as illustrated in the following quote:

*“It is about time or staff. Sometimes having fewer staff can be, it is complicated. If we had more, but then we cannot... I cannot... sometimes we think that if we had more (staff) we would have more time for doing things in a more peaceful way... because sometimes it seems that it is all... getting up, sitting, eating, going out, that’s it... I do not know if it could be equal, if it could make a difference” (Madalena).*

The struggle to adapt care to the residents’ needs while facing the aforementioned constraints, does not prevent the establishment of close bonds between the staff, the residents and their families, with the environment frequently described as family-like. A need for adequate communication between staff providing care and residents being cared for was highlighted. While carrying out their tasks, all staff interact with the residents, and frequently with families as well; as pointed out, even cleaners and cooks, although not providing personal care, talk with the residents when cleaning the bedrooms or serving meals. As no previous training exists, unpreparedness to communicate with more demanding families was felt.

There is a need to support care aides in their daily tasks, and unequivocally value their work. Care was deemed challenging, needing to be adapted day-by-day to each resident’s particularities or wishes, until the end-of life, even when residents are not able to state their preferences:

*“For instance, Mrs. M has always been a person who was dressed up, and we continue to keep that up, until it is possible, until the last day she gets out of bed. We continue to put on her the necklaces, make her up, do all that. (...) I think it is very important, yes ...*



*Mr. F is vegetarian, and even today he does not eat meat, regardless of whether he knows whether he is eating meat or not” (Clara).*

Although not accessible to all staff, a file with each resident’s preferences or particularities exists. However, information was sparse and not up-to-date, and improvement is needed as a way to enhance care.

Death is part of nursing home life as staff care for very old and frail residents. However, fear of talking about death exists. With death transferred to hospitals, many of the staff had never seen a deceased person before working at the nursing home, and were afraid of caring for someone dying, although no further explanations were provided. They learned what to do from more experienced staff, as no training or written rules exist. A sudden death is experienced in a different way to an expected one, with staff pointing out how distressing the former can be. On the other hand, when the resident's death is expected, staff get together and are more attentive to that person without having to be asked.

The experience of caring for older residents at the very end of life was usually considered to be positive, allowing nursing home staff time and opportunity to say goodbye. Care aides can call the nurse or the manager any time they need, and the local palliative care team can be contacted by telephone 24 hours a day. This strategy prevents unnecessary transfers to the hospital emergency service, improving the quality of care. The constant and supporting presence of the manager is experienced as a reassuring factor, particularly in the last days or hours of the resident’s life. This is certainly not unrelated to the fact that the manager is a nun, and when a death is expected, she usually sits near the resident’s bed, supporting the resident, the family and the staff.

#### **4.1.4 Death is hidden**

Until recently, death was usually hidden from other residents. However, not long before the first interviews took place, a photo of the deceased, provided by the funeral director, was posted on a board in the atrium, among other news. This was felt as undignified and inappropriate.

Disclosing a resident’s death to the others was perceived as challenging. Associated with the personal discomfort of communicating bad news, a lack of communication skills was also reported, and a need for additional training at that level required:

*“It is one of the areas in which it is necessary to heavily invest in training and especially in skills development. It is the area of... of... of mourning, and how to live death, and talk about death in the institution” (Teresa).*

Teresa expressed also a need to be open with the other residents and to make them aware of the death of one of them, with sensitivity:

*“I think it would be good to have... aaa... to have a time to talk about the person who died, with the other residents. (...) because when they die, they are not forgotten”.*

A need to enable the residents to mourn was also identified, allowing anyone who wanted to attend the wake, and eventually pray.

The opportunity to care for the resident’s body was treasured as a final way for staff to express their affection. These intense and private moments, valued not only by staff but also by the residents and families, contribute to providing closure. Reminding some of the moments lived with dying residents awakened the most intense emotions in the interviewees, who seemed to feel good sharing them. In my notes of several of these interviews, I have noted how emotions seemed to be part of the integrated care provided, contributing to reinforcing the bond between staff and residents, at the same time as providing closure for all.

#### **4.1.5 No time to mourn**

Having some time for staff to adjust to the resident’s death, before continuing their care of other residents, was deemed an important part of the grieving process. Simultaneously, the residents and staff are forced to forget the death of one of them, while facing their own mortality:

*“I feel that some of them are afraid. The fear of that word, which is the fear of death. Because automatically when they ask questions about the other, they are automatically identifying themselves” (Ana).*

Ways in which staff were able to mourn included being able to say goodbye to the family, in particular for those that were not present during the last moments, and having time for introspection. Expressing emotions immediately after the resident’s death, having a private moment as a team to talk about what happened, about personal feelings or difficulties, and to be listened to by the other staff were also significant:

*“That staff that is closer (...) in the final moments. They may need to have a greater need to express, to talk about, of those moments they lived, of those last hours that they passed with the resident” (Lúcia).*

Staff perceived a resident’s death as losing a member of their own family, with grieving symptoms experienced. However, taking care of the other residents usually takes precedence, and while providing care to the residents, staff have to struggle to cope with their own loss:

*“What I feel sometimes is that I don't have time to... I don't have time for my suffering, that is, the person dies, however much it is expected, it is always a loss for us, because they are elderly but they belong to our family, (...) what I feel is that there is no time (pause) to cry, to live that, because later there are another thirty-nine waiting for us and this is a factor that makes it difficult for me to mourn” (Sofia).*

Mourning is silent, although the deceased is remembered for a long time. Given the strong bonds established between the staff, residents and families, after a resident dies, staff and residents must cope with a double loss: both the resident and their family do not return to the institution. A need to be proactive to support mourning (in the nursing home as a whole: staff, residents and families) and to have space or a moment to grieve was repeatedly mentioned:

*“On the part of the nursing home, to be proactive and to do something ... in the sense of supporting mourning, does not happen ... and this is an aspect to improve. We really need to improve” (Teresa).*

No bereavement support services (for the residents, staff or families) exists in nursing homes, and even in the wider community, health services are scarce and only available in more severe situations.

The need to improve knowledge on mourning, to better support staff, the residents and families was also pointed out. Recognising this need corresponds to acknowledging that death and dying are part of nursing homes life, a step forward in a culture that usually denies death. In this way, death is not the end of a relationship, but allows the other residents, staff and families to adapt to a life in which the deceased continues to be present through memories.

#### **4.1.6 “I think all of us can contribute to change”**

The problems faced by the nursing home were outlined as culturally rooted in older practices and worldviews, a lack of end-of-life care knowledge and competency, and outdated rules,

which have an impact on the care provided. Implicit in the previously discussed themes is a need for institutional change that contributes to improvement in the care provided. Change must come from within the nursing home, driven by those who work there:

*“it is not just the manager that has the responsibility for organizing all, we all work here and have to collaborate in change... and help the manager to... alter and change things. We, all, the care aides, everybody” (Luísa).*

Repeatedly emphasised was the support nursing home staff felt they received from management when change was needed. However, the support of someone external to the nursing home was deemed helpful in identifying what could be improved and how:

*“I think an outsider can have a more objective vision and can help us to identify what things can work better” (Sofia).*

Although not regularly scheduled or realised, the importance of nursing home staff meetings was underlined, and participation regarded as needing change. They are not, however, common in the Portuguese nursing home context, and their usefulness and benefits are not perceived as necessary by most of the staff:

*“It was important that everyone participated in the meetings, or in the training” (Luísa).*

*“There is a need for the care aides to understand that when we meet, a work meeting or training, that it is productive time, and not only because it is mandatory” (Sofia).*

Education and training (previously discussed) were also regarded as needing to be implemented to improve care. Improvements in care related to end-of-life care and to support staff, residents and families in mourning, was at the centre of the participants' concerns, and organizational change was perceived as fundamental to reaching this objective.

The first findings from the analysis of the interviews were presented to the participants and reflected upon. The participants agreed that problems existed and that change was necessary: although some problems were related to external factors (governmental rules and laws, staffing levels, salaries), others stemmed from inside the nursing home, and could and should be managed internally, providing support existed. A decision was taken by all to continue as a group and prepare interventions to tackle the problems, which drove the research into the next Cycle.

## 4.2 Cycle 2

After the second recruitment phase, eight of the ten participants in Cycle 1 (two nurses, a care aide, a physiotherapist, an activities coordinator, a social worker, a receptionist and the manager) that had participated in the interviews consented to participate in Cycle 2 and 3. The focus agreed by the group, derived from the analysis of the interviews, was to develop an organizational intervention programme. A decision to use a PAR approach was made and the group began to analyse data and plan possible interventions as research progressed. The implementation and evaluation of the interventions programmed were also objectives of the action group that will be described later.

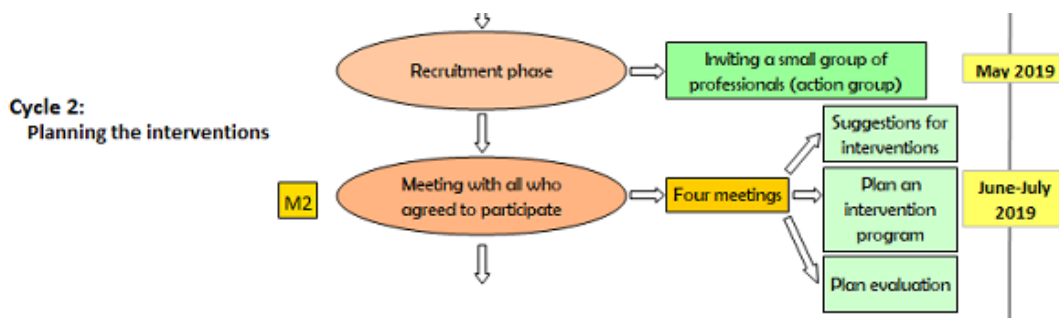


Figure 5: Cycle 2

Five interventions were planned, of which three related to the residents' care (Hydration, producing a Resident's File, beginning a global Resident's Evaluation), and two were related to grief (the Farewell Table, and the Celebration of the Resident's Life).

Table 10: The nursing home planned interventions

Interventions	Objective	Planning
	<p><b>Hydration</b></p> <p>De-hydration prevention</p>	<ul style="list-style-type: none"> <li>- Plan the reorganisation of the staff</li> <li>- Transmit and reinforce information to care aides</li> <li>- Update registers on every shift: until middle afternoon by the technical team, afternoon and night by the care aides</li> <li>- Improve water or tea flavours</li> <li>- Create new strategies: inform residents of the need to drink; the colour of the glasses; train new staff; introduce personalisation strategies</li> </ul>

Interventions	Objective	Planning
	<p><b>Dignifying death</b></p> <p>To announce a resident's death in a dignified way (known as the "Farewell Table")</p>	<ul style="list-style-type: none"> <li>- Set a table with the deceased resident's photo (chosen by the team)</li> <li>- Choose a frame for the photo</li> <li>- Provide a booklet with blank pages to be written in by residents, staff and families</li> <li>- Place this at the entrance of the main living room</li> <li>- Prepare the booklet at the nursing home</li> <li>- Leave there for no more than one week</li> <li>- Prepare a CD with the resident's photos and videos, to later give to the family inside the booklet</li> <li>- Have also a flower or a plant on the table</li> <li>- Store materials in the office</li> </ul>
	<p><b>Celebrating life</b></p> <p>To provide closure for staff, residents and family after a resident's death (known as "Resident's Life Celebration")</p>	<ul style="list-style-type: none"> <li>- Meet with the family about a month after the resident's death <ul style="list-style-type: none"> <li>-Will depend on family acceptance</li> <li>-To be held in a more restricted room</li> <li>-Open to staff, residents and families</li> </ul> </li> <li>- Make a presentation using the photos/videos of the resident, and playing the resident's favourite music(s)</li> <li>- Give time to everybody who wants talk about the person (funny memories, feelings)</li> </ul>
	<p><b>Care planning</b></p> <p>An individualised form with each resident's care needs or preferences regarding care (known as the "Resident's File")</p>	<ul style="list-style-type: none"> <li>- Have a sheet of paper with care specificities on one side and details of the needs associated with daily living activities on the other <ul style="list-style-type: none"> <li>-Be very specific</li> <li>-Use generic words and terms to make it easier for care aides</li> </ul> </li> </ul>
	<p><b>Residents' evaluation</b></p> <p>A comprehensive assessment of the</p>	<ul style="list-style-type: none"> <li>- Have a file for each resident</li> <li>- Begin after the doctor's holidays</li> <li>- Begin with doctor and nurses</li> </ul>

Interventions	Objective	Planning
	residents (known as the “Resident’s Evaluation”)	- Use the Palliative Performance Scale at the beginning

As the analysis of the meetings, field notes and my diary continued, three themes were generated, which were then named: Creating safe ground, “Communication is really one of the most important aspects”, and “I feel a bit lost, in terms of my own grief”.

#### **4.2.1 Creating safe ground**

Participation in the meetings went far beyond the presence of the nursing home staff that agreed to participate. The baseline research findings were presented and discussed at the first meeting, creating common ground. Openness about the research findings, returned to those who had ultimately produced them, and the possibility of freely interrogating the data, gave the participants the opportunity to learn about their nursing home and themselves.

In the following meetings, participants, through discussion, after an iterative process of analysing the data, created new knowledge later used to benefit those who lived and worked at the nursing home. I have learned to value participants’ lived experiences regarding the nursing home issues, to hear their voices and to encourage their participation in decision making. Simultaneously, the meetings elicited open discussions and supported the expression of different views or opinions without fear of being judged; this contributed to the building of trust among all. Honest discussion and joint reflection contributed to reaching a consensus and collective decisions being made and to the future being actively planned, which was only possible in the context of the common and safe ground that the research promoted.

#### **4.2.2 “Communication is really one of the most important aspects”**

Communication played a fundamental role in the development of the research. The letters inviting people to participate in the interviews, a written form of communication, played its own role in the research; a different text might have echoed differently in different potential participants (staff), leading to different results. Interviews were crucial in data gathering, providing a first view of the problems faced by nursing home staff when caring for older residents at the end of life. If different questions had been posed or different answers given, the

research could have taken a different direction. The group meetings, where interview results were presented and decisions made, contributed to the exposure of different personal views, and to creating a new and clearer view of the nursing home. Through discussion mutual understanding was developed, allowing for decisions about the future. Decision-making, through the participants' constant and evolving collaboration, contributed to strengthening the community spirit and to informing change. Communication contributed also to mobilising the entire staff of the nursing home, encouraging participation and contributing to the implementation of change.

In a communicative process, the data was collected and analysed; problems in need of being addressed were defined, and interventions prioritised, planned, implemented and reflected upon, allowing the ongoing definition of new lines of action. In this cyclical process, central to PAR, power was constantly negotiated and deliberately shared; the co-researchers' experiential knowledge was valued, and co-learning and action occurred. Communication highlighted the personal and collective voices of the participants, promoted insight and a deeper understanding of the nursing home problems, as well as lead to intense discussions about the actions that needed to be taken. It contributed to understanding, to facilitate discussion, to leverage staff articulation and to promote organisational change.

#### **4.2.3 "I feel a bit lost, in terms of my own grief"**

Although described in a veiled way, distress was present, particularly when death was approaching, but afterwards as well. It was not difficult to perceive distress in communicating a death to other residents or to note the lack of conditions for staff to deal with their grieving process. This was apparent every time a resident died.

As previously described, it is not just the way in which a death is formally announced, but how death is perceived conceptually and experienced at the nursing home. When staff had to continue to carry out their usual tasks after a death having no time for grieving, distress surfaced. Concerns were also raised about how the other residents and their relatives experienced these situations:

*"Really life goes on, but we should have a moment for all, for us, the team, and for the residents. (...) I do not know, personally, if what we provide to families is what they... if that mourning support is the one they need, or if they need more" (Sofia).*



There was a difference between what was said and how it was said. The non-verbal language common to all the interviewees (crying, sighs, body language) seemed to be the main way for them to express the suffering that speech was not able to. In one of my notes, I wrote that the non-verbal discourse was more intense than the words used, as if there was a certain shame in expressing feelings of sadness and discomfort related to the resident's death.

Based on the interviews results, and on the group's reflection, several interventions were planned. Details were discussed and adjustments made, after which a decision was made to begin with five interventions. Concerns were raised about other possible areas of intervention that had to be discarded, but an agreement was reached to leave those areas to a second phase, after the implementation and analysis of the first ones. After the group's agreement on the final design of the interventions, the research continued in the next Cycle.

### 4.3 Cycle 3

Cycle 3 focused on the implementation of the interventions. Two meetings were held to further refine some aspects of the ongoing programme. In the first one (17/07/2019) participated one care aide, one nurse, the activities coordinator, the social worker, and the receptionist. At the second one (24/07/2019) participated the two nurses, the activities coordinator, the manager, and the physiotherapist.

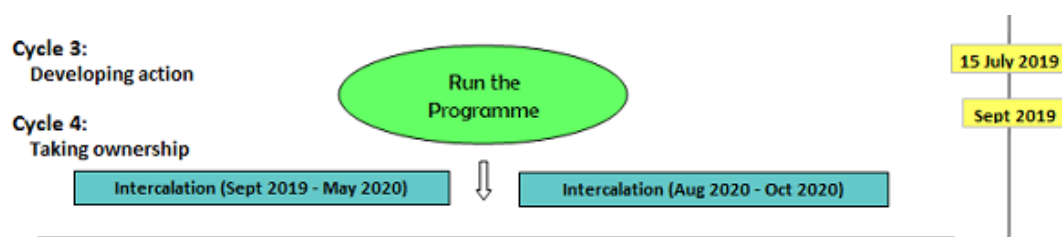


Figure 6: Cycles 3 and 4

The Residents' Files continued to be updated, and the co-researchers revealed that the entire staff was committed to adding information. Considering the amount of data gathered on each resident, several adjustments had been made to the residents' files, making them easier to read and use (Appendix 23). Residents' Evaluations had not yet been done. The co-researchers indicated that the Hydration intervention had led to improvement especially in the frailer residents, and in the staff's attention to preventive measures (who drinks or not, the need for

supervision). Some residents' water intake improved and water started to be provided to some other more dependent residents (Appendix 24).

As two residents had died during the first two weeks of July a table was set with the residents' photos. This was positively received and commented upon, with a few residents, families and staff leaving in a book of remembrance a few words of sorrow or memories of good moments together (Appendix 25). Residents with dementia had difficulty in understanding the objective of the remembrance table, so decisions were made to try to have a person (a staff member) responsible for explaining it. No meetings with families had taken place since the end of July 2019, but one was scheduled for the end of August 2019. One family was unable to attend, due to living very far from the nursing home.

As research progressed one theme was generated from data gathered during the meetings, in parallel with my diary and field notes, which was called: "We can make things happen" - Empowerment.

#### **4.3.1 "We can make things happen" - Empowerment**

The research process created a supportive environment in which, through a participatory approach, change at different levels occurred. A sense of urgency existed in the nursing home when research was presented and participation agreed upon. Individual consciousness of the nursing home's problems already existed; however, knowledge was scattered among the staff and no time or opportunity was available to collectively deal with the problems. The research study allowed the development of a collective consciousness about the problems, as well as a purposeful time and a safe space in which to discuss them, as stated by Teresa:

*"Your intervention at the nursing home makes people sit and think about the subjects, and makes people remember they are important".*

During research, the co-researchers' individual knowledge(s) became collective, contributing to collective learning: through reflection, new understandings were reached; decisions were taken collaboratively, goals were set and ways to achieve them defined; and the group engaged in collective action to bring about change. Participation (of co-researchers, of other staff and of residents in the interventions) through a bottom-up approach, contributed to empowering staff and ultimately the nursing home as a whole, improving the care and wellbeing of the residents. On an individual level, staff became more conscious of their roles, their knowledge and their power; at a collective level, staff (and the nursing home) became aware of their capacity for

transformative action. Empowerment was, in this context, simultaneously a process and a goal; a result of the PAR approach used.

Cycle 3 ended suddenly due to my ill-health and a period of intercalation (lasting nine months) was taken. As a result, no group analysis was formally done, but separately, both the co-researchers and I reflected not only on the progress of the interventions, but on the present circumstances as well. Decisions taken (see Cycle 4) by the nursing home group, and by myself as well, drove the research into the next Cycle.

#### **4.4 Cycle 4**

The focus of Cycle 4 was the development of the interventions without the researcher. This was led by the action group as I had to take a period of intercalation and was unable to be part of the research. During this period, the Covid-19 pandemic arrived, affecting nursing homes severely. The group continued to:

- develop the Resident's File, adapting it to become more practical, a working tool for the staff, and in particular for the care aides, in their daily tasks with the residents. During Covid-19 pandemic a photo of the resident was added to each file, to allow staff external to the facility to continue to provide individualised care in case of an outbreak;
- provide water to the residents (Hydration), trying new flavours and schemes of delivering water;
- communicate every deceased resident's death to the other residents in an adapted and respectful way (Farewell Table);
- celebrate the deceased resident's life (Resident's Life Celebration) with the relatives, staff and other residents;
- try to develop the Resident Evaluation (which was not possible).

##### **4.4.1 Personal reflection**

The co-researchers made me aware of their decision to continue the implementation of the interventions. If considerable ongoing support was needed to sustain change, I wondered how the nursing home would manage to continue without my presence and support. I knew that

whatever my decision was, the staff would, as usual, do their best to provide the residents with the best possible care; the changes that had been agreed upon would improve that care and contribute to the staff's wellbeing. Conversely, the other option would be to stop everything, wait until I could resume research, and then proceed with the whole process from where we left off. However, the co-researchers' decisions would not then have been taken into account, and, furthermore, a system (the nursing home) that had already begun an intervention, would not be the same as in the beginning.

I then realised that the action group had a vision of where the research could and should go, led by an empowered group taking research (as theirs, as mine) into their own hands. Without the desirable support and collaboration that research using a PAR approach requires, the nursing home proudly followed its own path.

From my own reflection on the events, one more theme was produced: Ownership.

#### **4.4.2 Ownership**

A strong motivation for change, greater than the immediately obvious, surfaced. Two types of ownership can be ascribed to this situation. One is the strong sense of community that the group showed, a feeling of belonging, which in PAR is called ownership. The other is the assumption that the interventions were theirs, resulting in the need to continue with their implementation. Although there was a shared ownership of the project, by exercising autonomy, the co-researchers continued the research when I could not do it. Trust and mutual respect were the research cornerstone, and participation the moving force.

Individually, and as a group, the co-researchers increased their capacity to make autonomous decisions. They assumed leadership with regard to the implementation of the interventions, encouraging staff to continue with the interventions already in development, thus having a direct impact on their consolidation in the nursing home. With the manager and their own internal support group, but without external support, the group had to overcome their disagreements, collaborate through dialogue, and aim to synthesise different types of knowledge, putting this into practice. Ownership was thus the mainstay of knowledge construction, transforming research results into action and bringing about change.

Research was resumed after nine months of intercalation (June-July 2020), when a new ethics approval was prepared. After a new period of three months of intercalation (August-October 2020) for ethics approval, research was resumed in November 2020. An evaluation of the implementation of the interventions and their impact was proposed to the nursing home co-researchers, taking the research into the next Cycle.

#### 4.5 Cycle 5

Cycle 5 focused on the evaluation of the interventions.

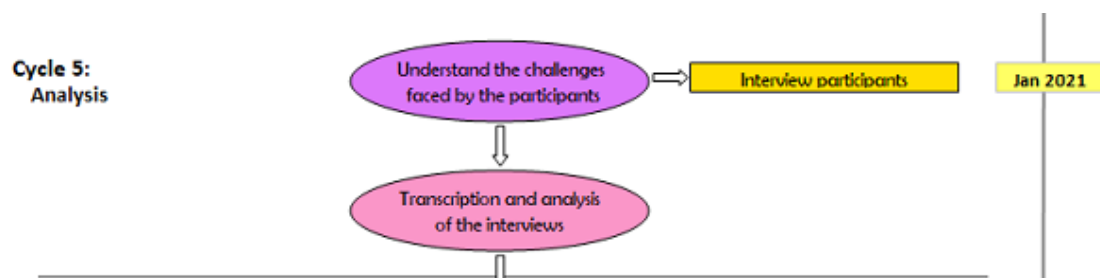


Figure 7: Cycle 5

Six participants (the physiotherapist, the manager, the receptionist, one care aide, and two nurses) consented to participate in Cycle 5 and were interviewed. Co-researchers were asked about their experience in developing and running the interventions, the challenges faced during my intercalation and the Covid-19 pandemic, and about suggestions for new interventions. Since the beginning of its implementation until the middle of March 2020 (when Covid-19 pandemic rules began to be applied to the nursing homes), Hydration protocols, the Resident's characteristics File, the Farewell Table, and the Resident's Life Celebration had been fully developed and integrated into the nursing home life. The last two had to be stopped due to Covid-19 pandemic rules, while the first two were maintained but adapted. Due to the need to separate the residents in different rooms, the Hydration plan had to be rearranged and the residents were no longer allowed to collaborate. The Residents' Files continued to be filled in for new residents, and updated when the clinical situation changed or new data about the resident was known. During the Covid-19 pandemic the Residents' Files were updated with each resident's photo, planning for the possibility of having external staff providing care in case of an outbreak.

The intervention concerned with the Residents' Evaluation had not been developed as planned, as evaluation of unstable residents was difficult and the nursing home doctor alleged a lack of time to meet with the nurses. While the other interventions had been fully planned and agreed upon by the action group (in Cycle 2) and begun to be developed in Cycle 3, this intervention had been postponed and was due to begin in September 2019. Without my support (due to intercalation), its implementation became problematic:

*"It's not because it's difficult, it's because the consultations have been changing and adjusting (...) And also the contact of the doctor and the nurse with the residents too... the doctor, as you know... is external to the institution" (Teresa).*

After some failed attempts it was abandoned:

*"We ended up losing the direction of this situation a little bit too..." (Alexandra).*

Interviews were transcribed and analysed using the same strategy as in Cycle 1. Two themes emerged from this Cycle: "Change needs to be supported" - sustaining the interventions - and Reflecting on care – the Covid-19 pandemic.

#### **4.5.1 "Change needs to be supported" - sustaining the interventions**

External and continued support is required to develop and maintain the interventions, as identified by Teresa:

*"This guidance would have been easier with you. A change programme without this support will not happen".*

The research project mobilized the staff who decided to participate, and created not only the conditions for discussing the nursing home problems, as seen in the theme Creating Safe Ground, but also for coming together and reflecting upon them and finding ways to solve them:

*"The most challenging thing was perhaps to bring the team together and at the same time manage to have some time to think about this. Perhaps that was the most challenging thing, this team availability" (Teresa).*

The interventions were jointly planned and decided upon, and their implementation began before my intercalation. Practical results were visible from the beginning, contributing to its acceptance and integration into the nursing home routines and life.

*“This has always been a joint effort, it has been planned together, techniques, assistants, it has been a joint effort and I think it will continue to be, because we like it a lot” (Maria).*

As remarked, staff commitment to participating and improving the end-of-life care of the residents, and ultimately adding to their own comfort in dealing with the residents’ deaths, were also key. When there was disagreement and external support was not present, interventions, like the Evaluation of the Residents’ condition, failed.

#### **4.5.2 Reflecting on care – the Covid-19 pandemic**

The impact of the Covid-19 pandemic permeated nursing home life. Caring for residents at the end of life became more difficult and staff struggled to maintain personalised and humanised care. The planned interventions were stopped by the pandemic or readapted to adjust to the new situation.

Staff apprehension over the impact the pandemic had on the residents’ end-of-life care was referred to different aspects: family and staff distancing; newly organized care routines; the need to prevent the introduction of the infection in the nursing home; and the impact staff stress had on caring:

*“The frailer they were, the more attention we gave them. We continue to give, but now we have to think beforehand. We have to disinfect hands first, we cannot touch the resident’s hands, we have to do this or that...” (Sofia).*

*“We have to adapt day after day, it is a pressure on the team to not allow Covid to enter, to not pass it to the residents” (Lurdes).*

Some positive aspects were mentioned, however. Teresa reflected on how the pandemic brought with it a national reflection on how care is provided in nursing homes, as well as on how education in end-of-life care can be improved:

*“This is the positive side, it is the reflection that has started, in the country, about what the work that is done in a nursing home really is. But we are far from achieving the necessary reflection. We are very slow, we are very focused on the number of cases, and very focused on the number of patients who die, but very little focused on the quality of care provided there”.*

The co-researchers’ exhaustion was obvious during the interviews, but at the same time there was relief at not having had any Covid cases up to that point. Despite the physical distance

between us caused by Covid rules and the use of full PPE, I experienced the interviews as a liberating moment for the co-researchers, in which they could talk openly about their experiences in a very demanding situation, which had and continued to have a severe impact on nursing home life.

Cycle 5 highlighted how the use of a participatory approach contributed to bring about change. Simple and culturally adapted interventions can improve nursing home older residents care, and support staff through grief. Empowerment and belonging, as experienced by nursing home staff, were the driving force for ongoing change that led research into Cycle 6.

#### 4.6 Cycle 6

Cycle 6 was about planning for the future. Two meetings, in which interview results were presented to the co-researchers, were held.

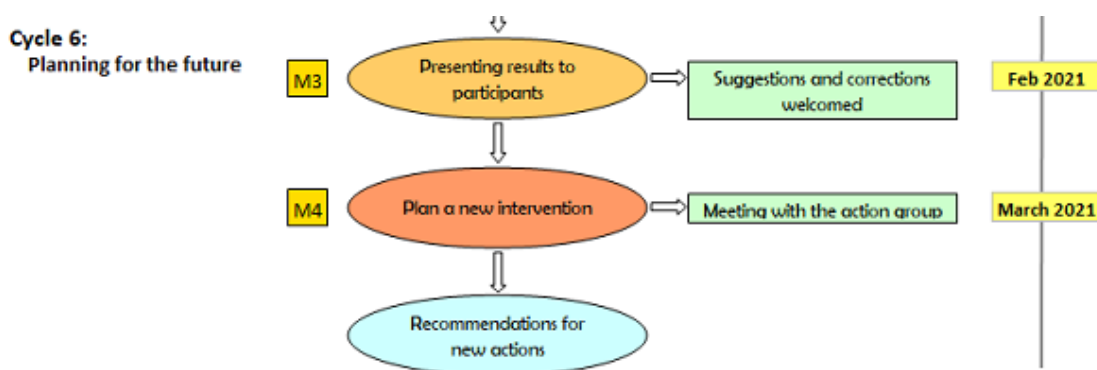


Figure 8: Cycle 6

Discussions about the Farewell Table and the deceased Resident’s Life Celebration were vivid, with the co-researchers reinforcing the need to resume both interventions (stopped at the beginning of the pandemic), as soon as possible, despite the pandemic and its constraints. The possibility of celebrating the resident’s life online and out-of-hours, allowing all the staff to participate, was suggested. The challenges the pandemic created regarding the development of the interventions were considered as having more of an impact on the nursing home than the lack of direct support in the second part of the implementation of the interventions.

At the second meeting, continuous education and the establishment of an advance care plan, which would allow the nursing home to improve end-of-life care, were defined as the new



interventions of the highest priority. Resuming the Farewell Table and the deceased Resident's Life Celebration were also considered a priority.

Continuous training on care was seen as fundamental due to high staff turnover, and discussion took place around the best way to do this; it was agreed that education should be practical, and images and videos should be added to short lectures to make them easier to understand. They should be available online so that staff could access them from the workplace or home, thereby encouraging learning. The different preparatory tasks were divided between the participants. My assistance in finding adequate videos and images was requested.

A written advance care plan and making the care aides aware of the residents' decisions on end-of-life care were considered important ways to improve care. A checklist to frame the preparatory meetings with residents and families was deemed necessary, and my help was requested to develop this intervention, namely in providing literary support and choosing the most adequate. The tasks assigned to each of the co-researchers were outlined and a new meeting scheduled based on the participants' shifts and data availability, which would aim to continue to develop the new interventions.

One theme emerged from the meetings in this Cycle and from Cycle 5 interviews, and was called Advance Care Planning and Education – two sides of the same coin.

#### **4.6.1 Advance Care Planning and Education – two sides of the same coin**

Distress was felt by staff when there was disagreement between the resident's preferences for treatment and care and the family, as described by Teresa, in particular in the last days or hours of life

*“We have had difficult situations and that is one of the most difficult aspects of caring for people at the end of life, it is when the family, besides all explanations, and besides all the evidence that the resident is better there than elsewhere, and the family does not accept that... to not send to the emergency service, no... does not accept that not sending is good”.*

Concerns about the residents' decisions regarding end-of-life care - when no written documents exist but the family is listened to - were raised by Teresa:

*“Many residents do not have the capacity to have that talk, because (...) about 75% of our residents have dementia, so they are not able to talk about that. But we try with families to understand which are their wishes”.*

Although the residents do not often talk about their death, as stated by Teresa, some approach the staff, in particular the care aides, to talk about the clothes they want to be dressed in when they die:

*“The person herself says I want to wear this outfit when I die, and this is common”.*

She also mentions a need for staff education, to raise staff awareness about the residents’ need to talk about end-of-life decisions:

*“To know that there are interventions that can reduce that suffering, reduces impotency feelings, the feeling of impotency to that suffering and to the end-of-life. But that can only be achieved with education and training”.*

Developing staff skills regarding having conversations with older residents about end-of-life decisions was frequently referred to as a need:

*“The most important intervention, that I think the nursing home should do is to develop some skills in that, and then to begin to implement an advance care plan. (...) With the resident, and stimulate and anticipate directions in the residents, in the ones that are capable of doing so” (Teresa).*

Despite having no experience in advance care planning, some staff were aware of the difficulties of its implementation without previous and ongoing education; moreover, to improving care was deemed necessary, as stated by Teresa, and staff were committed to this:

*“More scheduled meetings with staff, and their commitment in this end-of life-care area, of ethics, of dignity... these themes need reflection, to bring that forward with the team, it is important”.*

Education and advance care planning are, in the co-researchers’ opinions, inseparable. The theme also highlights a greater refinement of staff needs when caring for older residents at the end of life, a personal and institutional journey probably influenced by the research and the Covid-19 pandemic.

#### **4.7 Findings overview – contributing to knowledge creation**

A summary of the themes and interventions will be presented, followed by a summary of my interpretation of the data. Fifteen themes were identified and, associated to them, the staff different needs, at personal or institutional level, or both, when caring for older residents at the end-of-life (Table 11):

Table 11: The research themes and the associated nursing home staff needs

Themes		Nursing home staff's needs		
			Personal	Institutional
The complexities of caring for people at the end of life	Nursing homes are undervalued	- to be valued,	X	
		- to recognise the impact undervaluation has in relationships and care		X
	"There is no book to teach us" - education and training	- to improve competencies in communication and care		X
	Care at the end-of-life	- to feel supported	X	
		- to be competent when caring for an older resident approaching death		X
	Death is hidden	- to give death more visibility,		X
		- and dignity to the dead person, the other residents and staff		X
	No time to mourn	- to have the time and opportunity to mourn,	X	
		- to see grief recognised		X
		- to see mourning supported		X
	"I think all of us can contribute to change"	- to change routines and practices		X
	Creating safe ground	- to be able to trust	X	X
		- to share opinions		X

Themes	Nursing home	staff's needs	
		Personal	Institutional
“Communication is really one of the most important aspects”	- to use communication as a tool to reach objectives		X
“I feel a bit lost, in terms of my own grief”	- to recognise distress and its impact in institutional life		X
“We can make things happen” – Empowerment	- to recognise the power existent in each one and in the nursing home as a whole,	X	X
	- to use that power to bring about change		X
Ownership	- to feel part of a community,	X	X
	- to have a say in the nursing home life		X
“Change needs to be supported” – sustaining the interventions	- be supported throughout the change process	X	X
Reflecting on care – the Covid-19 pandemic	- to reflect individually and collectively on the care provided, in order to improve end-of-life care	X	X
Advance Care Planning and Education – two sides of the same coin	- to gain competence to plan care in advance,		X
	- to be able to respond to the particular needs of each resident		X

Five interventions were planned, but only four implemented, granting the nursing home staff not just insider knowledge, but their voices as well. With the exception of the Resident's Evaluation intervention, all the others are fully integrated in the nursing home life:

- the Resident's Evaluation, was never implemented, due to a lack of support;
- the Hydration intervention became a mobilising factor in the nursing home life, promoting not only more efficiency in staff's care, but also spontaneously mobilising residents to care for others;

- the Resident's File promoted an exchange of information among staff, continuously updating the Files, allowing of the constant use of that information in daily care;
- the Farewell Table allows for the announcement of a resident's death in a dignified and culturally adapted way;
- the Resident's Life Celebration provides closure to all nursing home, after a resident's death, in a culturally adapted way.

Altogether, they are simple and practical interventions that not only mobilised staff, but also residents and relatives, and promoted a reflection on care and mourning. They gave staff the confidence to continue to develop change, and promote care improvement.

A summary of my interpretation of the data is also needed before the end of this chapter. This research has been carried out in a place where life intersects with death and grief. The findings speak of interior spaces, intensely lived, but with some deliberately hidden. They speak of an impact mute, hidden and guarded. They talk of people, feelings and emotions. When this research talks about death, it is talking about life. Of the residents. Of the families. Of the staff. Because in a nursing home, these lives intertwine. And everyone's life revolves around death and grief.

Unlike what happens in a family, where, when someone dies, their memory is kept alive by those who survive, a nursing home is a place where an older person enters, lives, dies and disappears, becoming invisible. Although intimately remembered by staff and other residents, the deceased cannot be publicly named. They are replaced by another resident, and the cycle is repeated.

Death is silent and silenced. Silence settles over the person who died, but weighs heavily on the daily lives of those who survive, marking the cadence of each day. Death and grief impact and condition staff's lives inside the institution. This research shows how both condition the ways in which staff approach residents and their families, and deal with their own emotions, creating intense distress. Struggling to provide the best possible care for each one of the residents, staff members have to deal with their own losses, and are not always able to support the hidden residents' grief. The home is understaffed with regard to the residents' needs, with the staff continuously providing care, running from one resident to the other, with no time to listen to or deeply engage with them; beyond the obvious, caring for the body, the residents' spiritual and emotional needs become invisible, as staff have neither emotional availability nor competency to meet these. The same goes for staff relationships with the residents' relatives and their sometimes-unrealistic expectations: in this emotional climate, in which death is denied, and not

accepted as a natural result of the resident's evolution, it becomes difficult to define realistic care goals, particularly when no prior training in communication exists.

Staff are particularly affected as they shoulder an emotional burden that is not valued, and are paid little to do. Their professional life means constantly engaging with death and managing grief, while the undervaluation by society of nursing homes and those who work there is increased. In this context, relational conflicts are connected to the inability of sharing the emotions caused by each residents' death, with no proper space for it to be talked about and lived through together. This does not mean just a physical space, but especially the relational and emotional one needed to grieve and mourn, and ultimately to find closure.

The nursing home unconditionally embraced research as an opportunity to improve the care provided. By using a PAR methodology, the research not only allowed the construction of a time and a space for reflection and joint work, but above all, provided a safe space where emotions and concerns could be shared. The invisibility of death and grief, central for those who live and work there, became visible through the research. It therefore became amenable to intervention.

It is therefore not surprising that the co-researchers were committed to developing actions that, in general, made the invisible visible: the resident, death and grief. Improving the Resident's File brought all staff together; by organizing scattered knowledge, communication between staff members improved and the peculiarities of each resident became visible and were valued. Hydration changed from a practical and preventive intervention to a collective undertaking: from the invisibility of each resident to the awareness of each, through the mobilization not only of the staff but even of some residents. The Farewell Table did not only bring visibility to death, providing space for the residents, the relatives and staff to discuss death and dying; it also brought death out from a hidden corner into daily living. In a more intimate, but not less intense way, the Resident's Life Celebration brought all those who mourned together; it made visible the invisible, and made the mourning more communal, contributing to valuing the memory of the deceased and closing a cycle for those who had lived with him/her.

This research contributed to making the death and the associated grief of a previously unseen resident visible, this process continuing in the newly proposed actions. Education and Advance Care Planning keeps the discussion about life, death and grief present in the nursing home's actual and future life, contributing to empowering both residents and staff, and ultimately to improving care. Research provoked a reflective thinking process that the action group seems keen to continue. As well as this, the nursing home management has endorsed and funded the

development of an ongoing learning process, continuing its implementation and contributing to sustaining change.

#### **4.8 Reflexivity**

The research created a space where the participants talked about how they experienced life at the nursing home when caring for residents at the end of life. The basic interview data were pooled, after which the data were presented and discussed with the participants. The research design was shaped by the multifaceted, complex and context-bound understanding of the nature of reality (ontology) and knowledge (epistemology). Adopting one paradigm over another drove research in a certain direction, and ultimately produced a different knowledge.

A will to change and to improve care in the nursing home existed among staff. Management support for change was also present. An outsider's perspective and support for the implementation of change was guaranteed. An organizational assessment, in the staff's own words, has been made. Data were rich, vivid, detailed and contextualised. I have interrogated data, building and re-building different reality(ies) and truth(s), pursuing understanding and meaning. Data selection, re-aggregation and initial interpretation were based on my own ontological and epistemological philosophies, creating a personal and unique knowledge. Participants' comments contributed to its trustworthiness. The strategy for change was defined, and a decision made to take action on different aspects highlighted by the interviews. The research context (the nursing home) and the nature of the research question, as well as my own values, guided the choice of the approach.

The quest for knowledge brought research and participation together, intertwining them as a consequence of the "ontological and epistemological assumptions" I held regarding knowledge creation. Research took place in the nursing home context, with a strong contribution from the participants to the research process, a result of social interactions. Reality and ways of experiencing it were thus intertwined: co-created and context-bound, knowledge exists due to the fact that there is a reality and this can be known through knowledge progress.

PAR fostered the creation of a safe ground where emotions and ideas could be shared without fears of being negatively criticised, and where actions were planned and re-planned based on group decisions. Although present in the interviews, as if a certain shame existed in verbalizing the most intimate feelings related to the death of each resident, distress was less visible during

the meetings. The desire to do things differently, however, became more evident when the planning of actions started.

Building on evidence gathered from the interviews and subsequent group analysis, interventions, planned by all, were implemented. The group reflected on the different steps taken during the design of the interventions, and considered the possibility of needing to adapt some aspects of the interventions during their implementation. To maintain control over the development of the interventions, and to continue to collaboratively plan and analyse what was happening, during implementation, new meetings were agreed upon by the group. The cooperation of all co-researchers and the desire to bring about change, as well as continuous reflection on every step of the research journey, drove the research process from Cycle to Cycle in the adventure of implementing change.

I could feel the methodological tension between facilitating participation and decision-making or claiming the research ownership and prevent participation from happening. Participation, and shared-ownership, were then at its tip point: deliberation allowed all to construct meaning in relation to the problems presented and to the research in general. It also allowed me to reconceptualise myself as co-researcher and PhD student/researcher.

My researcher role was interconnected with the group's decisions. I worked as a mediator to help the group find the most adequate interventions, as a communication facilitator during the meetings, as a consultant offering suggestions with hydration techniques, all the while, actively participating in the discussions, while at the same time, as a researcher, observing the co-researchers. This last role made me aware that, although apparently detached from the research context, I was at the same time immersed in it, part of the multiple voices that came together, constructing and reconstructing reality(ies), uncovering problems and searching for outcomes.

Unanticipated consequences became visible from when the interventions were introduced: a sense of community (ownership), not just among staff but among the residents themselves (visible when residents understood the importance of hydration and provided water to other, older residents) grew. Likewise, the action group was able to mobilize the other staff (in a process of empowerment), with them all coming together to help solve problems and work for the residents' wellbeing.

The research process itself promoted the participants' reflections on the nursing home, its problems and the potential there was to act differently. Through PAR, staff were able to perceive the nursing home and their own needs more clearly and precisely and find ways to bring about change. Despite the presence of a severe external threat (the Covid-19 pandemic), the nursing



home was able to adapt and continue to develop some of the programmed interventions, which were then fully integrated into the routine of the institution. The ones that were stopped due to safety rules continued to be seen as fundamental to promoting the staff's and the residents' closure in face of a resident's death, and were restarted in 2022.

Research brought together the objective and the subjective, the stated and the understated, contributing to the expansion of the journey of discovery, as scientific as it is personal, that research encompasses. It gave space to the nursing home's multiple voices, building new and different realities, as evidenced by the development of knowledge. Far from being linear, the research was a constantly evolving process, which continues creating winds of change that will lead to further actions and change in the future.

## **Chapter 5 – Discussion and Conclusions**

### **5.1 Introduction**

The previous chapter presented the findings of this research. In this chapter I will appraise and compare the findings to those in the existing literature; the chapter will end with some considerations regarding the strengths and limitations of the research and suggestions for future research.

The aim of this research was to develop a culturally appropriate organizational programme to prepare nursing home staff to care for older people at the end of life. This research contributes to knowledge of end-of-life care in nursing homes through the identification of particular challenges faced by the nursing home staff when caring for older residents at the end-of-life. Additionally, this study identified the needs of staff and the cultural nuances in providing care at the end of life in nursing homes.

### **5.2 Summary of findings**

Findings can be grouped into two areas. First, this research uncovered several themes, and underpinning the needs of nursing home staff when caring for older residents at the end-of-life and the cultural nuances of providing care to those residents. Far beyond a set of needs voiced by the participants, this research highlighted that nursing home life revolves around death and grief, which are conditioning everyone's life. Caring for people at the end-of life is a complex undertaking, for which staff have no specific training; having to deal with a resident's death, without the time or space to grieve, staff feel intense distress.

Second, this research study focused on developing, delivering and running an organizational programme to care for older people at the end of life, and on evaluating the challenges faced by the participants. Using a PAR approach brought staff together. It created a safe emotional space and a committed time that allowed a profound reflection on the care provided, increased staff ownership, and contributed to staff empowerment. Concurrently, it allowed the planning of new interventions that will continue to implement change.

### **5.3. The needs of nursing home staff when caring for older residents at the end-of-life**

Staff in nursing homes in Portugal have to manage great complexity when caring for the older residents. Caring is a time-consuming and very demanding task; that puts a lot of pressure on

staff. The lack of sufficient staff to provide more than basic physical care, associated with the lack of specific preparation to do so, caused great distress. Staff struggled between the care they aspired to, and recognised as the best to provide, and the care they actually provided; between desired and actual care. Time constraints, together with staff shortages and lack of care competencies, were at its genesis. Staff wanted to not only provide the best possible, state-of-the-art care, but also to offer the residents the most individualised and dignified care, despite working in what Dwyer et al. (2009, p.191) call “the gap between ideals and the reality”.

**Education and Training:** Maintaining and improving competencies were seen as practical solutions to improving care. Practical and continuous education and training were deemed necessary in order to improve end-of-life care. In a study of seven European countries where end-of-life care is well developed, research showed that improvements in end-of-life care in nursing home is possible (Pivodic et al., 2018); nevertheless, Lamppu et al. (2021) suggest that improvements in end-of-life care may not be achieved through isolated and unsupported training interventions.

Although improvements in end-of-life care was the staff’s objective when referring to the need for more education and training, Lamppu and Pitkala (2021) point out that education alone has very little effect on the quality-of-life or comfort of residents in nursing homes, or even on reducing hospitalisations at the end of life. The risk of not integrating the educational needs expressed by nursing homes staff was also reported by Iida et al. (2021), in their literature review on palliative and end-of-life care interventions for nursing home staff. While outlining the difficulties found in the implementation of end-of-life educational interventions, due to their diversity and heterogeneity, these authors draw attention to the possibility of developing less standardised and more context-relevant educational programmes, and of creating curricula that address different types of competencies (core and specific) for different professionals.

Staff also expressed a necessity for “practical education” (training), better suited to the nursing home staff needs, with particular attention to local contexts, the characteristics and culture of the facilities, and staff training needs, when implementing interventions (Clark et al., 2020; Collingridge Moore et al., 2020; Froggatt et al., 2017; Froggatt et al., 2020; Iida et al., 2021). The use of new technologies and education tailored to staff needs (course availability, free-of-charge, adapted language, accessible at the users chosen time), as suggested by staff in the present research, are in line with other authors (Iida et al., 2021).

Ongoing palliative care education and training, requested by the nursing home staff, are also advocated by the EAPC to support palliative care implementation in long-term care facilities

(Froggatt et al., 2020). However, research shows that educational interventions have low effectiveness, with end-of-life care outcomes remaining largely unchanged, regardless of staff education and training (Iida et al., 2021; Lamppu & Pitkala, 2021). Thus, education and training alone are not enough to support change. Continuous internal and external support, and a culture of change, are needed to promote and maintain change (Carpenter et al., 2020; Iida et al., 2021; Lamppu et al., 2021).

**A change in organisational culture:** Staff described how time to provide basic care was limited, and how they felt unprepared to hold difficult conversations or to address the residents' spiritual needs. This research highlights an organisational culture oriented towards task performance rather than relationship with the residents, with a negative impact on the wellbeing of staff and residents, and a devaluation of both carer and cared for. Insufficient time to provide care and understaffing, as highlighted previously in this research, are seen as the most significant obstacles to good communication (Majerovitz et al., 2009).

**Communication:** A need to improve communication among staff themselves and with the residents and their relatives was also identified by staff, as improvement was also needed in valuing staff efforts to provide the best possible care. Communication among staff was deemed to be in need of improvement, particularly in respect to the organisation of work schedules. Schedule organisation, and the need to re-schedule due to missed work, had a negative impact on staff wellbeing, increasing tensions among the staff. As in this research, the literature calls attention to the fact that nursing home staff with direct care contact with residents are predominantly women, on the minimum wage, who also have extra-work personal responsibilities (shopping, cooking); a constant need to re-organise work-schedules creates more strain for management, as well as in staff relationships, and perpetuates occupational, class and gender inequities (Kossek et al., 2020).

In particular within the care aides' group, poor and dysfunctional communication affected the organisation of duties. Although this finding study might reflect an imbalance in the number of care aides who participated in the research, (with only two care aides compared with eight more trained health professionals), other research in Portuguese nursing homes has highlighted how organizational conflicts occur mainly within care aide teams (Gil, 2018). Conflict is thus a consequence of disempowerment, due to the lack of social and institutional recognition of care aides, to a power imbalance, and to communication problems (Coghlan & Brydon-Miller, 2014). Nevertheless, Pike (2011), in her research into organisational climates, has shown that education and skills development contribute to staff empowerment and reduce conflict.

Organisation of staff into teams, with a clearly defined hierarchy and leadership, in which different elements have different skills but shared goals, which is not the case in this nursing home, can also contribute to conflict reduction (Mickan, 2005).

Communication with relatives was also shown to be in need of improvement, because of unrealistic expectations and a difference in care-goals. A possible explanation for unrealistic expectations is given by Majerovitz et al. (2009), whose research link it to the difficulties faced by relatives in not being the main caregivers anymore, and in handing over care and responsibility to nursing home staff. Indirectly, unrealistic expectations put staff's role, skills and responsibilities in jeopardy. In its theoretical work on the necessary cooperation between the nursing home staff and residents' families, Jang (2020) outlines how role negotiation implies adequate communication, and mutual (and cooperative) involvement, where staff and family share different types of expertise. These both can contribute to improving the resident's end-of-life care, with professional and clinical inputs first, more personal and intimate second (Jang, 2020). This was not present in the current research where communication problems strained relationships and created distress and exhaustion. This research showed how not enough time to complete tasks, and conflict between staff and relatives, increased staff dissatisfaction, ultimately contributing to a decrease in the quality of care, in line with Abrahamson et al. (2009).

Nursing home staff in Portugal have an intense need for improvement in communication about death and dying at multiple levels. First, to communicate a resident's death to the other residents; second, to talk with the residents about death and their end-of-life wishes; third, to have a moment to grieve in private; fourth, to honor the resident's memory; and finally, to say goodbye to the resident's family. In addition to improving communication, a need exists to change the nursing home experience of a resident's death and grief.

**Death and Grief:** Staff and residents' grief is lived in a "culture of silence". Until recently death was hidden from the other residents, which contributed to staff distress (Ådland et al., 2021). Preventing breaches of confidentiality is the main reason given for not communicating the death of a resident to the others (Marcella & Kelley, 2015); however, in this study, a lack of confidence in communicating the bad news was at its basis. Having to deal with the other residents' day by day, while being unable to clearly communicate, to respond to the residents' emotional needs, and to living their grief, puts staff in a difficult position, denying them both the possibility of resolving their grief, and perpetuating the experience of unresolved grief. In this context, closure is needed, but time to grieve is not compatible with continuing with the usual caring tasks, as also noted by other authors (Pott et al., 2020; Waskiewich et al., 2012). Silencing these intense

emotional experiences, prevents staff from dealing with their grief and can contribute to impairing their capacity to carry on providing adequate care, a possible consequence that has previously been identified (Marcella & Kelley, 2015; Ramvi & Gripsrud, 2017).

In Portuguese nursing home caring for older residents is felt as rewarding, but saying goodbye is painful because of the family-like relationships which develop overtime between staff and the residents, and the repeated sharing of memories and experiences. McClement et al. (2009) underline the importance of this close relationship in the care provided, and draw attention to the loss suffered by staff when one of the residents dies. Not being family, however, puts staff in an ambivalent position; that of trying to make sense of a resident's death, while having to express grief in a culturally acceptable manner. Staff lose not just a caring relationship but one in which there is affection: the sense of loss experienced through the "family metaphor", as pointed out by Moss et al. (2003), forces a connection between private and professional, allowing staff to express grief otherwise seen as inappropriate. However, it is not just the loss of the resident that staff grieve: this research also showed that as families do not return to the nursing home after a resident's death, staff have to deal with a double loss. Validating grief and moving forward becomes difficult, in an institutional culture that pays little attention to the impact a resident's death has on staff, and prevents the recognition, let alone the expression of emotions, thus perpetuating grief.

This research shows that, although a regular part of nursing home life, death continues to be "silent and silenced" (Österlind et al., 2011) as no practical strategies or plans to acknowledge death and its impact in the nursing home exist. The feeling that it was possible and necessary to improve, despite not consciously knowing how, permeated each interview: staff knew that they needed to make sense of the resident's death to be able to reach closure and carry on. Grief allows the bereaved to construct meaning around the deceased's death, and of life without him/her, in a complex relational process between the self, others, and the local culture and contexts, where rituals reinforce the reality of death and encourage the expression of grief (Silverman et al., 2021). However, a risk of burnout or compassion fatigue exists when staff's expression of emotions related to the resident's death is denied (Ådland et al., 2021; Österlind et al., 2011).

Different strategies were highlighted by this research as having a positive effect on helping grieving nursing home staff deal with their loss (having time to adjust to the loss before an expected death occurs; knowing that the resident was comfortable, had symptom control and did not die alone; have some time to vent emotions (cry, pray); remembering the good moments

lived together; and being valued by the care provided (by the resident, the relatives or the management). In their research on care aides' grief, Anderson et al., (2010) found that an experience of growth from loss can be achieved if staff's feelings of loss were validated. Furthermore, valuing the end-of-life care provided, together with the creation of post-death debriefings or memorial services, can be valid approaches to this problem (Barooah et al., 2015). Similarly, after a resident's death, emotional support is recommended (Fryer et al., 2016), along with the organization of memorial services to support grieving staff (Marcella & Kelley, 2015; Pott et al., 2020). However, in Portugal neither of these is common.

Decisions made in the present research to implementing a "Farewell table" and a "Celebration of life", and the positive impact they had not only on staff, but on residents and families as well, are in accord with previous research. Rituals allow the expression of grief in a legitimized way: they celebrate the life of the deceased, and contribute to validating grief, bringing staff, family and eventually other residents together, and attempting to provide closure for all (Barooah et al., 2015; Maitland & Brazil, 2018). The negative impact of stopping these rituals during the Covid-19 pandemic, and the need to resume them has also been highlighted (Cardoso et al., 2020; Hockley et al., 2021). A particular responsibility on the part of the administration of nursing homes is present, encouraging the development of and participation in such rituals (Ådland et al., 2021). In this research, this was embraced by the manager immediately.

In summary, this research identified several different themes and underpinning the staff needs when caring for older residents at the end-of-life. The need for more time to care for residents and more staff to provide care were expressed and improvement in competencies was deemed necessary to improve the care provided. To fill the competencies gap, tailored ongoing education and training were considered fundamental. The improvement of communication (between staff, residents, and relatives) was also seen as necessary. The re-organisation of work and the existence of clear leadership were also considered important. Time and space to talk about a resident's death, to celebrate his/her life and to grieve were seen as fundamental.

#### **5.4 The cultural nuances of care**

This research identified cultural nuances as being important in nursing homes in Portugal: with staff; with residents and relatives; and also in the national policies and practice. The nursing home culture around death and dying is strongly influenced by local traditions (which are different in the countries of southern Europe than in those of the north) as well as by the policies and rules that guide nursing homes at a national level, all of which are considered below.

First, a culture oriented towards task performance. When providing basic care, staff still has to rush between one resident and the next. Very limited time is available to be with the residents and it is difficult to find time to hear their stories. In their research into English nursing home care aides, Kadri et al. (2018) reflect on how a task performance culture jeopardises the intrinsic value of care; when there is not enough time to care, caregivers not only fail to focus care on the person, but also feel deprived of their own personality as caregivers. Nevertheless, focusing on task completion, can be perceived as a denial of care. Not surprisingly this situation caused intense distress in staff and sometimes in the residents themselves. In addition, Abrahamson et al. (2009) refer to how the lack of time to care can reduce staff satisfaction in their caregiver role.

Second, a lack of competency in end-of-life care in the nursing home, in areas such as advance care planning or the communication of bad news. The recognition of an existing problem is a key driver for change; however, it is not enough to just improve competencies in end-of-life care. When presenting the ten core competencies in palliative care, the EAPC proposes the use of continuing professional development strategies, aiming not just for the improvement of skills and knowledge, but for opportunities for staff to reflecting on “personal attitudes, beliefs and behaviours” as well (Gamondi et al., 2013, p.144).

Third, in this nursing home, residents’ deaths had been hidden from the other residents; it was undisclosed and invisible. Whilst allowing staff to maintain emotional detachment, it was a source of distress. This is similar to other research which found that the invisibility of death allows staff to keep distance from a painful situation (Österlind et al., 2011), at the same time as increasing a suffering that is not possible to share. In their research into the perspectives of nursing home staff on death and dying, Dwyer et al. (2011) go further and attribute the invisibility of death to the lack of application of a palliative care philosophy.

Fourth, older residents rarely approach the nursing home staff to discuss end-of-life care, and when they do it is usually in a veiled or indirect way. Research undertaken with older people has found that they want to discuss end-of-life care (Vandervoort et al., 2014; WHO, 2015), but the majority of older residents never discuss their preferences for end-of-life care with their family or nursing home staff (Pivodic et al., 2018). An online survey of Portuguese adults regarding advance care directives revealed that although the participants had a positive attitude towards the directives, they lacked a thorough understanding of them (Laranjeira et al., 2021). A lack of knowledge of what advance directives of care are, call into question the timely discussion of the residents' wishes regarding end-of-life care.



Fifth, a lack of attention to the impact a resident's death has on staff is also apparent. Being hidden, as previously discussed, death becomes invisible; thus, the staff's grief is not acknowledged and therefore has no reason to exist. However, research shows that grieving symptoms similar to those of relatives are prevalent in nursing home staff, and directly related to the emotional attachment to the deceased and the length of time they have cared for them (Boerner et al., 2015). This lack of acknowledgment of the staff's grief leads to its suppression, preventing closure, perpetuating grief. A need for support exists, but is not available. Even in countries where palliative and end-of-life care is well developed, a lack of formal support for grieving staff is present, and staff have to rely on each other for support (Marcella & Kelley, 2015). To improve staff competency in recognising the importance of, and in being better able to handle grief, education and training in palliative care, as requested by this research participants, is recommended for nursing home staff (Jenull & Brunner, 2008). Research shows that basic education is not enough, and that support should be available to staff, the team and the organisation, individually and globally (Pott et al., 2020). This implies a recognition of death and grief, and a change in culture, where staff and residents' welfare are key.

### **5.5 The PAR Cycles and their influence in the life of the nursing home**

Task-oriented practice, a gap in the knowledge of end-of-life care, and a culture of silence surrounding death characterised the life of the nursing home, resulting in profound distress in the staff. An intense need for change was expressed by the participants, change that would improve care and support staff, the residents and their families in end-of-life care and mourning. Manifest or latent in staff discourses were a determination to change and, external support provided, the capacity (both personal and institutional) to do it, in what Weiner (2009) defines as change commitment and efficacy, both components of the more comprehensive concept of readiness for change. It is this need for change that explains and supports the co-researchers' decision to continue to implement change in my absence; as change was deemed urgent and necessary, a high commitment to change existed and a strong collective sense of confidence, ownership and empowerment was present. This research, and the PAR methodology used, served as a catalyst, facilitating a common and safe ground on which to discuss problems and draw lines of action, providing support, accompanying staff during the change process, jointly evaluating change and planning for the future.

Change came from within, in a slow but continuous process. It was developed by the co-researchers, the other nursing home staff, and the residents themselves. As a researcher I

created the opportunity for change to happen, but it was through shared responsibility that the interventions were developed. The findings are consistent with the literature on institutional change, which point to staff empowerment being not just a driver for taking action and achieving change, but a consequence of it (Errida & Lotfi, 2021; Weiner, 2009). Participation, through a PAR approach, promoted critical consciousness and contributed to a shared vision of the existing problems, facilitated communication and shared decision-making, and boosted staff empowerment, ultimately intensifying participation, which, in turn, created new knowledge and brought about change (Bendermacher et al., 2019; Doten-Snitker et al., 2021; Duan et al., 2020).

The research highlighted the intense distress present in the nursing home, and the feelings of the staff that change was possible and attainable. A collective consciousness about the problems developed, fostered by the participatory approach used. PAR increased the staff's critical consciousness of the problems, and at the same time as enabling the co-researchers' voices to be heard, raised awareness of power asymmetries, creating new knowledge. Research has shown that it is the development of this critical consciousness that leads to action (Khan et al., 2013). In this research, participation was not just a method of obtaining privileged information, but it aimed at developing change in the nursing home, through an empowering viewpoint that gave voice to a community, transforming hierarchy (Jacobs, 2010).

Research is a decision-making process in which, using a PAR approach, participation is not just possible but intended to. Merskin (2011) points out that PAR pays attention to the researchers' voices and the voices of others, while stressing the need for "deep listening, of engaged mindfulness, of being fully present." (p.5). In this research study, community voices were listened to, and experiences and information were exchanged and reflected upon, contributing to bringing about change. The use of a PAR approach enabled staff to increase their control over the adverse conditions that simultaneously affected research and the nursing home life. By guaranteeing that every co-researcher had a voice in the decision-making process, PAR fostered not just the research participants empowerment, but the empowerment of the nursing home as well.

Participation was key to empowerment, a reflex of the collaboration of the co-researchers and I, which allowed the participants' voices to be heard, knowledge to be co-created, power inequalities uncovered, and collective action to be developed (Coghlan & Brydon-Miller, 2014; Cusack et al., 2018). Participation, as defended by Bergold and Thomas (2012), by promoting the deconstruction and reconstruction of the participants' knowledge, was, in itself, empowering. A sense of community belonging developed, not only from the co-researchers' viewpoint, but my

own as well, promoted by PAR. In this context, empowerment brought about not only institutional change, but individual change (in the co-researchers and in me) as well, as highlighted by Coghlan and Brydon-Miller (2014). The co-researchers' decision to continue with the implementation of the interventions, enabled me to continue the research. Despite not being there, I was there. This research, which was never totally mine, became more intensely mine while being taken forward by the co-researchers, at the same time as being intensely collaborative. Ownership, which Bendermacher et al. (2019) define as a sense of belonging, was thus more than ever shared, but only possible because of the empowerment of the co-researchers. The group who assumed the interventions (and action) to continue, promoted the growth of empowerment, in a regenerative and transformational process that surpassed expectations.

This transformational process did not stop when the research study came to an end, but continues in the life of the nursing home. The sixth cycle of research showed the co-researchers planning new actions that they were continuing to develop, in a process of ongoing change. While the first set of interventions aimed to indirectly improve the care of the residents (with the exception of the Hydration intervention), the second set approaches care improvement in a mixed way, both directly and indirectly. Two types of interventions were planned and are being developed: an advance care planning intervention, and an educational and training intervention, both aimed at improving staff competency in care.

## **5.6 Planning for the future**

A need to continue to improve the quality of care of the nursing home was voiced in the interviews and group meetings. With a great number of cognitively impaired residents, the co-researchers decided to begin to undertake advance care plans for each one of the residents. They are now created at admission, and regularly reviewed when the resident's situation deteriorates. Recommendations exist regarding health staff beginning to talk about end-of-life decisions even prior to nursing home admission, when older persons still have the capacity to make decisions (Martin et al., 2016; Van Der Steen et al., 2014), so an early planning has been advocated (Martin et al., 2016).

In parallel, education and training to improve knowledge and develop communication skills in this area have been planned. Research shows that there is a high probability of older residents in nursing homes developing cognitive impairment and losing their decision-making capacity, making advance care planning (ACP) suitable for this frail population (Pivodic et al., 2018;

Vandervoort et al., 2014). Previous research has shown that education alone does not seem to be enough to initiate ACP, and there is a need for training in this area, as not all staff feel comfortable in engaging in such discussions with residents and their families (Ottoboni et al., 2019).

The interventions outlined in the final cycle of research, and that continue to be implemented by the nursing home, constitute a unique opportunity to continue to improve end-of-life care at the institution. Research into improvements in end-of-life care at nursing homes show that there are opportunities to better support older residents (Davis et al., 2016). Different aspects can facilitate person-centred palliative and end-of-life care: raising community consciousness about the end of life, the use of standard terminology, and clinical processes and legal frameworks that support advance care planning and advance care directives (Davis et al., 2016). This research promoted the beginning of this process.

However, certain concerns must be articulated. Although extensive research into advance care planning exists, studies conducted in nursing homes are scarce. Some studies indicate a decrease in emotional symptoms around death, and a reduced need for hospital care (Flo et al., 2016; Lamppu et al., 2021). However, others indicate that their effectiveness is scant: no standardised educational interventions exist and evaluation, more than about residents' outcomes, address staff knowledge and confidence in care provision (Anstey et al., 2016; Lamppu et al., 2021). It was found that advance care planning had limited or no impact on residents' quality of life (Agar et al., 2017; Husebø et al., 2019; Liu et al., 2020; Van Den Block et al., 2020), while the impact on the hospitalisations of residents resulted from staff being trained in ACP (Arendts et al., 2018; Connolly et al., 2015; Kane et al., 2017). No effects were obtained in a recent trial regarding the health-related quality of life of nursing home residents or the use and cost of hospital services, although the authors call attention to isolated and unsupported training interventions being insufficient to significantly improve the quality of care (Lamppu et al., 2021). Despite concerns about its effectiveness, ACP is advocated by the WHO and is part of the GSFCH (Thomas et al., 2014; WHO, 2011), so a decision was made to carry on with the intervention.

## **5.7 The impact of Covid-19 on research and care**

Improvements in the quality of care remains the goal of the nursing home. The Covid-19 pandemic brought other concerns, as well as obstacles to the immediate pursuit of some of the institution's objectives, and forced serious reflection on care. The situation the nursing home

was facing when research was being carried out was not much different from that of its counterparts, except for the complete lack of infections. The need to close off to the rest of the world and to quickly adapt to new procedures and routines, the fear of an outbreak in infections, the necessity to provide end-of-life care to its residents in an environment where the need to use PPE, on the one hand, and the absence of family members on the other, would make care more distant and depersonalized, although this was mitigated by the commitment of the staff. Paradoxically, and although there were no infections until the end of the research study, the pandemic made death more visible and opened up the possibility of being approached by each of the residents who wanted to.

Research shows that around the world, nursing and care homes have been at the forefront in terms of pandemic infection rates and deaths (Gordon et al., 2020). In the context of chronic staff shortages and deficient funding (Lynn, 2020), nursing homes had to face challenges related to disease detection and testing, PPE shortages, and higher than usual demands regarding the residents' health (Gordon et al., 2020; Iacobucci, 2020b, 2020a; O'Dowd, 2020; Oliver, 2020). Added to these issues, nursing homes faced problems with new admittances and with insurance, dilemmas regarding advance care planning, and a need to provide safe, empathic, hands-on care and more treatments actually in the nursing homes (sub-cutaneous fluids, O<sub>2</sub>) and psychological support, not least for residents dying without family involvement (Gordon et al., 2020; Iacobucci, 2020b; Martin, 2020).

Research calls attention to the need to rethink science itself, to quickly adapt to the challenges these difficult times demand and to see this as a time with new opportunities to learn more (Rosales-Mendoza et al., 2020). Due to Covid-19 pandemic rules the nursing home interventions had to be stopped or adapted. In other contexts (agriculture, industry, laboratories) on-site research has also been severely affected by Covid-19, stopping it or slowing it down around the world (Castelvecchi, 2020; Wigginton et al., 2020). A literature review on the impact of the Covid-19 pandemic on nursing homes, found the escalation of responsibilities and extra-work, the constant and repeated exposure to death, and the lack of emotional support or time to grieve, as the main challenges faced by staff (Spacey et al., 2021). In this research, the challenges were mainly related to extra-work, staff shortages and increased stress, a lack of emotional support, and a need to be self-sufficient in providing care at the end-of-life, since the support of the palliative care team was not possible in person. An intrinsic feeling of self-worth emerged, as staff tried to make sense of two conflicting matters: intrinsic pride in the care provided, but a sense, still, of being undervalued. Research on the impact of the pandemic on Spanish nursing home staff showed that, despite the challenges faced, a sense of satisfaction remained (Blanco-

Donoso et al., 2022). This sense of value gives meaning to nursing home staff practice when caring for older residents at the end of life, but needs to be nurtured and supported by the promotion of staff wellbeing initiatives and educational environments (ScottishCare, 2016; Venturato et al., 2006).

In line with other authors (Ouslander & Grabowski, 2020), this research highlighted the impact the pandemic had on both staff and residents: isolation, anxiety, family and staff distancing, adaptation to new routines. Although the nursing home had no advance care planning in place, the co-researchers considered that, although not binding, the Residents' File was an excellent tool, contributing to decreasing the staff's concerns regarding the continuity of care of the residents, in case staff had to leave the institution due to the pandemic. Still, the need for advance care planning development became urgent, and was later presented and accepted by all as an intervention to be developed in the near future.

Taking into account the characteristics of the nursing homes residents, there is a need to provide the homes with more staff; competency in end-of-life care is also required (Wild & Szczepura, 2021). However, adequate staffing and improved competencies in end-of-life care are not enough: as mentioned by the co-researchers, the Covid-19 pandemic highlighted a need for a national reflection on the end-of-life care provided in nursing homes and how to improve it. Similarly, Fallon et al. (2020) defend the need to develop high-quality nursing home care and to merge it with healthcare services, while Ouslander and Grabowski (2020) call for more, better paid and more skilled staff. Radbruch et al. (2020), moreover, urged for the integration of palliative care into global health provision, so that compassionate care is provided while suffering and isolation at the end-of-life are alleviated. Recognising the nursing homes residents' special characteristics, the importance of adequate staff allocation and training, and the need to invest in advance care planning, in particular after the Covid-19 pandemic crisis in the nursing home, are important steps in improving care. However, they are not enough: improvements in care need to be supported and sustained, otherwise there is a risk of failure.

## **5.8 Sustaining the interventions**

The external support provided during the research was seen by the co-researchers as fundamental not just to initiating change but to maintaining it. This is in line with previous research on nursing home interventions to improve end-of-life care, where ongoing support and the existence of a stable management are pointed to as key to supporting and maintaining change. Similarly, research shows that a commitment to change is central to the development

of a distinct culture of care (Aasmul et al., 2018; Hockley & Kinley, 2016); this was visible in this research in the way the co-researchers, from the beginning, embraced the project.

A continuous effort is needed to guarantee that the achieved institutional change is maintained (Martin et al., 2012). Such was the case in this research study: the interventions already developed and implemented continued during my intercalation, despite my lack of support, but with the strong and ongoing support of the action group. However, there was great difficulty in implementing the Resident's Evaluation, programmed to begin in September 2019, which, without support, failed.

Ongoing learning seems to be critical to integrating and maintaining change in the care culture of the nursing home. Educational interventions were programmed in cycle 6, in a context in which cultural change in the nursing home was already taking place. This is in line with Lamppu et al. (2021), who call attention to the need to integrate education with other interventions.

Another factor that seems to be key to sustaining change is to predict associated costs (Hockley & Kinley, 2016). This did not happen in this research, where all the interventions were integrated into the staff's regular work, or part of my research, to which no extra funds were allocated. However, future interventions might need a budget and the allocation of financial resources, especially if external trainers have to be paid for.

## **5.9 Reflexivity**

To capture data diversity (the participants personal perspectives, narratives and accounts, regarding the research issues, informed by cultural practices), and to provide a thorough analysis of the research process, required the choice of an appropriate research methodology. The research was driven by the participants' voices to uncover a constantly evolving, subjective and socially constructed reality (ontology), and to capture the complexity of the research environment. Alongside my own worldviews, participants' perspectives (epistemology) - presented through language, shared meanings and disparate experiences of life – contributed to knowledge co-creation (Mantoura & Potvin, 2012; Pansiri, 2009; Petty et al., 2012; Polkinghorne, 2005).

The recognition and assertion of who I am relative to the research, and how it was influenced by my values, ways of life and assumptions, is referred to as reflexivity (Pitard, 2017). Recognizing and making clear the researcher's positionality, along with maintaining a continuous and critical self-assessment of the dynamic and intense relationship between

research and researcher, contributes to an increase in research transparency, trustworthiness and ethics (Bradbury-Jones, 2007; Kalu, 2019; Lewis & Ritchie, 2003). Through reflexivity the researcher's social and cultural background, assumptions, expectations, thoughts and steps in the research process leading to certain decisions, but not others, become clear (Lambert et al., 2010; Smith, 2006). Research decisions can then be explained, the research process adapted, new knowledge created and the rigour of the research improved (Jootun et al., 2009; Smith, 2006).

In this constantly evolving process, I acknowledged the influence of my own philosophical beliefs and personal experiences (and what they convey of my subjectivity), and integrated them as an essential component of the research process (Horsburgh, 2003; Petty et al., 2012; Smith, 2006). In doing so, I identified my own influence in the production of knowledge, bringing in an epistemological perspective to the development of theory (Bishop & Holmes, 2013; Popoveniuc, 2014). The awareness of the self ("values, life experiences and assumptions" (Pitard, 2017, p.6)) and of its influence on the research (personal reflexivity), along with assessing and disclosing how the research was influenced by its design (epistemological reflexivity), is emphasised by reflexive practice (Pitard, 2017). A clear understanding of the process of knowledge production (Pillow, 2003) was granted throughout, disclosing my influence in the research context and on participants, on the way the research was conducted, and on the data collected, analysed and interpreted (researcher's situatedness) (Berger, 2015; Houghton et al., 2013).

Hence, while developing the research and writing up this thesis, I have:

- reflected on my personal background and how it has influenced the research (Darawsheh, 2014);
- considered how my personal epistemology influenced the choice of a research theme (Singh & Walwyn, 2017);
- attempted to be constantly aware of how my personal circumstances, as well as the context, influenced the entire research process (Pitard, 2017);
- used first-person language and declared my decisions and the underlying reasoning throughout the research process (Berger, 2015);
- maintained a reflective diary in order to keep an audit trail of my thoughts, observations or comments about the research process (Bashan & Holsblat, 2017; Glaze, 2002; Lindroth, 2015);
- analysed, interpreted and synthesized the data providing clear information about the decision-making process (Houghton et al., 2013);



- complied with the ethical principles underlying research that promote research integrity (Guillemin & Gillam, 2004).

Critical reflection on the research process at individual, societal and institutional level, which has been advocated (Cassell et al., 2018) in what Coghlan and Brydon-Miller (2014) refer to as first person, second person and third person action research (as discussed below) is still needed.

Individual / first-person level: during this research, I have had the privilege of learning with nursing home staff; learning from their experience, resilience, reflections, anguish and successes. I have been introduced to the inner life of the institution through the voices of the staff and that has had an impact on my own daily practice when dealing with other nursing homes. I have learned to listen more attentively, to value the “small details”, to discuss resident’s clinical situations with all the carers and not just the health team, to give the nursing home staff time to express their own feelings and not just talk about the situation.

Societal / second person level: the second person or societal level relates to working with others, to approach problems of shared interest. It involves the broader concept of co-researching in face-to-face small groups, establishing a mutually respectful relationship, that ultimately contributes to bringing about change (Coghlan & Brydon-Miller, 2014). A very important part of this research were the action group meetings, whose only purpose was to address the needs of nursing home staff, and during which the co-researchers met, analysed the data generated in the interviews, made decisions on interventions and planned them. Facilitating those meetings meant to actively listen, to encourage participation and to be aware of the less heard voices and of power relationships, to co-learn in a collaborative way. Despite having experience of professional group meetings, where I share my experience and opinions with my colleagues, in this research I learned how to be present in an almost hidden way; how to pose questions more than pass opinions; how to listen to what was behind what was said and to ask for clarification; and how to answer in a non-judgemental way. All of these contributed to building trust and collaboration and provided the basis to continue to collaborate with the nursing home after the research study ended.

Institutional / third person level: the potential impact research can have at institutional level, leading to sustainable organisational change, is also known as third person inquiry. While departing from a microlevel to a wider community of inquiry, learning and knowledge (research results) become widely visible when applied to real life practice, contributing to new knowledge generation by people with no direct contact with each other (Coghlan & Brydon-Miller, 2014).

Although generalisation was never an objective, several areas of reflection can be considered regarding the application of the research results to a wider universe.

In Portugal, more than 2,500 registered nursing homes exist (MTSS, 2021), in which the findings of this research study could be applied or serve as a basis for internal reflection. However, a more comprehensive reflection on the underlying problems this research has detected is necessary. I hope this study can, in the final analysis, contribute to promoting reflection that, more than at the local level, needs to be done at a national one.

### **5.10 Strengths and Limitations**

As far as I know this is the first research study carried out in a Portuguese nursing home looking at staff needs when caring for older residents at the end of life. Rich data was gathered from the participants voices. The use of multiple qualitative methods (individual interviews and action group (focus groups) meetings) and reflexivity on the research journey, ensured the validity of this research.

The needs of different nursing home staff were identified in this research, providing a comprehensive view of distinct professional areas. The research created safe spaces in which staff could discuss their needs and projects, a place where divergent voices were not just heard, but were welcomed. The nursing home action group developed into a working group that continues to reflect on the problems in the facility, and to develop action. The use of this participatory approach meant the research contributed to participants' critical awareness and skills development, to community change in a culturally adjusted way, to the improvement of life and social and relational change, and to increased viability of research end results.

Regarding the limitations of this study, the findings represent the needs of the staff at this particular care home, and may not be generalizable to a national or international context. However, qualitative research does not aim to produce findings that can be generalised, and generalizability was never intended. Participants' representativeness was also a limitation of this research. The participants in the first cycle were not the same as in the last ones. Research lasted for around four years, which made it impossible to conduct with the same staff; one of the care aides and one of the nurses left the facility, and the social worker only participated in the first cycles of the research.

Furthermore, questions regarding the representativeness of the care aides in the larger group could be raised: only two of the thirteen care aides that worked at the nursing home

participated. Care aides are not accustomed to participating in research; thus future research should consider this and be designed in a way that participation is encouraged. Staff were recruited based on their willingness and interest to be involved in the research, so it could be that the participants' views were not fully representative of the nursing home staff. Additionally, questions on gender bias could be raised: this research had no male participants, although this reflects predominantly female workforce in the nursing homes in Portugal.

Another limitation is related to the participation of only one nursing home. Had other facilities agreed to participate, the results might have been different. Moreover, another limitation concerns my role in the research. Its design was influenced by the PhD context, in which, despite all possible attention being given to the other co-researchers' roles, I had to take ownership of the different research phases. As a PAR approach was used, the co-researchers' collaboration would have been higher, from design to results dissemination, if in a context other than the PhD. Likewise, my capacity to support the co-researchers was less than desired. This would have been different, if the circumstances had been different. However, the same circumstances gave the co-researchers more freedom to implement the interventions, contributing to the PAR goal of empowerment.

The difficulty in implementing one of the interventions (the Residents' Evaluation) can be seen as a failure. However, this failure also constitutes an opportunity for reflection, and for learning about research sustainability. Constraints related to the Covid-19 pandemic also had an impact on this research: they led to the adaptation of some of the interventions, and the temporary suspension of others, which could be seen as another research limitation, even though it promoted even greater staff creativity, which could be regarded as a strength.

## **5.11 Implications for Policy, Research and Practice**

### **5.11.1 Implications for Policy**

The research identified several needs of nursing home staff when caring for older residents at the end of life. Although some of them are located at the organisational level, others, such as staffing levels, training and skills improvement, and support in mourning, are related to national policies, and have a severe impact on nursing home life. The Covid-19 pandemic created the opportunity to question the care provided and to discuss how to improve it. The establishment of minimum training levels, skills and end-of-life care competencies required for the nursing

homes staff, as well as regulations and supervision, demands the establishment of national directives, particularly in terms of health and social security.

### **5.11.2 Implications for Research**

Providing care to an older and often frail population, nursing homes are complex institutions with an added responsibility for providing quality care to residents at the end of life. Although research on nursing homes has developed mostly in the last twenty years in countries where end-of-life and palliative care are well established, it is scarce in southern European countries, and in particular in Portugal. Research in different areas is needed. This research highlighted the needs of the staff in one nursing home, but more and more comprehensive research is warranted on the subject, as well as research into the needs of residents and families. Areas such as care quality, education and training, mourning, and communication were also identified, and need further research. Further research into nursing home interventions, their development, implementation and outcome assessment, alongside the barriers and facilitators to their success, is also deemed necessary, as is research into the sustainability and cost-effectiveness of interventions. If the will and conditions exist, so do a wealth of different research areas.

### **5.11.3 Implications for Practice**

Previous research describes multicomponent and heterogeneous interventions improving nursing home end-of life care, together with facilitation strategies and barriers to successful completion of the interventions. The influence a resident's death has on care staff was emphasised in this research, as were the ways in which this could be addressed through interventions that facilitate mourning and provide closure. The study also highlighted the need to improve communication among staff, and between residents, families and staff. It showed how simple interventions can have a direct impact on the life of the nursing home, contributing to the empowerment of the staff (and the residents) and, ultimately, to improvements in care.

Innovative programmes to address the needs of nursing home staff who care for older residents at the end of life should be put in place, and incremental and supporting steps should be made to safeguard their integration into the nursing home culture of care. Educational interventions should have adapted content, be easily accessible and tailored to staff needs and context. The death of a resident should be communicated in a sensitive, respectful and adapted way, and

interventions intended to provide closure developed and implemented. The internal support of management and facilitators to implement and support change should be guaranteed in advance.

## **5.12 Conclusion**

As populations age, nursing homes have become places where frail and dependent older people live for the last months or years of their lives. Although research in northern European and northern American countries have highlighted the needs of nursing home staff when caring for older residents at the end of life, little is known about such needs in southern European countries. This research sought to identify those needs, in the particular context of a Portuguese nursing home.

A PAR approach was used, valuing participants and their contexts as dynamic collaborators in the whole research process. Using a PAR approach, this research contributed to critical reflection on the part of the nursing home staff regarding practices, for caring for older people at the end of life. The participants' contributions and expertise and the co-researchers' interactions and cooperation, concurred with the understanding of the staff's behaviours and attitudes to older people at the end of life. Their contribution assisted with rich and varied data that was used in drawing up an organizational programme, designed by staff, which covered their needs when caring for older people at the end of life.

My personal narrative, beliefs and expertise contributed to the creation of new knowledge and ultimately to social change. Together, the interviews, field notes and my reflective diary, collected and written during the research journey, formed a pool of data that contributed to eliciting the research participants' perspectives. Concurrently, the participants' experience in caring for older people at the end of life, in a nursing home context, as well as the co-researchers' interaction and reflexivity, contributed to the generation of understanding and the co-construction of knowledge, and ultimately turned these into action.

Due to its complexity and non-linearity, this process needed to be carried out in small sequential steps, and with the unequivocal participation of the institutional staff. Accepting the influence of context in people's lives and the participants' active and committed involvement in this collaborative journey, contributed to the development of the nursing home (a community itself) and the empowerment of the staff, as well as to knowledge development. Participants brought their own knowledge to the research context and co-controlled the research process. While

providing respectful and affectionate care, the staff felt the impact of social and institutional undervaluation, communicational problems and power imbalances. Distress related to a resident's death and the associated grief, and the way death was perceived and experienced at the nursing home, contributed simultaneously to the staff's dissatisfaction and to the pursuit of change. Research brought visibility to the invisibility of a resident's death, as well as to the hidden grief of the other residents and staff. The pooling of different knowledge and data contributed to the creation of the Resident's File. Acknowledging the discomfort caused by hidden grief, and understanding what was needed to provide closure after a resident's death, led to the creation of the Farewell Table and the Celebration of the Resident's Life. Control over the knowledge generated assisted with the emancipation and empowerment of the participants, as reflected in the participants' decision to continue to develop the interventions previously defined. The choice of the most suitable strategies contributed to bringing about effective and successful organizational change, and to improvements in knowledge.

## **Appendices**

Appendix 1 - The Medline search strategy

Medline Complete Search Strategy			
Sequence	Search Options	Limiters	Results
S19	S14 AND S17	Date of Publication: 20180101-20191231	34
S18	S14 AND S17		725
S17	S15 OR S16		429,542
S16	AB ("quality improvement*" OR "quality of life" OR "quality of care") OR TI ("quality improvement*" OR "quality of life" OR "quality of care")		308,266
S15	(MH "Quality Improvement") OR (MH "Quality of Life") OR (MH "Quality of Health Care")		260,123
S14	S5 AND S8 AND S9 AND S13		3,493
S13	S10 OR S11 OR S12		52,455
S12	TI ("nursing home*" OR "residential care" OR "retirement home*" OR "sheltered house" OR "care home") OR AB ("nursing home*" OR "residential care" OR "retirement home*" OR "sheltered house" OR "care home")		32,492
S11	(MH "Nursing Homes")		33,252
S10	(MH "Homes for the Aged") OR (MH "Assisted Living Facilities")		14,377
S9	TI (intervention* OR treatment* OR therap* OR program* OR strateg* OR training OR facilitation OR "role modelling" OR "needs assessment") OR AB (intervention* OR treatment* OR therap* OR program* OR strateg* OR training OR facilitation OR "role modelling" OR "needs assessment")		7,218,467
S8	S6 OR S7		3,338,257
S7	AB ("old* person" OR "old* people" OR elderly OR geriatric* OR OAP OR Pensioner* OR "senior citizen*" OR aged) OR TI ("old* person" OR "old* people" OR elderly OR geriatric* OR OAP OR Pensioner* OR "senior citizen*" OR aged)		746,501
S6	(MH "Aged+")		2,929,001
S5	S1 OR S2 OR S3 OR S4		1,259,951
S4	AB ("End of life care" OR "palliative care" OR terminal OR dying OR death OR "advanced disease" OR "long-term care") OR TI ("End of life care" OR "palliative care" OR terminal OR dying OR death OR "advanced disease" OR "long-term care")		191,955
S3	(MH "Long-Term Care")		807
S2	(MH "Palliative Care")		31,050
S1	(MH "Terminal Care")		15,762



**Appendix 2 - Excluded articles**

	<b>Article</b>	<b>Theme(s)</b>	<b>Comments</b>
1	Hanson, Henderson and Menon, 2002	Through the interviews of nursing homes staff and physicians it defines the most important issues to achieve a good death for nursing home residents.	It is not about interventions.
2	Politis <i>et al.</i> , 2004	The paper presents an intervention aimed to improve apathy of patients with dementia living in a nursing home.	Not related to end-of-life care.
3	Rantz <i>et al.</i> , 2006	It describes how to develop a programme aimed to improve nursing home residents' quality of care.	Methodological article not related to end-of-life care.
4	Gordon <i>et al.</i> , 2006	Describes a project aimed to improve the management of dementia and associated behavioural problems.	Not related to end-of-life care.
<a href="#">5</a>	Vinsnes, Harkless and Nyronning, 2007	Describes an intervention aimed to improve urinary incontinence among NH residents	Not related to end-of-life care.
6	McAiney <i>et al.</i> , 2007	Describes an initiative aimed to improve LTC resident's mental health problems' management.	Not intervention on end-of-life care
7	Hicks-Moore and Robinson, 2008	The study tests the effectiveness of interventions (music or hand	It is not specific for the care of

	Article	Theme(s)	Comments
		massage) implemented in nursing homes, for low level dementia patients, to reduce agitated behaviour.	patients at the end of life.
8	Sellers, 2008	The paper describes an intervention addressed to improve dementia patients' behaviour using animal assisted therapy.	Not related to end-of-life care.
9	Whiteman <i>et al.</i> , 2008	Describes an intervention study aimed to improve oral liquid nutritional supplementation of nursing home residents.	Not related to end-of-life care.
10	Turner and Snowdon, 2009	Describes a service designed to address challenging behavioural problems of older people diagnosed with dementia residing in Residential Care, that cause carers stress. Patients' assessment, strategies implementation and results' evaluation are described.	Not specific to patients at the end of life.
11	Tsai <i>et al.</i> , 2010	Presents a videoconference intervention program aimed to improve residents' social support, depression and loneliness.	Not related to end-of-life care.
12	Woo <i>et al.</i> , 2011	Describes an intervention to improve quality-of-life care for elderly patients with end-stage chronic disease.	Not nursing home intervention (convalescent facility)
13	Fulton <i>et al.</i> , 2011	Generic description of palliative care for patients with dementia in long-term care.	Not intervention on end-of-life care

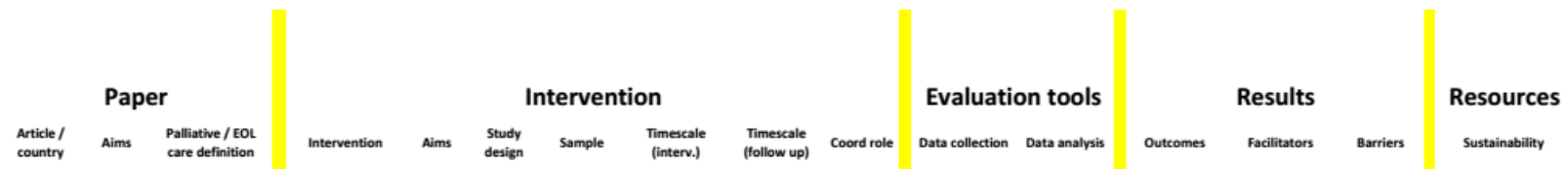
	<b>Article</b>	<b>Theme(s)</b>	<b>Comments</b>
14	Dyck, Schumacher and Friedrich, 2013	Describes organizational strategies aimed to prevent and treat unintentional weight loss.	Not related to end-of-life care.
15	McGilton, Profetto-McGrath and Robinson, 2013	Tests the feasibility of a three-part supportive supervisory intervention to improve supervisory skills of registered nurses in long-term care.	Not intervention on end-of-life care
16	George and Houser, 2014	It analysis the benefits experienced by the participants of a storytelling programme developed at a nursing home.	Not related to end-of-life care.
17	Ouslander <i>et al.</i> , 2014	Describes a quality improvement programme to improve the identification, evaluation, and management of acute changes in condition of nursing home residents	Not related to end-of-life care.
18	Sackley <i>et al.</i> , 2015	Cluster randomised controlled trial protocol of nursing home residents who suffered a stroke and were not receiving end-of-life care.	It excludes nursing home residents that receive end-of-life care. Not related to end-of-life care.
19	Van Zon, Kirby and Anderson, 2016	The paper describes a cognitive stimulation programme directed to long-term care residents with cognitive impairment.	Not related to end-of-life care.
20	McGilton <i>et al.</i> , 2016	Discusses the nurses' competencies and makes recommendations on actions to be developed at nursing homes	Not intervention on end-of-life care

	Article	Theme(s)	Comments
21	Andersson <i>et al.</i> , 2017	Describes, according to family members' opinion, the quality of care during the last 3 months and last 3 days of life of older persons who died in NH.	Not intervention on end-of-life care
22	Kinley <i>et al.</i> , 2017	Describes the implementation of an end-of-life care programme ("Steps to Success") in residential care homes.	No nursing homes
23	Connolly <i>et al.</i> , 2018	Describes an intervention aimed to reduce avoidable hospitalizations of long-term care residents.	Not specific for end-of-life care
24	Penney and Ryan, 2018	A support programme for care home managers to their improve leadership.	Not related to end-of-life care.
25	Chisholm <i>et al.</i> , 2018	Evaluates the nursing homes staff perception of adoption of an innovative approach to improve communication with families of residents with dementia.	Not specific for end-of-life care
26	Smets <i>et al.</i> , 2018	Describes the PACE Steps to Success intervention protocol to be conducted in seven European countries.	Intervention protocol
27	Smaling <i>et al.</i> , 2018	Protocol of an intervention programme for people living in nursing homes with advanced dementia.	Intervention protocol
28	Hartmann <i>et al.</i> , 2018	Intervention aimed to improve person-centred care.	Not specific for end-of-life care
29	Toscani <i>et al.</i> , 2019	Evaluates the care provided to nursing home residents with dementia in the last two months of	Not intervention on end-of-life care

	Article	Theme(s)	Comments
		life. Previous intervention not described.	
30	Bökberg, Behm and Ahlström, 2019	Intervention aimed to improve the quality of life of the family of nursing home residents.	Not intervention on end-of-life care
31	Gilissen <i>et al.</i> , 2019	Describes the programme developments but has no results.	Programme development
32	Waling <i>et al.</i> , 2019	Aged-care services access and use by gay and lesbian older people.	Not specific for end-of-life care
33	Sampson <i>et al.</i> , 2019	Intervention aimed to reduce avoidable hospital admissions.	Intervention protocol
34	Oosterveld-Vlug <i>et al.</i> , 2019	Evaluation of the implementation of the PACE Steps to Success Programme in seven countries.	Programme implementation evaluation
35	Tropea <i>et al.</i> , 2019	A simulation training programme on palliative dementia care	Intervention protocol

Data Extraction Tool

Review Question: Which interventions have been used to improve end-of-life care in nursing homes, and which resources are needed to sustain them?



**Appendix 4 - Quality appraisal tool**

<b>Paper</b>	<b>Abstract and title</b>	<b>Introduction and aims</b>	<b>Method and data</b>	<b>Sampling</b>	<b>Data analysis</b>	<b>Ethics and bias</b>	<b>Results</b>	<b>Transferability or generalizability</b>	<b>Implications and usefulness</b>	<b>Total</b>
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Appendix 5 - Papers methodological quality

Appendix 5 : Summary of the methodological quality of the included studies' (n = 33) using the appraisal tool by Hawker *et al.* (2002)

Paper	Abstract and title	Introduction and aims	Method and data	Sampling	Data analysis	Ethics and bias	Results	Transferability or generalizability	Implications and usefulness	Total
Keay <i>et al.</i> , 2003	4	2	3	2	2	2	3	2	2	21
Hanson <i>et al.</i> , 2005	4	2	3	3	4	2	3	4	2	26
Hockley, Dewar and Watson, 2005	2	2	2	3	2	2	4	2	3	22
Heals, 2008	2	2	3	2	1	1	3	3	3	19
Levy, Morris and Kramer, 2008	3	2	2	3	3	1	3	2	2	21
Phillips <i>et al.</i> , 2008	4	2	3	3	2	3	3	3	4	27
Waldron <i>et al.</i> , 2008	2	1	2	4	2	3	3	3	3	23
Badger <i>et al.</i> , 2009	3	2	2	2	3	2	3	2.5	3	21.5
Chan and Pang, 2010	3	2	3	4	4	4	4	4	4	32
Hockley <i>et al.</i> , 2010	3	2	3	3	2	2	3	3	3	24
Hall <i>et al.</i> , 2011	4	2.5	3	2	3	2	3	2	4	25.5
Hewison, Badger and Swani, 2011	2.5	2	3	4	2	1	3	3	3	23.5
Badger <i>et al.</i> , 2012	3	2	3	4	3	3	4	3	3	28
Beck, Törnquist and Edberg, 2012	4	4	3	2	3	3	4	2.5	3	28.5
Wen <i>et al.</i> , 2012	3	2	3	2	2	2	3	2	2	20
Finucane <i>et al.</i> , 2013	3	2.5	3	2	2	2	3	2.5	4	24
Livingston <i>et al.</i> , 2013	4	2	3	2	3	2	3	2.5	3	24.5
Beck, Jakobson and Edberg, 2014	3	2.5	4	3	4	3	4	4	3	30.5
Farrington, 2014	3	4	3	3	3	3	4	3	4	30
Hockley, 2014	3	3	4	3	3	3	4	4	4	31.5
Kinley <i>et al.</i> , 2014	4	2	4	4	3	3	4	4	4	32
Baron, Hodgson and Walshe, 2015	3	2	4	3	4	3	4	3	4	30
Cornally <i>et al.</i> , 2015	3	2	3	2	3	2	3	2.5	2	22.5
Brännström <i>et al.</i> , 2016	4	2	3	2	3	2	3	2	4	25
Hockley and Kinley, 2016	3	2	2	1	2	1	4	2	2	19
O'Brien <i>et al.</i> , 2016	3	3	4	3	3	3	4	4	4	31
Moore <i>et al.</i> , 2017	4	2.5	3	2	4	3	4	2.5	2	27
Aasmul <i>et al.</i> , 2018	4	2	3	3	3	3	4	3	3	28



Paper	Abstract and title	Introduction and aims	Method and data	Sampling	Data analysis	Ethics and bias	Results	Transferability or generalizability	Implications and usefulness	Total
Boogaard <i>et al.</i> , 2018	4	2.5	4	2	3	3	4	2	4	28.5
Chapman <i>et al.</i> , 2018	3	2	3	3	3	2	4	3	3	26
Verreault <i>et al.</i> , 2018	3	2	3	2	3	1	4	3	2	23
Bökberg <i>et al.</i> , 2019	3	3	3	2	4	3	4	2	3	27
Little, Rodgers and Fitzpatrick, 2019	3	2	3	3	2	1	3	3	2	22

Scoring items: 4 = good; 3 = fair; 2 = poor; 1 = very poor. Scoring total: 36 = very good; 35–28 = good; 27–19 = fair; ≤ 18 = poor quality

## Appendix 6 - Interventions summary

Paper	Intervention	Intervention	To	Strategy	Provided by	Online	Facilitator
Aasmul <i>et al.</i> , 2018	ACP (COSMOS trial)	Education programme Teaching how to: - involve relatives - initiate the communication process	two nurses from each NH (appointed COSMOS ambassadors)	train-the-trainer strategy two-day education seminar (lectures, training, and role-play)	?	No	-
Badger <i>et al.</i> , 2009	GSFCH programme phase 2	To initiate the GSFCH programme	care home staff	one-day workshops	GSFCH team	No	Local GSFCH facilitator
Badger <i>et al.</i> , 2012	GSFCH	to improving end-of-life care collaboration between nursing home staff and other health professionals.	nurse managers and senior nurses	Four one-day workshops	the GSFCH development team	No	Local GSFCH facilitator
Baron, Hodgson and Walshe, 2015	ACP education programme	ACP training based on the GSFCH programme Programme themes: 'Introduction to ACP', 'Legal and Ethical Issues', 'Communication' and 'Documentation'	nursing home staff	Four workshops (2h each) 4 - 6 weeks didactic teaching + role play + case study discussion	-	No	ACP facilitator
Beck, Jakobson and Edberg, 2014	Study circles and workshops on the palliative care approach	Based on the study circles		study circles (7x 2h) + interactive workshops (3 x 6h)	?	No	study-circle leader
Beck, Törnquist and Edberg, 2012	Study circles and workshops on the palliative care approach	study circle approach		study circles (7x 2h) + interactive workshops (3 x 6h)	?	No	study-circle leader
Bökberg <i>et al.</i> , 2019	Educational seminars (5) (Integrated in the project Implementation of Knowledge-based Palliative Care)	A knowledge-based palliative care intervention		Seminars (5 x 2h) during a 6-month period	The KUPA project	No	?

Paper	Intervention	Intervention	To	Strategy	Provided by	Online	Facilitator
Boogaard <i>et al.</i> , 2018	2 feedback strategies on perceived quality of end-of-life care and comfort in dying	The feedback reports were discussed in meetings Improvement actions were chosen from the suggestions or original ones	multi-disciplinary team	Feedback was provided by bereaved family caregivers	?	No	?
Brännström <i>et al.</i> , 2016	Symptom control using LCP or usual care	To compare the effects of the Liverpool Care Pathway for the Dying Patient and usual care on patients' symptom distress and well-being during the last days of life		evaluated by family members retrospective symptom assessments + 3-h session about the LCP and EOL care	?	No	?
Chan and Pang, 2010	Let Me Talk ACP programme	Encouraging participants to talk about EOL care wishes	residents		?	No	nurse facilitator
Chapman <i>et al.</i> , 2018	Palliative Care Needs Rounds	Proactive model of specialist palliative care	staff residents relatives GP nurse practitioner	direct and indirect clinical inputs, and case-based education monthly onsite clinical meeting (Palliative Care Needs Round) case-based education	a palliative care nurse practitioner	No	
Cornally <i>et al.</i> , 2015	'Let Me Decide' ACP programme	Structured approach to EoL care planning			-	No	No
Farrington, 2014	'Blended' (e-learning and facilitated workshops) training ABC course	Course	Group C staff (infrequent contact with EOL care)		nurses with significant experience in end-of-life care delivery and training	Yes	ABC course facilitators
Finucane <i>et al.</i> , 2013	Educational programme based on the Macmillan Foundations in Palliative Care for Care Homes GSFCH	Sustainability project using a low level of NH support		four modules 1 first principles, 2 communication, 3 pain and symptom management 4 bereavement	two community palliative care clinical nurse specialists	No	hospice-employed research facilitator

Paper	Intervention	Intervention	To	Strategy	Provided by	Online	Facilitator
	sustainability programme						
Hall <i>et al.</i> , 2011	GSFCH	The intervention is implementing the GSFCH			-	No	No
Hanson <i>et al.</i> , 2005	Educational sessions (6) for NH staff with a structured curriculum	Feedback at 0, 3, and 6 months	Palliative Care Leadership Teams	Staff recruitment and training six technical assistance meetings	Hospice providers	No	No
Heals, 2008	Ongoing education and training programme	To develop a link-nurse network in palliative care	qualified nurses		The study days are coordinated and facilitated by an education facilitator and supported by members of the multidisciplinary hospice team.	No	facilitated by members of the hospice multidisciplinary team and other specialists from the community and local hospitals
Hewison, Badger and Swani, 2011	Action Learning Set on best practices on EoL care	Action learning set (leadership development)	managers	working on real problems	Local PC experts	No	Hospice chief executive Senior lecturer in nursing
Hockley <i>et al.</i> , 2010	GSFCH + adapted LCP for Care Homes	High facilitation, in-house staff training 18-month programme			?	No	Yes
Hockley, 2014	Reflective debriefing groups after a resident's death	Facilitated learning at three different levels (being taught, developing understanding and critical thinking) enabled staff to feel supported and valued.		Ten reflective debriefing groups	a specialist palliative care nurse	No	No
Hockley, Dewar and Watson, 2005	Implementation of an 'Integrated care	To evaluate the implementation of an 'integrated care pathway (ICP) for the last days of life'			?	No	No

Paper	Intervention	Intervention	To	Strategy	Provided by	Online	Facilitator
	pathway (ICP) for the last days of life'						
Hockley and Kinley, 2016	GSFCH	GSFCH			?	No	nurse facilitators
Keay <i>et al.</i> , 2003	Half day educational programme			Half-day adult educational programme audit + feedback + quality improvement suggestions	?	No	No
Kinley <i>et al.</i> , 2014	High facilitation when implementing GSFCH	Help coordinators to implement the LCP,		High-facilitation: Training, support, visited nursing homes induction days every 6 months for all new staff on-going training role modelling	Facilitators	No	several GSFCH facilitators
Levy, Morris and Kramer, 2008	Implementation of the Making Advance Planning a Priority (MAPP) programme	Identify residents in high-mortality risk, addressing end-of-life care needs, referral for palliative care or hospice, use of an advance care planning tool			?	No	-
Little, Rodgers and Fitzpatrick, 2019	The Significant 7 tool	Early warning tool, the Significant 7, to facilitate identification and management of deterioration in residents			?	No	nurse specialist for older adults
Livingston <i>et al.</i> , 2013	Staff training programme (10 session) on Advance Care Wishes			ten-session manualized, interactive staff training programme	?	No	-
Moore <i>et al.</i> , 2017	Compassion Intervention	There are two core components	formal and informal carers	Facilitation + Education, training and support	interdisciplinary care leader	No	?
O'Brien <i>et al.</i> , 2016	The Six Steps to Success programme	Intervention is The Six Steps to Success programme		educational initiative workshops	?	No	Yes
Phillips <i>et al.</i> , 2008	Learning and development intervention	multi-faceted palliative care intervention, learning and development strategies	Nurses Care assistants GP	link nurse multi-disciplinary team meetings	?	No	No

Paper	Intervention	Intervention	To	Strategy	Provided by	Online	Facilitator
				specialist consultation			
Verreault <i>et al.</i> , 2018	Multidimensional intervention to improve quality of care and quality of dying in advanced dementia		Staff  Facilitators received a 35-h training in palliative care in advanced dementia	training sessions	?	No	Two nurse facilitators selected among staff
Waldron <i>et al.</i> , 2008	Case study course on palliative care	Facilitated learning programme (The Foundations in Palliative Care)		work-based case study approach	A palliative care education facilitator coordinated and delivered in-house teaching to link nurses	No	training facilitator
Wen <i>et al.</i> , 2012	6 educational lecture series	Quality improvement intervention of EoL care in NH			Local palliative care experts	Videorecorded For those who could not attend presential	

**Appendix 7 - Invitation letter (Cycle 1) (English version)**



**Dear Madam / Sir**

**Research Title:** “Developing end-of-life care at a Portuguese nursing home through participatory action research” (Cycle 1).

I am writing to invite you to participate in a research study that is aiming to develop a culturally appropriate organizational programme for nursing homes’ staff when caring for dying patients. This will be done through a partnership work between the researcher and the participants. In the first phase of the study I am looking to understand nursing home staff’s organizational needs. This is expected to be done through staff interviews and a group meeting. I would like to invite you to participate as a professional who is at the frontline of care for people at the end of their lives.

I enclose a Participant Information Sheet which outlines what participation in the study will involve for you. If you wish to participate please fill out the lower section of this page and return it in the enclosed self-addressed stamped envelope with your name and mobile phone number for interview scheduling. I will be contacting you 48 hours after receiving your letter.

Thank you for your time and for reading this Letter. Yours sincerely

**Cristina Galvão**

**Palliative Care PhD Student**

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I want to participate in the study “Developing end-of-life care at a Portuguese nursing home through participatory action research”(Cycle 1).

Name..... Phone ..... E-mail .....

Appendix 7 - Invitation letter (Cycle 1) (Portuguese version)



Ex.ma Senhora / Ex.mo Senhor

**Título da Investigação:** “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação” (1º Ciclo).

Esta carta tem como finalidade convidá-lo(a) a participar num estudo que tem como objetivo a criação de um programa organizativo de intervenção, culturalmente adaptado, destinado a profissionais dos lares que trabalham com pessoas em fim de vida, através de um trabalho conjunto entre os participantes e a investigadora. Na primeira fase deste estudo procurarei descobrir quais são as necessidades sentidas pelos profissionais que mais de perto trabalham em lares com pessoas em fim de vida, através de uma entrevista e de uma reunião. Como profissional que cuida de pessoas em fim de vida gostaria de o/a convidar a participar neste trabalho de investigação.

Anexo um Folheto Informativo para o Participante em que é pormenorizadamente descrito o que se espera com a sua participação. Caso deseje participar por favor preencha com os seus dados o destacável na parte inferior desta folha e devolva-o no envelope anexo. Contacta-lo(a)-ei nas 48 horas seguintes a receber a sua carta.

Obrigada pelo seu tempo e disponibilidade. Com os melhores cumprimentos

**Cristina Galvão**

**Aluna de Doutoramento em Cuidados Paliativos**

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Desejo participar no estudo “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação” (1º Ciclo)

Nome..... Tlm ..... E-mail .....



**Appendix 8 - Invitation letter (Cycle 2) (English version)**



**Dear Madam / Sir**

**Research Title:** “Developing end-of-life care at a Portuguese nursing home through participatory action research” (2<sup>nd</sup> Cycle).

Research enters now in a second phase and I would like to invite you to participate in the second cycle of this research project. The aim of the study is to develop a culturally appropriate organizational programme for nursing homes’ staff when caring for dying patients, through a partnership work between the researcher and the participants. In this phase of the study I am looking to develop and run an organizational programme, to evaluate the impact of the previous interventions and to recommend a next set of actions.

I enclose a Participant Information Sheet which outlines what participation in this phase of the study will involve for you. If you wish to participate please fill out the lower section of this page and return it in the enclosed self-addressed stamped envelope with your name and mobile phone number for interview scheduling. I will be contacting you 48 hours after receiving your letter.

Thank you for your time and for reading this Letter. Yours sincerely

**Cristina Galvão**

**Palliative Care PhD Student**

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I want to participate in the study “Developing end-of-life care at a Portuguese nursing home through participatory action research” (2<sup>nd</sup> and 3<sup>rd</sup> Cycles).

Name..... Phone ..... E-mail .....

**Appendix 8 - Invitation letter (Cycle 2) (Portuguese version)**



**Ex.ma Senhora / Ex.mo Senhor**

**Título da Investigação:** “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação” (Ciclo 2).

Esta investigação entra agora numa segunda fase e eu gostaria de a/o convidar a participar no segundo ciclo deste trabalho de investigação. O objetivo do estudo é a criação de um programa organizativo de intervenção, culturalmente adaptado, destinado a profissionais dos lares que trabalham com pessoas em fim de vida, através de um trabalho conjunto entre os participantes e a investigadora. Nesta fase do estudo pretendo, em conjunto com os profissionais que aceitem participar, preparar e implementar um plano de intervenção, avaliar os seus resultados e sugerir um conjunto de novas intervenções.

Anexo um Folheto Informativo para o Participante em que é pormenorizadamente descrito o que se espera com a sua participação. Caso deseje participar por favor preencha com os seus dados o destacável na parte inferior desta folha e devolva-o no envelope anexo. Contacta-lo(a)-ei nas 48 horas seguintes a receber a sua carta.

Obrigada pelo seu tempo e disponibilidade. Com os melhores cumprimentos

**Cristina Galvão**

**Aluna de Doutoramento em Cuidados Paliativos**

-----  
Desejo participar no estudo “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação” (2º e 3º Ciclos)

Nome..... Tlm ..... E-mail .....

Appendix 9 - Invitation letter (Cycle 5) (English version)



Dear Madam / Sir

**Research Title:** “Developing end-of-life care at a Portuguese nursing home through participatory action research” (5<sup>th</sup> and 6<sup>th</sup> Cycles).

Research is now at the end of its second cycle and I would like to invite you to participate in the evaluation of the organizational programme that has been developed. The aim of the study is to develop a culturally appropriate organizational programme for nursing homes’ staff when caring for dying patients, through a partnership work between the researcher and the participants. In this phase of the study I am looking to evaluate the impact of the previous interventions and to recommend a next set of actions.

I enclose a Participant Information Sheet which outlines what participation in this phase of the study will involve for you. If you wish to participate please fill out the lower section of this page and return it in the enclosed self-addressed stamped envelope with your name and mobile phone number for interview scheduling. I will be contacting you 48 hours after receiving your letter.

Thank you for your time and for reading this Letter. Yours sincerely

**Cristina Galvão**

**Palliative Care PhD Student**

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I want to participate in the study “Developing end-of-life care at a Portuguese nursing home through participatory action research” (5<sup>th</sup> and 6<sup>th</sup> Cycles).

Name..... Phone ..... E-mail .....

Appendix 9 - Invitation letter (Cycle 5) (Portuguese version)



Ex.ma Senhora / Ex.mo Senhor

**Título da Investigação:** “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação” (Ciclos 5 e 6).

Esta investigação entra agora no final do segundo ciclo e eu gostaria de a/o convidar a participar na avaliação do programa de intervenção que tem vindo a ser desenvolvido. O objetivo do estudo é a criação de um programa organizativo de intervenção, culturalmente adaptado, destinado a profissionais dos lares que trabalham com pessoas em fim de vida, através de um trabalho conjunto entre os participantes e a investigadora. Nesta fase do estudo pretendo, em conjunto com os profissionais que aceitem participar, avaliar o impacto do plano de intervenção e sugerir um conjunto de novas intervenções.

Anexo um Folheto Informativo para o Participante em que é pormenorizadamente descrito o que se espera com a sua participação. Caso deseje participar por favor preencha com os seus dados o destacável na parte inferior desta folha e devolva-o no envelope anexo. Contacta-lo(a)-ei nas 48 horas seguintes a receber a sua carta.

Obrigada pelo seu tempo e disponibilidade. Com os melhores cumprimentos

**Cristina Galvão**

**Aluna de Doutoramento em Cuidados Paliativos**

-----  
Desejo participar no estudo “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação” (5º e 6º Ciclos)

Nome..... Tlm ..... E-mail .....

## PhD IN PALLIATIVE CARE

““Developing end-of-life care at a Portuguese nursing home through participatory action research”

TO THE CLIENTS OF [REDACTED] NURSING HOME AND THEIR FAMILIES

To improve care for older people is a constant challenge for professionals working at nursing homes. This PhD study is about care improvement.

### What is this research about?

Research is about care at the end of life and how to improve it.

No residents will be identified in this study.

### Who will be involved?

Care staff working in this facility will be taking part in the study.

### Further information:

If you need further information please contact Dr. Cristina Galvão at the following email address [c.galvo@Lancaster.ac.uk](mailto:c.galvo@Lancaster.ac.uk)

### Who is undertaking the study?



Dr. Cristina Galvão, student of Palliative Care PhD at Lancaster University (UK).

[REDACTED] The study has been approved by the Lancaster University and by Comissão de Ética de Investigação Clínica (CEIC).

It is supervised by Dr. Sarah Brearley and by Dr. Caroline Swarbrick.



## DOUTORAMENTO EM CUIDADOS PALIATIVOS

“Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação”

### AOS UTENTES DO LAR [REDACTED] E SUAS FAMÍLIAS

Melhorar os cuidados às pessoas idosas é um desafio constante para os profissionais que trabalham nos Lares. Este trabalho de doutoramento incide sobre esta problemática.

#### Sobre que é este estudo?

O estudo é sobre cuidados em fim de vida e como melhora-los.

Os utentes não serão identificados neste estudo.

#### Quem participa no estudo?

Os profissionais que no Lar trabalhem diretamente com os idosos e que queiram participar.

#### Informações:

Caso deseje obter mais informação sobre este estudo por favor contacte a Dra. Cristina Galvão através do email [c.galvo@Lancaster.ac.uk](mailto:c.galvo@Lancaster.ac.uk)

#### Quem é a responsável pelo estudo?



A Dra. Cristina Galvão, aluna de doutoramento em Cuidados Paliativos na Universidade de Lancaster (RU) é a responsável por este estudo.

[REDACTED] A investigação foi aprovada pela Universidade de Lancaster e pela Comissão de Ética de Investigação Clínica (CEIC).

[REDACTED] É supervisionada pela [Dra. Sarah Brearley](#) e pela [Dra. Caroline Swarbrick](#).



## Appendix 11 – Participant information sheet (English version)



### Participant Information Sheet

**Research Title:** “Developing end-of-life care at a Portuguese nursing home through participatory action research” (1<sup>st</sup> Cycle)

My name is Cristina Galvão and this study is part of a PhD research on Palliative Care at the Lancaster University, UK. It is supervised by Professor Katherine Froggatt and by Dr. Sarah Brearley and has been approved by Lancaster University and by Comissão de Ética de Investigação Clínica (CEIC).

#### **What is the study about?**

The aim of the study is to develop a culturally appropriate organizational programme for nursing homes’ staff when caring for dying patients. This will be done through a partnership work between the researcher and the participants. During all the research process participants will have the opportunity to intervene and research will be adapted according to their suggestions. Research will take place during approximately two years.

#### **Why have I been approached?**

As nursing home staff, you are at the frontline of care for people at the end of their lives. The partnership work (between the researcher and the participants) intended to be developed at the nursing home, in the next two years, value the ideas and opinions of all.

#### **Do I have to take part?**

No. Taking part in the research is entirely voluntary. If you decide to take part you are free to withdraw at any time, without giving a reason and without detriment to yourself. Once the interview is completed, you will have two weeks to ask for data to be withdrawn from the study. When participating in group meetings it will not be possible to exclude individual data once the session has commenced, if decision of withdrawal is made.

### **What will I be asked to do if I take part?**

If you decide you would like to take part, you will be asked to participate in an interview and in one meeting. At the second phase of the research process another interview and meetings will be held, and if you want you can continue to participate. If so you will receive another invitation letter. Your participation, depending on your decision, can be just at the first interview and meeting or in the whole programme.

#### **1. Qualitative interview**

- the one-on-one interview, will take place at a next-door building to the nursing home where you work and will take between 30 and 60 minutes. The aim of the interview will be to understand the difficulties you have when caring for a terminally ill person and to find out what type of organizational changes you think can improve the situation. Personal information, including your gender, time working at the facility and occupation will also be collected.

#### **2. Summary group meeting**

- after all interviews completion, transcription and analysis has been done, a meeting to discuss what has been said at the interviews will be held, and participants' suggestions will be welcomed.

### **Will my data be identifiable?**

All information provided will be handled in confidence and anonymity will be guaranteed, that is, your name will not be mentioned. If you want, you can choose a pseudonym.

Participation in the group meeting means that you will meet the other participants and as a result your participation will not be confidential and quotes may be later attributable to



individuals. The transcription will eliminate any personal context in such a way that people not directly involved with the project or the group will not be able to identify who participated in the meeting.

All data will be kept by the researcher in an electronic password protected database and only the researcher conducting this study and her Lancaster University supervisors will have access to this data:

- Audio recordings will be destroyed and/or deleted once the final thesis has been submitted and the PhD awarded by Lancaster University.
- Hard copies of transcripts will be kept in a locked cabinet.
- The files on the computer will be encrypted (that is, no-one other than the researcher and her Lancaster University supervisors will be able to access them) and the computer itself password protected.
- Data will be kept for ten years after the end of the study.
- At the end of the study, hard copies of interview transcripts will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name.
- Anonymised direct quotations from your interview may be used in the reports or publications from the study, in presentations at future conferences, and for future training events and resources. Your name will not be attached to them.
- Anonymous data from this study may be shared and used by the researcher for further analysis in the future.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I must break confidentiality and speak to my supervisors at Lancaster University about this. If possible, I will tell you if I must do this.

### **What will happen to the results?**

The results will be summarised and reported to the Lancaster University. I will also aim to submit results for publication in an academic or professional journal and undertake conference presentations.

### **Are there any risks?**

There are no risks anticipated with participating in this study. However, if you experience any distress following participation support from a psychologist external to the facility will be available.

### **Are there any benefits to taking part?**

Although you may find participating interesting, there are no benefits in taking part. According to the Portuguese law no monetary incentives will be provided (Lei nº 21/2014). However, if you will need to travel to the facility to participate in the interviews or group meetings, your travel costs will be reimbursed.

### **Who has reviewed the project?**

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University and by Comissão de Ética de Investigação Clínica (CEIC).

### **Where can I obtain further information about the study if I need it?**

If you need any other information about this study feel free to contact me to the mobile phone number 919540208 or to my e-mail: [c.galvo@lancaster.ac.uk](mailto:c.galvo@lancaster.ac.uk)

### **Complaints**

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Steve Jones

Research Director

Division of Health Research

or

CEIC

Parque da Saúde de Lisboa

Av. do Brasil, 53 - Pav 17 - A

Lancaster University

Lancaster LA1 4YG

Tel: 01524 593382

Email: [s.jones7@lancaster.ac.uk](mailto:s.jones7@lancaster.ac.uk)

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Fax: 21 111 75 44

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Tel:+44(0)1524 593746

Associate Dean for Research

Email: [r.pickup@lancaster.ac.uk](mailto:r.pickup@lancaster.ac.uk)

Faculty of Health and Medicine

(Division of Biomedical and Life Sciences)

Lancaster University

Lancaster LA1 4YG

Thank you for your time and for reading this Participant Information Sheet.

If you decide to join the study please return the stamped addressed envelope enclosed, with your name and mobile phone number for interview scheduling.

**Cristina Galvão**

**Palliative Care PhD Student**

## Appendix 11 – Participant information sheet (Portuguese version)



### Folheto Informativo para o Participante

**Título da Investigação:** “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação” (1º Ciclo)

O meu nome é Cristina Galvão e este estudo faz parte de um trabalho de doutoramento em Cuidados Paliativos na Universidade de Lancaster, em Inglaterra. É supervisionado pela Professora Doutora Katherine Froggatt e pela Dra. Sarah Brearley e foi aprovado pela Universidade de Lancaster e pela Comissão de Ética de Investigação Clínica (CEIC).

#### O que é este estudo?

O objetivo do estudo é a criação de um programa organizativo culturalmente adaptado e destinado a profissionais dos lares que trabalham com pessoas em fim de vida. Tal será feito através de um trabalho conjunto entre os participantes e a investigadora. Durante todo o processo de investigação os participantes terão todas as oportunidades de intervir e a investigação irá sendo adaptada de acordo com as suas sugestões. A investigação decorrerá ao longo de aproximadamente dois anos.

#### Porque fui contactado (a)?

Uma vez que trabalha no lar encontra-se na primeira linha da prestação de cuidados a pessoas em fim de vida. O trabalho conjunto (entre a investigadora e os participantes) que se pretende desenvolver no lar nos próximos dois anos, valoriza as ideias e opiniões de todos.

#### Sou obrigado (a) a participar?

Não. A participação é voluntária.

Caso decida participar poderá em qualquer altura desistir de continuar na investigação, sem necessidade de dar qualquer explicação e sem prejuízo algum. Assim que a entrevista esteja terminada tem duas semanas para decidir sair do estudo. Ao participar em reuniões de grupo não será possível excluir informação individual a partir do momento em que a reunião comece, mesmo que decida desistir.

### **O que me será pedido se decidir participar?**

Se decidir participar ser-lhe-á pedido que participe numa entrevista e numa reunião de grupo. Numa segunda fase desta investigação serão efetuadas outra entrevista e reuniões, e caso deseje pode continuar a participar. Então receberá outra carta convite. A sua participação, dependendo da sua decisão, poderá ser apenas na entrevista inicial ou na totalidade do programa.

#### **1. Entrevista Qualitativa**

- a entrevista individual, que terá lugar no edifício do infantário, terá uma duração de 30 a 60 minutos. O objetivo é perceber que dificuldades sente quando trabalha com pessoas em fim de vida e que tipo de intervenções organizativas pensa que podem melhorar essa situação. Nenhuma informação pessoal para além de género, há quanto tempo trabalha no lar e profissão será colhida.

#### **2. Reuniões de grupo**

- quando todas as entrevistas tiverem sido feitas e o seu conteúdo transcrito e analisado será realizada uma reunião para apresentar os resultados e discutir o que foi dito nas entrevistas. Todas as sugestões que possam ser feitas pelos participantes serão bem acolhidas.

### **Os meus dados serão identificáveis?**

Os dados são confidenciais e todas as informações serão mantidas anónimas, isto é, o seu nome não será mencionado. Poderá, se o quiser fazer, escolher um pseudónimo.

A manutenção da confidencialidade sobre o que se passa em cada reunião é obrigatória para cada um dos participantes. Ao participar na reunião de grupo irá encontrar-se com outros participantes e por isso a sua participação não será confidencial. As afirmações que fizer poderão ser posteriormente reconhecidas por quem participou na reunião.

Nas transcrições eliminar-se-á toda a informação pessoal de forma a que quem não estiver ligado ao projeto ou não pertença ao grupo não possa identificar os autores das citações.

Todos os dados obtidos serão guardados pela investigadora numa base de dados de acesso restrito através de um código e apenas esta e as suas supervisoras da Universidade de Lancaster terão acesso a essa informação:

- As gravações audio serão destruídas ou apagadas logo que o documento final tenha sido submetido e aceite pela Universidade de Lancaster.
- As transcrições impressas serão guardadas num cofre.
- Os ficheiros eletrónicos serão encriptados (de forma a que ninguém, para além da investigadora e das suas supervisoras na Universidade de Lancaster, lhes possam aceder) e o computador estará também protegido por uma palavra-passe.
- Os dados serão guardados por dez anos após o final do estudo.
- No final do estudo as transcrições impressas das entrevistas serão guardadas durante dez anos num cofre, após o que serão destruídas.
- A versão escrita da sua entrevista será anonimizada, sendo retirada toda a informação passível de o(a) identificar, incluindo o seu nome.
- Citações anonimizadas da sua entrevista poderão vir a ser usadas em relatórios e publicações do estudo, em apresentações em congressos, em formações ou folhetos. O seu nome nunca será nomeado.
- Informação anonimizada deste estudo poderá vir a ser partilhada e usada pela investigadora em análises futuras.
- Todos os seus dados pessoais serão confidenciais e serão conservados em separado das respostas à entrevista.

Existem alguns limites à confidencialidade: se o que for dito nas entrevistas me fizer supor que o(a) entrevistado(a) possa estar em elevado risco de dano, terei que quebrar a confidencialidade e falar com as minhas supervisoras na Universidade de Lancaster. Caso seja possível, dir-lhe-ei que terei que o fazer.

### **Qual o destino dos resultados?**

Os resultados serão sumarizados e apresentados à Universidade de Lancaster. É também minha intenção submeter os resultados para publicação em revistas académicas ou profissionais bem como utiliza-los em apresentações em congressos.

### **Existe algum risco em participar nesta investigação?**

Antecipadamente não prevemos a existência de nenhum risco associado à investigação. No entanto, caso se sinta desconfortável durante a sua participação ser-lhe-á facultado o contacto e apoio de uma psicóloga externa ao lar.

### **Quais os benefícios em participar?**

Não existem benefícios na participação no estudo. De acordo com a legislação portuguesa (Lei nº 21/2014), não haverá qualquer pagamento por participar na investigação. Contudo, caso necessite de se deslocar propositadamente ao lar para participar no estudo, as despesas de transporte ser-lhe-ão reembolsadas.

### **Quem fez a revisão do Projeto?**

Este estudo foi revisto e aprovado pela Faculty of Health and Medicine Research Ethics Committee da Universidade de Lancaster e pela Comissão de Ética de Investigação Clínica (CEIC).

### **Onde posso obter mais informação sobre este estudo, caso necessite?**

Caso sinta que necessita de mais informação sobre este estudo poderá contactar-me através do meu telemóvel pessoal, com o número 919540208 ou através do meu e-mail: [c.galvo@lancaster.ac.uk](mailto:c.galvo@lancaster.ac.uk)

### **Reclamações**

Caso deseje fazer uma reclamação ou levantar alguma questão sobre qualquer aspeto deste estudo e não o quiser fazer com a investigadora poderá contactar:

Professor Steve Jones		CEIC
Research Director		Parque da Saúde de Lisboa
Division of Health Research	ou	Av. do Brasil, 53 - Pav 17 - A
Lancaster University		1749-004 Lisboa
Lancaster LA1 4YG		Telef. (351) 217985340
Tel: 01524 593382		Fax: 21 111 75 44
Email: <a href="mailto:s.jones7@lancaster.ac.uk">s.jones7@lancaster.ac.uk</a>		Email: <a href="mailto:ceic@ceic.pt">ceic@ceic.pt</a>

Caso deseje falar com alguém que não pertença ao Palliative Care Doctorate Programme, pode contactar:

Professor Roger Pickup  
[Tel:+44\(0\)1524 593746](tel:+44(0)1524593746)  
Associate Dean for Research  
Email: [r.pickup@lancaster.ac.uk](mailto:r.pickup@lancaster.ac.uk)  
Faculty of Health and Medicine  
(Division of Biomedical and Life Sciences)  
Lancaster University  
Lancaster LA1 4YG

Obrigada pela sua disponibilidade e por ler este Folheto Informativo para o Participante.

Caso deseje participar neste estudo por favor envie-me o envelope com o destacável anexo, depois de nele escrever o seu nome e número de telefone e contacta-lo/a-ei em breve para marcar a entrevista.

**Cristina Galvão**

**Aluna de Doutoramento em Cuidados Paliativos**





### **Participant Information Sheet**

Research Title: "Developing end-of-life care at a Portuguese nursing home through participatory action research" (2<sup>nd</sup> Cycle)

The second part of the research project is now underway, the third part will begin soon and I would like to invite you to participate in this phase of the research project. Before you decide about your participation I would like to explain you what is expected to happen.

#### **What is the study about?**

This study is part of a PhD research on Palliative Care at the Lancaster University, UK. It is supervised by Professor Katherine Froggatt and by Dr. Sarah Brearley and has been approved by Lancaster University Faculty of Health and Medicine Research Ethics Committee and by Comissão de Ética de Investigação Clínica (CEIC). The aim of the study is to develop a culturally appropriate organizational programme for nursing homes' staff when caring for dying patients, through a partnership work between the researcher and the participants.

#### **Why have I been approached?**

As nursing home staff, and having participated at the first Cycle of this research project you can, if you wish, to continue to participate.

#### **Do I have to take part?**

No. Taking part in the research is entirely voluntary. If you decide to take part you are free to withdraw at any time, without giving a reason and without detriment to yourself. Once the interview is completed, you will have two weeks to ask for data to be withdrawn from the study.

When participating in group meetings it will not be possible to exclude individual data once the session has commenced, if decision of withdrawal is made.

### **What will I be asked to do if I take part?**

If you decide you would like to take part, you will be asked to participate in up to four meetings to develop and run an organizational programme. However, if more people show an interest to participate than the required for the study, participants will be selected randomly from each professional group.

1. Action Group meetings
  - at these meetings, results from the first part of this research project will be prioritized, interventions will be defined and an intervention programme will be designed, after which it will be implemented.
  
2. Qualitative Interview and evaluation meeting
  - after the programme had been run, it is expected that you can also participate in a new interview and meeting to evaluate the impact of the previous interventions in your practice, to find out other participants' needs and to recommend a next set of actions.

### **Where can I obtain further information about the study if I need it?**

If you need any other information about this study feel free to contact me to the mobile phone number 919540208 or to my e-mail: [c.galvo@lancaster.ac.uk](mailto:c.galvo@lancaster.ac.uk)

### **Complaints**

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Faculty of Health and Medicine

(Division of Biomedical and Life Sciences)

Lancaster University

Lancaster LA1 4YG

Thank you for your time and for reading this Participant Information Sheet.

If you decide to join the study please return the stamped addressed envelope enclosed, with your name and mobile phone number for interview scheduling.

**Cristina Galvão**

**Palliative Care PhD Student**

## Appendix 12 - Participant information sheet (Portuguese version)



### Folheto Informativo para o Participante

Título da Investigação: “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação” (2º Ciclo)

A segunda parte da investigação está em curso, a terceira parte começará em breve e eu gostaria de o/a convidar a participar neste trabalho de investigação. Antes de tomar uma decisão sobre a sua participação gostaria de lhe explicar o que é esperado acontecer e como se pode processar a sua participação.

#### O que é este estudo?

Este estudo faz parte de um trabalho de doutoramento em Cuidados Paliativos na Universidade de Lancaster, em Inglaterra. É supervisionado pela Professora Doutora Katherine Froggatt e pela Dra. Sarah Brearley e foi aprovado pela Universidade de Lancaster (Faculty of Health and Medicine Research Ethics Committee) e pela Comissão de Ética de Investigação Clínica (CEIC). O objetivo do estudo é a criação de um programa organizativo culturalmente adaptado e destinado a profissionais dos lares que trabalham com pessoas em fim de vida. Tal será feito através de um trabalho conjunto entre os participantes e a investigadora.

#### Porque fui contactado (a)?

Uma vez que trabalha no lar, e tendo participado no primeiro Ciclo deste trabalho de investigação pode, se assim o desejar, continuar a participar.

#### Sou obrigado (a) a participar?

Não. A participação é voluntária. Caso decida participar poderá em qualquer altura desistir de continuar na investigação, sem necessidade de dar qualquer explicação e sem prejuízo algum. Assim que a entrevista esteja terminada tem duas semanas para decidir sair do estudo. Ao participar em reuniões de grupo não será possível excluir informação individual a partir do momento em que a reunião comece, mesmo que decida desistir.

### **O que me será pedido se decidir participar?**

Se decidir participar ser-lhe-á pedido que participe em até quatro reuniões para elaboração e implementação de um plano de intervenção. Contudo, caso mais pessoas do que as consideradas necessárias para integrar o grupo manifestem interesse em participar, os participantes serão selecionados de forma aleatória dentro de cada grupo profissional. Posteriormente, poderá participar numa nova entrevista e numa reunião destinadas a avaliar o impacto do programa de intervenção na prestação de cuidados, detetar outras necessidades sentidas pelos participantes e fazer recomendações sobre próximas intervenções.

### **Onde posso obter mais informação sobre este estudo, caso necessite?**

Caso sinta que necessita de mais informação sobre este estudo poderá contactar-me através do meu telemóvel pessoal, com o número 919540208 ou através do meu e-mail: [c.galvo@lancaster.ac.uk](mailto:c.galvo@lancaster.ac.uk)

### **Reclamações**

Caso deseje fazer uma reclamação ou levantar alguma questão sobre qualquer aspeto deste estudo e não o quiser fazer com a investigadora poderá contactar:

Professor Steve Jones		CEIC
Research Director		Parque da Saúde de Lisboa
Division of Health Research	ou	Av. do Brasil, 53 - Pav 17 - A
Lancaster University		1749-004 Lisboa
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Obrigada pela sua disponibilidade e por ler este Folheto Informativo para o Participante.

Caso deseje participar neste estudo por favor envie-me o envelope com o destacável anexo, depois de nele escrever o seu nome e número de telefone e contacta-lo/a-ei em breve para marcar a entrevista.

**Cristina Galvão**

**Aluna de Doutoramento em Cuidados Paliativos**



### **Participant Information Sheet**

Research Title: “Developing end-of-life care at a Portuguese nursing home through participatory action research” (5<sup>th</sup> and 6<sup>th</sup> Cycles)

The second part of the research project is now underway, the third part will begin soon and I would like to invite you to participate in this phase of the research project. Before you decide about your participation I would like to explain you what is expected to happen.

#### **What is the study about?**

This study is part of a PhD research on Palliative Care at the Lancaster University, UK. It is supervised by Dr. Sarah Brearley and by Dr. Caroline Swarbrick and has been approved by Lancaster University Faculty of Health and Medicine Research Ethics Committee and by Comissão de Ética de Investigação Clínica (CEIC). The aim of the study is to develop a culturally appropriate organizational programme for nursing homes’ staff when caring for dying patients, through a partnership work between the researcher and the participants.

#### **Why have I been approached?**

As nursing home staff, and having participated at the first Cycle of this research project as well as at the organizational intervention that have resulted, you can, if you wish, to continue to participate in the programme evaluation.

#### **Do I have to take part?**

No. Taking part in the research is entirely voluntary. If you decide to take part you are free to withdraw at any time, without giving a reason and without detriment to yourself. Once the

interview is completed, you will have two weeks to ask for data to be withdrawn from the study. When participating in group meetings it will not be possible to exclude individual data once the session has commenced, if decision of withdrawal is made.

### **What will I be asked to do if I take part?**

If you decide you would like to take part, you will be asked to participate in an interview and meeting to evaluate the impact of the previous organizational programme interventions in your practice, to find out other participants' needs and to recommend a next set of actions.

### **Where can I obtain further information about the study if I need it?**

If you need any other information about this study feel free to contact me to the mobile phone number 919540208 or to my e-mail: [c.galvo@lancaster.ac.uk](mailto:c.galvo@lancaster.ac.uk)

### **Complaints**

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

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Email: <a href="mailto:s.jones7@lancaster.ac.uk">s.jones7@lancaster.ac.uk</a>		Email: <a href="mailto:ceic@ceic.pt">ceic@ceic.pt</a>

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Faculty of Health and Medicine  
(Division of Biomedical and Life Sciences)  
Lancaster University  
Lancaster LA1 4YG

Thank you for your time and for reading this Participant Information Sheet.

If you decide to join the study please return the stamped addressed envelope enclosed, with your name and mobile phone number for interview scheduling.

**Cristina Galvão**

**Palliative Care PhD Student**



### **Folheto Informativo para o Participante**

Título da Investigação: “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação” (5º e 6º Ciclos)

A segunda parte da investigação está em curso, a terceira parte começará em breve e eu gostaria de o/a convidar a participar neste trabalho de investigação. Antes de tomar uma decisão sobre a sua participação gostaria de lhe explicar o que é esperado acontecer e como se pode processar a sua participação.

#### **O que é este estudo?**

Este estudo faz parte de um trabalho de doutoramento em Cuidados Paliativos na Universidade de Lancaster, em Inglaterra. É supervisionado pela Dra. Sarah Brearley e pela Dra. Caroline Swarbrick e foi aprovado pela Universidade de Lancaster (Faculty of Health and Medicine Research Ethics Committee) e pela Comissão de Ética de Investigação Clínica (CEIC). O objetivo do estudo é a criação de um programa organizativo culturalmente adaptado e destinado a profissionais dos lares que trabalham com pessoas em fim de vida. Tal será feito através de um trabalho conjunto entre os participantes e a investigadora.

#### **Porque fui contactado (a)?**

Uma vez que trabalha no lar, e tendo participado no primeiro Ciclo deste trabalho de investigação e nas intervenções organizativas que dele resultaram pode, se assim o desejar, continuar a participar na avaliação do programa.

### **Sou obrigado (a) a participar?**

Não. A participação é voluntária. Caso decida participar poderá em qualquer altura desistir de continuar na investigação, sem necessidade de dar qualquer explicação e sem prejuízo algum. Assim que a entrevista esteja terminada tem duas semanas para decidir sair do estudo. Ao participar em reuniões de grupo não será possível excluir informação individual a partir do momento em que a reunião comece, mesmo que decida desistir.

### **O que me será pedido se decidir participar?**

Se decidir participar ser-lhe-á pedido que participe numa entrevista e numa reunião onde se fará a avaliação do impacto da intervenção desenvolvida na sua atividade, e a deteção de outras necessidades sentidas pelos participantes e ser-lhe-á pedido que sugira novas intervenções.

### **Onde posso obter mais informação sobre este estudo, caso necessite?**

Caso sinta que necessita de mais informação sobre este estudo poderá contactar-me através do meu telemóvel pessoal, com o número 919540208 ou através do meu e-mail: [c.galvo@lancaster.ac.uk](mailto:c.galvo@lancaster.ac.uk)

### **Reclamações**

Caso deseje fazer uma reclamação ou levantar alguma questão sobre qualquer aspeto deste estudo e não o quiser fazer com a investigadora poderá contactar:

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Research Director		Parque da Saúde de Lisboa
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Associate Dean for Research

Email: r.pickup@lancaster.ac.uk

Faculty of Health and Medicine

(Division of Biomedical and Life Sciences)

Lancaster University

Lancaster LA1 4YG

Obrigada pela sua disponibilidade e por ler este Folheto Informativo para o Participante.

Caso deseje participar neste estudo por favor envie-me o envelope com o destacável anexo, depois de nele escrever o seu nome e número de telefone e contacta-lo/a-ei em breve para marcar a entrevista.

**Cristina Galvão**

**Aluna de Doutoramento em Cuidados Paliativos**

**Appendix 14 - Consent Form (Interview and Meeting 1) (English version)**



**CONSENT FORM**

**Interview and Meeting 1**

**Study Title:** “Developing end-of-life care at a Portuguese nursing home through participatory action research”

We are asking if you would like to take part in a research project. This study is part of a PhD in Palliative Care at the Lancaster University, UK. It is supervised by Professor Katherine Froggatt and by Dr. Sarah Brearley and has been approved by the Lancaster University Faculty of Health and Medicine Research Ethics Committee and by Comissão de Ética de Investigação Clínica (CEIC). The aim of the study is to develop a culturally appropriate organizational programme for nursing home staff when caring for dying patients, through a partnership work between the researcher and the participants.

Before you consent to participating in the study I ask that you read the Participant Information Sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Cristina Galvão.

**Participant Identification:** ..... **Pseudonym** .....

**Please Initial  
Each Statement**

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.
4. I understand that audio recordings will be kept until the research project has been examined.
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.
8. I consent to information and quotations from my interview being used in reports, conferences and training events.
9. I understand that the researcher will discuss data with their supervisor as needed.
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with their research supervisor.
11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.
12. I consent to take part in the above study.

**Name of Participant**

**Date**

**Signature**

**Researcher Cristina Galvão**

**Date**

**Signature**

## Appendix 14 - Consent Form (Interview and Meeting 1) (Portuguese version)



### CONSENTIMENTO INFORMADO

#### Entrevista e Primeira Reunião

**Título do Projeto:** “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação”.

Gostaria de a/o convidar a participar num projeto de investigação. Este estudo faz parte de um trabalho de doutoramento em Cuidados Paliativos na Universidade de Lancaster, em Inglaterra. É supervisionado pela Professora Doutora Katherine Froggatt e pela Dra. Sarah Brearley e foi aprovado pela Universidade de Lancaster, Faculty of Health and Medicine Research Ethics Committee, e pela Comissão de Ética de Investigação Clínica (CEIC). O objetivo do estudo é a criação de um programa organizativo de intervenção, culturalmente adaptado, destinado a profissionais dos lares que trabalham com pessoas em fim de vida, através de um trabalho conjunto entre os participantes e a investigadora.

Antes de aceitar participar neste estudo peço-lhe que leia o Folheto Informativo para o Participante e, caso concorde, assinale cada uma das frases abaixo com as suas iniciais. Caso necessite de mais algum esclarecimento antes de assinar o Consentimento por favor fale com a investigadora responsável, Cristina Galvão.

**Identificação do Participante:** ..... **Pseudónimo** .....

Por favor assinale  
cada caixa com as  
suas iniciais

1. Confirmando que li o Folheto Informativo e compreendo perfeitamente o que de mim é esperado neste estudo.
2. Confirmando que tive a oportunidade de fazer todas as perguntas e que elas foram respondidas.
3. Compreendo que a minha entrevista será gravada e posteriormente transcrita e anonimizada.
4. Compreendo que os registos audio serão mantidos até que o projeto seja avaliado.
5. Compreendo que a minha participação é voluntária e que sou livre de desistir em qualquer momento sem necessidade de me justificar, sem que os meus direitos legais sejam afetados.
6. Compreendo que assim que os meus dados sejam anonimizados e incorporados em temas possa não ser mais possível retirá-los, embora todos os esforços sejam feitos para extrair os meus dados, até à sua publicação.
7. Compreendo que as informações da minha entrevista serão agrupadas com as dos outros participantes, anonimadas e poderão ser publicadas.
8. Autorizo que as informações e citações da minha entrevista sejam usadas em relatórios, congressos e cursos/formações.
9. Compreendo que a investigadora irá discutir as informações com os seus supervisores, caso haja necessidade.
10. Compreendo que toda a informação por mim produzida será mantida confidencial e anónima, a menos que haja risco de dano para mim ou para terceiros, situação em que a investigadora poderá ter que partilhar esta informação com os seus supervisores de investigação.
11. Autorizo a Universidade de Lancaster a manter as transcrições da entrevista por um período de dez anos após o termo do estudo.
12. Consinto em participar no estudo supra mencionado.

Nome do Participante

Data

Assinatura

Investigadora Cristina Galvão

Data

Assinatura



**Appendix 15 – Consent Form (Interview Cycle 5 and Meetings Cycle 6) (English version)**



**CONSENT FORM 2**

**Interview and Meeting M3 and M4**

**Title of Project:** “Developing end-of-life care at a Portuguese nursing home through participatory action research” (5<sup>th</sup> and 6<sup>th</sup> Cycles)

The second part of the research project is now underway, the third part will begin soon and I would like to invite you to participate in this phase of the research project. This study is part of a PhD research on Palliative Care at the Lancaster University, UK. It is supervised by Dr. Sarah Brearley and by Dr. Caroline Swarbrick and has been approved by the Lancaster University Faculty of Health and Medicine Research Ethics Committee and by Comissão de Ética de Investigação Clínica (CEIC). The aim of the study is to develop a culturally appropriate organizational programme for nursing homes’ staff when caring for dying patients, through a partnership work between the researcher and the participants.

Before you consent to participating in this phase of the study I ask that you read the Participant Information Sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Cristina Galvão.

**Participant Identification:** ..... **Pseudonymous** .....

**Please Initial  
Each Statement**

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.
4. I understand that audio recordings will be kept until the research project has been examined.
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.
8. I consent to information and quotations from my interview being used in reports, conferences and training events.
9. I understand that the researcher will discuss data with their supervisor as needed.
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with her research supervisor.
11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.
12. I consent to take part in the above study.

**Name of Participant**

**Date**

**Signature**

**Researcher Cristina Galvão**

**Date**

**Signature**



**CONSENTIMENTO INFORMADO 2**

**Entrevista e Reuniões M3 e M4**

**Título do Projeto:** “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação”.

A segunda parte da investigação está em curso, a terceira parte começará em breve e eu gostaria de a/o convidar a participar nesta fase deste trabalho de investigação. Este estudo faz parte de um trabalho de doutoramento em Cuidados Paliativos na Universidade de Lancaster, em Inglaterra. É supervisionado pela Dra. Sarah Brearley e pela Dr. Caroline Swarbrick, e foi aprovado pela Universidade de Lancaster (Faculty of Health and Medicine Research Ethics Committee) e pela Comissão de Ética de Investigação Clínica (CEIC). O objetivo do estudo é a criação de um programa organizativo de intervenção, culturalmente adaptado, destinado a profissionais dos lares que trabalham com pessoas em fim de vida, através de um trabalho conjunto entre os participantes e a investigadora.

Antes de aceitar participar neste estudo peço-lhe que leia o Folheto Informativo para o Participante e, caso concorde, assinale cada uma das frases abaixo com as suas iniciais. Caso necessite de mais algum esclarecimento antes de assinar o Consentimento por favor fale com a investigadora responsável, Cristina Galvão.

**Identificação do Participante:** ..... **Pseudónimo** .....

Por favor assinale  
cada caixa com as  
suas iniciais

1. Confirmando que li o Folheto Informativo e compreendo perfeitamente o que de mim é esperado neste estudo.
2. Confirmando que tive a oportunidade de fazer todas as perguntas e que elas foram respondidas.
3. Compreendo que a minha entrevista será gravada e posteriormente transcrita e anonimizada.
4. Compreendo que os registos audio serão mantidos até que o projeto seja avaliado.
5. Compreendo que a minha participação é voluntária e que sou livre de desistir em qualquer momento sem necessidade de me justificar, sem que os meus direitos legais sejam afetados.
6. Compreendo que assim que os meus dados sejam anonimizados e incorporados em temas possa não ser mais possível retirá-los, embora todos os esforços sejam feitos para extrair os meus dados, até à sua publicação.
7. Compreendo que as informações da minha entrevista serão agrupadas com as dos outros participantes, anonimadas e poderão ser publicadas.
8. Autorizo que as informações e citações da minha entrevista sejam usadas em relatórios, congressos e cursos/formações.
9. Compreendo que a investigadora irá discutir as informações com os seus supervisores, caso haja necessidade.
10. Compreendo que toda a informação por mim produzida será mantida confidencial e anónima, a menos que haja risco de dano para mim ou para terceiros, situação em que a investigadora poderá ter que partilhar esta informação com os seus supervisores de investigação.
11. Autorizo a Universidade de Lancaster a manter as transcrições da entrevista por um período de dez anos após o termo do estudo.
12. Consinto em participar no estudo supra mencionado.

Nome do Participante

Data

Assinatura

Investigadora Cristina Galvão

Data

Assinatura



**CONSENT FORM**

**Meetings M2**

**Study Title:** “Developing end-of-life care at a Portuguese nursing home through participatory action research”

We are asking if you would like to continue to take part in the research project as a member of the Action Research Group. This study is part of a PhD in Palliative Care at the Lancaster University, UK. It is supervised by Professor Katherine Froggatt and by Dr. Sarah Brearley and has been approved by the Lancaster University Faculty of Health and Medicine Research Ethics Committee and by Comissão de Ética de Investigação Clínica (CEIC). The aim of the study is to develop a culturally appropriate organizational programme for nursing home staff when caring for dying patients, through a partnership work between the researcher and the participants. Before you consent to participating in the action group meetings of this study I ask that you read the Participant Information Sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Cristina Galvão.

**Participant Identification:** ..... **Pseudonym** .....

**Please Initial  
Each Statement**

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my participation in the meetings will be audio recorded and then made into an anonymised written transcript.
4. I understand that audio recordings will be kept until the research project has been examined.
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.
7. I understand that the information from my participation in these meetings will be pooled with other participants' responses, anonymised and may be published.
8. I consent to information and quotations from my participation being used in reports, conferences and training events.
9. I understand that the researcher will discuss data with her supervisors as needed.
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with her research supervisors.
11. I consent to Lancaster University keeping written transcriptions of the meetings for 10 years after the study has finished.
12. I consent to take part in the above study.

**Name of Participant**

**Date**

**Signature**

**Researcher Cristina Galvão**

**Date**

**Signature**

## Appendix 16 – Consent form (Cycle 2) (Portuguese version)



### CONSENTIMENTO INFORMADO

#### Reuniões M2

**Título do Projeto:** “Desenvolver os cuidados em fim de vida num lar em Portugal através de uma metodologia de investigação-ação”.

Gostaria de a/o convidar a continuar a participar neste projeto de investigação como membro do Grupo de Investigação Ação. Este estudo faz parte de um trabalho de doutoramento em Cuidados Paliativos na Universidade de Lancaster, em Inglaterra. É supervisionado pela Professora Doutora Katherine Froggatt e pela Dra. Sarah Brearley e foi aprovado pela Universidade de Lancaster, Faculty of Health and Medicine Research Ethics Committee, e pela Comissão de Ética de Investigação Clínica (CEIC). O objetivo do estudo é a criação de um programa organizativo de intervenção, culturalmente adaptado, destinado a profissionais dos lares que trabalham com pessoas em fim de vida, através de um trabalho conjunto entre os participantes e a investigadora.

Antes de aceitar participar neste estudo peço-lhe que leia o Folheto Informativo para o Participante e, caso concorde, assinale cada uma das frases abaixo com as suas iniciais. Caso necessite de mais algum esclarecimento antes de assinar o Consentimento por favor fale com a investigadora responsável, Cristina Galvão.

**Identificação do Participante:** ..... **Pseudónimo** .....

**Por favor assinale  
cada caixa com as  
suas iniciais**

1. Confirmando que li o Folheto Informativo e compreendo perfeitamente o que de mim é esperado neste estudo.
2. Confirmando que tive a oportunidade de fazer todas as perguntas e que elas foram respondidas.
3. Compreendo que a minha participação nas reuniões será gravada e posteriormente transcrita e anonimizada.
4. Compreendo que os registos audio serão mantidos até que o projeto seja avaliado.
5. Compreendo que a minha participação é voluntária e que sou livre de desistir em qualquer momento sem necessidade de me justificar, sem que os meus direitos legais sejam afetados.
6. Compreendo que assim que os meus dados sejam anonimizados e incorporados em temas possa não ser mais possível retirá-los, embora todos os esforços sejam feitos para extrair os meus dados, até à sua publicação.
7. Compreendo que as informações da minha participação nas reuniões serão agrupadas com as dos outros participantes, anonimizadas e poderão ser publicadas.
8. Autorizo que as informações e citações da minha participação nas reuniões sejam usadas em relatórios, congressos e cursos/formações.
9. Compreendo que a investigadora irá discutir as informações com os seus supervisores, caso haja necessidade.
10. Compreendo que toda a informação por mim produzida será mantida confidencial e anónima, a menos que haja risco de dano para mim ou para terceiros, situação em que a investigadora poderá ter que partilhar esta informação com os seus supervisores de investigação.
11. Autorizo a Universidade de Lancaster a manter as transcrições das reuniões por um período de dez anos após o termo do estudo.
12. Consinto em participar no estudo supra mencionado.

**Nome do Participante**

**Data**

**Assinatura**

**Investigadora Cristina Galvão**

**Data**

**Assinatura**



Appendix 17 – First Interview protocol (English version)



<b>Interview Protocol</b>			
<b>Participatory action research: end-of-life care staff organizational needs at a Portuguese nursing home</b>			
<b>Gender</b>	<b>M</b>	<b>F</b>	<b>Profession</b>
			<b>How long working in nursing homes</b>
<b>Time of interview:</b>			
<b>Date:</b>			
<b>Do not forget:</b>			
Explain the research project to participants Inform that participation is voluntary Inform that the interview can be stopped on their request Inform that they have the right to withdraw from the research project at any moment Inform that the support of a psychologist is available if needed Ask if the participant wants to make any questions Ask for informed consent signature and return a signed copy to the participant			
<b>Interview Guide:</b>			
<ol style="list-style-type: none"> <li><b>1. Working experience in caring for older people at the end-of-life</b>                          Eg. Have you ever cared for older people at the end-of-life? Where?                         <ul style="list-style-type: none"> <li>- place</li> <li>- what is easier</li> <li>- difficulties</li> </ul> </li> <li><b>2. Communication (with)</b>                          Eg. What is easier (more difficult) when communicating with older people at the end-of-life?                         <ul style="list-style-type: none"> <li>- older people</li> <li>- families</li> <li>- team</li> </ul> </li> <li><b>3. Need for further education</b>                          Eg. Have you ever felt the need to learn more about how to care for dying people?                          When?                         <ul style="list-style-type: none"> <li>- care</li> <li>- death and dying</li> <li>- communication</li> <li>- bereavement</li> </ul> </li> <li><b>4. Support</b></li> </ol>			

Eg. Who has supported you?

- who gives support
- what can be changed / improved

**5. Organization**

Eg. Is there anything at the facility organization that you think that helped you in caring for older people at the end of life? What could be improved? Who should make those changes?

- what helps
- improvements
- who can contribute and implement changes
- how to change

Thank the participant for participating in the interview. Assure anonymity of responses and inform about a future group meeting to discuss the data.

**Adapted from:** Creswell, 2013; Braun & Clarke, 2013

Appendix 17 – First Interview protocol (Portuguese version)



Protocolo da Entrevista			
Participatory action research: end-of-life care staff organizational needs at a Portuguese nursing home			
Género	M	F	Profissão
			Há quanto tempo trabalha no lar
Hora da entrevista:			
Data:			
Não esquecer:		<p>Explicar o projeto de investigação ao participante</p> <p>Informar que a participação é voluntária</p> <p>Informar que a entrevista pode ser parada a seu pedido</p> <p>Informar que tem o direito de abandonar o projeto de investigação a qualquer momento</p> <p>Informar que é possível ter apoio de psicólogo caso sinta necessidade</p> <p>Perguntar ao participante se quer fazer perguntas</p> <p>Pedir a assinatura do consentimento informado e devolver uma das cópias assinadas ao participante</p>	
Guia da Entrevista:			
<p><b>1. Experiência em cuidar de pessoas em fim de vida</b></p> <p>P.ex. Alguma vez cuidou de pessoas em fim de vida? Onde?</p> <ul style="list-style-type: none"> <li>- local</li> <li>- o que foi mais fácil</li> <li>- dificuldades</li> </ul> <p><b>2. Comunicação (com)</b></p> <p>P.ex. O que é mais fácil (ou difícil) ao comunicar com pessoas idosas em final de vida?</p> <ul style="list-style-type: none"> <li>- idoso</li> <li>- famílias</li> <li>- equipa</li> </ul> <p><b>3. Necessidade de mais formação</b></p> <p>P.ex. Alguma vez sentiu necessidade de aprender mais sobre como cuidar de pessoas em fim de vida? Quando?</p> <ul style="list-style-type: none"> <li>- cuidar</li> <li>- morte e morrer</li> <li>- comunicação</li> <li>- luto</li> </ul>			

#### **4. Apoio**

P.ex. Quem o tem apoiado?

- quem dá apoio
- o que pode mudar / melhorar

#### **5. Organização**

P.ex. Há alguma coisa na organização do lar que o ajude a cuidar de pessoas idosas em fim de vida? O que pode melhorar? Quem deve fazer essas alterações?

- o que ajuda
- melhoramentos
- quem pode contribuir e implementar as alterações
- como mudar

Agradecer ao participante por participar na entrevista. Garantir a anonimização das respostas e informar acerca de uma futura reunião de grupo para discutir os dados.

**Adaptado de:** Creswell, 2013; Braun & Clarke, 2013

**Appendix 18 - Second Interview Protocol (English version)**



<b>Interview Protocol</b>			
<b>Participatory action research: end-of-life care staff organizational needs at a Portuguese nursing home</b>			
<b>Gender</b> M F	<b>Profession</b>	<b>How long working in nursing homes</b>	
<b>Time of interview:</b>			
<b>Date:</b>			
<b>Do not forget:</b>	Explain the research project to participants Inform that participation is voluntary Inform that the interview can be stopped on their request Inform that they have the right to withdraw from the research project at any moment Inform that the support of a psychologist is available if needed Ask if the participant wants to make any questions Ask for informed consent signature and return a copy to the participant		
<b>Interview Guide:</b>			
<p><b>1. Organizational programme</b></p> <p>Eg. How do you see your experience in participating in a Participatory Action Research (looking at data, choosing the main interventional areas, defining a programme, planning the programme, beginning to run the programme)?</p> <p>Eg. Have you noted any differences in your practice? What has changed?</p> <p>Which were the implications of the interventions in caring for residents at the end-of-life?</p> <p>Which were the challenges you faced when running the programme?</p> <p><b>2. Need to change</b></p> <p>Eg. Would you do things differently? Such as...?</p> <ul style="list-style-type: none"> <li>- what can be changed / improved</li> </ul> <p><b>3. New actions</b></p> <p>Eg. How do you think that (participant suggestion) can be changed?</p> <ul style="list-style-type: none"> <li>- which interventions do you propose</li> <li>- who can contribute and implement changes</li> </ul>			
Thank the participant for participating in the interview. Assure anonymity of responses and inform about a future group meeting to discuss the data.			

**Adapted from:** Creswell, 2013; Braun & Clarke, 2013

**Appendix 18 - Second Interview Protocol (Portuguese version)**



<b>Protocolo da Segunda Entrevista</b>			
<b>Participatory action research: end-of-life care staff organizational needs at a Portuguese nursing home</b>			
<b>Género</b>	<b>M</b>	<b>F</b>	<b>Profissão</b>
			<b>Tempo a trabalhar no lar</b>
<b>Hora da Reunião:</b>			
<b>Data:</b>			
<b>Não esquecer:</b>			
<p>Explicar o projeto de investigação aos participantes</p> <p>Informar que a participação é voluntária</p> <p>Informar que a entrevista pode ser parada se o desejarem</p> <p>Informar que têm o direito de desistir de participar no projeto de investigação em qualquer momento</p> <p>Informar que o apoio de psicólogo será possível caso o considerem necessário</p> <p>Perguntar se querem fazer perguntas</p> <p>Pedir que assinem os consentimentos informados e devolver uma cópia aos participantes</p>			
<b>Guia da Entrevista:</b>			
<p><b>1. Programa organizacional</b></p> <p>P.ex.: Como vê a sua experiência em participar num Programa de Investigação-Ação (apreciar os dados, escolher as principais áreas de intervenção, definir um programa, planeá-lo, começar a implementar o programa)?</p> <p>P.ex.: Notou diferenças na sua prática? O que mudou?</p> <p>Quais foram as implicações das intervenções no cuidar de residentes em fim de vida?</p> <p>Quais foram os desafios que enfrentou no desenvolver do programa?</p> <p><b>2. Necessidade de mudança</b></p> <p>P.ex. Hoje faria outras intervenções? Como por exemplo...?</p> <p style="padding-left: 20px;">- o que pode ser mudado / melhorado</p> <p><b>3. Novas ações</b></p> <p>P.ex. Como pensa que (sugestão do participante) pode ser mudado?</p> <p style="padding-left: 20px;">- que intervenções propõe</p> <p style="padding-left: 20px;">- quem pode contribuir para a mudança e implementar as alterações</p>			
<p>Agradecer aos participantes por participarem na reunião. Garantir a anonimização das respostas e informar sobre a próxima reunião de grupo para discutir os dados.</p>			

**Adaptado de:** Creswell, 2013; Braun & Clarke, 2013

## Appendix 19 – Generating initial codes

Sometimes not during all the time we would like, but they do it. People sane of mind, and with their decision and cognitive capacity maintained, they can make a decision to go to physiotherapy, or not, they can make a decision to go now, or in ten minutes. They can make a decision, if... and they can decide, as sometimes they do "or you come now with me, or I don't go". Sometimes I can't go now, because they can need me somewhere else, that is the most difficult, although, I think, it has been worse. Because, of course, I think, that with time people get to know us, and they now know, that if I don't do immediately what they want, it is because I can't! They even tell me "I know, you haven't been seated," but I know that sometimes that hurts them, because they also need attention, because although they have maintained their brain capacity, they need the same the others need. Attention, tender love, and if I am ten minutes more with other people, it is ten minutes I am not with them. Maybe sometimes organizing my time is... because there are many things happening in the same day, at the same hour, and sometimes it is difficult to be able to attend to everybody, because we seem to be many, but we really are ~~with~~ very few...

To know someone

Need of attention

Time (management)

Lack/shortage of professionals

for the residents' needs

for the type of care

MC – To peoples' needs...?!

S – Yes, or to the type of care that we provide...

MC – That they would need, if the objective was to achieve the ideal...

S – Yes, because sometimes there are people, and sometimes there are also families that come, or they put here their relative and they think that they have a fulltime employee, or a fulltime "technician" or care provider, and that is not the case. They (the residents) are forty, we are the care aides and the technical team, but we can't be with everybody every day. It's unreal and it's impossible. What we can, yes, because we adapt ourselves to that, when a person is in a frailer moment, as after a surgery, that needs more attention, and more technical care. But, of course, that that also takes time from other people. It's more or less what I was saying before.

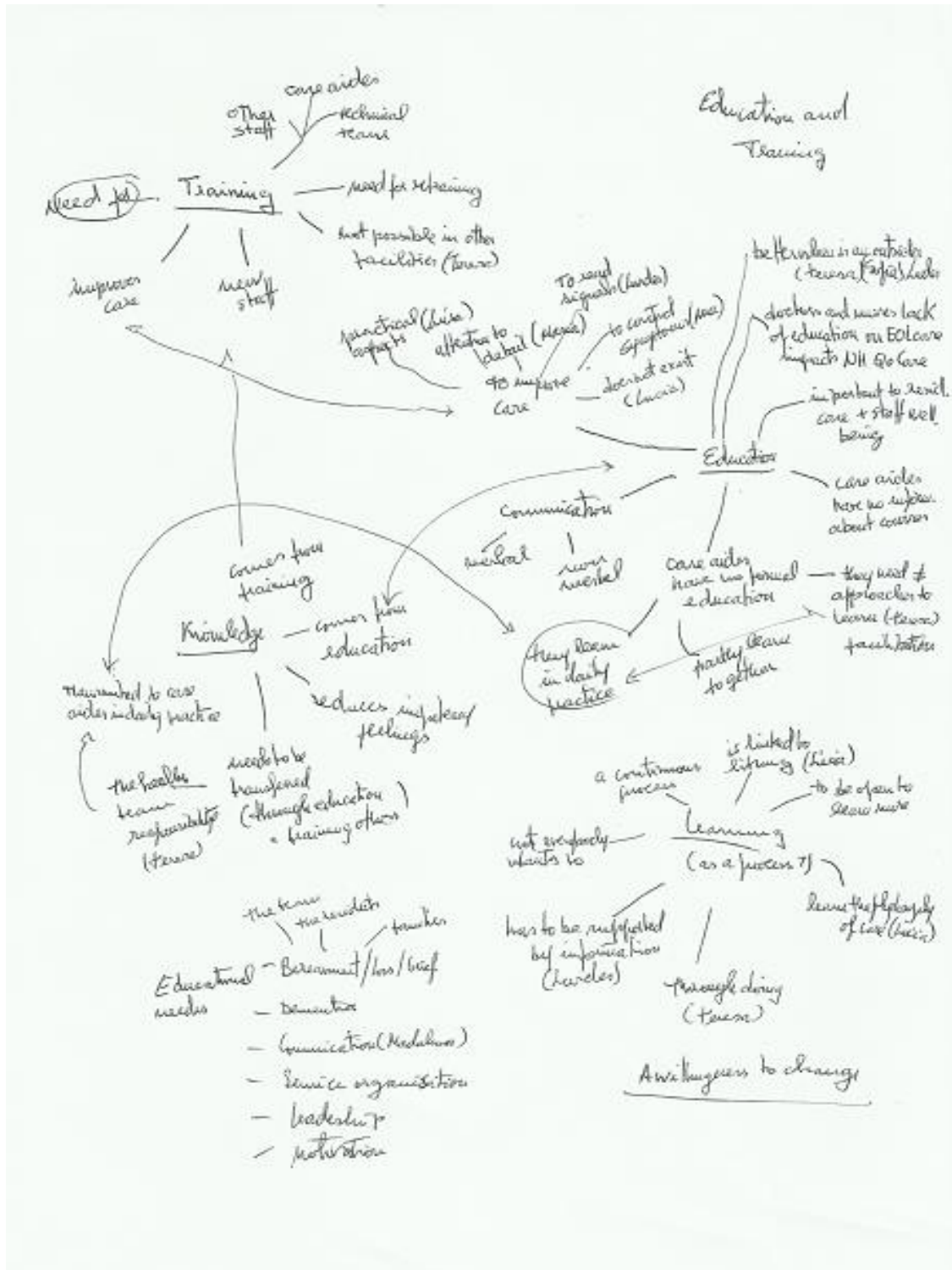
Families expectations

MC – So, conciliating the needs is also difficult.

S – It is, it is... Because I think, it is also a bit of us, because we want to be everywhere, humanly that is impossible, what..., I would sometimes would like to spend more time with people, and sometimes it is impossible, because, you see, sometimes there are people (professionals), that in those days they leave with somebody to a consultation or appointment, other days they have visits, it is good that they have, it is good that they leave, and that changes a little our agenda. And then it is not possible to...

Frustration? Professionals! Shortage?

MC – Come back to time management...





**Appendix 21 – Table with codes**

Name	Codes	Quotes	Page / Paragraph
Ana	To feel selfish	I thought... I was selfish, to not let the person go... to not want that the person left.	P 1 p. 2
Luisa	Families have unrealistic expectations	It is very difficult to explain them (families) certain things, to tell them about the residents' health, because... they normally do not accept... don't understand, it is very difficult to reach families, yes, it is always the most difficult	P 6 p. 2
Luisa	Easy access to the resident facilitates	The fact that they (families) can be here, their presence is very eased, they can go to the bedroom, they can come and talk at the time they want (...) creates trust with the team	P 6 p. 3
Luisa	Difficult to accept the older person is deteriorating	It is difficult to accept a few things... and even sometimes, even if they see things happening, they don't want to accept	P 6 p. 3
María	Education is important	Mrs. X is not just sleep problems, I think she also is in pain. And we need to be able to identify that, to know about those details... and I think I am more prepared now, yes, education is very important... to know how to identify that, it is not just... someone is restless. But is restless why?...	P 15 p. 2
Matilde	Role models make a difference	For me it was a bit strange, but as it was not what we used to do, so we follow a little what other colleague do	P 1 p. 3
Sofia	Care aides need motivation	There is a lack of motivation in care aides, because they do heavy work, and they lack motivation for training and self-learning. That I think, those are things that we need to improve.	P 7 p. 3
Lurdes	A strong commitment to change	If we have staff that... full of commitment, a commitment to learn, wishing to... to care for, let's say that we would have almost all	P 18 p. 8
Sofia	Bereavement A wake in remembrance of	And I think that we should also (...) do a wake in remembrance of that person, sometime after the	P 15 p. 4

		death occurred, or to post a photo, to choose a place in the nursing home to do that, I think that would help (to mourn). The residents themselves too.	
Ana	<b>Psych support</b> After a death staff needs to be supported	That support is really needed. There is a need to talk, also the technical team, to have the technical team also supported, but I think the care aides, I am nearer them, I feel that. They come to me to talk about, to talk. Of that grief.	P 18 p. 2
Clara	<b>Management gratitude is important</b>	If the nun praises us, or... when there is a good mood, that improves everything.	P 13 p. 4
Madalena	<b>Residents are a family member</b>	Because we grow more and more fond of ourselves, they are our family, and we are here all today long, it is difficult, it is a little bit difficult”	P 2 p. 8
Lúcia	<b>Death is hidden</b>	I think that there is still a camouflage about death	P 4 p. 3
Lúcia	<b>Families are demandant</b>	Then there are the families, that are very demanding, and sometimes they demand more than what they were capable to give at home. That is very complicate, that is very complicate.	P 4 p. 3
Teresa	<b>Care aides' education comes from practice</b>	Care aides have no theoretical education, they had no education to be here. Education is provided during daily activities.	P 5 p. 2
Teresa	<b>No time to debrief</b>	There is no space for care aides, for the care aides that had been present, for instance, because that is a heavy moment to them, to talk about what they feel, how it is, which difficulties they felt. They need to have that space. And the rest of the team too...	P 9 p. 2

**Appendix 22 – The Research Meetings**

<b>Cycle process</b>	<b>Phases</b>	<b>Meetings</b>			
<b>Cycle 1</b>	<ul style="list-style-type: none"> <li>- Recruitment phase</li> <li>- Interviews</li> <li>- Transcription and analysis</li> <li>- Meetings in small groups</li> </ul>				
		<b>M 1</b> Data summary presentation to participants			
<b>Cycle 2</b>	<ul style="list-style-type: none"> <li>- Recruitment phase</li> <li>- Action meetings group</li> <li>- Develop an organizational intervention programme</li> </ul>	<b>M 2 Action Group</b>			
		<b>First meeting</b>	<b>Second meeting</b>	<b>Third meeting</b>	<b>Fourth meeting</b>
		1. Basic meeting rules	1. Previous meeting summary	1. Previous meeting summary	1. Previous meeting summary
		2. Who does what?	2. Reflection on results	2. Define interventions	2. Finish intervention programme
		3. Confidentiality negotiation	3. Results' prioritization	3. Intervention programme	3. Prepare programme implementation
		4. Results presentation	4. Meeting summary	4. Meeting summary	4. Meeting summary
		5. Results discussion			
		6. Meeting summary			
<b>Cycle 6</b>	-Analyse the organizational intervention programme	<b>M 3</b>			
		Present results to participants			
	- Re-plan actions	<b>M 4 Action Group</b> Action group meeting Recommendations for new actions			

## Appendix 23 – The resident’s file (Examples)

### PLANEAMENTO INDIVIDUAL DE CUIDADOS

Nome do utente: Maria [REDACTED]  
 Data de Nascimento: 29/05/1 [REDACTED]  
 Familiar de referência: Al [REDACTED] (Filho)  
 Contacto do familiar: 96 [REDACTED]



#### Antecedentes pessoais:

- # colo fémur Agosto 2019
- Cifoescoliose grave
- Prótese ocular direita, glaucoma olho esquerdo, cegueira
- HTA
- EAM, cardiopatia hipertensiva, IC
- DPOC/Asma
- Prótese auditiva , hipoacusia

Área de Cuidados	Cuidados a ter
Banho	Necessita de ajuda
	Banho na cadeira de banho
	Toma banho à 3ª feira e ao Domingo
Higiene parcial - manhã/noite	Necessita de ajuda
Vestuário	Necessita de ajuda
Higiene oral	Utente autónoma
	Usa prótese dentária

Actualizado a 30/10/2020

Ida à casa de banho/mudança de fralda	Utente autónoma na utilização da sanita. É necessário levá-la e tirá-la da casa de banho
	Utiliza fralda cueca durante o dia (tamanho M) Usa fralda de adesivo durante a noite (tamanho M) Encomendam-se à "Ortopedia [REDACTED]"
Alimentação	Necessita de ajuda
	Comida pastosa
Medicação	Necessita de ajuda
	Gosta de controlar a sua medicação
Hidratação	Utente autónoma
Deslocar-se	Desloca-se em cadeira de rodas
	Percorre pequenas distâncias com andarilho
	Elevado risco de queda
Enfermagem	Realiza O <sub>2</sub> por óculos nasais a 2l/min para conforto (Sat O <sub>2</sub> sempre na ordem dos 93%/94%)
Outros	Sofre de cegueira. Tem prótese do olho direito
	Reconhece as vozes das funcionárias e de alguns utentes, relacionando-se muito bem com todos
	Gosta muito de conversar e de ouvir rádio (Antena 1)
	Gosta de estar no seu quarto entre o lanche e o jantar (é necessário ir levá-la após o lanche e ir busca-la para jantar)
	Toca várias vezes à campinha durante a noite

Actualizado a 30/10/2020

## PLANEAMENTO INDIVIDUAL DE CUIDADOS

Nome do utente: ██████████

Data de Nascimento: 27/11/1██████

Familiar de referência: M██████ (Sobrinha)

Contacto do familiar: 917██████



### Antecedentes Pessoais:

- IC
- FA permanente
- HTA

Nota: Utente em acompanhamento pela Equipa Comunitária de Suporte em Cuidados Paliativos Beja +

Área de Cuidados	Cuidados a ter
Banho	Utente autónoma, necessita de ajuda para lavar o cabelo (1x/ semana)
	Decide quando toma banho
Higiene parcial - manhã/ noite	Utente autónoma
Vestuário	Utente autónoma
Higiene oral	Utente autónoma
	Tem prótese dentária
Ida à casa de banho/mudança de fralda	Utente autónoma

Alimentação	Utente autónoma
Medicação	Utente autónoma, vigiar se toma Gosta de abrir os comprimidos
Hidratação	Utente autónoma
Deslocar-se	Utiliza andarilho com rodas
	Tem muita dificuldade em percorrer médias e longas distâncias; Muita dificuldade em subir/descer escadas
Enfermagem	Quando necessário, coloca os cremes receitados de forma autónoma
Outros	Faz a sua cama de manhã
	Participa em todas as actividades religiosas
	Quando necessário, ajuda na preparação dos alimentos para o almoço e/ou jantar (ex: arranjar os tomates para a tomatada)
	Gosta de muita atenção e de conversar individualmente com as funcionárias

Atualizado a 30/10/2020

Atualizado a 30/10/2020

Appendix 24 – Hydration



Appendix 25 – The Farewell table



## Abbreviations

ACD	Advance Care Directives
CEIC	Comissão de Ética para a Investigação Clínica/National Ethics Committee for Clinical Research
COSMOS	Communication, Systematic (pain assessment and treatment), Medication (review), Organization (of activities), Safety
ERSC	Economic and Social Research Council
FHMREC	Faculty of Health and Medicine Research Ethics Committee
GP	General Practitioner
GSFCH	Gold Standards Framework for Care Homes
LILACS	Literatura Latino-Americana e do Caribe em Ciências da Saúde (Latin American and Caribbean Health Sciences Literature)
MAPP	Making Advance Planning a Priority
MeSH	Medical Subject Headings
O <sub>2</sub>	Oxygen
PAR	Participatory Action Research
PhD	Doctor of Philosophy
PPE	Personal Protective Equipment
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised Controlled Trial
SPICE	Setting, Perspective, Intervention, Comparison, Evaluation
ULSBA	Unidade Local de Saúde do Baixo Alentejo
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation



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