Problematising Palliative Care: a ‘What’s the Problem Represented to be’ Analysis of WHO Guidelines

PhD dissertation

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Abstract

Background: The World Health Organization (WHO) has advocated for the establishment of palliative care programs globally, emphasizing evidence-based, cost-effective, and equitable care with a focus on home-based and universal coverage. However, despite efforts, access to palliative care remains uneven, primarily favoring countries with higher resource levels. Critiques have emerged regarding the WHO's approach, suggesting that its standardized frameworks may not adequately address the diverse needs of individual nations.

Aims and Objectives: This thesis critically examines the WHO guidelines supporting palliative care, aiming to uncover the underlying discourses shaping end-of-life care interventions. It questions how expert knowledge disseminated by the WHO mobilizes particular discourses for palliative care and aims to reveal how guidelines justify palliative care as a response to perceived 'problems.'

Methods: Using the "What’s the Problem Represented to Be?" framework for policy discourse analysis, the research identifies two main strands of discourse within the WHO guidelines: one focusing on the quality of care for specific patient groups and the other addressing disparities in care provision. These strands are conceptualized as "healthcare inadequacy" and "healthcare capacity," respectively.

Conclusions: The analysis reveals how these discourses are constructed and how they categorize countries, imposing limitations and subject positioning within guidelines. Importantly, it highlights the contingent nature of these interpretations, emphasizing the need to challenge dominant discourses and incorporate diverse sources of knowledge. The study underscores the importance of understanding the social and economic impact of palliative care implementation and advocates for a stronger connection between palliative care and social care. It calls for the WHO to embrace multiple approaches to palliative care and

acknowledges the significance of questioning underlying assumptions in technical frameworks supporting palliative care.

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Acknowledgments

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Chapter 1. The Rationale for the Study

This study is an investigation on the ways in which ‘palliative care’ is problematised within the World Health Organization’s (WHO) guidelines. The relationship between palliative care and WHO is not new. It has been 33 years since the WHO held an expert panel to review the state of cancer care drawing attention to the ways in which cancer patients were cared for at the end-of-life. This panel identified the need “to make recommendations to WHO on practical guidelines for the supportive care of cancer patients in the world” (Stjernswärd, 1997a). In the following years, there has been a tendency for WHO to issue recommendations and guidelines to support palliative care development internationally. The development of guidelines is considered by the WHO as one of its “core functions” (WHO, n.d.)and as such, the WHO can be thought of as a technocratic organisation since, it looks at technical knowledge to establish normative standards of health care practice and provision (Burda et al., 2014; Sturdy et al., 2013). In this thesis however, guidelines are assumed to be a form of communicating central concerns for clinical practice and public health policy. In this sense, guidelines can be an insight into the priorities, values, and forms of thinking about palliative care. Therefore, it seems important to critically examine guidelines as they offer insight on what is being considered as problematic in end-of-life care (EOLC) and the types of solutions that are deemed appropriate responses.

Understanding how guidelines constitute ‘palliative care’ can contribute to global end-of-life care debates. Yet, as I started my PhD journey, I was left with an uncomfortable impression that guidelines have been neglected by the literature concerned with global palliative care development. As this chapter will introduce the path taken to this study, I will further discuss the research problem and the rationale that gives shape to the research. In doing so, I will set out the research aims and objectives. Lastly, I will consider the relevance of this study and provide an overview of the thesis.

1.1 The path to the research problem

Before joining the PhD, it was already clear in the literature the relevant role the WHO's publications had within 'palliative care' as a research field. Within the field of international palliative care, the WHO's publications have been consistently recommending, promoting, and associating 'palliative care' with end-of-life care demands (J. Clark et al., 2018; Sepulveda et al., 2002; Stjernsward et al., 1996). Whether 'palliative care' was being recommended for advanced cancer patients (WHO, 1990, 2002), or for older age, frailty, and other non-communicable illnesses (Davies & Higginson, 2004; WHO, 2002, 2004) the message was always the same: that through palliative care people would have better quality of life and better care at the end-of-life. Palliative care, somehow would make dying better by addressing symptoms, respecting patients' individuality, and including their families in care.

Historically, the WHO guidelines associated palliative care as a form of care for the dying. Since the first official the WHO publication palliative care has been represented as something to improve dying: "quality of life and comfort before death could be considerably improved through the application of current knowledge on palliative care (…)" (WHO, 1990, p. 15). The focus soon shifted from the care for the dying to caring for all patients that suffer from an illness for which a cure is unattainable (WHO, 2002). Most recently, palliative care is recommended to relieve any serious *health-related suffering* due to cardiovascular disease, cancer, and other serious chronic conditions (Palliative Care, n.d., emphasis added). While at first sight, these changes do not seem to be significant, they indicate changes in the ways palliative care has been *represented* within the WHO publications. The issue of how palliative care is represented within WHO publications seemed to be relevant considering the role WHO plays in promoting palliative care internationally (Clark, 2012b; Sepulveda et al., 2002; Zaman et al., 2017).

Coming from Brazil as a psychologist in palliative care, I watched first-hand how practices and policies towards palliative care were developed having the WHO's publications as a reference. Organizations such as the National Academy for Palliative Care (ANCP in Portuguese) adopted the WHO's definition in its manuals and guidelines for healthcare professionals (ANCP, 2012; Maiello et al., 2020; Tavares de Carvalho & Afonseca Parsons, 2013). Most recently, WHO's definition for palliative care has been incorporated into national law. The resolution number 41 of 2018 by the Health Ministry establishes palliative care as an essential element of healthcare and requires its integration into our national health system (Ministério Da Saúde, 2018).

The efforts made to advocate for palliative care in Brazil were welcomed due to the largely unequal and sparse health care provision across the country (Paiva et al., 2022; Santos et al., 2020), yet my concerns referred to the uncritical reproduction of the WHO's definition of palliative care within Brazilian guidance for practice and national laws. In adopting the WHO's definition to palliative care, the path to discovering the Brazilian way of conceptualising palliative care is closed. There was no room to discuss how Brazilian values would shape palliative care in this context, which raised concerns over what Chakrabarty (2007 as cited in Zaman, 2017, p.77) called an "uncritical transfer of ideas, practices, and narratives from one context to another". As such, this thesis feeds into the concern that the end-of-life care programmes developed in Non-Western countries are influenced by guidelines developed in the Western context, which in turn may contribute to the maintenance of existing inequalities and processes of coloniality through EOLC provision.

At the beginning of my PhD journey, the only contact I had with similar concerns appeared in the literature. Several scholars have been demonstrating that the ways 'palliative care' is conceptualised *matters*. For example, as illustrated by Abel & Kellehear (2018), there are major differences in thinking about "death, dying, caregiving and loss" as "social problems with medical aspects to them" than "medical problems with social aspects" (p.25). The literature also emphasises that definitions of 'palliative care' have *implications*

(Radbruch et al., 2020). This view is supported by other scholars, for instance, Seymour and Cassel (2017), argued that despite international consensus on the elements required to establish palliative care services, there is no consensus on the *meanings* attributed to concepts such as ‘hospices’ and ‘palliative care’. Yet, the literature concerning palliative care at the global level pointed to a different direction – the direction of policy development and service provision (Clelland et al., 2020; Knaul et al., 2018; WHPCA, 2020).

It occurred to me that questioning the premises of WHO guidelines was an important and an interesting starting point to gain insight into ways in which palliative care has been conceptualised, and the kinds of problems ‘palliative care’ is proposed as a solution. It became even more important to do so, considering the recent inclusion of palliative care into the UN’s sustainable goals. If what we understand as ‘palliative care’ is not something subject to broad agreement (Clark et al., 2017; Zaman et al., 2017), then investigating how palliative care has been conceptualised and problematised within WHO publications is necessary.

1.2 Research Aims and Objectives

With such an important problem at hand, I was surprised to see that very little attention had been dedicated to investigating WHO’s recommendations for palliative care and the type of discourse it promotes. Despite some exceptions such as Radbruch et al. (2020), Zaman et al. (2017) and, Abel & Kellehear (2016), who demonstrate the limitations of WHO’s framework and definitions of palliative care, studies conducting a systematic discourse analysis on WHO publications in support of palliative care remained largely unexplored. Additionally, as demonstrated by Borgstrom (2013) and Durnová (2013) end-of-life care discourses can produce particular forms of governing which indicate how it may be important to conduct a systematic inquiry on the premises upon which WHO recommends ‘palliative care’. Moreover, as observed by Nagington et al. (2021) Foucauldian studies seemed to be “minimally applied to palliative care” (p.1), which is a gap this study aims to fulfil. Drawing from Foucauldian scholarship, this study therefore aims to examine how palliative care has been *problematised* within WHO guidelines.

If we consider that the purpose of a guideline is to make recommendations for clinical practice and public health, the implication is that they foster notions of what is perceived as ‘problematic’ within end-of-life care. Problematisations, therefore, refers to how something is being put forward as ‘problematic’ (Bacchi, 2012b), the reasons given for the ‘problem’, and the recommended solutions. This way, problematisations can be understood as the starting point to gain insight into the *rationale* underpinning the recommendations for palliative care.

As problematisations can refer to “particular regimes of practices of government, with particular techniques, language, grids of analysis and evaluation, forms of knowledge and expertise” (Dean, 2010, p. 38), they can give insight into the ways in which the discourse of palliative care can be used to mobilise interests and achieve specific goals. By using the term ‘problematisation’ I am suggesting both an *attitude* and an *analytic resource.* As an attitude, this research was built on questioning rather than accepting the taken-for-granted, that is, what is accepted as ‘natural’ or ‘evident’. As an analytic resource, problematising WHO guidelines engages with critical analysis of the types of knowledge, concepts, and rationale which underpin WHO’s promotion of palliative care.

In this sense, the objectives this research aims to achieve refer to understanding how the concept of palliative care has been interpreted and used within WHO technical frameworks and the kinds of rationality that they create. This investigation thus aims to gain insight into how a critical approach to WHO guidelines can offer a point of entry on the directions healthcare systems are invited to follow, the premises, assumptions and values shaping these directions and the goals to be achieved. As such, the study also aimed to gain insight on how problematisations of ‘palliative care’ are connected to particular end-of-life care *outcomes,* therefore giving insight on how discourses of palliative care constitute power relations.

1.1 Thesis overview

This thesis is composed of eight chapters which will be summarised below:

1.1.1 Literature Review (Chapter 2)

Since palliative care draws from multidisciplinary studies, the theoretical underpinning of this research belongs to the fields of sociology, medical sociology, global health, and policy studies. The literature review in the chapter that follows will bring together studies from sociology of death and dying to global development of palliative care. This reflects the many fields of study that constitute palliative care research.

The narrative review is organised into themes. Starting from a review of the literature focused on concepts such as ‘death’ and ‘dying’ prior to the emergence of palliative care, the first section will bring a discussion on sociological studies on the subject. Focused on the debate surrounding the social attitudes towards death in the twentieth century. Central debates are the idea of a ‘taboo’ of death, the process of medicalisation of dying, and the institutionalisation of death in modern hospitals. As will be discussed, the debates around death and dying prior to the emergence of palliative care focus on the negative aspects of the modern way of dying. Despite accomplishments in eradicating infectious diseases and increasing longevity, other challenges accompanied the changes in the way we die. One of which refers to the increasing medicalisation and institutionalisation of the dying, and to the depersonalisation and silencing surrounding death in health institutions.

The debate of medicalisation of death will be followed by a review on the ideas promoted by proponents of a new ‘care’ for the dying such as Kübler- Ross (1969) and Cicely Sauders (1993,1997, 2002). Amidst the critique of modern dying, these authors proposed alternative frameworks that understand death as an individual process and as a meaning-making experience. The literature review in this section begins by exploring accounts of the critique of modern dying and how it paved the way for the emergence of another conceptualisation of death. In this sense, the hospice movement and later palliative care, are not seen to rupture the medicalisation critique, but fundamentally incorporate this critique into their claims for better care for the dying. Moreover, the chapter will discuss the opening of St Christopher's hospice as instrumental for the development of palliative care as a medical discipline. Despite the noble principles that underpin the hospice movement, scholars raised concerns on the extent to which 'palliative care' was becoming a new form of medicalised dying. As such, this section also demonstrates the tensions that constitutes 'palliative care' as a concept.

The chapter then will turn to the endorsement of palliative care from the WHO, where focus of the literature shifts from a critique of medicalised dying to emphasise the lack of palliative care in the world. Framed as a global public health issue, WHO's efforts towards palliative care are discussed. The literature concerned with the global development of palliative care is predominantly concerned with issues such as levels of integration, capacity, and disparities in service provision. Meanwhile the disparities in concepts, meanings, and values that shape end-of-life care receives very little attention in the debate at the global level. Therefore, the chapter will emphasise the plurality of understandings, concepts, and practices that constitute the field of 'palliative care' internationally.

1.1.2 Methodology (Chapter 3)

This chapter focuses on the methodological considerations that led to the choice for a discourse policy analysis for this study. Beginning with the research aims and questions, the chapter will introduce the research gap, the aims and scope of the study and the questions raised. Moreover, drawing from a critique on the evidence-based policy movement within policy studies, I will argue on the importance of questioning rather than accepting, the use of expert knowledge informing practice and policy. It will then review the field of Critical Policy Studies in order to inform on epistemological opportunities it offers to this research.

The choice for the What's the Problem Represented to Be? (WPR) approach to discourse policy analysis is discussed, leading to a consideration of its ontological and epistemological premises and how they matter for the questions raised in this chapter. Constituted by six interrelated questions, the chapter provides an in-depth account of the theoretical underpinnings informing each of the six questions. It will also discuss the research design where consideration is given to the application of the WPR framework to WHO guidelines. The research design required adaptations to the WPR framework since it was applied to professional guidelines rather than policies. The chapter then turns to the strengths and limitations of this choice.

1.1.3 Identifying Problematisations (Chapter 4)

Having established the WPR and how the study ought to be conducted, this chapter will introduce the first findings. I will introduce a comparative analysis of WHO 'palliative care' guidelines from 1990 to 2018, with particular emphasis on the continuities and discontinuities of WHO proposals for 'palliative care'. This chapter will therefore be focused on identifying problematisations within WHO guidelines. As previously explained, problematisations are considered a starting point for further analysis, which will then lead to two other findings chapters. One chapter focused on the dominant problematisation identified within guidelines from 1990 to 2011 (chapter 5) and another chapter focused on the problematisation identified within guidelines from 2004 to 2018 (chapter 6). This distinction is merely didactic. Problematisations can be overlapping, and one guideline can foster more than one representation of what is being considered problematic.

1.1.4 Problematising Care (Chapter 5)

Chapter 5 will examine the problematisation identified in guidelines from 1990 to 2011. Identified as 'inadequate care', I will begin the chapter by teasing out the systems of meaning that has to be in place in order to make this problematisation intelligible. As such, I will draw attention to the premises, assumptions, and categories that sustain it. Moreover, I will also demonstrate how the problematisation emerged. The examination of documents, statements, declarations, and other literature will provide an account of the heterogeneous processes that led certain forms of thinking to reach WHO guidelines. Furthermore, I will draw attention to what the guidelines did not say and what has been excluded from them. To do so, a case study will be used to illustrate what the guidelines may exclude and to identify alternative ways to represent the problem. Lastly, I will examine how problematisations produce discourses of palliative care and identify subject positioning within them. That is, these findings will offer insight into the ways in which problematisations produce discourses, how they are constituted by particular systems of meaning, and to reveal the particular kinds of 'individuals' that they create.

1.1.5 Problematising Capacity (Chapter 6)

Chapter 6 is named after the second problematisation identified within guidelines. Entitled as *Capacity*, this problematisation offers insight into how guidelines propose to address problems of lack of access to palliative care services. As this chapter mirrors the same organisation and rationale of that of chapter 5, the examination of 'capacity' problematisation is conducted following the same order as the previous. In this chapter, key premises underpinning 'capacity' are under scrutiny, which leads to an investigation on the conceptual premises and categories used to confer meaning to the 'problem'. This will be followed by tracing the context and origins from which this interpretation emerged, and more importantly, how it reached the WHO. Then, I will direct attention to the silences created by the problematisation. To do so, a case study will be introduced in order to make visible the limitations of 'capacity' problematisation. Lastly, I will consider how problematisations produce discourses of palliative care and identifying subject positioning within them, thus demonstrating how it produces specific discourses and forms of subjectivity.

1.1.6 The Creation of End-of-Life Care Problems (Chapter 7)

Chapter 7 introduces a discussion on how the findings contribute to existing literature on palliative care and death and dying generally. In this chapter, I will introduce alternative ways to understand palliative care guidelines based on the findings from this study. I will argue that we need to rethink guidelines not as technical products, but as cultural products. The discussion in this chapter will also be organised by dominant themes. First, the chapter will discuss the changes in the meanings attributed to palliative care within WHO guidelines. The debate will discuss the *usage* of 'palliative care' to mobilise healthcare professionals, managers, and health authorities to adopt palliative care for a particular end. This is followed by discussing how particular forms of thinking about palliative care allow forms of *governing* end-of-life care. The debate on lack of capacity to palliative care services, usually framed in the literature as a lack of policy development and political will be considered in light of the guidelines where emphasis lay on training and education.

The last section of this chapter refers to the WPR approach. Since Bacchi's (2009) approach provided both the theoretical and the methodological basis for this study, I will direct attention to the contributions of this approach to end-of-life literature. Therefore, the discussion will turn to the ways in which studying problematisations can give insight to the rationalities governing 'palliative care' within WHO guidelines, how the WPR can contribute to future research in this field and to consider the limitations of the approach.

1.1.7 Conclusion (Chapter 8)

Finally, I draw my conclusions to the study in Chapter 8. In this chapter I will discuss how the findings from this study address the research questions. The discussion on the identified problematisations and how they were constituted, is considered in light of what they reveal about forms of thinking about 'palliative care'. Then, the debate will turn to the discourses produced within guidelines and they mean to the goal of universal palliative care coverage. Lastly, I will turn my attention to the implications of the identified problematisations to the 'people' involved in palliative care. The chapter will consider the implications of this study to the field of palliative care research as well as considering the implications for policy development. As this research revealed that guidelines produce particular kinds of subjects, I will theorise on the implications of these for palliative care practice. The chapter will then lead to a reflective section where I return to the objectives and goals set out for this study. In addition, there are other issues that can be further explored and for this reason, I will consider how this study may lead to future research.

1.2 Relevance

With WHO claiming that an estimated 40 million people require palliative care each year (WHO, 2018), investigating how WHO guidelines recommends ‘palliative care’ to different nations can give insight as to why ‘palliative care’ is largely restricted to high-income countries (Clelland et al., 2020; WHPCA, 2020). The most recent *Global Atlas of Palliative Care* (WHPCA, 2020) indicates that the implementation of palliative care services may favour some countries more than others. There are great disparities on capacity levels for service provision, morphine consumption and research contributions, that suggests palliative care to be mainly a premise of the ‘western’ world (Borgstrom & Ellis, 2019; Clark, Barnes, et al., 2018; Clark, Gardiner, et al., 2018; Pastrana et al., 2010).

Despite striking disparities, the debate on palliative care development at the global level is framed in terms of global health goals. For illustration, in 2014, the World Health Assembly Resolution (WHA 67.19) calls on all member states to implement and develop palliative care policies (WHO, 2014). Currently, the inclusion of palliative care as an essential element of the UN’s Sustainable Development Goal 3, means that the goal of Universal Health Coverage depends on palliative care provision to be achieved (Knaul et al., 2018; WHPCA, 2014). As such, the critical inquiry on the WHO guidelines for ‘palliative care’, is important to understand the implications of discourses that may relate to goals of universal coverage, organisation of services and delivery of ‘care’.

Chapter 2. Literature Review

In the previous chapter I discussed how the research problem emerged from my own experiences with palliative care in Brazil. I observed how the WHO' definition for palliative care has been influential in the Brazilian context, shaping practice and policy development, which raised questions on the implications of the uncritical importation of WHO's proposals in Brazil. Add to that, the literature seemed to raise similar questions, pointing out that palliative care is far from a consensus, an understanding that was further supported by research conducted with palliative care professionals and institutions. This suggested that further inquiry into WHO's approach to palliative care was required. This chapter will introduce the multidisciplinary studies that underpin this research. The theoretical underpinnings of this study are organised into themes organised chronologically: the origins of the concept of dying that prompted the emergence of hospice care; the transformation of hospice care into palliative care; how palliative care reached the WHO; global development of palliative care and, lastly, the critical approaches to WHO's model of palliative care.

2.1 Approaching the literature

A British sociologist once said that death presents many challenges for social sciences (Clark, 1999). He argued that through death we can gain insight into social relationships such as societies and individuals, private and public, and men and women (Clark, 1993). As such, death has been discussed in academia since the 1960s and has gained increased academic interest ever since (Borgstrom & Ellis, 2017). Questions around how to manage dying, how to support bereavement, and how to care for those suffering from an incurable illness are some of the concerns that constitute the sociology of death and dying as a rich research field. Such wide range of concerns cannot be fully addressed by one single theory, it requires a wide range of professional disciplines (Howarth, 2007).

Due to the multidisciplinary nature of the field this literature review includes a variety of literature such as sociological studies on death and dying; empirical papers and nonempirical discussion papers on palliative care development internationally; global health debates on end-of-life care; WHO framework to palliative care; and a range of grey literature such as *Global Atlas of Palliative Care*; WHO expert reports and guidelines. The literature was consulted through databases such as library catalogue, BMJ, JSTOR, ScienceDirect, SAGE journals, websites for international organisations in support of palliative care such as: World Hospice and Palliative Care Alliance (WHPCA), WHO, the European Association for Palliative Care (EAPC) and the International Hospice Association for Palliative Care (IAHPC).

The literature consulted varied from 1955 to 2022. This was deemed appropriate due to the interest in considering key debates on death and dying that appeared in the literature prior to palliative care. Thus, beginning with authors such as Gorer (1955) and Feifel (1959) were deemed important to contextualise the literature amidst which the hospice movement and later palliative care originated. As the hospice movement emerged in the 1960s the literature concerning death and dying prior to that time was also included. Search terms will be presented in Appendix 1.

It is important to observe that one major issue within the field of ‘death’ studies remains the relatively under-represented and under-theorised death experiences in non-anglophone countries (Pastrana et al., 2010). Given that America and the United Kingdom have long dominated research in this field (Borgstrom & Ellis, 2019; Walter, 1993), it is no surprise that this is a field dominated by “Anglophone perspectives” (Borgstrom & Ellis, 2017, p. 11). Although the need for more representation of death-related experiences is already established within the literature (Howarth, 2007; Seale, 1998; Walter, 2020; Zaman et al., 2017), there is still a majority of research in ‘palliative care’ conducted within European countries and other high-income countries, mainly published in English-language (Clark, Gardiner, et al., 2018; Pastrana & Ostgathe, 2008; Zaman et al., 2017). In the interest of including non-western perspectives, papers discussing other experiences with palliative care were included such as in Macao, Turkey, Brazil, and Colombia. However, all papers included in this research are in the English language, which once more indicates the dominance of English-speakers within palliative care as a research field.

2.2 Sociology of Death and Dying: a review of 'modern dying'

Sociological studies of death and dying aim to illuminate the ways in which societies make sense of mortality and the changing nature of attitudes towards death, dying, and bereavement (Clark, 1993). During the 20th century, the study of societal attitudes toward death appears as a prominent debate within the literature. Paradoxically, the debate on death and dying in the mid-twentieth century sociological literature seem to focus on *the lack of debate* and a perceived social 'taboo'. For instance, Gorer (1955) argued that death had been replaced by sex as the "unmentionable" in Anglo-Saxon societies. Death-bed scenes and descriptions of final days as they were available in the 19th century, no longer exist (Feifel, 1961). One of the reasons for that, the author argues, refers to the progress of public health making death at a young age less likely (ibid). It is interesting to observe, however, that while death-bed scenes are much less public and spoken about, violent death, on the other hand, is *everywhere.* Movies, thrillers, and violent deaths are offered in our everyday lives while natural occurring deaths are progressively fading from the public eye (Gorer, 1955).

Likewise, psychologists such as Feifel (1959), argued that society 'avoided' an awareness of death. In 1961, he observed the lack of literature on attitudes towards death and dying and criticised how psychology, and more broadly, 'western' culture "has tended to run, hide, and seek refuge in euphemistic language" (Feifel, 1961, p. 66). Death, dying and more emphatically, discourse on death and dying is now occupying a territory that previously belonged to cancer, tuberculosis, and sex (Feifel, 1961). In The Meaning of Death (Feifel 1959 as cited in Lamers, 2012), art, literature, medicine and other disciplines are brought together to reflect about death. This publication represents, as Ariès (1974, p.537) put it, “the awakening” moment of an otherwise neglected topic.

In societies such as Anglo-Saxon that openly speak about the issues of family, politics, religion, and sex, Ariès (1974) will argue that scholars have been silent on the issue of death. At the same time, he argues, they are the very place where death is rediscovered (Ariès, 1974, p. 537). While he recognised the return of death to sociology and psychology, he also indicated that they lacked historical awareness of the transformation of social attitudes towards death.

Ariès (1974, 1976) is particularly relevant on the ways in which European societies dealt with death in the past, and how they deal with death in the 20th century. His theory argues that from the Middle Ages to the late 20th century, there are four different mentalities toward death and dying that reflect how death has been understood through time (Ariès, 1974; Ariès, 1974, 1976). The death-mentality theory demonstrates a progressive narrative whereupon dying in the Middle Ages is discussed as something familiar and a part of everyday life. Such a common experience regards no special treatment and therefore is something shared by everyone in the family, where they have the opportunity to learn what to do when their time comes. In his historical descriptions of the time, death was less private but rather ritualistic with important steps to be learned and followed (Ariès, 1974; Aries, 1974; Jacobsen, 2016).

The death mentality ‘tamed death’ is particularly relevant as it represents an attitude of preparedness and acceptance towards death (Ariès, 1974). In comparison, his writing on modern dying through the mentality of ‘forbidden death’, reflects the opposite. He argues that late 19th century and early 20th centuries western societies radically changed their attitudes towards death and dying whereupon dying becomes shameful and therefore, forbidden (ibid). The ‘taboo’ on death deprives us of the opportunity to share our emotions with those bereaved. Mourning is no longer a distinctive time of life, and the bereaved are encouraged to suffer in silence (Aries, 1976). As demonstrated above, death in the twentieth century seem repressed, denied, and condemned to isolation. As Becker argued, it is a survival mechanism, to defer from knowledge of our mortality (Becker, 1973).

The relationship between ‘modernity’ and ‘death’ therefore, often refers to the ways in which death has been perceived as a “personal, individual loss and located within the private domain” (McManners, 1981 as cited by Howarth, 2007, p.21). As such, it is not uncommon to find authors describing the progressive medicalisation and sequestration of death as related to economic changes, urbanisation and the fading role of religion and tradition (Ariès, 1974; Illich, 1975; Walter, 1994).

Yet, despite the many examples provided so far, ideas of a ‘taboo’ of death are not widely accepted. British sociologist Walter (1990, 1994) challenges the death-taboo theorists and raised important theoretical and methodological points. Without negating the relevance authors such as Ariès (1974) and Gorer (1955) have to the field, he argues that caution is advised. He argues that ideas of a ‘taboo’ of death are not universal in Britain nor, are they the norm in modern societies. Instead, he says “all conversation is rule governed, there is always a right place and time for any conversation topic” (Walter, 1991, p. 296). To Walter (1994), while death-taboo theorists argue that death is socially denied, death becomes more and more talked about. Alternatively, Kellehear (1984) argued that death-denying theorists had important methodological problems. He argues that they emphasised aspects of denial and taboo that reinforced their own perspectives (Kellehear, 1984).

In turn, critics of modern dying such as Glaser and Strauss (1965) and Sudnow (1967) believed that the problem of modernity refers less to the ways societies perceive death but to the social organisation of death within medical institutions (Howarth, 2007). When death enters the hospital, so does the medical control over the dying process (McManus, 2013). Thus, rather than morality over a perceived taboo (Gorer, 1955) or repression (Becker, 1973), the problem of modern dying lays with the social organisation of death within hospitals.

2.2.1 Hospitalisation

With a focus on cure and symptoms, there is no place for the dying in medical institutions (Howarth, 2007; McManus, 2013). The process of transferring death to hospital settings is understood by Ariès as the configuration of a ‘forbidden death’ (Ariès, 1974) - conducted in hospitals, managed by health professionals and placed away from loved ones (Aries, 1974, 1976; Jacobsen, 2016). Regarding the theme of hospitalisation, there are many accounts in the literature describing in detail how death is managed, perceived and, organised within modern hospitals.

Sudnow’s (1967) study of the social organisation of death within hospitals, demonstrated how the dying process was organised in a way to favour institutional routine rather than human dignity (Hart et al., 1998; Sudnow, 1967). Central to this argument is the idea of social value. As dying patients do not offer any opportunity to demonstrate technical competence, they were found to be uninteresting to medical professionals (Sudnow, 1967). Thus, as observed by Timmermans (1998), how patients are valued determined how healthcare staff would care for them. Highly valued patients are more likely to be resuscitated than those with a perceived lower social value (Timmermans, 1998).

Therefore, this work gives insight into the types of relationships established within hospital settings. Filled with anecdotes from his ethnography in American institutions, Sudnow (1967) introduced the concept of ‘social death’. Social dying refers to “that point at which socially relevant attributes of the patient begin permanently to cease to be operative as conditions for treating him, and when he is, essentially, regarded as already dead" (Sudnow, 1967, p. 74). Even worse, the patients classified as socially dead were observed to die sooner (Sudnow, 1967). Dying in hospitals, therefore, was a product of a decision (Sudnow, 1967; Timmermans, 1998).

Moreover, as health staff operate as "gatekeepers of life and death" (Pelligrino 1986 as cited in Timmermans, 1998 p.454), physicians also operate as gate-keepers of what the patient can or cannot know. As reflected in Glaser and Strauss (1965) study on awareness of dying, patients were denied knowing their own health status. Their typology of awareness, i.e. closed awareness, suspicion, mutual pretence and open awareness, reflected how communication was central to the interactions with the dying person (Glaser & Strauss, 1965; Howarth, 2007).

From closed awareness, where the patient is denied any possibility of knowing their status, interactions were limited. Family, friends, and nurses had to agree to keep the silence (Glaser & Strauss, 1965). Moreover, nursing care was restricted to bodily care, leaving patients with none or very little psychological support. With open awareness, however, patients and families were empowered to make decisions on the management of care and prepare arrangements for death (Glaser & Strauss, 1965; Howarth, 2007). As such, the investigation of communicative practices within hospitals brought visibility to power relationships between doctors, patients, families and other health professionals.

In examining the ways in which dying patients were treated in hospitals, the negative aspects of dying under medical care are emphasised. As Seymour (1999) observed, medical intervention in the dying process is predominantly associated with inhumane and unnatural death: "highly technological clinical settings, such as intensive care, where medical intervention is so clearly visible, are held up as extreme examples of the metamorphosis of contemporary death from a ‘natural’ process into ‘unnatural’ events” (Seymour, 1999, p. 692). The transition to hospital dying indicates that instead of evolving to a better way of dying, the emergence of the modern individual unlearned how to deal with death, expropriating tradition from the dying process (Illich, 1975; Walter, 1994). Dying in hospitals according to Elias (2001), not only deprived people of their own deaths, but also condemned them to die in solitude.

2.3 New Approaches to Death and Dying: Kübler-Ross and Cicely Saunders

With several studies describing disturbing accounts of dying in modern hospitals, the discourse begins to shift to the need for a new regime of care for the dying (Armstrong, 1987; Glaser & Strauss, 1968). One emblematic example is the book *On Death and Dying* by Kübler-Ross (1969). Despite criticisms (see Walter, 1994 and Seale, 1998), Kübler-Ross’s (1969) book famously directed attention to the needs of dying patients. She emphasised the importance of listening to their stories by conducting interviews, documenting in detail the unmet needs of patients dying at a medical facility (Kübler-Ross, 1969). Alternatively, Cicely Saunders (1993, 1997) was central to the emergence of the hospice movement. Her new regime of pain relief combined with a holistic approach to pain, voiced much of the concerns with medicalised deaths and proposed new forms of care. Thus, these authors had significant contributions to the field of palliative care.

2.3.1 Kübler-Ross

The book On Death and Dying, does more than just tell the patients’ stories. It tells personified stories of ‘modern dying’. For instance, Kübler-Ross (1969) argued that the days of “dying peacefully at home surrounded by loved ones was long gone” (Kübler-Ross, 1969, p. 19). An idea that arguably reflects those of a ‘tamed death’, that is no longer possible, which implies the linear progression to the ‘forbidden death’ (Ariès, 1974). Moreover, death is described as something to be feared, “to be hidden in euphemisms” (Kübler-Ross, 1969, p.

19), thus engaging with ideas of a death-taboo (Feifel, 1961; Gorer, 1955). Finally, the book describes dying as “solitary, gruesome, lonely, mechanical and dehumanised” (Hart et al., 1998, p. 68). Thus, reproducing much of the gruesome imagery promoted by authors that came before her, such as Sudnow (1967) and Glaser and Strauss (1965, 1968). In this sense, the book offers a perspective of death shaped by the perceived failings of medicine in the care of the dying.

Overall, the book *On Death and Dying* (Kübler-Ross, 1969) inaugurated a new discourse of dying that emphasises the emotional needs of patients. Dying from cancer is described in terms of emotional/psychological stages (Denial, Anger, Bargain, Depression and Acceptance). Each stage is characterised by observable behaviours and emotions (Kübler-Ross, 1969), dying therefore, is presented as a series of stages where the patient is progressively ‘accepting’ death. While the stages may vary and not everyone is expected to go through them all, the stage-theory allowed health professionals to make sense of an otherwise disruptive event (Howarth, 2007).

In her public presentations, writings, and other performances she argued that the gruesome process of dying through medical care had become replaced by stories of peacefulness, and acceptance:

> Her message is that so long as carers do not engage in conspiracies of silence, so long as they let the patient be and express feelings, then death is not to be feared – patients will naturally progress to the final peaceful stage of acceptance (Walter, 1994, p. 71).

As a new narrative of dying emerges, new expectations also begin to take shape. For instance, the last stage of the five stage-theory (acceptance) implied that dying could be a process that reaches a resolution. As described by Seale (1998, p.127), acceptance can be seen as “a return to a peaceful, oceanic, womb-like state” where there is no more suffering and pain. For those who embraced their dying roles, death can be a peaceful event (Seale, 1998). As the acceptance stage leads to ideas of peaceful dying, there is a risk of transforming 'acceptance' into a goal to be achieved. Thus, transforming acceptance as a normative ideology of 'good dying' that reflects "the ideal of dying with dignity, peacefulness, preparedness, awareness, adjustment, and acceptance" (Hart et al., 1998, p. 65). As stage theories such as Kübler-Ross (1969) began to enter the curriculum for health professionals' education (Clark, 1998; Seale, 1998), it can be argued that this could lead to problematic consequences.

Assumed uncritically, theories that commonly describe the dying and grieving experience into stages could lead to a classificatory system from which professionals can separate 'bad deaths' from 'good deaths' (Hart et al., 1998; Seale, 1998; Zimmermann, 2007). The classification into 'good' and 'bad' deaths also reveals normative expectations of what is approved behaviour and what is not. Thus, patients who experience different emotions could be interpreted as 'bad' patients (Hart et al., 1998).

2.3.2 Cicely Saunders

While Kübler-Ross work and ideas were disseminated in America, Cicely Saunders ideas of a new way to care for the dying were already underway (Clark, 1998, 2016). As described by Clark (1998), Saunders's' paper entitled '*Dying of Cancer*' (1958), discussed ideas of new 'homes' for the terminally ill aimed at offering specialised care to address patient's needs. Her arrival at St Luke's Hospital in 1948, allowed her to gain insight into new forms of thinking and caring for the dying (Saunders, 1993). There Saunders would develop a new regime of opioid administration to control pain from advanced cancer. Beforehand, patients were "earning their morphine" due to fears of dependence (Saunders, 1993, p. 5).

In 1963, there was already a growing number of health professionals interested in Saunders' proposal of care (Clark, 1998). Emphasising personhood, Saunders' proposal of care for the dying was influenced by psychology (Clark, 2016; Seale, 1998). In turn, the new ideas shaping ‘care’ implied a new form of conceptualising dying deeply rooted in the idea of an individual self (Hart et al., 1998; Lawton, 2000; Walter, 1994).

Her contribution of pain relief led to a new conceptualisation of pain as ‘total pain’. ‘Total pain’ separates pain into different components (physical, psychological, social, and spiritual) in order to reconstitute ‘pain’ as a ‘whole’ experience (Howarth, 2007; Lawton, 2000). To her, total pain was a way to “try to understand and respond to them and free the patient to find his own path along his final journey and the unexpected gains that are so often found there” (Saunders, 1993, p. 7).

In a paper in 1968, Saunders proposed a complete shift in death and dying literature when she argued that death should not be thought of as a defeat but as an opportunity of growth (Clark, 2016). As such, the hospice movement emphasising awareness, control, and choice builds on the voices of those challenging the medicalisation of the dying and consolidated the early beginnings of the hospice movement (Clark, 2016; Howarth, 2007; Seale, 1998).

2.3.3 Challenging death and dying - new discourse, new powers

The modern hospice movement emerged in the late 1960s in the UK with the opening of St Christopher’s Hospice (Clark, 1998). With a commitment to principles rather than protocols, hospice care was founded on the following: “openness, mind together with heart, and deep concern for the freedom of each individual to make his or her own journey towards their goals” (Saunders, 1997, p. 4). Like Kübler-Ross (1969), hospice pioneers and supporters emphasised the shortcomings of medical care towards the dying (Lawton, 2000).

The ‘modern’ hospice movement challenged mainstream modern medicine with an approach characterised by James & Field (1992) as “unashamedly reformist” (James & Field, 1992, p. 1363). According to the authors, the hospice movement pioneers not only advocated for changes in the doctor-patient relationship, but they also made the “necessary organisational changes” to accommodate them (James & Field, 1992, p.1368). In many ways, the hospice movement emerged as a response to the predicaments that dying patients faced in modern hospitals (McNamara et al., 1994).

Underpinning the response to medicalisation of death, the hospice movement’s goal to “make the experience of dying better” (Walters, 2004, p. 404). This way, there is a close relationship between the hospice movement and ideas of a ‘good death’:

> The hospice movement was to devote itself purely to the care of dying people and in this respect having a narrow focus was, therefore, able to provide better quality of care than other institutions such as the hospital or residential nursing homes. Furthermore, the ethos was dedicated to facilitating a good death (Howarth, 2007, p.139).

The ‘good death’ associated with hospices is characterised as a death free from pain and other symptoms, and with psychological, social, and spiritual comfort (Howarth, 2007; McNamara et al., 1994; Walters, 2004). As an opposition to hospitalised and medicalised deaths, where patients were known to have been denied knowing their own health status, hospices emphasised notions of awareness and dignity (Granda-Cameron & Houldin, 2012; Howarth, 2007; McNamara, 2004). Overall, hospices have been known for advocating for the patients’ right to choose where they want to die (Borgstrom & Walter, 2015; Walter, 1994) which makes hospice care an “ideal form of care” (James & Field, 1992, p.1368) for dying patients.

Hospices represented a new approach to the institutionalisation of patients. Ideas of patient-centredness places power on the hands of the dying, shifting paternalistic tendencies to autonomy and choice (McNamara, 2004; McNamara et al., 1994). As hospices promote the idea that patients should die as they choose, then they have to be aware of their dying (Walter, 1994). This idea of 'good dying' is reflected in Saunders' mission statement where hospices "encourages freedom of expression and belief and affirms the sacredness of each individual and the range of individual needs in the final days of their human journey" (Saunders, 1997, p. 7). In this sense, 'good dying' would mean being aware of your own death and having the autonomy to make your own journey toward death.

Ideas of awareness, control, and individuality have, as Walter (2017, p.15) argues "inherited the assumptions of the 1960s counterculture that taboos are there to be broken; that denial and repression are bad, and that feeling should be acknowledged". Walter's critique voices concerns that the opposition to one death typology may be imposing another typology equally classificatory. In other words, as explained by Seale (1998) the opposition to medicalisation "hospice care, then, draws on broader currents of patient-centeredness and psychological scripts to construct dying and grief as orderly experiences, guided by a knowing expertise" (p.118). Moreover, as Lawton (2000) observed, hospice rhetoric of individuality is premised upon a "disembodied" concept of dying which ignores the reality of bodily deterioration. Upholding the 'good death' values also underplays the challenges imposed by institutionalised practices (McNamara et al., 1994), as well as economic pressures that shape healthcare (Lawton, 2000). Therefore, the hospice movement, commonly framed as an alternative to the medicalisation of dying is not exempt from challenges that come with an emerging discipline, namely, palliative care.

2.4 From the Hospice Movement to Palliative Care

The opening of St. Christopher's hospice in London in 1967 by Cicely Saunders is considered to be the world's first modern hospice. It quickly became known as a centre of excellence in the care for the dying (Clark, 1998, 2016). The basic principles of hospice care practiced at St Christopher's hospice are (Saunders, 1997 p.7):

- A skilled analysis of pain and symptom control (total pain – physical, psychological, social, and spiritual pain).
- A multidisciplinary team is needed to relieve the experience of ‘total pain’.
- To maximize the quality of life, not only physical but also in relationships and ‘inner values’ that is, to “assist them to explore the meaning, purpose, and value in their lives”.
- The whole family is involved in care both during and after the patient’s illness and in bereavement.
- Hospice teams are ready to assist each other coping with the emotional burden of helping the dying.
- Hospice work should combine scientific rigour and compassion.
- Searching for meaning is a not only a challenge for patients and families – many workers are compelled to seeks answers or to develop readiness to live with questions.

Although the opening of St Christophers Hospice is taken as the beginning of the modern hospice, scholars recognise that ‘hospices’ can be traced back to medieval times when these were religious institutions aiming to provide refuge for pilgrims (Clark, 2016; Lewis, 2007; Saunders, 1993; Seale, 1998). According to Saunders (Saunders, 1997), however, St Christopher’s is a continuity from early Christian hospices not only in its foundation but on “the belief that God revealed in Christ shared and shares the darkness of suffering and dying and has transformed the reality of death” (p.8). Thus, aiming to offer a new home where patients and their families could live and be cared for, St Christopher’s is founded and shaped by Christian values.

The commitment to education and research at St Christopher's Hospice allowed professionals from English-speaking countries like America, Canada, and Australia to come and experience the hospice model leading to a rapid spread of hospice services in the English-speaking world (McNamara et al., 1994; Saunders, 1993; Walter, 2020). Education and research involved three main subjects: psychological theories of grief and bereavement; the assessment of the hospice's model in relation to other facilities and pharmacological research on the different narcotics (Clark, 2016). Since the very beginning, hospice principles were being through of as adaptable and applicable in different cultures and settings, which paved the way for 'palliative care' to emerge as a clinical specialty (Saunders, 1993).

The recognition as a medical specialty came in 1987 in England, from then on, the specialty 'palliative care' quickly spread to Australia and New Zealand in 1988, which demonstrates a closer association with traditional medicine (Clark, 2016). The definition of 'palliative medicine' in 1987 as "the study and management of patients with the far-advanced disease for whom quality of life is the focus of care" (Lewis, 2007, p. 121), indicates a shift in the conceptualisation of dying from the hospice movement from an emotional and autonomous process to the result of a 'disease'. The definition above also demonstrates a shift in what is being regarded as 'the focus of care'. Previously, the hospice movement focused on ideas of a good death that highly emphasised individuality and choice (Howarth, 2007; Saunders, 1997). The focus on quality of life, however, suggests a more active role for professionals in the care for the dying (Lewis, 2007). The performative aspect of palliative care is clearly expressed by Kearney (1991 as cited by O'Brien, 1993, p. 34):

> Patients with incurable illness must no longer be viewed as medical failures for whom nothing more can be done. They need palliative care, which does not mean a hand-holding second-rate soft option, but treatment, which most people will need at some

> point in their lives, and many from the time of diagnosis, demanding as much skill and commitment as is normally brought into preventing, investigating and curing illness.

The shift from care to treatment demonstrates how much ideas shaping death and dying have changed throughout the years. The consolidation of 'palliative care' as a medical discipline prompted significant changes in the values and priorities shaping this form of care. For instance, as explained by Clark (2016) the development of 'palliative care' as a medical discipline "called for a detailed understanding of pain. This led to some rich areas for pharmacological as well as phenomenological insight, efforts to describe and measure pain, and innovative approaches to pain relief" (p. 118). Furthermore, research demonstrating evidence of the effectiveness of hospice care in comparison to conventional treatments for pain relief contributed to the establishment of hospice and palliative care as a legitimate medical discipline (Seale, 1998).

The development of hospice care into palliative care transforms what was once the identity and uniqueness of the movement (Hart et al., 1998; James & Field, 1992). What was once identified by values of individuality and holistic care is now clearly associated with symptom relief and 'treatment'. For instance, O'Brien (1993) argued that "effective relief of pain" is fundamental for palliative care, which in turn, is a form of care concerned with "patients whose disease is not responsive to curative treatment" (p.34). Yet, for Clark (2016), this shift was necessary, that is, it was out of the necessity of expanding the field, that hospice doctors would have to speak the language of modern medicine and healthcare systems.

The relationship with medicine allowed developments such as peer review journals, including Palliative Medicine in 1987, followed by the publication of the Oxford Textbook of Palliative Medicine in 1993, and the first issue of the European Journal of Palliative Care in 1994. In 1992 the European Association for Palliative Care (EAPC) published a palliative medicine curriculum for medical students and other professionals and, in that same year, 22 out of 28 medical schools in Europe were teaching palliative medicine, thus consolidating this field as a discrete area of medicine (Lewis, 2007).

Alongside the expansion of palliative care research, training, and literature, the dissemination of hospice care to other settings raised questions on the possibility to uphold the original philosophy (McNamara, 2004; McNamara et al., 1994; McNamara et al., 1995). Those who claim that the 'good death' is central to the modern hospice philosophy claimed that the institutionalisation of hospices could override the original principles of hospice care (Hart et al., 1998; McNamara et al., 1994). The encroachment with modern medicine and the intent to enter mainstream healthcare has been argued as a threat to the principle of a 'good death' and led to claims that hospice care was being reduced to symptom management (Clark, 2002; McNamara, 2004; McNamara et al., 1994). As such, while the literature in the middle of the twentieth century emphasised the emergence of an alternative, humanised care for the dying, by the end of the century it had indicated the possible risks of compromising the movement's ideology.

2.5 Global Development of Palliative Care

Moving away from the early hospice movement where palliative care was underpinned by ideas of a 'good death', the endorsement from the WHO allowed 'palliative care' to officially enter global health publications which are characterised by discourses of public health and policy development (Stjernswärd et al., 2007b, 2007a; Whitelaw & Clark, 2019). The impetus to disseminate palliative care to healthcare systems allowed the WHO to work in collaboration with other organisations, thus forming an emerging literature on the 'global' development of palliative care (Clark, 2008, 2012b; Clark & Graham, 2011; Stjernswärd, 1997a; Teoh & Stjernswärd, 1990).

2.5.1 The WHO and Global Health

One of the main challenges for global health was the transformations of the world brought about by globalisation. Despite being a contested concept open to different interpretations and traditions, globalisation is often associated with the reduced role of the State-Nation and social welfare which in turn has implications for health (Matta & Moreno, 2014). Amidst the increasing globalisation, new health challenges originated which paved the way for international health frameworks to emerge (Ruger et al., 2014). The WHO together with non-state actors emerged aiming to improve global health (Brown et al., 2006; Ruger et al., 2014). The WHO is an essential actor in global health governance with the role of monitoring, establishing norms and standards, and coordinating efforts to achieve common goals (Prah Ruger et al., 2014). As described by Ruger and Yach (2014, p.3):

> The work of the WHO is defined by its Constitution, which divides WHO’s core functions into three categories: (1) normative functions, including international conventions and agreements, regulations and non-binding standards and recommendations; (2) directing and coordinating functions, including its health for all, poverty and health, and essential medicine activities and its specific disease programs; (3) research and technical cooperation functions, including disease eradication and emergencies.

Establishing norms, directing and coordinating global health actions and producing research to assist national governments and health care providers to take informed decisions on health-related issues is considered a knowledge production activity (Chang et al., 2010). In fact, as argued by Study et al. (2013), the effectiveness and successes that the WHO has had in coordinating global health efforts and influencing health policies has relied heavily on its ability to produce and mobilise expert knowledge. In this sense, the WHO can be thought as a “knowledge-based” international organisation (Sturdy et al., 2013, p. 534). Regarding palliative care, the WHO has served as a catalyst for international palliative care development (Sepulveda et al., 2002). It has also served as a “neutral” base from which to develop a consensus method for cancer pain relief; providing research and technical cooperation toward palliative care programmes and policies (Stjernswärd et al., 1996). Promoting a public health approach to palliative care, the WHO's advocacy for palliative care aimed to influence the development of national policies, and implementation of services (Callaway et al., 2018; Sepulveda et al., 2002; Stjernswärd, 1997; Stjernsward et al., 1996).

One of the WHO's core functions is developing evidence-based guidelines to inform policymakers, healthcare professionals and other stakeholders to make informed decisions on health interventions (Burda et al., 2014; Chang et al., 2010; WHO, n.d.). In this light, the production of expert knowledge is seen to facilitate tackling perceived problems of global importance.

According to Littoz-Monnet (2017), expert knowledge is understood as:

> […] the forms of codified knowledge that are either produced by specialists (as indicated by qualifications or institutional affiliation) or which involves specialist or technical methods, equipment or accumulated knowledge that is generally assumed to require skills and experience not possessed by professional administrators (Littoz-Monnet, 2017, p. 2)

There is widespread consensus that expert knowledge can help influence political action as an essential part of global health governance (Burda et al., 2014; Lavazza & Farina, 2020; Littoz-Monnet, 2017; Sturdy et al., 2013).For instance, in the latest Lancet Commission (Knaul, Farmer, et al., 2018; Knaul, Rodriguez, et al., 2018) for palliative care development, it was argued that global health agencies concerned with access to palliative care and pain relief should promote and facilitate action by countries through the production of "[…] global public goods, especially knowledge-related goods" (Knaul, Farmer, et al., 2018, p. 1396).Expert knowledge is thus an important strategy for palliative care development globally. Likewise, the *Lancet Comission Report* affirmed that: "Knowledge exchange is crucial to effective investment in change and is needed to assist countries to effectively adapt and adopt systemic innovations” (Knaul, Farmer, et al., 2018, p. 1396). In other words, mobilising knowledge is an avenue through which one can open space for change.

As an illustration of how knowledge exchange can be important for global health, during the COVID-19 pandemic, the mobilization of expert knowledge became instrumental to inform governments on how to counteract the spread of the virus (Lavazza & Farina, 2020). In this context, relying on experts and their epistemic authority was instrumental injustifying the implementation of quarantine measures. Yet, these measures can also be argued as relieving political authorities of responsibility in case the results are negative or unwelcomed (Lavazza & Farina, 2020). That is, expert knowledge can play an important role on global health practice as well as in *politics.*

It is important to note that the production of expert knowledge can be disputed. As demonstrated by Chang et al. (2010), while guidelines establish normative standards that inform patient care and health policy, there are inconsistencies in the production of guidelines. For instance, they argue that the WHO guidelines are found to be inconsistent with each other and with its own recommended processes for guideline development (Chang et al., 2010). In response to criticism, the WHO established the Guidelines Review Committee (GRC) aimed to ensure that guidelines produced by the WHO are made through transparent evidence-based processes and meet the highest international standards(Burda et al., 2014). Yet, research suggests that concerns remain, and further improvements are still needed (Burda et al., 2014; Chang et al., 2010).

In the field of palliative care, there are disputes over the meaning of palliative care and how to provide it, which led to the production of a consensus-based definition for palliative care (Radbruch et al., 2020). As evidenced by Radbruch et al. (2020, p. 755):

Participants had significantly different perceptions and interpretations of PC [palliative care]. The greatest challenge faced by the core group was trying to find a middle ground between those who think that PC is the relief of suffering and those who believe that PC describes the care of those with a very limited remaining life span.

Thus, establishing normative standards can be challenging. If we take into consideration that expert knowledge can be a way to orient political action (Littoz-Monnet, 2017, 2022), then resorting to standardized, normative approaches to knowledge may maintain an "appearance of the rational, apolitical character of the policies they promote" (Littoz-Monnet, 2017, p. 1). That is, given that international organisations such as the WHO are knowledge-based institutions, their technocratic approach to knowledge - where focus relies predominantly on technical knowledge as the basis for setting out normative standards for policy and practice - can hide the political nature of knowledge-making practices (Abimbola et al., 2021; Littoz-Monnet, 2017; Richardson, 2019; Wackers & Markussen, 2015).

As demonstrated by Littoz-Monnet (2022), her study on the making of global mental health knowledge revealed the processes of consolidation of the dominant biomedical approach to mental health. She argues that this approach is far from a consensus. Rather, she demonstrates how this approach was *made*, through mechanisms of circularity and exclusivity. Expertise, she argues, is produced in an "enmeshed and interwoven space" where there is no distinct separation between the actors and organisations with a tendency to exclude or marginalize dissident voices (Littoz-Monnet, 2022). As an example of the mechanism of circularity, she demonstrates that within the field of mental health, there is a symbiotic relationship between prestigious research clusters, policy actors and academia, where expert reports, statistical data, and other studies are disseminated and maintained. Her study thus demonstrates the elitist nature of the knowledge-production field, and this concern is voiced by many others across different s aspects of health. For instance, Richardson's (2019) paper on the coloniality of global health argues that epidemiology, a seemly unbiased scientific field, can be thought of as an accomplice to contemporary colonialism. Public health is involved in historical circumstances which have been obscured through "a speciously, rigorous scientism" (Richardson, 2019, p. 110). That is, representing knowledge as an a-historical entity can continue to maintain power asymmetries within global health as it obscures structural forces that shape people's experiences towards healthcare (Richards, 2022; Richardson, 2019).

Similarly, Abimbola et. al (2021) have argued that it is imperative to decolonise and decentralise global health, which includes acknowledging, and being accountable for processes of colonisation. The authors also claim that decolonising global health would have to include a deeper understanding of a countries' context through a bottom-up approach, that is, "without a supremacist lens on the world" (Abimbola et al., 2021, p. 3). Further, they voice concerns on the exclusivity of global health knowledge production, where most of what we know about the status of 'global health' is produced by or based in HIC universities (Abimbola et al., 2021). Likewise, Pastrana et al. (2010) and other palliative care advocates for palliative care in the global south voice concerns on the marginal role that LMICs play in research and policymaking at the global level (Pastrana et al., 2010; Rosa et al., 2022; Soto-Perez-de-Celis et al., 2017).

The literature presented in this section appears to demonstrate, as argued by Lavazza and Farina (2020), Richardson (2019) and Wackers (2015), that there are several epistemic issues regarding the use of expert knowledge in global health governance. Knowledge systems can be argued as epistemic practices as they arguably do more than just *inform* decisions, but they constitute *modes of ordering the world* (Law and Mol 2002 as available in Wackers & Markussen, 2015). Similarly, Borgstrom (2016, p.243) directs attention to the ways in which policy documents themselves can be thought of as "thinking activity", which echoes the idea that policies, guidelines, and other prescriptive texts (Bacchi, 2009), are embedded with forms of shaping the world, and as such, can be thought as a source of power (Sturdy et al., 2013).

While there seems to be a consensus that there are unresolved issues regarding the processes of knowledge production, the WHO continues to be a key stakeholder in the field of palliative care not only through knowledge production, but also through establishing relationships with national governments and other international organisations to advocate for palliative care implementation. The next section will demonstrate how the WHO has consolidated its central role on palliative care advocacy throughout the years and the types of 'knowledge' it produces in support of palliative care.

2.5.2 The endorsement from WHO: entering the realm of global health

Palliative care appeared in WHO global health debates mainly associated with issues of 'cancer pain'. In a meeting held by WHO in 1989, only two years after 'palliative care' had become a medical specialty in the UK, experts from different fields were concerned with the status of cancer pain in the world and recommended pain relief and supportive care for cancer patients globally (Stjernswärd et al., 1996; Teoh & Stjernswärd, 1990). The meeting led to the first WHO practical guideline to be published in the following year. The *Cancer Pain Relief and Palliative Care* guideline (WHO 1990) defined palliative care as:

> The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families (WHO, 1990, p. 11).

Despite focusing on cancer pain alone, the guideline engages with palliative care more widely indicating what healthcare systems could provide in order to support patients at the end-of-life (Sepulveda et al., 2002; Stjernswärd et al., 1996; Whitelaw & Clark, 2019). According to Whitelaw & Clark (2019), this work is "a landmark in the history of palliative care, which had now been framed by the WHO as a global, public health issue" (p.2). Framing palliative care in this manner allowed another form of conception of palliative care, one that is premised on measures for integration into healthcare systems and policy development.

Beginning with the WHO Cancer Pain Relief programme under the guidance of a Swedish oncologist named Jan Stjernswärd (Stjernswärd, 1997a, 2013b; Stjernswärd et al., 2007b) encouraged a network of government and non-governmental institutions to tackle the issues of end-of-life care, such as pain and suffering around the world (Stjernswärd et al., 1996). As Chief of Cancer at the WHO, Stjernswärd played a decisive role in raising palliative care status in the global context (Zaman et al., 2017). Before him, cancer was not yet considered a problem in low-resourced countries, and palliative care was yet to be considered a public health issue (Stjernswärd, 2013b; Zaman et al., 2017). His idea of a public health approach to palliative care globally promoted a vision of palliative care integrated into ‘evidence-based’ and ‘cost-effective’ approaches to public health (Stjernswärd et al., 1996; Stjernswärd et al., 2007b, 2007a). He argued that resources for cancer control are limited and unequally distributed, thus WHO cancer care programmes should aim to achieve a “common future” for cancer care for all, including both developed and developing countries (Stjernswärd, 2013b; Zaman et al., 2017).

Stjernswärd’s (2007) vision of palliative care is reflected in WHO’s Public Health Strategy (PHS) launched in the same year as the *Cancer Pain Relief and Palliative Care* guideline (WHO, 1990; Stjernswärd et al., 2007b). PHS, it is argued, “offers the best approach for translating new knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in the population” (Stjernswärd et al., 2007b, p. 486). PHS in this perspective set forth measures for public health in order to reach the population. This included education, drug availability, and policies in support of pain relief and palliative care (Stjernswärd et al., 2007b). In 2007, the revised PHS includes a fourth measure ‘implementation’, which indicates how policies are a precondition so that the other measures can be developed (Clelland et al., 2020). This way, the endorsement from WHO expanded the debate surrounding palliative care from a critique of hospitalisation and medicalisation to be centred around policies:

> National policies are the cornerstone for facilitating the implementation of palliative care programmes that will provide care for all people in need of these services. These policies can be empowering and can ensure equitable access to affordable medications and therapies or, can be restrictive and lead to unnecessary suffering by patients, families and the society (Stjernswärd et al., 2007a, p. 514).

The literature on the WHO’s framework for palliative care, begins to demonstrate an increasing conception of palliative care in terms of healthcare and national policies. In the early years of WHO’s support for palliative care, the Cancer Control programmes already had an important role in emphasising the need for policy development to address issues such as ‘cancer pain’, the PHS however, expands the need for policy development to include palliative care at all levels of healthcare systems (Clelland et al., 2020; C. Sepulveda et al., 2002; Stjernswärd et al., 2007a).

National policies, Stjernswärd et al., (2007a) argues begins with advocacy to raise awareness globally and locally on the importance of palliative care. Advocacy documents such as consensus-based reports, declarations, and commitments begin to have a place in the literature regarding palliative care globally (Inbadas et al., 2016). Advocacy documents serve to increase awareness of policymakers and the general public on the importance of palliative care and the “size of the problem and the solutions” (Stjernswärd et al., 2007a, p. 515). Therefore, it places the WHO and other international organisations in support of palliative care in a privileged position of influencing global health agendas.

Awareness is the first step to sensitisation of key stakeholders who will in turn facilitate further action (Stjernswärd et al., 2007a). Meetings, workshops, and other activities then can be developed to propose changes to healthcare policies and programmes (ibid). Additionally, the WHO has also implemented programmes to increase research and training on issues such as quality of life, palliative care and symptom evaluation through collaborating centres (WHO, 1990). Amsterdam, Milan, Oxford and Wisconsin are among the WHO collaboration centres aimed at research on palliative care and other similar themes, which demonstrates the international reach of WHO's approach to palliative care development (ibid). Demonstration projects were developed in Kerala, Catalonia, and Uganda, demonstrating possibilities for palliative care development in different contexts (Gómez-Batiste et al., 2016; Stjernswärd, 2013a). Moreover, other supranational entities such as the UN International Narcotics Control Board (INCB) working in collaboration with the WHO outlined measures to facilitate that morphine and other opioids are available to patients around the world and reached an even broader scope of activities (Teoh & Stjernswärd, 1990; WHO, 1990).

These initiatives from WHO have helped compel governments into taking action to legalise and distribute opioids in many parts of the world where pain relief would be unobtainable (Saunders, 1997). From this perspective, it could be argued that the dissemination of palliative care internationally was motivated by pain and suffering from cancer. Consequently, cancer pain relief can be seen as the spearhead for the development of palliative care approaches in the world (C. Sepulveda et al., 2002; Stjernswärd, 2013a; Stjernswärd et al., 2007b).

2.5.2 Global Network for Palliative Care Development

Together with the WHO, other individuals and organisations in support of palliative care worked to raise awareness on the issues of end-of-life care in many parts of the world, which demonstrates the emergence of a global network in support of palliative care.

> The World Health Organization (WHO) served as a catalyst to develop policies and advance treatment strategies to benefit patients with cancer and pain. The WHO

> Cancer Pain and Palliative Care program now extends beyond the boundaries of the United Nations organization; its mandate is carried out in the real world. Governments, non-governmental organizations, institutions and a strong network of individuals are pledging, starting or actively implementing cancer pain relief and palliative care according to established WHO principles (Stjernswärd et al., 1996, p. 65).

In Europe, the European Association of Palliative Care (EAPC) is perhaps one of the most influential organisations towards palliative care within WHO publications. Emerged in 1997, the EAPC was instrumental for the development of a WHO palliative care approach. As evidenced by Materstvedt (2003), the EAPC published its definition of palliative care which then was endorsed by the WHO and published in WHO's *Cancer Pain Relief and Palliative Care* (WHO, 1990). Concerning palliative care development in the European region, the EAPC offers guidance on norms and standards for professionals and decision-makers to improve access in European countries (EAPC, n.d.; Materstvedt et al., 2003).

In the United States, the International Palliative Care Initiative (IPCI) was founded in 1998 aimed to disseminate palliative care, increase awareness and education, and advocate for palliative care integration into public health systems (Callaway & Foley, 2018). The IPCI understands palliative care to be a public health issue and a basic human right (ibid), thus reproducing similar conceptions of palliative care as the ones promoted by the WHO. Importantly, the IPCI strategy included working with other global health actors such as international leaders, non-governmental organisations, and national governments at the same time promoted activities within individual hospices, programmes, and with key individuals (Callaway & Foley, 2018). Thus, IPCI involved both top-down and bottom-up strategies, which gives an indication of the ways in which the WHO's views of palliative care may indirectly have shaped activities at different levels.

Additionally, the International Association for Hospice and Palliative Care (IAHPC) aimed to help countries develop their own palliative care services (de Lima & Radbruch, 2018). One of the IAHPC programmes refers to supporting institutions and programmes with technical and financial support for palliative care development (ibid). The IAHPC launched a committee to survey experts around the world to create an essential list of palliative care medicines, the published findings were later adopted in the WHO's List of Essential Medicines for Palliative Care (de Lima, 2007; de Lima & Radbruch, 2018).

Founded in 2008, the Worldwide Hospice Palliative Care Alliance (WHPCA) concerned itself with working towards universal access to palliative care services (Connor & Gwyther, 2018). Working in association with IAHPC, EAPC, and Human Rights Watch, these organisations came together to develop the Prague Charter which argued for the inclusion of palliative care into healthcare systems and budgets (Connor & Gwyther, 2018; Radbruch et al., 2012). As a non-governmental organisation in official collaboration with the WHO, WHPCA is actively participating in the development of important global health agendas and mapping levels of service provision (Connor & Gwyther, 2018; WHPCA, 2014; WHPCA, 2020).

On that account, the period between the 1990s and early 2000s was key to the emergence of global palliative care development. With support from the WHO and other organisations working in collaboration, this was a period of important international commitments to international development (Clark, 2012b). Amongst them, the Florianopolis Declaration in 1994 drew attention to opioid availability in South America (Stjernswärd et al., 1995). The Venice Declaration by the IAHPC in collaboration with EAPC called upon governments to develop palliative care strategies in developing countries (Assembly & Africa, 2006) and the Budapest commitments put forward by the EAPC set out common goals "within a common framework" and commit to achieving them in the next following years (Foley, 2009, p. 269). Yet, despite the growing support for palliative care at the global level, several issues remained.

To Radbruch & Payne (2009), the development of palliative care internationally challenges decision-makers to determine “where and when palliative care services should be developed, but also how they should be equipped and configured” (p. 278). Add to that, while there was a rise in opioid consumption in industrialised countries, the development of palliative care showed relatively little impact in the rest of the world (Clark, 2008; Sepulveda et al., 2002; Stjernswärd, 1997a; Wright et al., 2008). There are major disparities in levels of provision, opioid availability, and integration into healthcare systems (Clark, 2012b; Radbruch & Payne, 2009; Sepulveda et al., 2002). From this perspective, we can see that the emergence of palliative care internationally raised challenges to advocacy, policy development, and service distribution. Therefore, the next section will provide an overview of the development of palliative care in the world and the challenges remaining.

2.5.3 Measuring Palliative Care Globally

As palliative care develops around the world, the disparities in service provision and opioid availability are heightened (Stjernswärd et al., 1996; Stjernswärd et al., 2007b, 2007a). The disparity in opioid consumption continued to create a gap between and within global regions, challenges such as the reluctance of healthcare professionals in prescribing opioids, fears of addiction, and little engagement from state and national governments in addition to economic and legal restraints remained (Clark, 2008, 2012a; Sepulveda et al., 2002). Moreover, while there were reports of palliative care development in different countries, there were gaps in systematic knowledge about levels of development between countries (Clark, 2012b; Wright et al., 2008). An issue that several mapping efforts tried to address.

The interest in offering comparable data on the status of palliative care internationally can be traced back to a Task Force commissioned by the EAPC to trace the development of palliative care in European countries (Radbruch & Payne, 2009). Several countries were surveyed, and the results were published in the first EAPC Atlas of Palliative care in Europe (ibid), inaugurating what was going to become a key characteristic of palliative care as a research field – classifying countries according to their levels of service provision. From the years the 2000s onwards, it is possible to see a rise in publications tracing the levels of development and seeking to create quantitative data on the distribution of services between countries. One example of this trend is Wright and colleagues (2008) four-part typology for palliative care development.

Wright and colleagues (2008) categorised palliative care development in each country. The four-part typology separated the 234 countries under the United Nations list allocated into the following categories: (1) No known hospice-palliative care activity, (2) capacity building activity, (3) localised hospice-palliative care provision and (4) countries where hospice-palliative care services are reaching a measure of integration with mainstream providers (Wright et al., 2008, p. 470). Palliative care provision was identified in 115 out of 234 countries with at least one or more services (Wright et al., 2008). However, only a small proportion (15%) had achieved some level of integration with mainstream service providers and policy integration (ibid). The first mapping of its kind demonstrated a positive correlation between high GDPs per capita and palliative care integration (Wright et al., 2008), which gives insight into the types of conditions upon which palliative care services prosper.

A subsequent mapping exercise was repeated after considerations regarding the method of categorisation in 2011 (Lynch et al., 2013). The updated findings revealed a rising in the number of countries with registered palliative care activities to a total of 136 from a previous total of 115 (ibid). Yet, they also continued to demonstrate that palliative care services are more likely to be integrated into healthcare systems in countries with a higher Human Development Index (HDI). Countries with lower levels of resources continued to be classified in its majority as group 1, that is, no known palliative care activities (Lynch et al., 2013). The format of typologies for palliative care development appeared also in subsequent publications such as the *Global Atlas of Palliative Care at the End-of-Life* by the WHPCA in 2014, where the classificatory system is regarded as “a way to monitor the growth of palliative care worldwide” (WHPCA, 2014, p. 34). Thus, these studies not only reveal a new trend in palliative care research but also indicate what is the focus of attention: the number of services in the world. This is further supported by the estimates of people in need of palliative care. The *Atlas* estimates that 20 million people in the world require palliative care, the majority of them 78% living in low-and-middle-income countries indicating where palliative care development is most needed (WHPCA, 2014).

The *Atlas*, a collaboration between the WHO and WHPCA is one of the main advocacy documents used to raise the issue of palliative care in the global health agendas (WHPCA, 2014). It was the first time that an advocacy publication included a quantitative estimate on the need for palliative care based across disease groups (ibid). Importantly, the *Atlas* also raised issues on the conceptual understanding of palliative care where it is argued:

> Palliative care is expanding in the developed world in spite of myths and misunderstandings about its nature and purpose but is only beginning to be available in the developing world where it is needed most. (WHPCA, 2014, p. 4).

The statement above highlights the disparities in service provision while also giving insight into the type of problem that underpins these disparities, such as the lack of conceptual understanding of palliative care. To this end, the *Atlas* offers definitions for palliative care from the WHO while addressing the need to further explain this definition in order to “clarify the comprehensive nature of palliative care” (WHPCA, 2014, p. 7). Therefore, the *Atlas* indicates that there are limitations to the definitions of palliative care from the WHO. Moreover, as evidenced by this document, attitudes, and beliefs toward death and dying are considered an obstacle to the implementation of palliative care (WHPCA, 2014). The *Atlas* attributes the limited reach that palliative care has amongst policymakers to the psychological fear of death and avoidance (ibid), thus reproducing much of the same ideas of those death-denying theorists from the mid-twentieth century.

Overall, the 2014 *Atlas* echoes Lynch and colleagues (2013) findings reinstating that palliative care remains far from being accessible to everyone that needs it. The evidence provided in this study aimed to stimulate debates on “the need for integrating palliative care into existing healthcare systems” (WHPCA, 2014, p. 41). The Economist Intelligence Unit, however, provided a different view where a country’s level of palliative care development indicated its “quality of death” (EIU, 2015).

The Quality of Death Index from 2010 revised in 2015 indicated another perspective from previous studies on palliative care development in the world. In the first edition, the 40 countries listed were compared according to 24 indicators in 4 categories: 1) basic end-of-life healthcare environment; 2) availability of end-of-life care; 3) cost of end-of-life care and 4) quality of end-of-life (EIU, 2010; Clark, 2012b). Similarly to previous studies, the EIU (2010) ranking also revealed that developed countries had better palliative care infrastructure and integration into healthcare systems with the UK at the top of the list. In 2015, the same ranking was updated to include another 40 countries, thus classifying the quality of death in a total of 80 countries (EIU, 2015). Using five categories namely, palliative and healthcare environment; human resources; the affordability of care and quality of care, and lastly, the level of community engagement; the EIU (2015) quality of death index puts the UK once more at the top of the list. Their findings emphasised the characteristics and conditions of countries with a high quality of death as:

> a strong and effectively implemented national palliative care policy framework; high levels of public spending on healthcare services; extensive palliative care training resources for general and specialised medical workers; generous subsidies to reduce

> the financial burden of palliative care on patients; wide availability of opioid analgesics and strong public awareness of palliative care (EIU, 2015, p. 7).

Considering that palliative care previous scholars emphasised the lack of opioid availability, lack of appropriate funding for palliative care and the lack of awareness and education (Clark, 2008, 2012b; Sepulveda et al., 2002; WHPCA, 2014), the conditions above excludes the majority of countries from reaching a high quality of death. Recently, in another effort to measure the quality of palliative care delivery within health systems, Sepúlveda and colleagues (2022) observed that meeting metrics does not translate into quality of care. Moreover, the authors indicate that the previous efforts to measure the quality of death from the EIU (2010, 2015) also fail to acknowledge patient and caregiver preferences (Sepulveda et al., 2022).

The numerous studies mapping services in the world overwhelmingly suggest that palliative care is still insufficient to meet the needs of the population (Carrasco et al., 2021). Amidst disparities in service provision between countries, the World Health Assembly Resolution 67.19 (WHO, 2014) aimed to address gaps in provision by calling governments to action on palliative care availability in the world. The resolution urges countries to include palliative care in their healthcare budget, and policies and reinstate the need to provide adequate pain relief medicines (de Lima & Radbruch, 2018; WHO, 2014). In the same year, the WHPCA published recommendations for Universal Health Coverage toward palliative care (WHPCA, 2014).

2.6 Universal Health Coverage

One of the major developments toward global palliative care development was the inclusion of palliative care in the Sustainable Development Goals (SDGs). The UN 2030 Agenda for Sustainable Development requires countries to commit to Universal Health Coverage by 2030 stating that in order “to promote physical and mental health and wellbeing, and to extend life expectancy for all, we must achieve universal health coverage and access to quality health care. No one must be left behind" (UN, 2015). Using the same motto "do not leave those suffering behind" the WHPCA (2014), affirms the need for palliative care services within UHC:

> Palliative care is an essential and needed healthcare service within Universal Health Coverage as defined by the World Health Organization. As the Sustainable Development Goal discussions continue, it is critical that Universal Health Coverage is a key component of that framework but also that no-one is left behind. That includes the millions of people who are living and dying around the world without access to hospice and palliative care, including pain treatment (WHPCA, 2014, p. 2).

A key premise of UHC, therefore, lies in the equitable distribution of palliative care services and pain relief (Clark, Gardiner, et al., 2018). The UHC requires that all people, independently of income or disease, can have access to the "promotive, preventive, curative, rehabilitative and palliative health services they need" (WHPCA, 2014, p. 2). Thus, the basic understanding behind the UHC agenda is that palliative care is a fundamental aspect of healthcare, and it is the government's role to ensure its availability to the population in need (WHPCA, 2014). However, as recognised in this publication, palliative care is far from being universally accessible. In 2014 it was estimated that only 20 countries in the world have palliative care integrated into their healthcare system, and 42% of countries do not have any registered activity (WHPCA, 2014).

To the WHPCA there are a few reasons that explain the lack of UHC toward palliative care. First is the lack of opioid availability, which has also been observed by the WHO (Stjernswärd, 1997a, 2013a; Stjernswärd et al., 1995, 2007b). Second, is the lack of appropriate training and education for healthcare professionals in palliative care which similarly has also been identified by the WHO (ibid). Moreover, the WHPCA argued that the lack of financial protection and lack of insurance coverage are understood to be barriers to UHC as well as the lack of evidence on the costs associated with palliative care delivery (WHPCA, 2014). Lastly, the WHPCA argues that another challenge to UHC is the lack of engagement of UHC advocates with palliative care which has been neglected in “key discourse, commentary, analysis and research on the issue of Universal Health Coverage (WHPCA, 2014, p. 7).

With possibly the exception of the latter, it is possible to argue that the barriers mentioned above draw from a Donabedian framework which is a framework focused on measuring structural indicators that are “presumed to be associated with good end-of-life care” (Sepúlveda, et al., 2002, p.458). Thus, excluding indicators that may be relevant for increasing palliative care coverage. Palliative care indicators are known to be difficult to establish (Clark, Barnes, et al., 2018; WHPCA, 2014). Due to their non-prescriptive nature and varied outcomes, there is no consensus on global indicators to measure development (Clark, Barnes, et al., 2018).

Moreover, while the document identifies several challenges to UHC, the publication does not offer any insight on how to overcome them. Lastly, given the scenario of great disparities which indicate that countries are failing to provide UHC, the WHPCA reinstates the need for advocacy on the issue (WHPCA, 2014). However, as Clark, Barnes and colleagues (2018) argued, advocacy for palliative care mainly frames the debate on the need for palliative care as a human rights issue, which may be constricting rather than facilitating global development (Clark, Barnes, et al., 2018). This suggests that rather than focusing on monitoring the levels of UHC, attention should be directed to the ‘frame’ in which UHC to palliative care is proposed to different governments and funding agencies.

The limitations of advocacy for the UHC toward palliative care can also be observed in the following years. Three years after the WHPCA publication, palliative care provision was still only available for 14% of the global population, mainly in European countries with global demand expected to increase by 87% by 2060 (Clark et al., 2020). In 2020, Clelland and colleagues identified that only 55 out of 198 countries had a national strategy for palliative care with varying levels of implementation. In 47 of them, there was evidence of palliative care in national law and 24 had a "stand-alone national law" on palliative care provision or palliative care is recognised as a right in their constitution. While in 66 countries there was a government section dedicated to palliative care provision (Clelland et al., 2020). Both studies thus indicate that while there has been some progress towards UHC, universal access to palliative care is yet to be achieved.

Without a wider understanding of the challenges involved in the issue of 'palliative care', especially in regards to the wider social aspects of palliative care in which healthcare systems are inserted, recommendations regarding how palliative care can be implemented are at risk of producing standardised models of service delivery largely based upon professional constructs of death and dying that may suit the needs of some, but not all (Monroe et al., 2011; Zaman et al., 2017). For Clelland and colleagues (2020) there is a lack of clarity on consistent indicators of what constitutes a 'policy response' for palliative care, which contributes to our lack of understanding of policy development. There is also limited consideration given to the experiences of countries with a successful national policy that may contribute to policy developments elsewhere (Clelland et al., 2020). Thus, in order to achieve UHC and hence, to make palliative care universally accessible to health systems (WHPCA, 2014), we need to first acknowledge that there is no consensual understanding of what constitutes 'palliative care' at the global level, the indicators that constitute high-quality palliative care, and clear guidance on how to overcome funding barriers.

2.6.1 'Palliative care' conceptualisations

While there is clear evidence that global development of palliative care is far from being universally accessible, less attention has been directed to the pluralistic understandings of palliative care. Radbruch and Payne (2009) argue that confusion over terms and concepts has existed since 1975 when Balfour Mount introduced the term ‘palliative care’. Since then, there has been an ongoing debate to find a common language on key terms such as ‘hospices’ and ‘palliative care’ (Radbruch & Payne, 2009). In the late 80s, the EAPC recognised that there were different understandings of palliative care across the European Region (Materstvedt et al., 2003). National, regional, and cultural differences influenced the organisation and delivery of palliative care (ibid). Since then, the debate over palliative care conceptualisations continued.

There are enormous challenges involved in a common global framework for palliative care. For instance, there are inevitable cultural disparities in what constitutes end-of-life, varied meanings and understandings of death and dying that will lead to different perspectives and priorities of care that can make the dying process “an arena for contested cultural assumptions” (Zaman et al., 2017, p. 74). Thus, the debate on UHC would have to include pluralistic views on palliative care. Yet, what Zaman et al. (2017) have observed is that while end-of-life can be a contested field, the WHO has promoted ideas of a ‘common future’ for palliative care. A premise that both Zaman and colleagues (2017) and Walter (2020) have challenged.

Zaman et al. (2017), focused on how ideas of a ‘common future’ for palliative care reproduce European values as palliative care standards, it places many cultures as ‘underdeveloped’, “sitting in the waiting room of history” waiting to be modernised (Zaman et al., 2017, p. 75). Walter (2020) demonstrates that in different cultures palliative care will be shaped by different values such as the case in Japan, where hospice and palliative care advocates relying on Anglophone perspectives, proposed the practice of open disclosure which conflicted with Japanese culture. As a result, the introduction of hospice and palliative care in Japan was slow (Walter, 2020). The literature on palliative care development in other cultures supports claims that end-of-life care is culturally shaped.

Turkish and Moroccan families prefer to be under curative care until the end of their lives which is conflicting with palliative care principles (de Graaff et al., 2010). Furthermore, decision-making is also shaped by cultural values. Arab families are usually the ones making decisions on end-of-life care rather than the patient and they often withhold information, since disclosure can be perceived as harmful (Osman & Yamout, 2022). Thus, considering that interpretations of what constitutes good end-of-life care will inevitably be shaped by different values and priorities, reaching the goal of UHC relies on the possibility of different practices, concepts, and services to exist.

2.6.2 Challenging dominant perspectives to palliative care

Debates on global palliative care have led scholars to claim for a wider, more inclusive concept of palliative care that challenges the dominance of a disease-oriented model (Abel & Kellehear, 2022). Those who propose a New Public Health approach to palliative care are critical of forms of care that are predominantly based on professional expertise, arguing that dying is fundamentally a social experience (ibid). New public health approaches advocate for a model that recognises the role of communities in care, claiming for reforms in the ways in which palliative care is promoted and advocated (see Abel & Kellehear, 2016; Sallnow & Paul, 2018).

> The model we have proposed employs teams of naturally occurring supportive networks enhanced by making best use of families, friends, neighbours, local government and businesses, as well as community members and supported by health and social care professionals looking after people in their communities. We do well to remember that death, dying, caregiving and loss are social problems with medical aspects to them and not medical problems with social aspects (Abel & Kellehear, 2016, p. 25).

The model described above provides insight to a different perspective of care that escapes the realms of mainstream healthcare systems, invoking a different understanding of palliative care and ‘public health’. The ‘new public health’ approach to palliative care is critical of forms of care that disempower communities to support death and dying, loss and care and promotes a model that mainly relies on community engagement rather than individual care (see Abel & Kellehear, 2016; Sallnow & Paul, 2018). Furthermore, as argued by Whitelaw & Clark (2019) despite new public health approaches to palliative care being “widely established” the relationship between palliative care and public health is ‘asymmetrical’ and in need of significant developments of “theoretical, practical and critical engagement” (Whitelaw & Clark, 2019, p. 1). There may be potential conflicts between these two disciplines and public health may not be implicitly constructive (ibid).

Another dominant perspective on palliative care refers to community-based care, premised upon ideas of compassionate communities. Zaman and colleagues (2018) analysis of the rhetoric of compassionate care in western societies indicate how this rhetoric is insufficient to create a culture that allows compassion to exist in the first place. This is argued as a subproduct of socio-political factors that are shaped by ideas of individualism and privacy (Zaman et al., 2018). Their insightful analysis indicates how socio-political factors underpin forms of thinking that create obstacles rather than facilitate the desired changes. Alternatively, Sallnow and Paul’s (2015) *Spectrum for Community Engagement in End-of-Life Care* framework based on a new public health approach, focuses on grassroots community action and offers possibilities to engage with palliative care beyond the realms of direct provision. These studies suggest that are far more possibilities for palliative care than the dominant perspectives that underpin discourses of UHC and service development allows to acknowledge.

2.7 Summary and concluding arguments

This chapter aimed to describe the journey through which notions of dying and ‘palliative care’ have taken in sociological literature and in global health. Especially considering the emergence of the hospice movement in the UK, the literature indicates the underpinning ideas that shaped hospice values. Particularly, this chapter demonstrated that intrinsic to hospice values were ideas of a ‘death taboo’ and medicalisation of the dying that led to suffering at the end of life. The critique of modern dying combined with a new medical domain allowed hospice care to develop into a medical subdiscipline, namely palliative care. Endorsed by the WHO, palliative care reached global health debates where new organisations in support of palliative care development internationally worked in collaboration with the WHO to advocate for palliative care in the world. More than that, these organisations helped create a new field of palliative care studies aimed at systematically understanding levels of palliative care development in the world and quality of death.

Framed as a ‘global health issue’ palliative care entered the realm of public health debates where the WHO consistently argued for palliative care to be integrated into national healthcare systems. The development of palliative care in other countries allowed to make visible systemic issues such as disparities in opioid availability, coverage, and policy development. Efforts to increase coverage such as UHC, included palliative care as a ‘human rights’ issue, demonstrating once more a picture of the great inequalities that shape palliative care globally. It was observed that UHC indicators were measured on structural aspects of care, which arguably reveals the limitations of how palliative care has been measured internationally.

Moreover, the chapter argued that palliative care is not universal. There is no lack of disagreement on the various definitions, models, and frameworks of palliative care, that remain unresolved debates. Thus, the chapter suggested that the path to UHC must necessarily engage with a pluralistic perspective of palliative care rather than trying to achieve a ‘common future’ for palliative care globally. Moreover, the chapter demonstrated the various ways of framing, interpreting, and engaging with palliative care that surpass the WHO framework of palliative care, the path to UHC may pass through a critical examination of the values of the WHO guidelines.

The chapter highlighted how global agencies have contributed to actively shaping the field of international palliative care development. With some exceptions (Abel & Kellehear, 2016, 2022; Clark, Barnes, et al., 2018; Sallnow & Paul, 2018; Walter, 2020; Zaman et al., 2017, 2018), little attention has been dedicated to questioning the WHO framework for palliative care and even less attention has been dedicated to systematically questioning the premises of the WHO recommendations for practice and service development. In this perspective, considering that advocacy publications have a role in the ways in which palliative care is promoted internationally (Sepulveda et al., 2002; Stjernswärd et al., 2007a; WHPCA, 2014), critical attention should be directed at understanding how they constitute ‘palliative care’ in order to gain insight on their implications for policy and practice.

Chapter 3. Methodology

This chapter focuses on demonstrating the rationale underlying the research design and chosen methods. I will first review the research aims, setting out the research questions which informed the research design. I will then discuss the underlying epistemological and ontological premises underpinning this study, and the theoretical perspectives that informed the research. I will discuss the role of Foucauldian studies in social research and give emphasis on the Foucault-influenced poststructuralist approach to policy analysis form of inquiry that allows engaging with prescriptive texts as meaning-making agents. I will then outline the method used to inform the research design and then consider the ethical implications that went into designing this study.

3.1 Identifying the Research Gap

The literature on palliative care revealed that palliative care is demonstrably associated with the history of the concept of a ‘good death’ shaped by developments in medicine, in the social organisation of dying, the rise in psychological discourses, and to changes in global health. The literature brings forward the tensions between the emergence of the hospice movement in the UK and the transformation of palliative care into a medical subdiscipline. As a medical subdiscipline, the debate shifts from the emergence of an alternative way to improving the quality of life through the relief of pain and other symptoms. The literature identified the important role that the WHO played in advocating for palliative care and the need for UHC amidst a scenario of great disparities. There I observed that despite the many questions on the WHO’s approach, such as their palliative care definition and disease-oriented framework, very little attention has been dedicated to the premises upon which palliative care is recommended in the first place. In this sense, the literature does not provide any systematic insight into the premises, assumptions, concepts, and values that shape the WHO’s guidance directed at palliative care, leaving guidelines for palliative care practice and development largely unquestioned.

3.2 Research Aim

With the intent to bring visibility to guidelines as an important object for systematic investigation, this study aims to critically examine how palliative care is problematised within the WHO guidelines. In this regard, it is important to raise the premises that inform the aims and scope of this research. Beginning with the premise that guidelines are an object for investigation in itself, the study is based upon a particular understanding of texts as a legitimate object for qualitative investigations. As observed by Silverman (1997), qualitative research does not need to focus solely on issues of subjective meaning, rather, they can go beyond issues of language and representation.

Guidelines, in this sense, can offer an entry point to the ways in which palliative care has been represented within the wider discourse of global health. Indeed, as Prior (1997, p.67) stated, "a text instructs us how to see the world, how to differentiate the parts within it, and thereby provides the means by which we can engage with the world". From this perspective, I argue that guidelines are the means through which people, governments, and institutions can engage with palliative care.

Moreover, as the WHO guidelines instruct governments and health professionals on the issues related to palliative care, this study is premised on an understanding that guidelines offer instructions on how to perceive global health *problems* and to appoint the appropriate solutions to address them. Thereby, guidelines themselves produce means to *problematise* palliative care in the realm of global health, thus offering insight on how issues are thought about, the goals set out for palliative care, and the type of individuals constituted within them.

3.3 Research Questions

Considering that this study intends to direct attention to how guidelines produce understandings of palliative care, the questions raised here were informed by the premises described above. As such, the following questions guide the focus of this study:

1. How is palliative care problematised within the WHO guidelines?
2. What are the implications of palliative care problematisations to the goal of universal coverage?
3. What are the implications of palliative care problematisations to people involved in care?

It is important to take note of their scope. The first question reflects the first premise that texts are a means by which we can engage with the world (Prior, 1997). As such, the first question is concerned with the ways in which guidelines put forward end-of-life care problems and to which palliative care is the recommended solution. In producing problematisations, the second question is concerned with the ways in which they produce elements that "pose problems for politics" (Rabinow, 1984, p. 384). Thus, problematisations may give insight into ways in which palliative care is articulated through a relationship to political goals, aspirations, and targets for intervention. Finally, the last question reflects a concern with the production of subjectivity within guidelines. Once more, I refer to a Foucauldian perspective underpinning this study. Foucault is known for pursuing ways to enquire about "the different modes by which, in our culture, human beings are made subjects" (Rabinow, 1984, p. 7). In this sense, my question reflects inquiries on the ways in which individuals are made subjects within palliative care guidelines. In turn, the last question also allows insight into the type of subjects that has been excluded from them.

3.4 Ontological, epistemological, and theoretical perspectives

The research questions above give insight into the underpinning theoretical perspective informing this study. Foucauldian scholarship has "rendered visible" aspects of human experience that profoundly shaped social studies (Rabinow, 2003, p. 3). The impact of Foucault's analysis of power/knowledge shaped much of the research on health- related topics concerned with the body, the production of the modern subject, and the control of individuals and populations (Foucault, 1977, 1994a; Lemke, 2014; Rabinow, 2003; Rabinow & Rose, 2003). His work enabled us to observe how power appears embodied in day-to-day practices, such as the treatment of the mad in *Madness and Civilisation* (Foucault, 1965) and the clinic in *The Birth of the Clinic* (Foucault, 1973).

Foucault observed how knowledge such as medicine and psychiatry were "profoundly enmeshed with social structures" (Foucault, 1994b, p. 111). Thus, paving the way to see the relations between truth and power as intrinsically bound to social apparatuses such as the school, the clinic and the prison.

> And he enabled us to visualise the different kind of relationships between practices that sought to know and manage human individuals and the emergence of conceptions of ourselves as subjects with certain capacities, rights and a human nature that can ground all sorts of demands for recognition (Rabinow, 2003, p. 3).

The relationship between power and subjectivity became more clearly outlined in his analysis of governmentality (Turner, 1997). Governmentality is a concept that refers to the ways knowledge operates in informing or shaping our conduct (Bacchi & Goodwin, 2016; Dean, 2010; Rabinow & Rose, 2003). It offers a bridge between Foucault's earlier analysis of disciplinary power and the later work on the 'technologies of the self'(Turner, 1997, p. x). To Foucault, governmentality refers to the ways in which populations came to be controlled and regulated through an apparatus of security (Foucault, 1977, 1984; Turner, 1997). From his work of power and knowledge perceived as inextricable, Foucault enabled social scientists from different fields to attempt to understand forms of power operating in the social fabric of our everyday life.

3.5 Theoretical Perspectives: Governmentality

Although there is not a unified theory from Foucauldian scholarship, his work provided social scientists with the resources to build a new domain of study (Dean, 2010;

Rabinow, 2003). Ettlinger (2011) explains that governmentality offers ways of connecting discourses with everyday practices by focusing on the relation between the two. The combination of ‘govern’ and ‘mentality’ the term governmentality often refers to the rationalities of government (Dean, 2010; Ettlinger, 2011). Rationality refers to “any way of reasoning, or way of thinking about, calculating and responding to a problem, which is more or less systematic, and which might draw upon formal bodies of knowledge or expertise” (Dean, 2010, p. 24). Mentality in turn, refers to a collective activity expressed through discourses that attempt to regulate everyday conduct in accordance with particular norms (Bacchi & Goodwin, 2016; Dean, 2010). Government thus entails relationships between power/knowledge and the production of identities (ibid). Studies concerned with governmentality, therefore, entail how we are invited to think ourselves. It is constituted upon two analytical grounds, one that seeks to analyse how government occurs - through which sets of knowledges, norms and to what ends – and the other that seeks to analyse the types of subjects we are invited to become (Bacchi, 2009, 2010; Bacchi & Goodwin, 2016; Dean, 2010).

Dean (2010) affirms that analytics of government begins by examining the ways in which regimes of practices “are called into question (or problematised) by such programmes” (p.32). The action of questioning some aspect of governmentality refers to the concept of ‘problematisation’ (Dean, 2010). Bacchi (2012) illustrates this point with an example from *Madness and Civilisation* (Foucault, 1965), where Foucault calls into question how ‘madness’ was made into an object for thought as a mental illness where he argued that the answer to this question relied on how madness was problematised: “politics and ethics established ‘madness’ as a particular domain of scientific knowledge, and also analysing the effects of the latter on political and ethical practices” (Foucault, 1984, p.8 as cited in Bacchi, 2012, p. 2).

It is important to note that in the statement above Foucault argues that madness was problematised through *practices*. Practices, according to Foucault, are places where "what is said and what is done, the rules imposed and the reasons given, the planned and the taken-for-granted meet and interconnect" (Foucault, 1994a, p. 225). To analyse them, is to analyse programs of conduct "that have both prescriptive effects regarding what is to be done" and "codifying effects regarding what is to be known" (ibid). Thus, practices contain norms, and rules that are associated with claims to truth.

> These practices reveal how an issue ("madness") is questioned, analyzed, classified and regulated—how it is problematized. Hence, we can study the emergence of "madness" as an object of knowledge by examining the practices that classify and regulate, that problematize and constitute, those designated "mad". The suggestion here is that it is possible to get at "knowledge" ("what could be known") about "madness", by examining what is done, how the "mad" are dealt with (Bacchi, 2012b, p. 3).

Bacchi (2012) argues that Foucault (1994a) focused on the practices that are involved in governing that contain "legitimated claims to truth" (Rabinow, 2003, p. 20 as cited in Bacchi, 2012, p.3). Knowledge can be understood as Rabinow (2003) described it, "governed by certain rules which establish can be said truthfully at any one time, the criteria of evidence, the forms of proof and even the very object of which they can speak" (p.7). In this perspective, the relationship between knowledge and government addresses a key point in the analysis of government. As stated by Dean (2010), problematisations emerge from "particular regimes of practices of government with particular techniques, language, grids of analysis and evaluation, forms of knowledge and expertise" (p.38), thus, suggesting that problematisations concerns with the operation of thought. The goal in governmentality analysis refers to accessing the 'thought' within governing practices (Bacchi, 2012).

Problematisations in this sense play a key role in understanding how thought operates in governing practices.

As considerable attention has been directed to the role of experts and professionals in governmental practices (Fischer et al., 2015b; Fischer & Gottweis, 2012), governmentality offers the possibility of interrogating the type of rationalities fostered in the WHO guidelines. Given that in this perspective, ‘government’ entails a range of knowledges involved in societal administration (Bacchi, 2009, 2016; Bacchi & Goodwin, 2016), the key feature of governmentality, that is problematisations, offers the possibility to think on the ways in which ‘palliative care’ became an object for thought within the WHO guidelines, how thought operates within them, the claims of truth upon which they are structured and to make visible the relationships that converge into particular kinds of ‘problems’.

3.6 Ontological Perspectives

Governmentality, according to Dean (2010) “emphasises the way in which the thinking involved in practices of government is explicit and embedded in language and other technical instruments but is also relatively taken-for-granted, i.e., is not usually opened to questioning by its practitioners” (p.25). This understanding thus reveals an ontological premise, that is to reject the existence of a “knowing subject” (Prior, 1997, p.63). According to Prior (1997), social research is generally premised on the presence of a knowing subject, that when questioned could reveal aspects of social life and behaviour. Foucauldian analysis is markedly characterised by the redirection of critical attention from “a theory of a knowing subject, but rather on a theory of discursive practice” (Foucault, 1970, p. xiv as cited in Prior 1997, p. 64).

In this sense, the analytical task becomes probing discourses themselves, how they are constituted by and constituted through power/knowledge relations. Moreover, taking ‘discourse’ as an organised pattern of knowledge through which forms of subjectivities are produced, it would be wrong to assume ‘discourse’ analysis is an investigation of patterns of language or rhetoric (Bacchi, 2012b; Bacchi & Bonham, 2014). Rather, as illustrated in his work in the *Archaeology of Knowledge*, Foucault (1972) directs attention to:

> What can and cannot be thought, the ways in which knowledge can be represented, the nature of the grid by means of which thought can be expressed and classified, and the rules concerning who is, and who is not, entitled to pronounce on the nature of a given phenomenon (Foucault, 1972 as cited in Prior, 1997, p. 77).

The analytical task is therefore to analyse discourses in their own terms. In doing so, Foucault does not seek to uncover meanings behind discourses but focuses upon which rules, norms, and conditions that something can or cannot be thought about and by whom (Prior, 1997). As such, the ontological premise underpinning this study is indicated by refusing to seek out the meaning behind guidelines or to be concerned with the WHO’s intent in producing them. Rather, as Prior (1997) emphatically said, texts themselves instruct us what to ‘see’ and how to structure our understanding of the world. In this sense, by rejecting intentionality, the study does not aim to uncover how the WHO (assumed as a thinking agency), produced rationalities for palliative care, but rather how the guidelines *themselves* produce meaning.

In this sense, this study on the ways in which the WHO guidelines produce discourses of palliative care may provide insight into the premises upon which these are constituted and the effect they may have on the development of palliative care at the global level. In this sense, the study engages with a critical perspective in two ways. First, in adopting the term problematisation, I am raising concerns about the ways in which the WHO guidelines ‘produce objects for thought’ (Bacchi, 2012b, p. 1). Second, the questions are an indication of the productive nature of guidelines, thus rejecting them as a neutral, technical product, with no political implications.

> We must cease once and for all to describe the effects of power in negative terms: it “excludes,” it “represses,” it “censors,” it “abstracts,” it “masks,” it “conceals.” In fact, power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him (sic) belong to this production (Foucault, 1984, p. 204/205).

Instead, this study argues that guidelines should not be viewed as an “expression of neutral rationality”, but as an ‘expression of power’ (John 1998, p.165 as cited in Bacchi & Goodwin, 2016, p. 10).

3.7 Epistemological premises: Policy Research

The literature on policy studies, drawing from the evidence-based policy making, demonstrated a higher focus on debates on knowledge utilization in the policy field (Daviter, 2015). Although the concept of ‘policy’ may be one of varied definitions, the general consensus is that policies refer to the “principles and practices of pursuit by government of social, political, and economic outcomes” (Fawcett et al., 2010 cited in Goodwin, 2011, p. 168). The academic debate in policy research is driven by debates on the place of knowledge within the policy process.

For years, researchers in the UK have been called to contribute to knowledge and to inform policy and practice. The field of policy research has been dominated by data-driven, evidence-based research aimed to inform and improve policymaking (Markauskaite et al., 2011). As reflected in a speech from the Economic and Social Research Council (ESRC) in 2000: “we need to be able to rely on social science and social scientists to tell us what works and why and what type of policy initiatives are likely to be most effective” (Blunkett, 2000 as cited in Young et al., 2002, p. 215). Mainly led by UK researchers, this ‘utilitarian turn’ (Solesbury, 2001) had implications in the ways policy research is perceived as a means for economic and social development rather than as a cultural end.

Evidence-base policy is underlined by the premise that research and policy are linearly connected, that is that the ‘evidence’ produced may lead to policy changes or that policy problems may lead to research objects (Young et al., 2002). Yet, ideas of linearity are contested by those that approach the policy process and decision-making as a disputed space:

> Goals are ambiguous, and the means to achieve them are uncertain. Decisions are less about projected consequences and more about process of legitimation. Politics is about shaping interpretations and expressing preferences. Information is never conclusive but reflects the indeterminacy of cause-and-effect relationships; it is infused with values (Young et al., 2002, p. 218).

In this sense, researching policies can be a way to contribute to an informed debate by highlighting the “competing interpretations, preferences and values that constitute a given policy or policy agenda” (Young et al., 2002, p. 218). It can also be thought of as a way of understanding contemporary social and cultural practices (Goodwin, 2011), and as a field that dedicates critical attention to the reliance of policymaking on scientific knowledge and explores the ways in which these have been operationalised within policies and to what end (Fischer, 2003; Fischer et al., 2015). There has been a growing concern within the field of policy research with the role of policies as constituting reality via language and discourse (Goodwin, 2011), one of them being Critical Policy Studies (CPS).

3.8 Critical Policy Studies

CPS is a field concerned with the usage of expert and technical knowledge within policies. According to Fischer and colleagues (2015), common to policy studies are ideas that government should be informed by knowledge and second, that this knowledge should precede politics. They describe how ideas of policymaking indicate an array of experts involved in governmental practices, that are presumed to be neutral and to be working on behalf of our interests as a society (ibid). Their description gives insight to one of the main concerns of this field. That is, to question the “aura of objective rationality” (Fischer et al., 2015a, p. 7), that surrounds policymaking and the policy process in general. The obvious consequence of such a stance on policies is that policies must be interrogated rather than accepted at face-value (Bacchi, 2009, 2010; Fischer et al., 2015a, 2015b).

Particularly critical of the dominant evidence-based movement in policy studies, CPS raises questions on the nature of knowledge used to inform policymaking and the policy process, which kinds of knowledge are used to inform implementation, and the type of assumptions governing decisions (Fischer et al., 2015). Assuming a postpositivist approach to policy studies (ibid), CPS inquiry involves enveloping the cultural values, interests, and power relations involved in policymaking (Fairclough, 2013; Montesano Montessori et al., 2019). For this reason, since the ‘argumentative turn’ (Fischer & Gottweis, 2012), studies within CPS aimed at examining the contingent aspect of policy formulation and implementation often focus on the role that the language, discourse, and communicative practices play in the constitution of policy problems and the solutions it proposes (Fischer, 2003; Fischer & Gottweis, 2012; Montesano Montessori et al., 2019). Since the publication of *The Argumentative Turn in Policy Analysis* by Fischer and Forester in 1993, the analytical orientation developed within social sciences aligns with social constructivism, discourse, and interpretive methods (Fischer et al., 2015b). Conceptualised as constituted by and mediated through communicative practices, “focus is thus on how actors in the public sphere argue, rhetorically and deliberatively, within and across discourses” (Fischer & Gottweis, 2012, p.14).

Although it is widely argued that policy problems are constituted through discourse, language, and other communicative practices (Fischer & Gottweis, 2012), we also must recognise that concepts such as ‘language’ and ‘discourse’ are often disputed ideas. As this section will show, there are differences in the use of ‘discourse’ in policy studies which leads to epistemological and methodological divergences. Thus, CPS involves: “a vast array of theoretical approaches, which draw on a diverse epistemological and ontological assumptions, and which often contradict or even exclude each other” (Montesano Montessori et al., 2019, p. 5). In order to gain deeper understanding of their differences, three approaches are emphasised here: interpretive, critical and poststructuralist (Fischer et al., 2015a).

Interpretive approaches, according to Goodwin (2011), propose the analysis of meaning and symbolism in the policy process. They consider policies as human productions and highlight the impossibility to separate policy problems from “values and meanings and of the analyst’s own beliefs and feelings” (Yanow, 2016, p. 6). Central to this approach is the premise that knowledge is inevitably subjective as all actors involved in the policy process ‘interpret’ data to make ‘sense’ of the policy (ibid). Interpretive approaches, therefore, start from the premise that ‘reality’ can be interpreted in various ways. In policy analysis, this is evidenced through the different ways in which policy ‘problems’ can be understood. For instance, Rein and Schön (1977) dedicated attention to the ‘framing’ of policy problems and the ways in which a problematic situation became naturalised (Bacchi, 2016; Fischer et al., 2015a). Alternatively, Kingdon (1984) focuses on the ways in which conditions become ‘problems’, thus, directing attention to the status of problems rather than the frame. Whether attention is directed to the ‘framing’ or ‘status’ of policy problems, it is common to interpretive approaches to policy analysis to direct attention to the ways in which policy actors create meaning in the policy process (Bacchi, 2016).

Moving beyond interpretivism, the critical approach to policy enquiry “interrogates the policy process and the epistemological roots of policy work, examining the players involved in the policy process, reveals policy constructions” (Young & Diem, 2015, p. 79). A critical perspective is associated with the ways in which policies construct one possible ‘version’ of a problem (Montesano Montessori et al., 2019, p. 6). Policy problems are constituted through the available evidence and ‘shaped’ according to particular forms of governing (ibid). It proposes a relationship between language and forms of governance. That is, language is not only the means through which particular versions of problems come to life but are also engaged in the constitution of subjectivities, which reveals two important premises of critical approaches: one that policies are discursively constituted and the other that they mediate the constitution of subjectivities (Fairclough, 2012, 2013; Montesano Montessori et al., 2019). Similar to critical approaches, poststructural approaches also challenge ideas that ‘reality’ is something that exists outside of discourse.

A poststructural perspective indicates that phenomena are not fixed, nor do they have an ‘essence’. Rather, they are better understood as an assemblage, a network of diverse elements that are arranged and patterned “to appear as a convergence” (Bacchi & Goodwin, 2016, p.14). In this perspective, rather than focusing on the being of things, attention is redirected to their “becoming” (ibid). Objects thus are perceived as “in continuous development, as in formation, rather than as fixed. In effect practices and relations replace objects” (Veyne, 1997 as cited by Bacchi & Goodwin, 2016, p.15). Although poststructuralism cannot be argued as a unified field with a single theoretical framework, there is a shared understanding that a poststructural approach to policy studies would direct attention to the heterogeneity of knowledge practices through which forms of rule occur (Bacchi, 2012b; Bacchi & Goodwin, 2016).

Bacchi (2009), offers a Foucauldian-influenced poststructural approach to policy analysis which aims to enquire on how policies themselves create policy ‘problems’. Her approach to policies thus, is to “dig deeper than usual into the meaning of policies and into the meaning-making that is part of policy” (p.vi). Because policies commonly refer to government programmes, she argues, they assume that policies are produced to ‘fix’ something (Bacchi, 2009). Policies, however, do not explicitly declare what is being perceived as problematic, rather, this notion is implicit in the very idea of policy. Thus, she argues, we should take a closer look into how policies imply the existence of problems, consequently policies "give shape to problems" rather than addressing them (Bacchi, 2009, p. x). Policies are thus, "problematising activities" (ibid, p. xi). If policies assume that there's a problem that needs fixing, then what follows is that problematisations are central to the strategies they propose. Consequently, as Bacchi (2009) proposes, "we are governed through problematisations rather than policies" (ibid). For this reason, she shifts the attention from policy analysts away from the 'problems' policies assume need fixing and into the ways policies problematises issues.

Bacchi's (2009) framework, namely What's the Problem Represented to Be? (Bacchi, 2009), similarly to critical approaches, recognises the discursive nature of policies and policymaking, and their productive character (Bacchi, 2009, 2010, 2012b), yet it disagrees with the use of 'discourse' as language or rhetoric. For Bacchi (2015) discourse is assumed as inextricable from practices in the Foucauldian sense, rather than agents (Bacchi, 2015) diverges both from interpretive approaches, critical and even other poststructuralist approaches as she proposes the shift from the problematising agents involved in policymaking to the problematisations themselves (Bacchi, 2009, 2012b).

From the exposed, it is easy to see that there are fundamental ontological disagreements on the constitution of political subjectivity in policy analysis. While one may focus on policy actors, and hence, assume the existence of a subjectivity 'outside' of policies, others, emphasise that political subjectivity in itself is discursively constituted within policies, and hence, cannot be thought as existing 'outside' of discourse (Bacchi, 1999, 2009, 2015). Overall, despite ontological differences, CPS offers a framework to enquire about the operationalisation of thought and the role expert knowledge plays in the constitution of policy problems that are at the basis of governmental practices.

Yet, I argue that the questions raised in section 3.3 are specifically in alignment with Bacchi's (2009) Foucault-influenced poststructural approach to policy. In raising questions on how guidelines produce problems, the WPR is aligned with the goal to critically enquire on the ways in which discourse within the WHO guidelines produces problematisations. In doing so, the WPR is also aligned with the ontological and theoretical perspectives informing this research, in the sense that, by focusing on problematisations themselves, the approach focuses on how thought operates through policies not through the perspective of an 'actor' but from the problematisations themselves. Moreover, the approach engages with governmentality, in the sense that in focusing on the ways in which policies 'make' problems, it offers ways to make visible the rationalities of government underpinning policies. Due to the alignment of the WPR with the questions and premises discussed previously, the WPR framework was chosen as the analytic strategy for this study.

3.9 'What's the Problem Represented to Be?' approach to policy analysis

The WPR framework to policy analysis is better described as an analytic strategy rather than a research method (Bletsas, 2012). WPR is not concerned with 'method' as the procedures and rules that leads to the production of scientific knowledge, but instead aims to "enable the analyst to obtain knowledge that is critically different from the existing systems of meaning" (Goodwin, 2011, p. 171). Aligned with the epistemological orientations of this approach previously discussed, the purpose of a WPR approach is not to uncover how things are represented to be, but how they were 'made' to be. To do so, Bacchi (2009) organised a set of six questions that guide the analysis of discourse. Each question requires a particular analytic task, including Foucauldian genealogy and archaeology, the identification of silences, and the analysis of the 'lived effects' (Bacchi & Goodwin, 2016; Goodwin, 2011). Given that each question requires a robust analysis, Goodwin (2011) argues that Bacchi's framework is more than an analytic strategy, it is in itself an epistemology. In this section, I will introduce the six questions that constitute the WPR framework.

3.9.1 Question 1: What’s the ‘problem’ represented to be in a specific policy?

This first question: is defined as a clarification exercise (Bacchi, 2009). As stated before, this approach to policy analysis is based on the premise that policies contain implicit representations of problems (problematisations). It relies on the assumption that looking at what is proposed in a policy can uncover how the issue is being thought about (e.g., of ‘problem gamblers’, ‘drug use/abuse’, domestic violence, global warming, health inequalities, terrorism, etc.) (Bacchi, 2009, 2012b). Thus, the first question is an exercise to ‘work backwards’ from the policy proposals to reveal what is implied as problematic (Bacchi, 2009). Although this seems a straightforward interpretation, Bacchi (2009) warns to the complexities involving identifying problem representations as policies can have more than one representation and representations can be conflicting. Yet, she argues that identifying problem representations offers the entry-point to enquire on the deep-seated assumptions and presuppositions in which they rely.

3.9.2 Question 2: What presuppositions or assumptions underlie this representation of the ‘problem’?

This second question refers to the continuing process of analysis that enquires on the ‘conceptual logics’ (Bacchi, 2009) that underpin the problem representation. If the purpose of question one is to uncover what is being implied as problematic within policy proposals, question two is aimed at probing the system of meaning that allows the problem representation to be ‘in the true’ (ibid). This involves identifying presuppositions, assumptions, knowledges, concepts, and categories which are required to allow the problem representation to be intelligible (Bacchi & Goodwin, 2016). What follows is that this question involves a form of Foucauldian archaeology (Bacchi, 2009, 2016) which involves examining how discourses are operationalised within particular circumstances to attain the status of ‘truth’. It thus involves investigating how some discourses are accepted as “fact” or “science” while others are not (McMahon & Harwood, 2007). To Bacchi (2009), the archaeological task within the WPR approach is to bring visibility to how what is said (e.g., representation of the problem) was made ‘sayable’ by probing into the system of meanings that sustains them. Although the aim to identify ‘systems of meaning’ or ‘conceptual logics’ might seem obscure as a methodological proposal, Bacchi (2009) argues that these can be made visible by identifying three main elements within a policy: binaries, key concepts, and categories.

Identifying binaries gives insight into the hierarchical relationships that constitute policies and their problem representations. Binaries and dichotomies imply that one side does not belong to the other which gives insight into the meanings that are being valued, and privileged (Bacchi, 2009). Furthermore, central to policies are concepts such as ‘drugs’ or ‘health’ that are often assumed uncritically (Bacchi, 2009; Bacchi & Goodwin, 2016). With this question, the WPR requires the interrogation of concepts to identify the meanings attributed to them. For example, as argued in chapter two, there is a significant difference in understanding palliative care as a medical problem with social aspects instead of a social problem with medical aspects (see Abel & Kellehear, 2016).

The premise of UHC encompasses conceptual logics embedded in political disputes that can be constricted or silenced by thinking ‘palliative care’ as universally feasible (Zaman et al., 2017). In this light, question two is not just about identifying conceptual logics that sustain particular forms of thinking but discovering how the system of meanings in place constricts what can be thought and said about them, limiting the opportunities for contestation (see Bacchi, 2009, p. 8). A similar intent underpins analysing policy ‘categories’.

Categories, and in particular ‘people categories’ have an important role in how thought is operated within policies. Categories (e.g., disease categories, gender, sexuality) are defined by Bacchi (2009, p. 9) as “concepts that play a central role in how governing takes place”. As such, the last goal of question two is to identify how people categories are operationalised to give meaning to ‘problem representations’. Continuing to reflect on the contributions of a WPR to the field of ‘palliative care’, the very concept of palliative care is related to particular forms of disease and how these affect people’s lived experiences of end-of-life. Ideas of a ‘good death’ are deeply rooted in the lived experience of living with cancer and in particular discourses of patienthood developed in mid-twentieth century English-speaking countries (Borgstrom, 2013; Borgstrom & Walter, 2015; Walter, 1994, 2017, 2020). Thus, if we are to enquire on the premises upon which the WHO recommends palliative care to achieve certain goals, enquiring on the type of categories created within guidelines and identifying the meanings attributed to them is essential.

3.9.3. Question 3: How has this representation of the ‘problem’ come about?

Question 3 reflects upon the specific developments that contributed to the emergence of a given problem representation. Thus, the purpose of this question is to shed a light on the conditions that allowed a particular problem representation to become dominant (Bacchi, 2009). This question requires a form of Foucauldian genealogy. Genealogies are about tracing the ‘roots’ that allow the formation of a problem representation. These tend to reveal that contrary to historical accounts, the particular forms of representing problems are not an “inevitable product of natural evolution” (Bacchi, 2009, p. 10), they are rather contingent on the conditions that allowed certain forms of thinking to dominate over others. The genealogy proposed in question three, therefore, directs us to “find out how a problem took on a particular shape” (Bacchi, 2009, p.11). However, it moves beyond examining the origins and conditions for the emergence of a problem representation, by directing attention to the mechanisms that encourage some representations to become dominant.

Because policy texts only contain limited or no information regarding the origins of problem representations, question 3 allows the analyst to go beyond policy text to include other sources as to historically contextualise key themes or concepts identified in question 2. For example, Bacchi (2009) conducted a genealogy of 'unemployment' to the rise of social survey-based research; the emergence of a holistic conception of society, and political demands from the labour movement (Bacchi, 2009, p. 62). Her analysis involved consulting comprehensive literature regarding the processes that led to the concept of 'unemployment' we have today. In this sense, it is important to note that the process of a WPR analysis requires more than policy analysis to encompass the social, political, and historical contingencies in which policies are embedded.

3.9.4 Question 4: What is left unproblematic in this problem representation? Where are the silences? Can the 'problem' be thought about differently?

The analysis proposed in question four aims to identify the limits of problem representations. Bacchi and Goodwin (2016, p.22) describe this question as an exercise of "thinking otherwise": to imagine the alternative ways in which a problem could be problematised. Alternative problematisations are proposed as an exercise of questioning and redefining the assumptions underlying a given problem representation (Bacchi & Goodwin, 2016). In this light, instead of assuming the problem representation as given, the exercise of 'thinking otherwise' allows to reveal hidden assumptions, biases, and exclusions through examining the discourses that constitute them. However, Goodwin (2011) argues this is an exercise of comparison.

The opportunity of 'thinking otherwise' opens space to compare other possibilities for thinking palliative care beyond what has been proposed within the WHO guidelines. To do so, Goodwin (2011) recommends engaging in comparisons in different contexts to reveal what has been excluded from the problematisation under investigation. It is important to observe as argued by Bacchi (2009), that comparing problematisations allow visibility on how problematisations may reflect specific contexts and hence reveals their contingent nature. This form of analysis is set to prompt questions on the circumstances in which a given situation may be perceived as problematic in one context and not in another and in this sense, case studies may be a methodological contribution to conduct the analysis required by question 4.

Since this study is based upon technical guidelines from the WHO, the "exercise of comparison" includes technical guidelines in support of palliative care other than the WHO. This is because this study emerged from questions regarding the dominant role WHO has played in determining how we understand and represent the very concept of 'palliative care' and the associated implications for both service development and policy. Examining national guidelines from countries that adopt the WHO framework for palliative care could therefore help gain insight into the ways in which local governments are representing the problem. In this sense, using national guidelines as case studies to explore how the problem is represented to be by national governments would allow a comparison with the dominant representations found in the WHO guidelines (as part of questions 1, 2 and 3). To do so, case studies will be used to analyse problematisations in national contexts.

According to Yin (2018, p.13), a case study is "an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between the phenomenon and context are not clearly evident". Case studies, therefore, allow researchers to gain in-depth understanding of a specific context which in turn, provides a nuanced understanding of the social, cultural, and historical factors influencing the issue under investigation. That is, case studies are contextual studies (Priya, 2021). Since the goal of question 4 in this research is to compare problematisations within guidelines from national governments, case studies will help gain insight on the types of problematisations that national guidelines produce, and to gain in-depth understanding of the *context* in which guidelines have been produced. As such, case studies provided a useful method fitting to the analytical goals established by this question.

3.9.5 Question 5: What effects are produced by this representation of the 'problem'?

Question 5 reflects Bacchi's concerns in identifying the reasons why 'change' can be difficult to achieve (Bacchi, 2010). She argues that discourses have implications not only for how something can be thought about but in the political implications that follow particular modes of thinking. It is in this light that Bacchi (2009) enquires about the effects of problem representations. Question five requires the analysis of three interconnected effects of identified problem representations (Bacchi, 2009, p. 15).

Considering that the analysis of discourses from a Foucauldian perspective involves identifying the internal rules and regulations that govern statements that determine "what can be said, by whom, in what context and to what effect" (Gordon, 1994, p. xv), question five can therefore be argued to be an in-depth analysis on the regime of discourse, the politics of statements (see Foucault, 1994c, p. 114) and the political implications of such regime. Thus, this question is concerned with the effects of the characterisation of a 'problem' in order to see "where and how they function to benefit some and harm others, and what can be done about this" (Bacchi, 2009, p.15). As such, here I consider each of the proposed effects to show how they interconnect.

3.9.5.1 Discursive effects

Discursive effects build on the previous questions. The underlying premise is that certain ways of constituting the problem and the discourses that legitimise them can 'close off' some of the possible avenues for social intervention (Bacchi, 2009). To use an example more applicable to this research, Zaman et al. (2017) argues that considering 'palliative care' as a 'common goal' to all countries closes off considerations between colonisation and dying standards that feed into the inequalities this goal is aiming to address in the first place. It is important to note that although question 4 also regards the silences imposed by discourse, it is predominately concerned with identifying ways that the problem could be thought of differently. Question 5, however, builds on the silences and alternative problematisations to consider the restrictions imposed in the type of social analysis and how these might affect other groups.

3.9.5.2 Subjectification effects

The second effect to be considered is ‘subjectification’ effects. ‘Subjectification’ refers to a crucial aspect of Foucauldian scholarship concerned with subjectivity. As Foucault writes:

> I would like to say, first of all, what has been the goal of my work during the last twenty years. It has not been to analyse the phenomena of power, nor to elaborate on the foundations of such an analysis. My objective instead, has been to create a history of the different modes by which, in our culture, human beings are made subjects (Foucault, 1994b, p. 326).

With this question, Bacchi (2009) seeks to identify how policies encourage certain practices of the self to achieve specific ends, contributing to normalising a particular kind of subject, a subject that is constituted by valorised knowledges with expert support. In this sense, a WPR analysis goes beyond the identification of subject categories to consider the political implications of the subject constitution. Moreover, drawing from what Foucault calls ‘dividing practices’ (Foucault, 1994b), where the “subject is either divided inside himself or divided from others – the sick and the healthy, the mad and the sane, the criminals and the good boys” (Foucault, 1994b, p. 326), subjectification effects also require attention to be dedicated to the ways in which policies are involved in dividing practices. This brings “visibility to the type of behaviours that are deemed ‘desirable’ for the majority; the establishment of targeted minorities; as well as to bring visibility to attributions of responsibility” (Bacchi, 2009, p. 16). As previously discussed in question 2 of the WPR, policies are often based upon ‘people categories’ that are articulated to confer meaning to problem representations. In this sense, to gain insight into the subjectification effects, Bacchi and Goodwin (2016) recommend going back to question 2 and observing the type of subject positioning made available through people categories. The last ‘effect’ from problem representations refers to their material implications, or as Bacchi (2009) calls them: lived effects. It is to this point that I now turn.

3.9.5.3 Lived effects

Lived effects might be the most difficult element of a WPR analytical strategy. Bacchi’s (2009) argument is that the way a problem is represented has material implications because it affects people’s lives directly. The ethos of this task is to consider the implications of discursive and subjectification effects to people’s lives. To illustrate I turn to Bacchi’s (2009) analysis of problematisation of youth unemployment within the Australian Work for the Dole Bill (WFTD). She identified that the bill was based upon concepts of youth as unreliable, dependent and in need of new skills which required the ‘youth’ to engage in specific type of activities in order to receive ‘youth allowance’. This imposes limits in the type of activities that are deemed ‘appropriate’ and sets many that fail to engage in the ‘appropriate’ activities to experiencing hardship and poverty (Bacchi, 2009).

As a WPR analysis is not constricted to text policies alone and includes multiple practices of signification (Bacchi, 2020), different sources of analysis can be included to perform an analysis of lived effects. As explained by Bacchi and Goodwin (2016) the WPR could include empirical techniques such as quantitative measures, ethnographic studies, and interviews just as long as these materials are aligned to poststructural commitments. For instance, despite including ‘interviews’ as a way to explore ‘lived effects’ poststructural commitments require the rejection of a sovereign subject as previously discussed (section 3.6). Moreover, any discussion on the possible ‘lived effects’ needs to be considered as ‘ongoing formation’ which requires that the analysis focuses on the material, the policies themselves and/or others “open to disputation, variations, and revision” (Bacchi & Goodwin, 2016, p. 23).

Having considered the multiple effects (discursive, subjectification, and lived) of problem representations we continue to observe the underlying goal is not to distract from poststructural commitments in producing new claims of truth, or to produce ‘answers’ but to critically investigate the grounds of the systems of meaning and the “politics involved in its making” (Bacchi, 2020, para 5). It is in this light that the following question, question 6 aims to destabilise the claims of ‘truth’ that disseminate and help consolidate a particular problem representation (Bacchi & Goodwin, 2016).

3.9.6 Question 06: How/where has this representation of the ‘problem’ been produced, disseminated, and defended? How could it be questioned, disrupted, and replaced?

The basis of question 6 is to build on question 3 (genealogy), which aims to destabilise the taken-for-granted nature that problem representations often assume, insisting on the possibilities for contestation (Bacchi & Goodwin, 2016). It is in this light that Bacchi says: “the goal of question 6 is to pay attention both to the means through which some problem representations have become dominant and to the possibility of challenging problem representations that are judged to be harmful” (Bacchi, 2009, p. 19).

In this sense, by considering counter-conducts, Bacchi (2009) opens space to observe the other possibilities not explored by the forms of rule constituted by the problem representations at hand. The last step of the WPR approach is applying all the six questions to the analysts’ own problem representations. The purpose of this self-problematisation is to ensure reflexivity in the process of analysing policies (Bacchi, 2015; Bacchi & Goodwin, 2016). Thus, the WPR framework continues to be committed to poststructural values in embracing contingency of knowledge produced through this strategy. By subjecting your own problematisations through the WPR questions, Bacchi reinforces the commitment to reflexivity as intrinsic to the analytical task, reaching “beyond easy-to-make declarations” (Bacchi & Goodwin, 2016, p. 24).

Moreover, as the WPR requires the engagement of the analyst subjectivity throughout the analysis, the application of questions can be also done selectively, according to the analyst's interests just as long as the commitment for self-problematisation is maintained (Bacchi & Goodwin, 2016, p. 24). In this sense, not every question needs to be answered and they can be asked more than once, given that problematisations are often complex and tend to 'nest' within each other (Bacchi & Goodwin, 2016).

Thus, by choosing to apply the WPR as the analytical strategy for this study, it distances itself from that of other analytical frameworks already discussed in this chapter (e.g., Fairclough 1992, 1993; Kingdon 1984; Montesano et al. 2019), to enquire on the problematisations themselves. As Bacchi's approach does not begin with a series of pre-defined steps, rather she provides a "conceptual 'checklist'" to guide the analysis (Goodwin, 2011, p. 171), the next section will be dedicated to discussing how the WPR analytic strategy, was applied to this study.

3.10 Method

3.10.1 Research Design

Throughout this study, I have argued on the importance of questioning rather than accepting technical frameworks such as the WHO guidelines. This argument is based on the premise that similarly to policies, guidelines produce particular interpretations of a 'problem'. With that said, table 1 summarises the relationship between my research questions and Bacchi's (2009) theoretical underpinnings on the poststructural Foucauldian-influenced approach to policy analysis:

Research Question	Goal	Underpinning theoretical concerns	Connections to the WPR framework and six analytical questions

How is palliative care problematised within WHO guidelines?	To identify how palliative care has been made object for thought in technical guidelines from WHO.	A Foucauldian understanding of discourse. Discourses refer to sets of practices that constitutes what is 'in the true'. WHO's guidelines for palliative care are discursively constituted	Policy problems are discursively constituted. Problem representations are a way to identify how a policy problem is constituted 'as the real' (Q1, Q2, Q3).
What are the implications of such problematisations to the goal of universal coverage?	The goal is to consider the ways in which WHO's discourses of palliative care impose restrictions upon what can be done and said regarding palliative care.	This question reflects a concern with the limits impose by forms of discourse on the type of social analysis that can be made regarding a given issue. This question is based on Foucauldian concept of discourse not as an oppressive power but as a productive one. Thus, creating new political problems.	Policies produce discursive and lived effects (Q5). Particular representations of problems can impose restrictions upon what can be done and said regarding the 'problem'. (Q5) Identifying alternative problematisations can help identify the knowledges being excluded from guidelines (Q4).
What are the implications of such problematisations to the 'people' involved in care?	This question is concerned with the subject of palliative care. Thus, the goal is to identify who is the subject of palliative care while also considering who is not being considered as 'subjects' of palliative care.	A Foucauldian understanding of subjectivity is discursively constituted. It reflects a concern with the production of political subjects – how human conduct can be regulated controlled and shaped in order to achieve certain goals in palliative care. Evoking certain types of human conduct on one hand open space to consider the 'counter-conduct' or resistance.	Policies not only produce representations of the problems, but these representations enable the constitution of subjects of particular kinds – subjectification effects (Q5).

Table 1. Research questions, theoretical concerns and the WPR contributions

The alignment between the WPR questions 1 to 5 and this study research's questions, as demonstrated in the table above, are connected by an underpinning Foucauldian understanding of discourse and power relations. As explained by Bacchi and Goodwin (2016) "not every question needs to be asked every time one engages with the critical thinking the approach offers" (Bacchi & Goodwin, 2016, p. 24) and in many instances, problem representations can ‘nest’ within one another, they recognise that not all questions are applicable to the type of analysis being made. The practical application of the WPR therefore can be done by using the questions selectively, which does not contribute to establishing how the analysis is to be conducted.

Question 6 was not applied in this study as the guidelines themselves are ways of sustaining, reinforcing, and disseminating problem representations. Although additional research questions could have been added that looked at this aspect, this study does not aim to enquire on how problematisations were sustained, but how they were produced. Therefore, the last question escapes the scope established for this research.

Moreover, since Foucauldian concepts are often disputed, and his methodological propositions can be used in multiple ways (Kendall & Wickham, 2011), the theoretical underpinnings of the research questions can be argued to reflect Bacchi’s (1999, 2009) *usage* of Foucauldian scholarship, rather than Foucault. In this sense, the alignment between the WPR as an analytic strategy and this research is bounded by the theoretical underpinnings of the WPR.

It is in this light that I argue that the WPR is more than just a ‘methodology’ although this is already a disputed term. From my perspective, although one can use the WPR as independent from the theory that constitutes it (Bacchi & Goodwin, 2016), the research design, questions, and knowledge to be produced by this framework are, in my view, deeply rooted in Bacchi’s (1999, 2009) theory of problematisations, or as she calls it the ‘Foucault- influenced poststructural policy analysis’ (Bacchi, 2015). Since this section was dedicated to explaining the process to reach this research’s questions and how these have informed the choice for Bacchi’s (1999, 2009) theory and analytic framework, we now turn to how these also shaped my sampling process and data gathering.

3.10.2 Establishing the territory of analysis

Moving on to the sampling process, which I understand to be establishing the ‘territory’ for the analysis and data gathering. Bacchi indicates that a WPR analysis begins with texts (Bacchi, 2009; Bacchi & Goodwin, 2016; Goodwin, 2011), yet does not provide specific directions around which texts should be considered. Goodwin (2011) argues that 'texts' in a WPR approach can include "written, verbal, or nonverbal communication" that can be subjected to interpretation (Goodwin, 2011, p. 171). That is, the WPR can include varied sources of signification such as "documents, legislation, judicial decisions, bills, speeches, transcripts, media statements, budgets, contracts, research reports and statistical data" (Goodwin, 2011, p. 15).

The wide variety of sources that are relevant to the WPR can make the first task of defining the territory for the analysis challenging. However, Bacchi suggests selecting 'texts' that are aligned with the research's analytical interests (Bacchi, 2009). This is why she argues that the researcher's subjectivity is involved in the sampling process: when you select a policy for examination, the choices you made will reflect your interests and concerns (ibid). Moreover, despite not indicating how one should make the selection process, she does indicate what characteristics to look for in a 'text' to be subjected to a WPR analysis.

Drawing from Foucault (1984), Bacchi argues that the WPR focuses on the "knowledges through which rule takes place and the influence of experts and professionals on and through these knowledges" (Bacchi, 2009, p. 26) and, as such, the texts selected for the analysis should be prescriptive in nature. That is, the selected texts should be concerned with "offering rules, opinions, advice on how to behave as one should" (Foucault 1984, p.12-13 as cited in Goodwin, 2011). In this perspective the definition of guidelines by the WHO fit the criteria for a WPR analysis. The WHO defines guidelines as:

> (…) any information product developed by WHO that contains recommendations for clinical practice or public health policy. Recommendations are statements designed to help end-users make informed decisions on whether, when and how to undertake specific actions such as clinical interventions, diagnostic tests, or public health

> measures, with the aim of achieving the best possible individual and collective health outcomes (WHO, n.d.).

The statement above indicates the aim to contribute to decision-making and to indicate ‘what works’ in healthcare systems. Central to this argument is the reliance on scientific knowledge, as indicated in the statement that follows, guidelines are argued to be “of a high methodological quality and are developed through a transparent, evidence-based decision-making process” which is “subject to a rigorous quality assurance process that helps to ensure that each and every published guideline is trustworthy, impactful and meets the highest international standards” (WHO, n.d.). These statements seem to indicate a positivist paradigm, where guidelines express a direct relationship between knowledge produced by the WHO and healthcare practice. Moreover, the statements above are premised upon the existence of technical governance working on behalf of human health.

Clark (2012) described palliative care as a field characterized by “an inward-looking culture” (Clark, 2012, p. 9) where those who sit ‘outside’ can gain access mostly through the voices of those who already belong. In this inward- looking culture, our knowledge of ‘palliative care’ at the global level could be highly constrained by the type of ‘voices’ that dominate this field. With the WHO being a ‘catalyst’ of palliative care services in the world (Sepulveda et al., 2002), the WHO publications then become an important window from which it is possible to critically examine dominant voices in the field. In this sense, I agree that there is a great need to build an ‘internal critical mass’ (Clark, 2012) within global palliative care studies, something that I was determined to pursue. In addition, the choice for the WHO guidelines facilitated the resolve of methodological problems, such as an unrestricted access to publications both from Global and Regional Offices. The consistency of publications over the years, in the form of guidelines and manuals, provided the opportunity to investigate the ways in which ‘palliative care’ is problematised and to compare these over time.

3.10.2.1The Sampling Process

This section will address how the sampling process was conducted to make explicit how the 'texts' were selected for the final sample. I previously demonstrated that in a WPR analysis, the selected policies or texts should offer a "framework of everyday conduct" (Goodwin, 2011, p. 172), to which I argued the WHO guidelines would fit the criteria; however, the question still remains which WHO guidelines should be considered for this analysis and the reasons why. Given that the selection of texts should be guided by the researcher's own interests and concerns, the sampling process was conducted by observing the aims and goals of the research and the research questions as discussed below.

The sampling strategy used in this research was purposive or theoretical sampling (Barbour, 2001), which involved the theoretical knowledge of the phenomena to conduct the sampling. Having theoretical knowledge of the background of the issues being considered for a WPR analysis, rather than an impediment, is a necessity as expressed by Bacchi (2009): "to understand your selected policy you need to have a solid understanding of the background to the issues you are considering. You also need to see how specific issues fit into wider debates" (Bacchi, 2009, p.20). Theoretical sampling is a strategy that refers to the theorising exercise used to select the criteria, thus deciding on the elements that are likely to be relevant to the systematic comparison once the data has been generated (ibid).

The literature review (chapter 2) demonstrated that the WHO recommendations for palliative care has been identified since the 1980s (Stjernswärd et al., 1996; Stjernswärd et al., 2007), however, the first official WHO palliative care guideline aimed at governments and health professionals was only published in 1990 where the WHO provided the first definition of palliative care (WHO, 1990). The second definition of palliative care was published in another guideline published in 2002 (WHO, 2002). Currently, central to advocacy of palliative care are issues related to UHC and disparities between HICs and

LMICs, however, the literature does not mention particular guidelines on these issues. In this sense, although the literature provided the historical background on the issue of palliative care guidelines by the WHO, the literature alone is insufficient in gaining insight into all of the WHO's publications on palliative care, which leads to the need to search the WHO's databases to retrieve guidelines.

Since the WHO has multiple sources of databases where publications can be retrieved, I started my sampling process by exploring the IRIS database which can be understood as a repository for institutional publications. Using the keyword 'palliative care' without any other filter, the search produced 3861 results. Given that the sampling process required extensive readings, additional criteria was included to select guidelines in the English language and with the WHO's authorship. At the time of this selection, 140 results came back after the inclusion of authorship and language criteria. The results included guidelines for cancer prevention, HIV, malaria, cancer control, list of essential medicines (see APPENDIX 2).

The section entitled 'Forward' is an introductory chapter whereupon the goals and purpose of the guidelines are expressed and highlight what they aim to achieve. Those guidelines not aimed at 'palliative care' but included 'palliative care' as a related subject were excluded. This way the remaining documents are presented chronologically below:

- Cancer Pain Relief and Palliative Care (WHO, 1990),
- National Cancer Control Programmes – policies and managerial guidelines (WHO, 2002),
- Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers (WHO, 2018),
- Integrating palliative care and symptom relief into paediatrics: a WHO guide for health-care planners, implementers and managers (WHO, 2018),

- Integrating palliative care and symptoms relief into responses to humanitarian emergencies and crises: a WHO guide (WHO, 2018).

In the interest of selecting guidelines focused on 'palliative care' and exploring all the possible avenues, the next step of the sampling process was to cross-reference the sample above with the publications available on the WHO's health topics 'palliative care' webpage. This webpage gathers information on palliative care globally. The webpage is composed of sections namely: 'Fact Sheets', 'Guidance', 'WHA Resolution', and 'WHO Team'. In the 'Guidance' section eight guidelines were found. They were all in English language and from WHO authorship which fit the criteria established for this study. However, only four guidelines were found to be primarily about 'palliative care'. As a result, after excluding duplicates, one guideline was added to the sample:

- Planning and implementing palliative care services: a guide for programme managers (WHO 2016).

Lastly, I consulted the webpage for each WHO Regional Offices under 'health topics' and searched for 'palliative care'. Only the European Regional Office provided palliative care guidelines that were included in the sample. They are:

- Palliative Care: The Solid Facts (Davies & Higginson J., 2004)
- Better Palliative Care for Older People (WHO, 2004) ,
- Palliative Care for Older People: better practices (WHO, 2011)

The sampling process resulted in eight guidelines which were retrieved online in PDF format from the databases described. These guidelines were read in-depth to understand their relevance to the WPR framework, from which two guidelines were excluded: Integrating palliative care and symptom relief into paediatrics: a WHO guide for health-care planners, implementers, and managers (WHO, 2018) and Integrating palliative care and symptoms relief into responses to humanitarian emergencies and crises: a WHO guide (WHO, 2018). The first referred to the integration of palliative care into paediatrics which involved only one group of the population and reproduced much of the same arguments from the guideline aimed for adult care which was already included. The second focused on the inclusion of palliative care services in humanitarian crisis. Both were considered to escape the purposes of this research. The final sample and their relevance to the research problem are demonstrated below:

Guidelines	**Author & Target**	**Summary/Key Points**	**Relevance to the problem of 'palliative care' implementation**
Cancer Pain Relief and Palliative Care (1990)	World Health Organization Aimed globally Clinical guideline	Aims to review the status of cancer care and introduce palliative care as effective 'pain relief' for cancer patients. Affirms cancer pain as a neglected public health 'problem' Recommends policies directed towards pain relief and palliative care including opioid availability, training, and home base care.	The guideline establishes the clinical framework for cancer patients at the end- of-life and how patients, families and healthcare workers should be regarded.
National Cancer Control Programmes (2002)	World Health Organization Aimed globally Policy/Programme implementation	Aims to establish what its feasible and desirable in a National Cancer Control Programme. Focuses on rational use of available resources for different resource levels. Provide an updated definition of 'palliative care'. Establishes the framework of integration of palliative care into healthcare systems.	The guideline provides insight to the 'desirable' framework for palliative care for LMICs and HICs and provides the definition of palliative care still in use by WHO. Attention is displaced from the clinical signs of 'quality' and into service distribution and integration of services especially in resource-deprived settings.

Palliative Care - The Solid Facts (2004) **Better Palliative Care for Older People (2004) & Palliative Care for Older People: Better Practices (2012)**	World Health Organization Regional Office for Europe Regional: Europe Policy/Programme implementation	The booklets raised the issue of 'neglect' of older people by healthcare systems. Establishes the need of palliative care due to the demographic transition. Challenges the conception that palliative care as 'only for the end of life'. Emphasis on a patient-centred approach.	Understands the need for palliative care to be due to epidemiological transition in Europe. Emphasis on 'active living' as 'quality of life' and 'planning' and 'choice' encourages patient engagement. It is based on views of individuality and autonomy.
Planning and Implementing Palliative Care Services (2016)	World Health Organization Aimed Globally Policy/Programme implementation	Presents a framework for the implementation of palliative care services into primary health care. Emphasis on community/home-based care. Emphasis on 'simplicity' and 'inexpensiveness of palliative care'.	Palliative care services are recommended to avoid overwhelming healthcare systems. Implementation through training the existing staff and relying on community workers and home base care for end-of-life care patients.
Integrating PC and Symptom Relief into Primary Healthcare (2018)	World Health Organization Aimed Globally Policy/Programme implementation	Described the problem of 'access' to palliative care and the disparities between LMICs and HICs. Emphasises training of all healthcare staff over 'specialist' palliative care services. The integration of palliative care into primary healthcare is argued as a way to fill the gaps in provision of healthcare whilst making specialist services less needed.	Palliative care is assumed as a cost-effective measure for healthcare systems to address end of life care needs. Displace palliative care from specialist services to the community and the home. Palliative care is understood as a strategy to make less use of healthcare resources and optimising care.

Table 2. Final sample and relevance to this study

The sampling process represented a comprehensive search on WHO databases for palliative care guidelines. Based on the inclusion criteria of authorship, English language, and primary focus on 'palliative care' guidelines, the final sample represents a wide range of guidelines where palliative care is argued for different purposes and offer the possibility to compare them over time. Additionally, given the inclusion of guidelines from both the European and Global Office, there is room to explore some of the concerns expressed in the literature on the dissemination of palliative care models developed within the ‘western’ context and how they may be developed in non-western contexts (Walter, 2020; Zaman et al., 2017). The sample also allows consideration on the possible influences of the ‘British model’ for palliative care on WHO guidelines. Finally, the table above allows clarification over which key aspects of the guidelines were included and their relevance for investigating how palliative care has been problematised.

3.10.3 Data analysis

Bacchi’s (2009) methodological proposition does not determine how the data should be analysed, thus leaving the decision on how to interact with the data entirely to the analyst. As affirmed by Goodwin & Bacchi (2016), engaging with policy analysis involves theorising. Previously I positioned the WPR not as a method, but as an analytical strategy. In this perspective, there are no fixed steps to be taken, but rather, the WPR works as tool, a ‘conceptual checklist’, to guide the critical analysis (Rigby et al., 2021).

Drawing from Bacchi’s (2009) framework for policy analysis, the WPR approach begins with ‘working backwards’ to reveal what is represented as a problem within the selected proposals. Working backwards to uncover how policies foster problems is premised upon the condition that the selected texts as ‘prescriptive’ in nature. I argued previously that guidelines can be characterised as ‘prescriptive’ as they offer advice on how to behave toward palliative care both within healthcare and policy development. As the first step of a WPR consists in identifying a ‘proposed solution’ in order to ‘read off’ the implicit representation within it, the same logic of ‘reading off’ policies is applicable to ‘read off’ problems fostered in the WHO guidelines. However, guidelines are often more complex than policies. Thus, identifying ‘problem representations’ required an in-depth analysis of the aims and purposes of the guidelines.

In order to operationalise the framework to fit the nature of the sample, I had to limit the scope of analysis to the dominant problematisations in the selected guidelines. This allowed looking for patterns of problematisations and making visible how they are reproduced, reinforced, and maintained across multiple guidelines. It is important to note that identifying problem representations is only the entry point to the steps that followed. As such, each question required an extensive process which will be described in-depth next.

3.10.3.1A note on ‘coding’

It is important to note that in order to conduct the analysis based on a WPR framework it was required continued relationship between the researcher and the data. Thus, this involved both manually coding and using CAQDAS (Computer Aided Qualitative Data Analysis) strategies. However, manually coding, summaries and memos only partially allowed comparisons between documents and the observation of trends, patterns, and differences. Thus, this is the reason behind the choice for using a CAQDAS software, in this case NVivo, to facilitate organising the data for the remaining analytical steps. There is a variety of analysis methodologies such as grounded theory, textual analysis to narrative analysis that can be facilitated by the usage of software, however similarly to quantitative approaches, the software does not produce the analysis (Weitzman, 2006). Given that qualitative analysis requires the management of large amounts of data, such as texts, codes, memos, and summaries that require consistent and systematic management (Gibbs, 2002), NVivo facilitated both management and analytical procedures in this research. As indicated in the beginning of this section, Bacchi (2009) does not determine or explain what is used to produce her theorisations on social and political problems. In this sense, creating a strategy for data analysis that was consistent, systematic, and most importantly transparent was challenging.

Moreover, as guidelines are complex, the coding process was long and required a strategy in order to reduce bias in the coding process and to ensure the reliability of the data.

In this sense, the coding process was conducted inductively, that is in the form of open codes that appeared to represent the data (Thomas, 2006). This was followed by revisiting the data to merge codes and organise them according to WPR questions (APPENDIX 3).

3.10.3.2 Analytical steps

Step 1: Identifying ‘Problems’

This step included reading and re-reading the documents to develop a summary of their key ideas (chapter 4). Familiarising myself with the guidelines allowed me to gain insight into their structure. The forward/introduction section is the place that discusses the aims and purposes of the guidelines, and the reasons given to justify that particular publication which is premised upon key ideas of ‘proposals for change’. Since these ideas guide the recommendations for action throughout the guideline, the forward/introduction section was key to reading off the implied problems. For example, the introduction of the WHO *Cancer Pain Relief and Palliative Care* (WHO, 1990) guideline, established that the guideline was produced aiming to review the status of cancer care and to introduce palliative care as an effective pain relief for cancer patients. This brief introduction implies that current protocols for pain relief are ineffective, hence this is how the problem is *represented* to be. Thus, the first step of the WPR, that is, answering the question “what’s the problem represented to be in a specific policy?” (Q1) involved first coding the ‘proposals for change’ predominantly presented in the forward section. Secondly, as explained previously, guidelines are complex, and ‘proposals for change’ appear throughout the guidelines. In this sense, the first step also required analysing how the problem representation was reflected in the recommendations to Member States. For instance, continuing to use the example above, the recommended action in this guideline referred to drug availability and education of healthcare professionals in pain relief and palliative care which once more implies that there are problems with how cancer patients in pain are cared for in healthcare systems. This way, the forward section and the recommendations for action both contained key elements that gave shape to ‘proposals for change’. In doing so, I observed the continuities and discontinuities between the guidelines that gave insight into possible patterns or ‘styles of problematisation’ (Bacchi, 2009).

Step 2: Systems of Meaning

Having summarised all documents and manually coding statements indicating ‘proposals for change’, Step 2 further developed the coding process where focus was directed to coding key elements for the WPR framework required for the archaeological analysis in question 2 (Q2). A quick reminder that Question 2 refers to the deep-seated presuppositions and assumptions that underlie the problem representation (Q2) (Bacchi, 2009), thus indicating that to continue the analysis I directed my attention to identifying the *meanings* (presuppositions, assumptions) that need to be in place for the representation to become intelligible (Bacchi & Goodwin, 2016). Moreover, to understand how problem representations acquired “truth” status (Bacchi & Goodwin, 2016), it was necessary to probe into the ‘knowledges’ that conferred meaning to them, for instance, epidemiology, ‘total pain’ etc.

Second, Question 2 also involves examining how the problem is *constructed* (ibid), thus, attention was directed to the elements that give structure to the problem representation. That is, identifying which ‘concepts’, ‘categories’, and ‘binaries’ upon which the identified representation relied. A note on binaries here seems important. Binaries are understood by Bacchi (2009) as a dichotomic relationship created by problem representations. For instance, considering the relationship legal/illegal, a binary argument will be structured around an A/not-A relationship, which reveals what is being favoured and what is being excluded from policies (Bacchi, 2009). She recommends watching how binaries appear in policies and how they are operationalised within the system of meanings in place to give shape to the problem (ibid). Identifying binaries in the WHO guidelines indicates thus, what was being favoured in terms of ‘conduct of conduct’, that is the directions that were deemed ‘appropriate’ while excluding others.

NVivo was used to store and organise the codes ‘concepts’, ‘categories’, and ‘binaries’ and ‘knowledges’ that are required for the archaeological analysis in Question 2 (Q2). Some of the guidelines offered information on the context in which the publication emerged which were codified as ‘context’ offering insight on the genealogy required in Question 3 (Q3). The codes ‘categories’ such as ‘disease’ and ‘people’ categories for Question 2 were also used to examine the subjectification effects required for Question 5 (Q5). Subjectification effects refers to how ‘subjects’ are positioned in problem representations, “how they are produced as specific kinds of subjects” (Bacchi & Goodwin, 2016, p.23). Thus, codes such as ‘people’ categories and ‘disease’ categories are used to indicate their subject positioning in order to consider their effects in giving shape to subjects as subjects of a particular kind.

Step 3: Contextualising and Comparing

This step involved mapping discourses and practices that produce problem representations. This step refers to Question 3 (Q3), where in order to answer the question “how has the representation of the problem come about”? I looked into codes on ‘context’ that gave some insight into the context in which the guideline was published to trace back the discourses, practices, and institutions that are involved in producing the problem representation. This step involved going back to the literature to trace the assemblage of discourses and practices that converged into a particular form of thinking. Contextualising ‘problematisations’ demonstrated that the decade previous to the publications indicated the emergence of similar discourses outside of the WHO publications, which in turn brings visibility to ‘where’ these discourses were produced before the WHO. Thus, statements, declarations, resolutions, and literature on the genealogy of international health, and historical accounts of palliative care, were consulted to make visible the complex assemblage of practices and discourses that converged into the forms of thinking expressed in the WHO guidelines.

Question 4 (Q4) is concerned with what has been left unproblematised and requires what Bacchi & Goodwin (2016) call “a critical practice of thinking otherwise” (p.22). The goal of this question is to encourage analysts to destabilise an existing problematisation by drawing attention to the silences they impose, but also, as Goodwin (2011) suggests, to seek out other forms of thinking about the problem. To identify what was being silenced by imposed problem representations, the analysis here involved going back to Question 2 to observe how the binaries excluded some directions while favouring others. Hence, Question 2 aims to give insight into what has been silenced within the WHO guidelines.

The analytical task described above can be further developed by seeking out how the problem has been represented in other cultures, countries, and other moments in history that may indicate alternative ways to problematise them (Goodwin, 2011). As discussed elsewhere in this thesis (chapter 3, section 3.4.9), identifying alternative problematisations involves an exercise of comparison on the ‘problems’ identified within the WHO guidelines, and those proposed within national guidelines by using case studies. Having selected the analytical strategy to conduct the analysis proposed in this question, the question then became how to compare problematisations when comparisons within the field of palliative care are remarkably difficult to establish (Clark, Barnes, et al., 2018). Making comparisons within palliative care research can be difficult because the very concept of ‘palliative care’ is open to multiple interpretations, thus entailing in a wide variability of service organisation and delivery (Pastrana et al., 2010; Radbruch et al., 2020; Radbruch & Payne, 2009). While it can be argued that ‘palliative care’, ‘end-of-life-care’ are terms open to interpretations and can vary from context to context, normative standards for palliative care provision and development have been developed by the WHO through the WHO's Public Health Strategy (PHS) (Stjernswärd et al., 2007b). Thus, guidelines selected for comparison had to be from countries in alignment with the WHO PHS model for palliative care.

To overcome such difficulties, selecting national guidelines fitting for the purposes of this thesis (critically examining how guidelines produce problematisations) occurred through purposive sampling (Barbour, 2001). The criteria used to select national guidelines were alignment with the WHO framework for palliative care, access to guidelines and extensive literature on the development of palliative care strategies in their national context. According to Clelland et al. (2020), few countries have national laws and policies dedicated to palliative care, the majority being HICs. Pastrana et al. (2022) found that in many countries there are no monitoring systems in place to provide data on palliative care development in Latin American countries. That is, country-specific studies on palliative care development in LMICs can be limited. Two countries however, were found to meet the criteria: Colombia and England.

Colombia is a national context with robust literature on the development of palliative care strategies that have been argued as aligned with the public health model proposed by the WHO (Leon et al., 2011; Pastrana et al., 2021; Soto-Perez-de-Celis et al., 2017). The influence of the WHO Public Health Model can be observed in the Colombian Palliative Care Observatory (Observatorio Colombiano de Cuidados Paliativos OCCP) report of palliative care development in the country. Since 2016, this agency has monitored palliative care development by looking into policymaking, opioid availability and education as indicators (Vargas-Escobar et al., 2022), which are a clear reference to the WHO Public Health Strategy. To understand palliative care development in a national context however, global indicators such as the PHS do not offer much detail on the barriers and challenges local services face when developing palliative care strategies. Several studies have been conducted in Colombia providing insight into palliative care development in the country and the challenges they face (Hernández-Rico & Ballen-Vanegas, 2021; Leon et al., 2011; León, 2014; Pastrana et al., 2021; Vargas-Escobar et al., 2022). This literature on palliative care in the national context offers information on the national contexts which goes beyond the WHO framework and therefore provides an opportunity to examine how problems are represented to be in a LMIC context.

In turn, England has a long history with palliative care literature. England's End-of-Life Care Strategy (EOLCS) developed in 2008 (Department of Health, 2008), explicitly reveals the influence of the WHO into the development of their own palliative care programmes. The WHO has also acknowledged the English strategy as a case of successful implementation of palliative care programmes (WHO, 2011) alongside of other comparative efforts, although not without limitations, have long regarded the UK as a high-quality standard for end-of-life care (The Economist Intelligence Unit, 2010; The Economist Intelligence Unit (EIU), 2015; Zaman et al., 2017). England thus provided a useful case to critically examine the types of problems that are made to exist in a 'high-quality' context.

Therefore, in Q4 of the WPR approach there are two analytical tasks at hand. One that seeks to identify the silences within the guidelines by looking into how they were constituted (question 2) and to identify how the problem may be thought otherwise, that is, seeking to identify alternative problematisations. In this thesis question 4 first addresses the silences identified within the WHO guidelines by looking into question 2. This was followed by using Columbia and England as case studies to examine their national guidelines in support of palliative care and identify how the 'problem' of palliative care was represented (that is, applying the first question of the WPR framework), which supported a comparison of the problematisations identified within the WHO guidelines. Hence, Question 4 in this case did not reach a cross-country comparison with all countries adopting the WHO public health strategies but sought to understand how problematisations appeared in two national contexts (Colombia and England) as they offered the conditions (i.e., documents, guidelines and other literature) to bring visibility of the aspects shaping problematisations in that context.

Step 4: Theorising: discursive effects and subject positioning

I previously argued that categories codes such as ‘people’ and ‘disease’ were used to identify subject positionings. Thus, Question 5 (Q5) concerned with discursive effects, I returned to Question 4, 3 and 2 to understand how these constituted particular ways of interpreting the problem and how they impose limits on “what can be thought and said” (Bacchi & Goodwin, 2016, p. 23), about palliative care. Thus, identifying discursive effects required interpretating how the constitution of particular problematisations constricted palliative care discourses into particular aspects of healthcare. In turn, examining subjectification effects required interpretation of the ways in which ‘people’ are implicated in problem representations (Bacchi & Goodwin, 2016). Drawing from the ‘people’ categories in Question 2, the analysis sought to understand how problematisations require particular kinds of subjectivity for them to make sense. The idea is to trace how problematisations create social relationships and indicate the ‘roles’ people are assumed to play within them. Thus, ‘people’ categories such as patients, professionals, family members, community health workers, and volunteers are of particular importance to bring visibility to the social relationships created and to the meanings attributed to them.

Table 3 provides an overview of how the WPR analysis was conducted in relation to the different analytical steps discussed above, informed by the WPR questions (developed from Goodwin 2011, p. 173):

WPR questions	Goal	Strategy	How it was conducted

1. What's the problem represented to be?	To identify the implied problem representation.	Identification of the problem as it is implied in the policy	Summarising guidelines, memos and manual identification of statements expressing what needs changing in order to identify what is being assumed as problematic (Step 1)
2. What presuppositions or assumptions underlie this representation of the problem?	To ascertain the conceptual premises or logics that underpin specific problem representations.	Foucauldian archaeology involving discourse analysis techniques, such as identifying binaries, key concepts, and key categories	Identifying key premises that underpin the problematisation. Identifying concepts, binaries, and categories (people and disease) that sustains the problem representations. Having identified the conceptual premises, identifying how they are operationalised in order to give meaning to the problem representation (Step 2)
3. How has this representation of the problem come about?	To highlight the conditions that allow a particular problem representation to take shape and assume dominance.	Foucauldian genealogical analysis involves tracing the 'history' of a current problem representation to identify the power relations involved in the prevailing problem representation.	Retrieving the 'context' codes to give insight into the context in which the publication emerged and traced back the different discourses and practices that converged into the problematisations reaching the WHO guidelines. (Step 3)
4. What is left unproblematic in this problem representation? Where are the silences? Can the 'problem' be thought about differently?	To raise for reflection and consideration issues and perspective that are silenced in identified problem representations.	Genealogical analysis, and cross-cultural, historical, and cross-national comparisons in order to provide examples of alternative representations.	Questions 02 and 03 provide the basis for theorising what is left unproblematised. Identification of silences and how particular conceptualisations 'exclude' other forms of thinking that can be observed in cross-national comparisons. This included comparing guidelines and the literature from Colombia and the UK regarding pc development. (Step 3)

5. What effects are produced by this representation of the problem?	To ascertain discursive effects, subjectification effects, and lived effects.	Discourse-analysis techniques include the identification of subject positions, dividing practices where subjects are produced in opposition to one another, and the production of subjects regarded as ‘responsible’ for problems. Impact analysis: consideration of the material impact of problem representations on people’s lives	Examining ‘people’ categories and the identification of subject positioning and diving practices and the attribution of responsibility. Discursive and lived effects could be theorised from the information provided in questions 2,3 and 4. (Step 4)
6. How/where is this representation of the problem produced, disseminated, and defended? How could it be question, disputed and disrupted?	To pay attention to both the means through which some problem representations become dominant, and to the possibility of challenging problem representations that are judged to be harmful.	Identification of institutions, individuals and agencies involved in sustaining the problem representation. Mobilising competing discourses or reframing the ‘problem’.	Since I was investigating WHO guidelines, the identification of institutions and how the problem representation is sustained was deemed not suited for this research.

Table 3. Data Analysis

The table above demonstrates how the WPR framework in this study developed into a robust, systematic, and rigorous process of visiting and revisiting the data in order to provide a detailed in-depth account of the ways in which guidelines constitute forms of thinking. In applying 5 out of the 6 questions from the WPR framework, the study prioritised depth over scope. Thus, despite the limited number of guidelines selected for this study, the application of the WPR framework allowed a robust in-depth analysis of the WHO guidelines.

3.11 Ethical considerations

The previous section aimed to demonstrate the robust and comprehensive analysis that was developed through the WPR framework in relation to the WHO guidelines. The table above summarises the steps taken, and the analytical tasks involved to address each of the questions from the WPR framework applied in this study. In doing so, it offered a detailed and transparent account of the steps taken to conduct the analysis. Furthermore, it highlights the reflexivity involved in developing each of the analytical steps which leads to ethical considerations for this study. The UK Research and Innovation guidelines on research integrity (UKRI, n.d.) establish that everyone engaged with research must “consider how the work they undertake, host or support affects society and the wider research community” (p. 4). Integrity in the concordat draws on several criteria applicable to all areas of research, namely: honesty, rigour, transparency, care and respect for all participants in research including the environment and cultural objects (ibid, p. 6).

The commitment to research integrity is reflected throughout this study in providing a detailed account of steps taken in the process of designing the study, selecting the sample, and analysing the data to maximise transparency. This point is significant given that as described previously, the chosen analytic strategy (i.e. WPR) is not defined as a series of predetermined steps to be followed rigorously, but rather to reflect rigorously on how to apply them. The WPR as Bacchi (2009) argued “self-analysis or reflexivity of this kind is necessary because we are immersed in the conceptual logics of our era and because of who we are” (p. 19). Thus, it is no secret that the researchers’ subjectivity is involved in the research process. Subjectivity in this framework is not deemed as an impediment to research but a necessity. However, as Bacchi (2009) acknowledged above, reflexivity is also required to analyse our own practice as researchers. Thus, acknowledging that my own subjectivity is an intrinsic part of the analysis conducted, it became even more important to comply with transparency and honesty in making explicit the reasoning that went into each part of the study.

Moreover, Bacchi (2009) argues that the commitment to self-reflexivity must be applying all six questions to your own problematisations, to ensure that “we do not simply buy into certain representations without reflecting on their origins, purposes and effects” (p.19). The premise underpinning the need for self-problematisation is that knowledge is contingent and hence, the researcher's location, the historical and social context in which the research was produced must be subjected to our own thinking (Bacchi, 2009). Based on Mol's (1999) 'ontological politics', Bacchi (2012, p. 142) recognizes that research "is an active component in the shaping of different realities" and in this sense must be recognized as a political practice. Hence, there is no intent to view this research' results as objective or realist responses to societal problems. Rather, they must be understood in the context of the premises and assumptions brought to this research and how I addressed them throughout the analysis.

As presented in the opening to this study (chapter 1), this thesis was born out of a concern with the uncritical transference of palliative care frameworks from the WHO to countries with different cultural, political and health care systems such as Brazil. That is, there is a critical proposition that I have been arguing throughout the thesis that the WHO framework for palliative care may suit some countries more than others. This position, in turn, reveals my concern with the colonialisation of end-of-life care by the WHO through problematising issues related to palliative care in ways that may favour some countries more than others. Whilst this concern stemmed from my own professional practice as a psychologist in palliative care, this study mirrors other studies looking at power asymmetries in global health (Abimbola et al., 2021; J. Clark et al., 2018; Littoz-Monnet, 2022; Richardson, 2019), it also stems from studies analysing policy discourse for end-of-life care (Borgstrom, 2013, 2016). Taking into consideration the studies that have been conducted in the field, it can be argued that this research was developed having an epistemological background. However, qualitative research demands reflexivity, as in the ability to acknowledge that research emerges from a particular standpoint, one that the researcher must be open to challenge in the process of conducting research (Attia & Edge, 2017). Such as stance requires that the researcher recognise that their lived experiences are a part of the research process, but also to take responsibility for the directions taken in the pursue of knowledge (Attia & Edge, 2017).

In this research, critically examining guidelines produced by the WHO required both personal and epistemological reflexivity. As discussed above, my concerns as a psychologist working with palliative care in Brazil influenced the choice to focus on the WHO as a global knowledge actor with the power to influence global health agendas, practice and policies (Burda et al., 2014; Sturdy et al., 2013; Wackers & Markussen, 2015). It also influenced the formulation of research questions and poststructural strategies for data analysis. Epistemologically, self-reflexivity required an awareness that the problematisations identified within the WHO guidelines would be *interpreted*, and as such, they would be contingent to this research premises, my position as a researcher from the global south and my experiences with palliative care in Brazil. In order to ensure that my interpretation although influenced by my lived experiences would not turn into bias, the WPR framework was applied more than once. This was to ensure that the analysis that followed were supported by the data retrieved from the guidelines through careful and thorough summarising, coding, and revisiting the guidelines to reach the findings presented in the following chapters (chapters 4, 5 and 6).

Lastly, Taking Bacchi's (2012, p. 142) understanding that research is "an active component in the shaping of different realities and therefore is, at its core, a political practice", it was important to maintain the critical ethos of contesting taken-for-granted assumptions, including my own. Each stage of the analytical process was shared with both supervisors and the initial analysis was also shared with peers at academic conferences and congresses. The later led to two publications of extended abstracts in important journals such as the Palliative Medicine journal (see "Abstracts from the 17th World Congress of the EAPC 2021," 2021) and in the Palliative Care and Social Practice (see "7th Public Health Palliative Care International Conference. Democratizing Caring, Dying and Grieving: Participation, Action, Understanding and Evaluation," 2022). As the research was being developed, sharing outcomes with supervisors, engaging with research fellows and conferences were opportunities to step back and reflect upon the analysis, interpretations, and primary results. In this sense, the process of engaging with this research reflects what Attia and Edge (2017) named as a process of continuous transformation and development, where doing research is better understood as a process of *becoming.*

3.12 Challenges and Contributions of the WPR to this study

While previous sections are dedicated to describing the research design and the reasoning that went into the choice for the WPR as the analytical strategy for this study. Drawing from Bacchi (2009), this study engages with a critical perspective on the very concept of 'method'. Based upon a poststructuralist approach to research, the WPR is a framework that rejects the existence of a reality that exists sitting outside of discourse (Bacchi, 2009, 2012b). For this reason, underpinning the WPR framework is the assumption that methods are not a technical means to retrieve 'the real' (Bacchi, 2009; Bacchi & Goodwin, 2016). Yet, research design literature frequently associates research with conflicting assumptions of those of Bacchi (2009, 2012a). For instance, King et al. (1994) talk about how the rules of inference in social science may not be significant for all social scientists, but they are relevant for all research in which the goal is to "learn facts about the real world" (King et al., 1994, p. 6). Legitimate research in social sciences, is one that arrives at valid inferences through a "systematic use of well-established procedures of inquiry" (King et al., 1994, p. 6). This demonstrates different understandings of the role of research, the very concept of 'method', and the validity of interpretations generated by research in social sciences.

Taking King and colleagues (1994) understanding of scientific research as characterised by the goal of inference understood as "attempting to infer beyond the immediate data to something broader that is not directly observed" (p. 8), alongside using explicit methods to generate and analyse data so these can be assessed; and publicly expressing the "rules of inference upon which its validity depends" (p.9). My understanding is that to Bacchi (2012), this notion is insufficient as it reproduces the premise of technicality over reflexivity.

Bacchi (2019) argues that methods are not and "could never be, innocent or purely technical" because they necessarily "produces truths and non-truths, realities and non-realities, presences, and absences, but also arrangements with political implications" (John Law, 2004, p.143 as cited in Bacchi, 2019). Her notion of 'methods' refers more to the reflective dialogue that researchers are invited to take part and to interrogate the ontological and epistemological premises of their research and how these matter for the arguments they want to make (Bacchi, 2021). To Bacchi, doing research is not merely a knowledge production activity but rather a political practice as these shape realities (Bacchi, 2012a).

In this sense, I argue that being aligned to Bacchi's WPR framework requires much more than explaining the steps taken to obtain knowledge, but a reflexive exercise on the premises that led to these steps. The proposal of a reflexive, poststructuralist approach to research methods requires the researcher to create their own strategies to apply Bacchi's (2009) WPR framework which was at times conflicting with the language commonly used in research practice. Despite the challenges here observed, the study develops a framework of inquiry upon technical frameworks such as guidelines. It developed systematic steps of analysis based on Bacchi's (2009) WPR framework that provides a robust basis from which further research can be developed.

3.13 Summary

This chapter was dedicated to discussing the theoretical, epistemological, and ontological perspectives that shaped this study. I began by discussing the research gap which highlighted the gaps in our knowledge of the ways in which palliative care has been problematised within the WHO guidelines. There, I raised concerns over the lack of literature on the premises that give shape to the WHO recommendations for palliative care. Considering that guidelines, as policies, foster problematisations, the research questions reflect a concern with the ways in which palliative care has been problematised and inquired on possible implications of these for the goal of UHC and to the 'people' involved in palliative care. The usage of the term 'problematisation' is aligned with the Foucauldian concept of 'governmentality'. In this perspective, attention is directed to how issues are made into problems, which directs attention to their process rather than materiality. This perspective of problematisation indicates an ontological perspective where attention is directed to the problematisations themselves rather than an agency that produced them. As such, although there are many approaches to policy studies that allows investigating 'problematisations', they differ in their epistemological and ontological premises, which led to the choice for the WPR approach.

The WPR approach was discussed in depth in this chapter, giving insight to the theoretical, ontological and epistemological alignment with this study. In doing so, I then turned to how this approach was applied to the WHO guidelines. The section research design provided in detail how guidelines were selected, the reasoning that went into this choice and their main ideas. The analytical process was developed through steps where each step described a particular analytical strategy based on Bacchi's (2009) framework. Yet, as this framework is highly reflexive, the chapter also addressed ethical commitments and challenges raised by adopting the WPR.

The next chapters will be presenting the findings of this research. In chapter four, following the analysis described in step 1, I will demonstrate how problematisations were identified, comparing the different ways in which palliative care is proposed within guidelines. Chapter five and six will discuss findings from analytical steps two, three and four, following the identification of two dominant problematisations in chapter four. Thus, the chapters that follow will discuss the two problematisations identified in this research, their archaeology, genealogy, identification of their silences and theorising on their effects.

Chapter 4. Identifying Problematisations

The previous chapter focused on presenting the methodological considerations taken in this study. Considering that a WPR application begins by ‘reading off’ policies to identify how they constitute ‘problems’, this chapter will begin by introducing what is proposed for ‘palliative care’ in the selected WHO guidelines. Drawing from the WPR framework, this chapter aims to address the question ‘What’s the problem represented to be?’ (Q1) to identify the problem representations within them. Hence, the chapter that follows will first introduce the ways in which the guidelines propose palliative care services chronologically (i.e., 1990,2002,2004a,2004b, 2011, 2016, 2018). Second, the chapter will then identify the dominant ways in which the guidelines foster palliative care problems.

4.1 What is proposed as change in the WHO guidelines?

This section will discuss the recommendations for palliative care in the WHO guidelines from 1990 to 2018. For this reason, the section will be organised chronologically and separated into subsections for each guideline to give insight into the ways they propose ‘palliative care’ through time. As the guidelines from 2004-2011 were published as a series they are being discussed as a group and not as individual publications.

4.1.1 Cancer Pain Relief and Palliative Care (WHO, 1990)

Starting with the 1990 *Cancer Pain Relief & Palliative Care* report, the document is introduced with the purpose of reviewing the “current status of cancer care and pain relief and to promote recommendations and guidelines to improve the quality of life of cancer patients” (WHO, 1990, p. 7). Palliative care is recommended as an important measure for the WHO Cancer Control Programme, concerning the status of ‘cancer pain relief’ in which ‘cancer pain’ is regarded as a “neglected public health problem” (ibid, p.8). In response to this problem the WHO proposes the implementation of a comprehensive care, namely palliative care:

> However, cancer pain relief cannot be considered in isolation. For most patients, suffering is not purely physical, and pain is only one of the several symptoms. Pain relief should therefore be seen as part of a comprehensive pattern of care which encompasses the physical, psychological, social and spiritual aspects of suffering and which has come to be known as palliative care (WHO, 1990, p.11).

Suffering is assumed to happen due to the lack of “totally effective measures for prevention early diagnosis and curative treatment” and the absence of appropriate health facilities and trained professionals (ibid, p. 11). For these reasons, active supportive care will be the “only humane approach for many patients” (ibid, p.7). Underpinning this understanding is a concern with patients that will reach advanced stages of cancer.

The report draws attention to the quality of life a particular group of cancer patients: “nothing will have a greater impact on the quality of life of these patients than the dissemination and implementation of the knowledge available in relation to pain relief and symptom management” (ibid, p. 7). The group of cancer patients to whom palliative care is recommended is characterised as “patients whose disease is not responsive to curative treatments” (ibid, p.11). Hence, the targeted population for palliative care measures is patients dying from cancer, who are assumed to be in pain and suffering.

To confer meaning of the scale of the ‘problem’, the guidelines associate the need for palliative care measures to the rising trends of cancer mortality rates in the world. The WHO estimates that at least 8% of all deaths in the world are caused by cancer and that at least 67% of male and 60% of female cancer patients will die from their disease (ibid, p.12). The rising trends in cancer mortality in the world is considered to be evidence of the necessity of palliative care provision:

> These figures provide evidence that national health plans must include the provision for palliative care for the millions of people who would otherwise suffer considerably

in the weeks and months before death (ibid, p.14).

To this effect, the WHO proposes policy measures towards a pain relief and palliative care programme, in which governments should recognise “cancer pain and other symptoms” as a “neglected public health problem” (p.60):

> After formulation of guiding principles as a foundation, the first prerequisite in establishing a national policy on cancer pain relief and palliative care is *the recognition that cancer pain and other common cancer symptoms are undertreated*, and that this is a neglected public health problem (WHO, 1990, p.60, emphasis added).

The extract above indicates that the WHO is problematising the lack of adequate treatment for cancer pain and other cancer symptoms. This problematisation is further evidenced by other proposals such as ensuring that healthcare workers will be trained in managing pain and other symptoms of cancer; the availability of analgesics both opioids and non-opioids and those laws and regulations governing professional conduct allows “the adequate treatment of cancer patients in pain” (WHO, 1990, p.61). Due to the rising number of cancer patients in the world, adequately treating cancer pain and other symptoms are presumed as a global concern. Thus, the report requires all Member States – that is, all countries that are a member of the WHO – to ensure palliative care programmes within their healthcare systems (WHO, 1990). This is followed by other recommendations such as: that health professionals are adequately trained in palliative care and pain relief; that home base care has the appropriate support including “systems of recompense” for family caregivers; and resist the pressures for the legalisation of euthanasia by keeping informed on the developments of palliative care (WHO, 1990, p.65).

The recommendations in place are associated to ideas of symptom management, training of health care workers, facilitating opioid availability and allowing the deinstitutionalisation of patients through home base care including providing support for the families. The last recommendation, to resist euthanasia, comes from an understanding that with the provision of palliative care, pain and other distressing symptoms will no longer be a ‘problem’ and hence, patients can have a comfortable death, expressed in the sentence:

> The committee adopted the position that, with the development of modern methods of palliative care, legalisation of voluntary euthanasia is unnecessary. Now that a practicable alternative to a death in pain exists, there should be concentrated efforts to implement programmes of palliative care, rather than yielding to pressure for legal euthanasia (WHO, 1990, p.55).

This way, palliative care is proposed to change the quality of care for patients dying with pain and other symptoms, which as a consequence, will prevent them from requesting assisted dying.

4.1.2 National Cancer Control Programmes (WHO, 2002)

In the *National Cancer Control Programmes* (WHO, 2002) the WHO presented a public health framework for cancer control:

> This monograph aims to provide a framework for the development of national cancer control programmes. Its underlying approach is the application of science to public health practice, providing a concise statement of what is *feasible and desirable* in cancer prevention and control, with the ultimate goal of reducing cancer morbidity and mortality, and improving quality of life in the targeted population (WHO, 2002, p.ix, emphasis added).

The extract above reflects similar goals to the 1990 *Cancer Pain Relief and Palliative Care* previously discussed. For instance, the need to implement a national control programme is associated with the goal of improving the quality of life of cancer patients through palliative care intervention (WHO, 2002). Despite being mainly focused on advising healthcare managers and providers on how to improve the use of available resources for a national cancer control programme, the 2002 guideline also expressed concerns with patients at late stages of illness: “education in pain relief and palliative care must be an essential component of training for all health workers who may be expected to treat patients with advanced chronic illness” (WHO, 2002, p.87). Note that the guideline’s goal is to develop national cancer control programmes, but palliative care here is thought of as something to be offered to patients with ‘advanced chronic illness’, suggesting an expanded concept of palliative care.

Moreover, the recommendation to develop a national cancer control programme is justified once more by the rising trend in the mortality of cancer:

> Despite an overall 5-year survival rate of nearly 50% in developed countries, the majority of cancer patients will need palliative care sooner or later. In developing countries, the proportion requiring palliative care is at least 80%. Worldwide, most cancers are diagnosed when already advanced and incurable (ibid, p.86).

Alongside cancer, the guideline estimates that mortality from other noncommunicable illnesses will increase in the next 20 years, thus indicating the need for palliative care services: “for millions of people, access to palliative care will be the core essential need” (ibid, p.86). Within a national cancer care programme, palliative care is recommended for patients with incurable illnesses, however, the focus of palliative care refers less to the relief of pain and other symptoms as seen in 1990, and more to ‘prevention and relief of suffering’:

> Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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' (WHO, 2002, p. xvi).

This demonstrates slight changes from the previous guideline where palliative care was being proposed to relieve pain and other symptoms and prevent euthanasia requests (see WHO, 1990, p.60). Instead, palliative care is being proposed as a preventive strategy. As expressed in the statement below:

> Palliative care should be recognised as an exercise in prevention – prevention from ultimate suffering through *prioritising diagnosis* and *skilful management of sources of distress,* both in the form of physical symptoms and of psychosocial and spiritual concerns, at the earliest possible moment (MacDonald, 1991 as cited in WHO, 2002, p.85, emphasis added).

It is important to observe that similarly to 1990, palliative care is still rooted in ideas of 'treatment', thus aspects of healthcare such as diagnosis and symptom management are greatly emphasised. This understanding is further evidenced by the frame in which patients are understood. Patients with AIDS and other noncommunicable diseases are understood to "suffer with problems similar to those commonly encountered in cancer patients" (ibid, p.86). The statement clearly indicates that patients with illnesses are understood through what they have in common with cancer patients. In this sense, it is possible to observe how end-of-life care is being proposed based on experience with cancer. This understanding is further evidenced by the idea of a common 'symptom etiology' that is "often common across diseases" (WHO, 2002, p.86). Because patients have a common symptom etiology then the same strategies of pain relief and symptom management are applicable to other patients as indicated in the new definition above. Furthermore, palliative care will be most effective if offered at earlier stages of illness:

> Palliative care should be applied as early as possible in the course of any chronic,

> ultimately fatal illness. This change in thinking emerged from a new understanding that problems at the end of life have their origins at an earlier time in the trajectory of disease. *Symptoms not treated onset become very difficult to manage in the last days of life* (WHO, 2002, p. 83 emphasis added).

Thus, based on what has been proposed so far, what is being thought of as problematic is the *timing of intervention,* as well as the scope of palliative care, which can be argued to be discontinuities from the 1990 *Cancer Pain Relief and Palliative Care*. Yet, the 2002 *National Cancer Control Programmes,* continues to position palliative care as an end-of-life strategy aimed at symptom management, which represents a continuation of the previous guideline. This inference is better illustrated by the role designated to palliative care in the recommended Cancer Control Programme.

The programme is constituted by different measures aimed at different outcomes; thus, it separates strategies into prevention, early diagnosis, treatment and palliation (WHO, 2002). In this sense, even though palliative care is being interpreted as a preventive measure against dying in pain and suffering (see WHO, 2002, p.85), palliation is recommended only when all the other measures have failed:

> Enough is now known about the causes of cancer and means of control for suitable interventions to have significant impact. At least one-third of the 10 million new cases of cancer care each year are preventable by such means as controlling tobacco and alcohol use, moderating diet, and immunizing against viral hepatitis B. Early detection, and therefore prompt treatment, of a further one-third of cases is possible where resources allow. Effective techniques are sufficiently well established to permit comprehensive palliative care for the remaining, more advanced, cases (WHO, 2002, p.xi).

For countries where resources are limited, palliative care is the recommended care for most patients, since “it is not logical to provide extremely expensive therapies that may benefit only a few patients, while the majority of patients presenting with advanced disease and urgently in need of symptom control must suffer without relief” (WHO, 2002, p. 86). For these countries where resources are constricted “cure of the majority of cancer patients is likely to remain beyond reach for years to come” (WHO, 2002, p.xv), palliative care can be “the most significant contribution of a national cancer control programme” (WHO, 2002 p.xxi). What follows from these statements is problematising cancer care where resources are low. Underpinning statements regarding low-resourced settings, healthcare infrastructure is likely to be inadequate or insufficient, which in turn creates a greater need for palliative care.

4.2.3 The Solid Facts; Better Palliative Care for Older People; and Palliative Care for Older People: Better Practices (Davies & Higginson, 2004; WHO, 2004, 2011)

Moving on to 2004 until 2011, the WHO published three interrelated documents which argue that the lack of ‘palliative care’ is an important public health problem for those reaching older age as well as those living and dying with chronic illnesses. Beginning with *The Solid Facts* (Davies & Higginson, 2004), this guideline draws attention of policymakers to “plan now to meet the needs of ageing population” and to “place greater emphasis on the care of people with all ages who are living with and dying from a range of chronic diseases” (Davies & Higginson, 2004, p. 11).

The expressed problem of ageing population and chronic diseases suggests a concern with the epidemiological transformations that are likely to change how populations die. As observed in the statement:

> As part of population ageing, the pattern of diseases people suffer and die from is also changing. The last century saw a dramatic reduction in deaths from infectious diseases in infancy and childhood. Increasingly, people die at older ages following illnesses due to serious chronic conditions, which cause a wide range of physical, psychological and social problems (Davies & Higginson, 2004, p.8).

The ageing population is assumed to be living with chronic illnesses, to which the WHO states: "this means that there will be more people needing some form of help towards the end-of-life" (ibid, p.10). While the concern with ageing populations is still associated with 'end-of-life', illustrated by the changing patterns of death in European societies, other issues such as changes in the family structure are also considered as an 'end-of-life' related problem (Davies & Higginson, 2004). In addition, people living with serious conditions are understood to suffer "from a wide range of problems and each illness brings *specific symptoms*" (Davies & Higginson, 2004, p.12, emphasis added). This statement is important as it demonstrates an effort to highlight the *specificities* of illnesses and symptoms rather than the commonalities with cancer.

In 2004, emphasis is given to *differentiating* the needs of people living with chronic illnesses from those of cancer patients. For example, it is argued that the "course of illness" of cancer can be predicted while the course of other chronic illnesses is presented as "uncertain" (Davies & Higginson, 2004, p.13). Moreover, 'people' are assumed to be individuals with different experiences and values, thus distancing from an understanding of patients through their symptoms:

> People who are very sick or are coping with serious chronic illnesses have their own experiences and values. People vary greatly in their willingness and ability to talk openly about their illness of its prognosis, the needs they wish to acknowledge, the

> level of symptom control they find acceptable, the interventions they will consider and whom they wish to care for them (WHO, 2004a, p.16).

In this light, the booklet the *Solid Facts* proposes the following recommendations for policy: first, policymakers are required to invest in palliative care services “as a core part of healthcare systems”; they should also identify “the *unmet needs* for care for all common serious diseases” at a population level and “identify the people living with chronic illnesses in the different settings such as the community, nursing homes and hospitals, including intensive care” and offer support for family members similarly to those recognised for paternity or maternity responsibilities (Davies & Higginson, 2004, p.13). These measures imply that what is being problematised is the type of care offered to the population living with chronic illnesses, including older people. Palliative care is recommended for patients due to its flexibility which fits the purpose of meeting the complex needs presumed to have been ‘unmet’: “palliative care has focused on controlling pain and symptoms, defining needs around patients and their families, and being flexible about doing what is necessary to help people adapt and cope with their situation” (Davies & Higginson, 2004, p.14). Additionally, this understanding of palliative care as something that helps people ‘adapt and cope’ with their situation reveals significant differences in the way palliative care is being interpreted in this guideline in comparison to previous ones.

Although the concept of palliative care gained a different connotation, here less associated with pain relief, diagnosis and symptom management (see WHO, 2002, p.85), the *Solid Facts* continues to direct attention to perceived problems on the ways in which palliative care is being delivered in European countries.

> As ageing populations develop new needs, healthcare systems need to be equally flexible in their response, and perceptions about care towards the end of life need to *change*. Traditionally, palliative care has been offered most often to people suffering

> from cancer, partly because the course of this illness has been more predictable making it easier to recognize and plan for the needs of patients and their families. One consequence of this has been the perception that palliative care is only to the last few weeks of life – when no other treatments are beneficial and can be delivered only by specialized services (Davies & Higginson, 2004, p. 14-15).

What is being considered problematic is how palliative care delivery has been limited by the association with cancer patients at the end-of-life. In this sense, attention is redirected to the years before reaching the late stages of illness, as expressed in the statement: “people and their families experience many problems throughout the many years of illness and need help at the time and not an easily definable point just before death” (Davies & Higgins, 2004, p.15). Thus, shifting the understanding of delivery of ‘palliative care’, once deeply associated with ‘dying from cancer’, towards ‘living with chronic illness’.

For this reason, the booklet recommends adopting an alternative concept of palliative care, one “that can be offered alongside potentially curative treatment” (Davies & Higgins, 2004, p.15). The proposed changes in the concept of palliative care are expected to allow palliative care to be offered more broadly within healthcare systems: “on the basis of ‘need’ in terms of symptoms and problems and their effectiveness in meeting that need, rather than on the basis of diagnosis” (ibid).

Intrinsic to the idea of meeting people’s needs is the concept of choice. An idea that was further developed in the publication that followed in the same year, *Better Palliative Care for Older People* (WHO, 2004a), where public health systems should “acknowledge people’s right to high-quality palliative care and to make decisions about it, whatever the nature of disease they suffer from. These rights should be enshrined in health and social care legislation” (WHO, 2004a, p.17). Healthcare is understood as a response to people’s need to make choices at the end-of-life, where it is the responsibility of healthcare professionals to be sensitive. As expressed in the statement: “enabling people to become involved in decision- making requires sensitivity to personal and cultural values, empathy and an ability to inform and empower people to make choices about their care when they wish” (p.16), choice and respecting people`s wishes become a central feature of palliative care services. Not surprisingly, meeting people`s preferences are argued as the “ultimate measure of success” (ibid, p.17), a proposition that significantly implies that the ‘problem’ is not how palliative care has been delivered, but rather, the problem is that healthcare does not allow patients to choose.

The third and last publication in this group, the *Palliative Care for Older People: better practices* (WHO, 2011), aims to introduce examples of successful palliative care programmes from which other countries can build their own strategies provided that they make the necessary adaptations to their own demographics, culture, and socioeconomic conditions (WHO, 2011). Moreover, palliative care is presented as a way to “improve health by preventing disease and disability” as well as to “improve the quality of life that remains, enabling people to live well, and, when the time comes, to die well” (WHO, 2011, p.v). Arguably, there are two overlapping interpretations of the concept of palliative care shaping this booklet. One that is more commonly associated with end-of-life and the notion of dying well and the other related to health promotion where palliative care is associated with ideas of living well. Palliative care, therefore, is proposed in response to meeting the needs of ageing populations living with chronic illness towards the end-of-life, identified as a “challenging and growing public health issue” (ibid).

From the exposed it is possible to argue that the guidelines from the European Regional Office emphasise the need to provide palliative care based on patients’ needs; the inclusion of palliative care into healthcare policies; and to emphasise the provision of care in response to individual preferences. This is, as expressed in the 2004 guideline, “a key human right and maintaining it must be a core ethical value for society and health services" (WHO 2004b, p.18). Moreover, as a group, it is possible to observe efforts to shift the ways in which palliative care has been conceptualised in the past. To this group of guidelines, the interpretation of palliative care as "relevant only to the last few weeks of life (when no other treatment is beneficial)" is outdated (WHO, 2011, p. 6).

In essence, palliative care is proposed as a strategy to help people cope with their illnesses until death, while also enabling them to make choices regarding the care they want to receive. The recommendations for policies include the recognition of other illnesses and ageing populations as targets for palliative care intervention; the integration of palliative care in all levels of healthcare systems; addressing the gaps in equitable provision; public education and research (Davies & Higginson, 2004; WHO, 2004). Overall, this section demonstrated that there are significant differences in the palliative care being proposed within guidelines targeting European countries. As the guidelines argue that palliative care should be offered upon diagnosis and developed alongside curative treatments to help patients live well and die well, the proposal for palliative care involves changing how palliative care is understood; enabling people to make choices and respecting their preferences.

4.1.3 Planning and Implementing Palliative Care Services (WHO, 2016)

Palliative care is introduced in this guideline as an approach that goes beyond pain relief to include "efforts to enhance the quality of life, and even influence the course of illness in a positive way" (WHO, 2016, p.9). This suggests that the interpretation of palliative care aligned with the interpretation provided in the *Solid Facts* (WHO, 2004a). As illustrated by the description of palliative care as an "approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness" (WHO, 2016, p.5). Yet, since the targeted measures include both "patients with a wide range of life-limiting health problems" and that "palliative care is needed in 40-60% of all deaths" (ibid), the 2016 guideline seems to foster overlapping understandings of palliative care. This point is further evidenced by the statement: “the majority of dying patients require palliative care, as well as a large proportion of patients living with chronic, complex, life-limiting health problems” (WHO, 2016, p. 10).

Compared with guidelines introduced so far, differences can be found not only in the way ‘palliative care’ has been interpreted, but also on the purposes of palliative care. In this guideline, palliative care is introduced in response to gaps in *service provision*, as suggested by the way the guideline is introduced as “a practical manual aimed for health managers at all levels (national, provincial and district) to plan, implement or integrate palliative care into healthcare services” (WHO, 2016, p. 1). The publication, aiming to offer guidance on strengthening and implementing services within existing healthcare systems, targets implementation in low and middle-income countries. As observed in the statement below:

> It aims to describe a range of options and starting points for building and strengthening palliative care services. A stepwise approach is outlined in each section as much as possible, with an emphasis on approaches that are feasible for low- and middle-income settings (WHO, 2016, p.1).

The stepwise approach is recommended in response to inequalities in accessing palliative care: “access to palliative care has been identified as a fundamental right. With this manual WHO reaffirms its commitment to work with Member States in order to ensure that this becomes a reality for everyone: adults, older people and children” (ibid, p.1). The publication responds to a request from Member States “to develop evidence-based tools on integrating palliative care into national health systems, across disease groups and levels of care” (ibid). Thus, a central argument for this guideline is to build capacity in existing health systems to increase coverage. In this perspective, it is possible to infer that what is being problematised is the lack of equity in accessing palliative care services:

> This manual should contribute to providing equitable access to good palliative care in the context of Universal Health Coverage; it should help countries to strengthen palliative care programmes especially at primary healthcare level and across disease groups (WHO, 2016, p.1).

Advice is focused on how to set up palliative care across all levels of the healthcare systems with the goal to ensure an “integrated approach in a district” (WHO, 2016, p. 17). Despite not focusing on protocols for care, the guideline offers insight into the concepts of palliative care in place as well as who is thought to be the targeted population for palliative care measures.

Ideas of positively influencing the course of illness appear as a possible outcome of palliative care measures (WHO, 2016). Moreover, in the intent to increase coverage, palliative care should also be seen as a service that will not add more responsibilities “without either adding more staff or reducing existing responsibilities” (WHO, 2016, p.23). The advice to engage professionals in developing services indicates that advocacy should “focus on the savings resulting from investment in palliative care services, by reducing hospital admissions and length of stay” (ibid). This suggests that palliative care implementation is beneficial not only to patients but also to the healthcare systems themselves.

In the 2016 guideline, the proposed palliative care programme includes a wide range of services that should be able to: identify the patients in need of palliative care; “assess and reassess patients for physical, emotional, social and spiritual distress” as well as their families; “relieve pain and other symptoms; address spiritual, psychological and social needs; [and] clarify the patient’s values and determine culturally appropriate goals of care” (WHO, 2016, p.9). The programme thus is focused on individualising care through culturally appropriate values and respecting patients’ values. Moreover, ‘palliative care’ must be adapted to national context, and hence should reflect local needs (WHO, 2016). This suggests that palliative care is being thought of as something that requires social integration:

> The service delivery model must take into account the country's social and health system context. All examples described in this guide will require further adaptation to meet local needs. Palliative care services can be established or expanded in a number of ways, depending on the local situation (WHO, 2016, p.17).

However, this understanding conflicts with the measures proposed. For instance, the palliative care programme is proposed to begin with training the existing staff and sensitising them to the "medical and moral reasons" for palliative care making clear that "palliative care services will not overburden them" (WHO, 2016, p.23). Thus, continuing to position 'palliative care' as something that is provided by healthcare professionals.

Healthcare provision of palliative care is further evidenced in the way the guideline recommends home-based care to be developed. Home-base care is a service that should be offered to "patients with chronic and limited conditions who feel more comfortable in their home rather than a healthcare setting", thus offering "easy access to care" by family members (WHO, 2016, p. 18). However, at the same time, the guideline argues that home-based care is understood to be best delivered "by a multidisciplinary team trained in palliative care, including doctors, nurses, community health workers and volunteers" (ibid). The idea shaping this understanding is that care is to be performed by qualified, trained people.

Creating a wider range of trained carers is expected to avoid overburdening healthcare systems. Even hospital based palliative care is articulated in this guideline as to reduce the burden of care and to ensure comprehensive symptom control, to respond to patients values, prognosis, and goals of care and to "reduce a patient's length of stay in hospitals and can enable a smooth transition in the care of community" and "reduce the use of non-beneficial or harmful treatments near the end of life" (WHO, 2016, p. 26). Thus, the guideline suggests another problem which is the burden of care. Combined with the lack of access to palliative care services, the recommendations suggest displacing the burden of care from healthcare institutions to the community.

It is through this guideline that the notion of community participation appears through involving the people in the community to "solve their own problems" (WHO, 2016, p. 21). This includes the involvement of the community in "needs assessment, planning, implementation, resource mobilization, day-to-day management and evaluation of the programme" (ibid). Building up community services "can be a way to achieve significant coverage of services for patients with chronic, life-limiting health problems" (ibid). Thus, largely shaped by arguments on the ways in which palliative care is beneficial to healthcare systems, this section demonstrates an important shift in the ways in which palliative care has been proposed.

4.1.4 Integrating Palliative Care and Symptom Relief into Primary Healthcare (WHO, 2018)

The rationale for implementation is introduced in the 2018 publication *Integrating Palliative Care and Symptom Relief into Primary Health Care*, where advice is offered on how to integrate palliative care into primary healthcare (PHC). Integration of palliative care is also introduced in response to inequalities of access, described as "one of the greatest disparities in global health care", and understood as the cause of "avoidable suffering on a massive scale" (WHO, 2018, p.1). Focus is given to the integration of palliative care into primary healthcare to help 'strengthen' healthcare as expressed in the statement:

> This document is not a clinical manual and does not provide clinical guidelines. Rather it contains detailed information about what palliative care is and should be, the rationale for it being a medical and a moral imperative, an Essential Package of Palliative Care for Primary Healthcare (EP PHC) and a method for implementing

> palliative care within primary care in a way that strengthens healthcare systems (WHO, 2018, p.1).

In the 2018 guideline, palliative care is defined as “the prevention and relief of suffering of adult and paediatric patients and their families’ facing problems associated with life-threatening illnesses” (WHO, 2018, p.5), reflecting continuities with the definition presented in the National Cancer Control Programme in 2002. The difference, however, lies in the understanding of ‘suffering’ as socially determined, expressed in the statement: “the specific types and severity of suffering vary by geopolitical situation, socioeconomic conditions and culture” (ibid). Previous guidelines also discuss ‘suffering’, however, as expressed in 2002 and 1990 suffering referred to pain and other symptoms.

In 2018, the notion of suffering is expressed through ideas of social problems: “people in LMICs often endure less healthy social conditions. They also typically have less access to disease prevention, diagnosis, and treatment, to social support, and to specialists and specialised services of many kinds than people in high-income countries” (WHO, 2018, p.5). The focus on socioeconomic conditions suggests a change on the aspects assumed to be shaping healthcare:

> But in low-resource settings, prevention, and relief of acute or non-life-threatening suffering typically are inadequate or unavailable. In countries where pain medicine does not yet exist as a specialty and where prevention and relief of pain from trauma or burns or surgery are inadequate, clinicians trained in palliative care can fill this therapeutic void. In these settings, clinicians trained in palliative care can intervene either by training colleagues in symptom control, by providing direct symptom relief, or both (WHO, 2018, p.6).

The statement above indicates how palliative care is thought of as a strategy to fill the gaps in a healthcare system. It is thus, in the 2018 guideline, that the emphasis on service provision is proposed through a “reorientation of healthcare to prioritise primary and community services and continuous care” (WHO, 2018, p.10). As indicated in the statement expressed below:

> Rather, most palliative care can and should be provided by primary care practitioners with at least basic training in palliative care of at least 35 hours (Annex 5). These practitioners may include general practitioners, family physicians, clinical officers, assistant doctors, nurse-practitioners, feldsher, nurses, social workers and trained and supervised lar counsellors based at community health centres (CHCs). Community health workers (CHWs) can provide frequent emotional support for the patient and family and report to a clinician at CHCs (WHO, 2018, p.10).

The preference for home-based care is an argument used in favour of the integration of palliative care into primary care and to make care available “in the community” and in “the patient’s homes” (ibid). A strategy largely provided by community health workers (CHWs). In relation to setting up community care, the guideline states that “with little as three to six hours of training, CHWs not only can provide important emotional support, but also recognise uncontrolled symptoms, identify unfulfilled basic needs for food, shelter, clothing or improper use of medications, and report their findings to a nurse-supervisor at a CHC” (WHO, 2018, p. 24). They should therefore serve as the “eyes and ears of their clinicians” (ibid), thus suggesting that the “community-based care” could serve as an extension of expert care.

In both guidelines the WHO demonstrated concerns about increasing palliative care coverage (2016 and 2018). Attention is redirected from specialised professionals and healthcare institutions to the competencies of ‘people’ involved in healthcare, including families and members of the community. Thus, the focus is not on allocating resources or building healthcare structures but building human resources: “before a palliative care service is established there must be clarity on what mix of paid staff and volunteers is best and which professional staff will be needed and with what level of expertise” (WHO, 2016, p. 36). Likewise in 2018, the WHO states that “professional designation is less important than competencies (…) thus, appropriately trained and supervised non-physician health workers, including CHWs, can have important roles in PHC” (WHO, 2018, p.16).

> However, there is evidence that palliative care, when well-integrated into a healthcare system and including home care can save money for the healthcare system by reducing the need for hospital admissions near the end of patients’ lives. Thus, over time, palliative care integration into public healthcare systems may pay for itself and save money thereafter (World Health Organization, 2018, p. 29).

A well-integrated palliative care programme is understood to be capable of “improving their performance, reducing costs and promote UHC” (WHO, 2018, p.45). In both guidelines the network constituted by home care, community and hospital-based care are argued to improve the quality of life of patients, while also reducing the length of stay in hospitals and facilitate the transfer to the home or to the community. The latter is emphasised in the guideline as being particularly important for those at the end-of-life.

4.2 What’s the problem represented to be in WHO palliative care guidelines?

This chapter began by introducing how palliative care services were proposed in the WHO guidelines from 1990 until 2018. Drawing from the WPR framework attention will now be directed to discuss how these proposals for implementation constitute ‘problems’ as problems of a certain kind, in other words, the extent to which the guidelines foster problem representations (Bacchi, 2009).

Beginning with the guidelines from 1990 and 2002, the argument for palliative care implementation is based on the idea that without 'palliative care' cancer patients would suffer considerably in the weeks and months before death. The problem of 'cancer pain' expressed in 1990 draws attention to the necessary changes in the protocols for patient care that can only be implemented through policy development, training healthcare professionals and opioid availability. In 2002, the proposed measures for a cancer control programme includes the implementation of palliative care measures to prevent 'ultimate suffering' and requires the reorganisation of resources to increase coverage for patients in advance stages of disease in low-resource settings. In both instances, palliative care is associated with ideas of pain relief and control of symptoms and other problems, which implies that the problem is being thought of as a 'clinical' problem. The definitions of palliative care presented in both 1990 and 2002, are associated with ideas of "control of pain and other symptoms" (WHO, 1990, p.11), "early identification, impeccable assessment and treatment of pain and other problems" (WHO, 2002, p.84), thus indicating the clinical purposes of palliative care. Both the 1990 and 2002 guidelines therefore problematise the protocols for patient care in place for cancer patients.

Problematising protocols for patient care targeted population implies that current protocols are inadequate, and hence, this is how the problem is represented to be. Understanding the problem as the 'inadequacy' of protocols for patient care, implies that changes must be made to the ways care is provided, health professionals are trained, and policies are developed guided by ideas of pain relief and control of symptoms. Additionally, since palliative care is identified as the most appropriate clinical protocol in both guidelines, they require reorganisation of resources to ensure palliative care for patients with advanced stages of disease, as proposed in the 2002 *National Cancer Control Programmes*.

Problematising protocols of care as 'inadequate' is also observed in the guidelines from 2004 until 2011, where the emphasis on the public health implications of problems such as “serious chronic progressive illnesses” (WHO, 2004b, p.6) and “ageing population” (Davies & Higginson, 2004), are understood to create challenges for healthcare systems (WHO, 2011). Healthcare systems are assumed to be failing to meet the needs of those living with chronic illnesses and to offer ‘substandard’ end-of-life care. With an emphasis on individual needs, palliative care measures are proposed “from the time of diagnosis, alongside potentially curative treatment, to disease progression and the end-of-life care” (WHO, 2011, p. 6).

These measures extend the scope of the clinical applicability of palliative care and, in this sense, the problem is also being identified in clinical terms, through ideas of inadequate protocols of care. Adequate protocols of care are now understood as directed to help people adapt and cope with their condition as well as promoting better care at the end-of-life. Moreover, the new standards for patient care required ‘flexibility’ from healthcare systems to allow ‘care’ to be provided according to individual preferences and choices. This need for flexibility implies a problem of capacity where healthcare systems are being required to implement ‘palliative care’ more broadly within healthcare systems as exemplified by the statement:

> A more appropriate concept is that palliative care is offered from the time of diagnosis, alongside potentially curative treatment, to disease progression and the end of life. Palliative care component of healthcare that can be needed at any time in life, starting at a low base and rising to eventually become the predominant theme for many people (WHO, 2011, p.6).

What the extract above indicates is that there are overlapping problematisations where the 'inadequate care' justifies the changes proposed in the system's 'capacity'. The problematisation of healthcare capacity was emphasised more recently in the guidelines from 2016 until 2018. Within these documents, palliative care services were expressed as being associated with goals to increase coverage which in turn is articulated as a particular necessity for countries with fewer healthcare resources (WHO 2016, 2018). Palliative care is associated with ideas of healthcare 'performance', 'costs' and 'coverage' problematising the deficiencies of healthcare provision and the socioeconomic conditions of LMIC's.

In this sense, the problem is being thought about in terms of healthcare capacity, indicating a wider understanding of 'palliative care' in response to social rather than medical problems. Representing the problem as 'capacity' directs attention to healthcare competence instead of the burden of palliative care services on healthcare systems and health institutions. This representation requires changes in service delivery that are mainly focused on deinstitutionalised care.

Having identified how problems were constituted within the WHO guidelines for palliative care first as a clinical problem conceptualised as 'inadequacy of care' and as a service provision problem implied as a 'healthcare capacity' problem, this chapter answers the first task of a WPR framework represented by the question entitled in this section. A key proposition of the WPR is that we are governed through 'problematisations' (see chapter 3), and in this sense, further development is required to understand how the representations of problems as 'inadequacy of care' and as 'healthcare capacity' are operationalised within guidelines.

4.3 Summary

This chapter aimed to perform a central task of the WPR framework and the first step of the analytical strategy, which is to understand how problems are 'made' into specific types of problems. In order to understand how problems were constituted, the chapter first discussed how palliative care is proposed in the selected guidelines from 1990 until 2018. The discussion organised chronologically allowed comparisons on the ways in which guidelines have recommended palliative care over time. The table below provides a summary on the type of problems guidelines were set to address and how these led to the identification of 'inadequacy of care' and 'healthcare capacity' problematisations:

Guideline	Proposals for change	What is deemed as problematic	Problematisation
Cancer Pain Relief and Palliative Care (1990)	Offers protocols for adequate pain relief and palliative care	Failing to meet advanced cancer patients needs for pain relief and symptom management leads to a death in suffering	What is being problematised is the lack of appropriate clinical protocols for patient care for advanced cancer patients.
National Cancer Control Programmes (WHO, 2002)	Offers recommendations for patient prioritisation and resource allocation considering the different levels of resources.	Patients with cancer and other life-threatening illnesses should be able to receive palliative care earlier in the illness trajectory.	What is being problematised is the timing of clinical intervention and patient prioritisation considering low levels of resources.
The Solid Facts (Davies & Higginson, 2004);	Argues for the inclusion of palliative care measures for 'older people'	The population is ageing, and healthcare systems should be prepared to meet their needs.	What is being problematised is the lack of palliative care measures for older people due to constricted services to cancer care.
Better Palliative Care for Older People (WHO, 2004)	Proposes palliative care in order to 'meet' older peoples' needs and preferences of care	The needs of 'older people' are unmet due to underassessment and lack of palliative care measures	
Palliative Care for Older People: Better	Proposes forms of service integration	Countries must integrate palliative care measures broadly so that other end-of-	

Practices (WHO, 2011)	aiming meet the needs of ‘older population’	life care needs such as ‘older population’ can be met.	
Planning and Implementing Palliative Care Services (WHO, 2016)	The publication aiming to offer guidance on strengthening and implementing services within existing healthcare systems, targets development of palliative care services in low- and middle- income countries.	Approach outlined is recommended in response to inequalities in accessing palliative care.	What is being problematised is the lack of access to palliative care services due to lack of integration into healthcare systems.
Integrating Palliative Care and Symptom Relief into Primary Healthcare (WHO, 2018)	Advice is offered on how to integrate palliative care into primary healthcare (PHC).	Implementation of palliative care is also introduced as in response to inequalities of access, to which PHC is the recommended strategy.	What is being problematised is the lack of integration of palliative care services within PHC. This leads to voids into healthcare coverage and contributes to the lack of access to palliative care services

Table 3. Summarising problematisations

The next chapters will be dedicated to demonstrating the findings from the subsequent tasks such as identifying the systems of meanings in place, offering a genealogical perspective in order to offer temporal and spatial context, identifying the silences in representing the problems as ‘inadequacy’ and ‘capacity’ and lastly questioning how understanding the problem in this manner produces subjects, constricts what can be done and said regarding palliative care.

Chapter 5. Problematising Care

The previous chapter was dedicated to discussing how guidelines constitute problems as problems of a certain type. Aiming to answer the question “what’s the problem represented to be in palliative care guidelines?”, the previous chapter brought visibility to the rationale provided for palliative care programmes across the WHO guidelines and how these rationales fostered specific ‘problems’. These ‘problems’ were conceptualised as ‘inadequacy of care’ and ‘healthcare capacity’.

Focusing on the ‘inadequacy of care’ problematisation, this chapter will follow the analytical steps two, three and four as described in chapter three. Beginning with an examination of the premises and assumptions underlying the representation of ‘inadequacy’. The first part of the chapter will introduce an analysis of the system of meanings in place, thus involving how concepts, categories, and binaries constitute the problematisation (step 2). The analysis will bring visibility to the necessary meanings that need to be in place to confer meaning to the problem as ‘inadequacy’. This section will be followed by a genealogical perspective that allows disentangling of the threads that led to the emergence of ideas of ‘inadequate care’ (step 3). In sequence, I will consider the silences imposed by thinking of the problem as ‘inadequacy’ and examine how understanding the problem as ‘inadequate care’ makes it difficult to see ‘palliative care’ in a different light (step 3). Lastly, the chapter will focus on identifying how the problematisation produced discursive effects and on understanding how ‘inadequate care’ produces subjects as particular kinds of subjects (step 4).

5.2 Examining the conceptual premises of ‘inadequacy of care’ (Q2)

To recap the WPR approach, as discussed in chapter three the examination begins by investigating what is proposed as change and working backwards to understand how they constitute ‘problems’ (Bacchi, 2009). As identified in the previous chapter, WHO guidelines from 1990 until 2011 recommend palliative care to promote quality of life and comfort in the advanced stages of illness, before death and when actively dying, for cancer patients; and to meet the needs of the older population living with chronic illnesses. The measures proposed by the guidelines aimed to introduce palliative care to address the perceived clinical problems regarding the care of cancer patients and older people. In turn, I argued that these recommendations implied that current protocols for 'care' are being thought of as 'inadequate', hence the problematisation 'inadequacy of care'. This brief outline of how the problem of 'inadequacy' was constituted (for more details see chapter 4), offers the basis for identifying the grounding assumptions within this problem representation. Starting with the conceptual premises underpinning the 'inadequacy of care' problematisation, the next section begins by identifying categories, key concepts, and binaries to understand how they confer meaning to 'inadequacy', the guidelines will be examined in chronological order.

5.2.1 The Premise of Quality of Life

Starting with the 1990 *Cancer Pain Relief and Palliative Care* guideline, statements such as "the quality of life in these patients would be greatly improved by access to palliative care throughout the course of their illness" (WHO, 1990, p.15) as well as "the greatest improvements in quality of life of cancer patients and their families could be effected by implementation of existing knowledge of pain and symptom control" (WHO, 1990, p.14), indicates a concern with the suffering of cancer patients. Other statements such as: "the goal of palliative care is achievement of best quality of life for patients and their families" (WHO, 1990, p.11) and "palliative care aims to maintain or improve quality of life of patients with incurable illness, and its impact may be evaluated by 'measuring quality of life'" (WHO, 1990, p.18). These statements establish a central premise of the guideline, that is, the achievement of quality of life through palliative care.

In 2002, the *National Cancer Control Programme* guideline introduced the development of cancer control programmes which involved prevention and control "with the ultimate goal of reducing cancer morbidity and mortality and improving the quality of life of the targeted population" (WHO, 2002, p.ix). As such, this framework, like the *Cancer Pain Relief and Palliative Care* (WHO 1990) also expressed the goal to improve quality of life. Quality of life is expressed through palliative care as "an approach that improves quality of life of patients and their families' facing problems associated with life-threatening illness (…)" (WHO, 2002, p.xv), thus arguing that palliative care will lead to 'quality of life' for cancer patients.

Likewise, in 2004 until 2011 the guidelines also expressed similar goals and ideas, that improving the quality of life of older people: "healthcare systems must be able to meet the needs of these people by reducing suffering and supporting people of all ages to live well and maintain their quality of life for as long as possible" (WHO 2004a, p.8). In this instance, it is argued that palliative care should be extended to a wider range of illnesses and conditions, quality of life is argued through the 'effectiveness' of palliative care to diseases other than cancer (WHO, 2004a, 2004b).

As discussed previously (chapter 4), the premise that palliative care will lead to a better quality of life is articulated through the notion of suffering of cancer patients (WHO 1990), to preventing symptoms becoming unmanageable (WHO, 2002) and through meeting the needs of older people and those living with chronic conditions other than cancer (WHO 2004a, 2004b, 2011). In all cases, palliative care is recommended as a 'solution' to perceived clinical problems. Underlying the concept of 'quality of life' is the idea that palliative care is valuable to 'people' such as 'cancer patients' and 'older people' which are key categories, as will be discussed next.

5.2.2 Categories: People and Disease

The previous section identified that the inadequacy problematisation is underpinned by the premise that palliative care will improve patients' quality of life. In this section, I will examine how the categories such as 'cancer patients' and disease categories such as 'pain', 'symptoms' and 'problems' associated with 'cancer' and 'suffering' are operationalised to confer meaning to palliative care as the 'adequate' form of patient care.

In 1990, the people category of 'cancer patients', is portrayed through the notion of suffering: "it is also conservatively estimated that at least 4 million people are currently suffering from cancer pain, with or without satisfactory treatment." (WHO, 1990, p.19). It therefore makes it important to make visible the concepts that underpin the notion of suffering cancer patients are perceived to experience. The suffering of 'cancer patients' is therefore due to inadequate pain relief. The category of 'pain' is understood in terms of 'total pain':

> Identification of both the physical aspects and the non-physical components is essential to the provision of appropriate treatment. The concept of "total pain" to encompass all relevant aspects of pain is useful; it includes the noxious physical stimulus and also psychological, social and spiritual factors (WHO, 1990, p. 20).

The category 'cancer patient' is thus inextricable to the category of 'cancer pain' which in turn is operationalised through the concept of 'total pain'. Key to the premise of quality of life described above is the assumption that controlling 'total pain' would lead to an increased quality of life for these patients. Their 'quality of life' is measured by the 'suffering'. In the 1990 guideline, the effectiveness of palliative care is measured by a reduction of 'suffering' (ill-feeling) and "changes in positive feelings and happiness" (well-being) (WHO, 1990, p.18). This implies that having 'total pain' managed will enable patients to feel better and eventually have a better life:

> Length of survival is frequently taken as the only measure of treatment success: for example, a recent review of chemotherapy studies in patients with incurable cancers could not identify any data on pain relief or other aspects of quality of life. Yet, how are a few months of additional life, involving treatment at a high cost and with major adverse effects be evaluated? During this time the patient may have no capacity to enjoy life and suffer pain, despair and isolation from family and friends (WHO, 1990, p.18).

Additionally, the association of 'pain relief' to wellbeing also refers to ethical concerns where 'pain' needs to be treated even if it affects the patients' life expectancy (WHO, 1990, p.52). 'Quality of life' is therefore the ethical principle guiding clinical practice in managing the dying process. For example, it is argued that "in many countries, people have come to accept the notion that aggressive life-support, at intolerable personal cost, is not the right course to take" (WHO, 1990, p.53); yet patients should be allowed to die peacefully (ibid) free from pain "that may leave the patient physically and mentally incapable of reaching whatever goals he or she may want to achieve before death" (WHO, 1990, p.52). 'Quality of life' thus serves as a guiding principle for 'cancer patients' who are assumed to want to have their lives improved, thus drawing attention to notions of personhood, of a self who has goals to achieve (to be further developed in section 5.5).

In the 2002 *National Cancer Control Programmes*, palliative care is also argued as to "improve the quality of life of patients and their families" (WHO, 2002, p.84). Likewise, the category 'cancer patient' is also discussed in relation to suffering from pain and other distressing symptoms. However, in this guideline 'symptoms' are articulated as preventable: "symptoms not treated onset become very difficult to manage in the last days of life" (WHO, 2002, p.83). In this sense, the goal of achieving quality of life refers less to ideas of 'pain relief' and helping patients achieve their 'goals' and more to ideas of preventing symptoms from becoming unmanageable.

The premise of ‘quality of life’ is understood through notions of “impeccable control of symptoms throughout the course of illness” (WHO, 2002, p.83). The impeccable control thus, would influence patients’ quality of life by reducing suffering but also positively influencing the length of life “through mediation of cytokine-stress reaction associated with symptoms” (ibid). This understanding seems to be rooted in a biomedical perspective of ‘health’ as the absence of ‘disease’, which in this case is articulated by associating quality of life to the absence of symptoms.

The category of patient is expressed as: “patients with advanced cancer suffer from multiple symptoms that need to be assessed and charted on a regular basis” (WHO, 2002, p.87). This definition indicates how the category of ‘patient’ is understood in biomedical terms of ‘symptoms’ that need to be regularly assessed to achieve the desired ‘symptom control’. Importantly, since the guideline recognises that patients should receive psychological, social and spiritual support, controlling symptoms also requires that healthcare professionals “assess these needs” in order to “respond with a holistic approach” (WHO, 2002, p.87), which inserts psychological, social and spiritual needs in the same logic of ‘symptom control’.

Moreover, while the 1990 guideline asserts that achieving quality of life is associated with ideas of ‘enjoying life’ and ‘reaching goals’, in the 2002, psychological support is understood in terms of helping people accept the reality of death. Here, patients are understood to “want information about their illness” (WHO, 2002, p.90), to which good communication and an atmosphere of sensitivity and compassion will enable patients to ‘accept’ their reality: “progressive acceptance by the patient of what is happening often occurs naturally and slowly in a truly supportive environment” (ibid). Understanding ‘what is happening’ is a condition for patients to “unburden themselves” and “share their anxieties and fears", without it, "pain and other symptoms may become the intractable avenue through which psychosocial distress is expressed" (Twycross, 1994 as cited in WHO 2002, p.90). In this sense, 'expression' becomes a necessity for adequate pain relief. Unburdening patients of fears and anxieties reproduce the notion of the patient as a psychological self, associated with dying as a psychological/emotional process rather than physical. This notion of the patient as a psychological self-differs from the previous ideas of 'patients' operationalised through ideas of symptoms, thus identifying a variation in ontological assumptions (see section 5.5 for subjectification effects).

Providing 'quality of life' is particularly important to 'older people' whose suffering is understood as the 'unmet needs' of people. Healthcare should be 'tailored' to respond to people's needs which includes: "ensuring good pain and symptom control, comfort, sensitive communication, clear information and a coherent package of care" (WHO, 2004a, p.8). WHO asserts that the recommended changes can help "people live meaningfully until the end of life and support their families afterwards" (WHO, 2004a, p.9), which implies similar understandings of the premise established in 1990. In this light, ensuring palliative care would help people live more meaningful lives which continues to reproduce notions of the patient as a psychological self and a good death as something that can be achieved with the help of palliative care professionals.

As expressed in the booklet the *Solid Facts*, healthcare should be offered in "respect for individuality" in which "every patient has his or her own story, relationships and culture, and is worthy of respect as a unique individual" (Saunders in Davies & Higginson, 2004, p. 7) . What follows is that the notion of suffering in this case refers to "values and preferences" (Davies & Higginson, 2004, p. 18). Especially regarding the place of death, choice is understood to be "a core value of palliative care" (ibid, p.19).

The notion of patient choice is explicitly expressed in the 2011 booklet where the

WHO ‘health systems’ approach is introduced with three goals: to improve the health status of the population; to improve fairness of financing; and to improve responsiveness to the non-medical expectations of the population with respect for people and client orientation. The WHO argues that palliative care is “especially relevant to the latter because it is concerned with the psychosocial aspects of care, dignity and quality of life of individuals and their families” (WHO, 2011, p.7). In this sense, this understanding of healthcare reflects notions of patients as ‘consumers’ to which palliative care is being proposed in response to people’s choices and preferences, to meet individual needs rather than ‘symptoms’.

This section discussed the premise that palliative care will lead to improved quality of life. I have argued that this premise is constituted and articulated through specific meanings attributed to people categories such as ‘patients’ and ‘older people’ associated with disease categories of ‘cancer’, ‘pain’, ‘symptoms’ and ‘needs’. The association of quality of life and palliative care confers meaning to other forms of care as inadequate. One obvious interpretation of this premise is that palliative care is argued through a binarism inadequate care versus adequate care, whereby palliative care is positioned on the positive pole.

5.2.3 Binarism Inadequate Care vs Adequate Care

As discussed above, problematising care is articulated through a binary structure (i.e., inadequate vs adequate), which places palliative care as adequate. Each guideline gives insight into the appropriate conditions countries must ensure in order to provide palliative care. It is to this point that I now turn.

5.2.3.1 Opioid availability

Starting with the 1990 guideline, government action towards palliative care is divided into those who contribute to the quality of life of cancer patients and those who neglect them. The argument for palliative care integration into healthcare systems reflects how government action is understood through this notion of suffering: “these figures provide evidence that national health plans must include the provision of palliative care for the millions of people who would otherwise suffer considerably in the weeks and months before death" (WHO, 1990, p.14). In this sense, neglecting palliative care is the same as neglecting patients: "globally however, palliative care is still a neglected area, and several million cancer patients suffer needlessly everyday as a result" (WHO, 1990, p.14). In contrast, countries where service provision exists, improvement on the quality of life of patients and their families is attributed to:

> The development of palliative care centres; a greater understanding of the use of analgesic drugs; demands from patients and families for better symptom control and a consensus that adequate symptom control and good quality of life are particularly important in patients with advanced disease (WHO, 1990, p.14).

The majority of countries are understood to be in the negative pole of the binarism inadequate/adequate due to a variety of factors relating to deficits in: "national policies on cancer pain relief and other aspects of palliative care" (WHO, 1990, p.15); education across "healthcare workers, policymakers, administrators and the general public"; and restrictions imposed by regulatory and legal constraints regarding opioid availability (ibid). Regarding the latter, the evidence provided in the 1990 guideline indicated that higher levels of pain control are related to the higher levels of opioid use: "one reason for better results was a significantly greater use of orally administrated morphine and related drugs (…). These results indicate that professional and public expectations about the successful management of cancer pain can be raised considerably" (WHO, 1990, p.22).

In this sense, the line that separates countries into adequate/inadequate is significantly associated with the use and availability of analgesics, as expressed in the statement that follows there is no pain relief without drugs: "the field tests confirm that treatment with non-opioid, opioid, and adjuvant drugs is the mainstay of cancer pain management" (ibid). This logic is expressed in the classification of countries according to their levels of morphine consumption as an indicator of 'pain relief'. Although it is acknowledged that this indicator is limited, as there are other drugs used for cancer pain relief, it is still perceived as the best criteria to give insight to the status of cancer pain treatment (see WHO, 1990, p.24).

Countries from the global north are identified as having higher morphine consumption as demonstrated by the top 10 countries: Denmark, New Zealand, United Kingdom, Iceland, Canada, Australia, Ireland, Norway, Sweden, USA (WHO, 1990, p.26). WHO argues that countries consuming more morphine will be able to offer cancer patients higher standards of care than those who lack adequate provision (WHO 1990). Opioid availability can be seen more widely available in countries of the global north which suggests that countries in the global south could be disadvantaged by understanding the lack of opioid availability as 'inadequate' care.

5.2.3.2 Service/Absence and Efficiency/Inefficiency

The premise that palliative care leads to improved quality of life is observed in the 2002 guideline where WHO states that is the "fundamental responsibility of the healthcare profession is to ease the suffering of patients" (WHO, 2002, p.86). However, instead of focusing on classifying adequate/inadequate provision, this guideline emphasises the insufficient provision of palliative care within public health and disease control programmes:

> Throughout the world, governments, medical-nursing societies and nongovernmental organizations have expressed strong support for WHO's definitions of palliative care and have endorsed the integration of their principles into public health and disease control programmes. Despite this acceptance, a yawning gap is evident between rhetoric and realisation. A national disease control plan for AIDS, cancer and noncommunicable disorders cannot claim to exist unless it has an identifiable palliative care component (WHO, 2002, p.87).

In this light, the statement above introduces a binarism, palliative care providers versus non-providers, where countries who provide palliative care are in the positive pole. There is a moral aspect in the interpretation of government action where without "strong political motivation and leadership" palliative care measures will not succeed (Stjernswärd, 1993 as cited in WHO, 2002, p.87). As a result, it is argued that the lack of service provision will lead to many people dying "from preventable cancers and suffering unnecessarily from pain and anguish at the end of their lives" (WHO, 2002, p.iv). Thus, the binarism service/absence attributes responsibility for the status of cancer pain relief to government's lack of engagement. This opens space to question a governments' ability in the provision of palliative care:

> Lack of a comprehensive, systematic approach, weaknesses in organization and priority- setting, and inefficient use of resources are obstacles to effective programmes in both industrialized and developing countries. In far too many cases, primary prevention, early detection and palliative care are neglected in favour of treatment-oriented approaches, regardless of whether they are actually cost-effectiveness or whether they improve patients' quality of life. This happens because of lack of knowledge, lack of political will and lack of national capacity in policy development and programme implementation (WHO, 2002, p.v).

Conversely countries with a "well-conceived, well-managed" national programme are "able to lower cancer incidence and improve the lives of people living with cancer" (ibid). Setting out these standards of care delivery introduces another binarism of efficient care versus inefficient care. What is proposed in this efficiency/inefficiency binarism is that provision or not of palliative care services is associated with a country's ability to efficiently managed a healthcare system: "without careful planning, there is a risk that the resources available for cancer control will be used inefficiently, and that the benefits to the population will not be realised" (WHO, 2002, p.114). Attention therefore is redirected to management and resource allocation: "in the absence of any national coordinating mechanism, it is possible that limited resources will largely be consumed for the treatment of cancer by prestigious hospitals" (ibid). Conversely, "an effective cancer control programme comprises an integrated set of activities covering all aspects of cancer prevention and control, and it operates with an appropriate allocation of available resources among the various activities and equitable coverage of the population" (ibid), thus indicating that countries who adopt the measures proposed in this document will succeed, while countries who do not adopt the measures will fail. Once more binarism leads to a classificatory system in which countries are separated. The binarism efficiency/inefficiency is used to classify a country's ability in managing a cancer control programme and to attribute responsibility for those in the negative pole for their lack of engagement.

5.2.3.3Meeting Preferences

Appropriate care for patients and families leads to helping people live a "meaningful life" as observed in the 2004 guideline (WHO, 2004a). Offering palliative care more widely and integrated broadly into healthcare systems should address the 'neglect' palliative care has received from public health. As observed previously, 'quality of life' is associated with ideas of individuality and preferences, the adequacy/inadequacy binarism is also the structure through which 'healthcare' is interpreted as responding to individual needs as the adequacy pole.

As indicated in the guideline there are important concerns over the way in which care should be delivered and how people's choices can be responded to (WHO, 2004a, p.16).

WHO assert that simple measures of palliative care can improve patients' outcomes: "these include adequate pain and symptom relief, good communication and information, and coordinated care from teams of skilled professionals who help meet preferences for care" (WHO 2004b, p.32) and, in doing so, demonstrate healthcare as a response to peoples' preferences.

> However, if people do not receive information on what care is available, it is difficult to argue that the best care has been offered. Currently, most healthcare systems are not set up in a way that makes it easy for people to receive palliative care or to die where they would wish. In many countries data on place of death are not collected nationally (WHO, 2004a, p.17).

Meeting preferences continues to be developed in the WHO approach to public health introduced in 2011, where emphasis is given to palliative care in response to a client-orientation approach, thus enabling 'choice' and meeting 'preferences' is the line that separates adequacy from inadequacy. Since responding to individual needs is the measure of success, countries where ideas of making end-of-life care choices is not culturally appropriate are disadvantaged.

5.2.3.4 Summary

The discussion above identifies that the argument for palliative care fostered in WHO guidelines from 1990 until 2011 is centred around the notion of 'suffering' attributed to people categories such as 'cancer patients' (WHO, 1990), patients living with chronic illnesses (WHO, 2002) and older people (Davies & Higginson, 2004; WHO 2004, 2011). The guidelines were argued to constitute a binarism where the population assisted by palliative care measures are deemed to have a better quality of life, symptoms controlled, their needs met, and preferences respected. Conversely, the absence of palliative care measures is deemed problematic.

Additionally, since palliative care is positioned in the positive pole, other forms of care such as prolongation of life and curative treatments are silenced. Governments who provide palliative care measures are deemed as contributing to patients' quality of life while the absence of palliative care are constituted as neglect. Moreover, establishing meeting preferences as the line that separates adequate and inadequate care places issues such as cultural diversity and equity into a cultural competence problem. In this sense, the system of meaning in place confers 'inadequacy' to countries who do not conform with opioid availability, who have problems in managing healthcare systems efficiently and those who fail to meet individual preferences.

5.3 Contextualising 'inadequacy of care' (Q3)

The previous section was dedicated to discussing how the 'inadequacy' problematisation is constituted by examining premisses, key categories and binaries. The premise that palliative care implementation is an investment towards people's quality of life holds the idea that through palliative care, patients would be better cared for, which generates quality of life which in turn reduces suffering at the end-of-life. This section will be dedicated to tracing the genealogy of ideas of inadequate care.

A genealogy on 'inadequacy' is better suited to examine the heterogeneous conditions upon which a new idea emerged, specifically regarding the power struggles and subjugated knowledge that underlies the notion of 'inadequate care'. In this sense, the goal of this genealogy is to examine how 'inadequacy of care' is embedded in a social and cultural context and to identify which processes and knowledge went into identifying 'care' at the end-of-life as problematic.

5.3.1 Shaping Inadequacy

According to Saunders (1993), the opening of St Christopher's alongside other institutions such as independent hospices, and initiatives such as National Society for Cancer Relief led to the development of the principles set out in the Cancer Pain Relief and Palliative

Care report (WHO, 1990). Here, palliative care affirms life and regards dying as a normal process; neither hastens or postpones death; provides relief from pain and other distressing symptoms; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; and offers a support system to help the family cope during the patient's illness and in their own bereavement (WHO, 1990, p.11). The emergence of palliative care within WHO's agenda was therefore the direct outcome of professional and institutional knowledge. However, as argued by Clark (1998), the notion that developments from the hospice movement were arbitrary is unsatisfactory. Instead, he argues that the opening of St Christopher's hospice, which culminated in developments such as those exemplified above, was rather the outcome of "ideas and strategies developed prior over the preceding decade" (Clark, 1998, p.44) to incite better care for the dying (see chapter 2).

As this genealogy will show, ideas of inadequacy were not constricted to medical practice but involved other institutions and processes such as changes in the clinical criteria of death and religious practices towards the dying. The assemblage of practices converged to suggest that the care of the dying was in fact inadequate. Political and economic struggles were also involved in the process of adopting the 'inadequacy' discourse as this examination will demonstrate below.

At first, ideas of a new model of care for the dying was sitting at the margins of formal healthcare and international healthcare debates. Saunders was beginning to demonstrate the clinical possibilities of 'terminal care' in the late 50's through the paper entitled 'Dying of cancer'. Published in 1957, this paper addressed the issue of cancer patients where she expressed the ideas that later would become central features of the modern hospice philosophy. These ideas identified the value of special homes for dying patients; spiritual concerns of the dying; the disclosure of diagnosis; nursing care and pain management (Clark, 1998). Not long after her first publication, drafts of what later would become the hospice movement, entitled at first as ‘The Scheme’ revealed a concern with proposing and disseminating ideas for a home dedicated to care for the dying (ibid). Clark (2016) argues that these propositions emerged in the British National Health Service (NHS), in a time when there was no formal commitment to terminal care as a clinical issue nor a system dedicated to care for those near death. Even though her ideas gained support from peers in the late 50’s there was still no significant changes in how services were provided.

According to Clark (2016), in the period from 1948 to 1967, a new “disposition towards the care of the dying” emerges, which includes the development of a new “specialised focus within medicine and healthcare” (Clark, 2016, p.16). Stolberg (2017) also identifies significant changes in the disposition towards the care for the dying in the post-war era, especially in English-speaking countries, when attention was being directed to “the grave deficiencies in the prevailing treatment of the terminally ill and dying patients in hospitals” (Stolberg, 2017, p.174). A number of researchers concerned with the terminally ill published their personal stories, highlighting their battle with prolonged illness (Kubler-Ross, 1969), the search for meaning (Saunders, 1990) but also portraying the struggle against dying under medical care and hospital settings (Sudnow, 1967). These came accompanied by notions of ‘alienation’ and ‘paternalism’ that prevented patients from having any “authentic” experience of dying as well as raising questions on how treatment led to a decrease in ‘quality of life’ (Stolberg, 2017, p.177).

In parallel, the mid twentieth century, the formative years of the hospice movement is also marked by changes in the international landscape of ‘health’. Defined in the early years of the constitution of WHO ‘health’ is “not only the absence of illness”, rather a “fundamental human right and an obligation of states” (Cueto, Brown and Fee, 2011 as cited by Cueto, 2018, p.5), thus formalising ‘health’ as something beyond physical care. Ideas of health as ‘wellbeing’ began to appear in the international landscape through WHO, associated to issues of “social security, housing and nutrition” (Larsen, 2021, p.8), indicating a broader concept of ‘health’ in alignment with welfare policy. In 1948, the Universal Declaration of Human Rights established health and wellbeing as a ‘human right’ (ibid), which indicated a concern with problems other than the cure of acute infectious diseases as experienced in the previous century (Turner, 1996). According to Larsen (2021), the conceptualisation of health in terms of wellbeing was prompted by political and scholarly ambitions to expand the understandings of health and health policies beyond medicine, which envisioned WHO as an organisation to secure health insurance and social security globally.

In the second half of the 20th century, doctors in industrialised societies, were confronted with the increase of chronic diseases as the leading cause of death, which, for prolonged periods of time, prevented individuals from social life (Turner, 1996). This marginalisation of people living with chronic disease paved the way for ideas of rehabilitation and care, over cure (ibid). As Turner (1996) identified: “general practitioners will come to depend more and more on sociological skills as their education in the physiological, chemical and biological aspects of disease and illness becomes increasingly less relevant in the treatment and management of patients” (Turner, 1996, p.8). Knowledge that were otherwise subjugated in the field of medicine were therefore constitutive of medical practice. District nurses began to survey patient’s needs of appropriate housing and level of information about their illness, as well as increased care provision of night nursing (Clark, 2016). In doing so, healthcare began to look more like what Turner (1996) observed as an increased integration of sociological knowledge into medicine: “the problem of long-term illness and its management will be addressed more effectively by sociological perspectives than by purely biomedical perspectives” (Turner, 1996, p.8).

Additionally, ideas of dignity and wellbeing were also reflected in the Vatican’s attitudes towards the dying when, in 1957, the Vatican established ‘passive euthanasia’ as an acceptable medical practice. As expressed in the Pope’s address to the Italian Society of Anesthesiology, voluntary euthanasia is a morally condemned practice, however, with the patient’s consent it is allowed for patients to have their suffering relieved using analgesics, even if these may lead hastening the dying process. In this case, the Pope argues that death was not directly willed, it was an unavoidable consequence of disease and thus using medication to relieve the suffering is deemed as “proportionate reasons authorize measures that will hasten her arrival” (Pius XII as available in AAS 50, 1958, p.687-696). Despite not mentioning the hospice movement or Saunders, it is possible to observe that ideas of reliving suffering to maintain dignity at the end of life are in clear alignment with Saunders’ proposals of hospice care.

The alignment between Catholicism and Saunders ideas discussed above is not new. From 1958 to 1967 Saunders had 30 publications targeting various audiences, which included the Church Unions (Clark, 1998). Additionally, in 1993 Saunders aligned the development of the modern hospice to the early hospices of the 19th century (see chapter 2 for more details). Her experience in these institutions shaped much of what it would later become her proposal for new homes for the dying: “It was the first few years of experience at St Luke’s and an awareness of much pain and isolation in both hospital and at home that led me to another step, medical training, with this area of need in mind” (Saunders, 1993, p. 5). It was also in a Christian hospice working with nuns that she developed the regular opioid regime that was later adopted by the WHO in the Cancer Pain Relief and Palliative Care (WHO, 1990).

Saunders correspondence included professionals and academic institutions in the US that allowed a visit to perform several activities from producing an extensive study on US’s approaches to terminal care, lectures in different cities and visits in institutions such as hospitals, home care settings and academic institutions, galvanised support for her ideas

(Clark, 1998). Her connections with colleagues at Yale in the 60's produced the new model of hospice care that led to the establishment of palliative care in an acute hospital in 1976 at St Thomas' Hospital in New York (Lewis, 2007). Clark (2014) attributes these developments in the US as a reaction "against the wrong sort of involvement of medicine with the dying" (Clark, 2014, para) where ideas of home care surrounded by family members combined with a holistic approach to patient's needs replaced ideas of depersonalisation and suffering associated with acute hospitals. This was a time when medical technology allowed the creation of new criteria to separate life and death, raising debates on the benefits of artificially prolonging life.

In 1968 the ad hoc committee of Harvard changed the clinical criteria of death to 'brain death' supplanting the previous clinical signs of death such as stopped heartbeat and respiration (Giacomini, 1997), comes associated to technologies of life support blurring the lines between life and death. As Giacomini (1997) observes, on one hand medical technology allowed the creation of new types of dead bodies and on the other created new lives through new technologies such as organ transplant. The first heart transplant performed in 1967 intensified the need to reconceptualise the moment of death in the following year (ibid). In parallel in the same year Cicely Saunders called for a 'positive' approach towards death not as a medical failure but as "life fulfilment" (Clark, 2016, p. 104) allowed new forms of thinking 'end-of-life', continued to reflect questions on the use of medical technology on the care for the dying.

5.3.2 Inadequacy of Care and WHO

Ideas of inadequate 'end-of-life' seemed to have permeated professional circles in contact with Saunders' ideas as well as religious authorities who began to recognise the limitations of modern medicine. However, such concerns did not reach WHO's activity in the early 50's and 60's, when the focus on international health was concentrated on vertical campaigns to eradicate infectious diseases through technological, administrative, and financial operations, seemingly favouring a technocratic approach to ‘health’ (Cueto, 2018).

The technocratic activity from the WHO can be demonstrated in the emergence of expert committees, where experts around the world were concerned in establishing the lines between “acceptable”, “mistaken” or “unorthodox” knowledge (Cueto, 2018), thus signalling the beginning of systematically organised expert approved knowledge that are at the basis of WHO’s publications. One accomplishment of the WHO at this time was the first International Health Regulations (IHRs), that provided a legal framework establishing a country’s rights and obligations concerning international public health (ibid). The IHR appeared in 1969 and was mainly concerned with infectious diseases such as ‘cholera, plague, smallpox and yellow fever’ (ibid). The focus on vertical campaigns aiming to eradicate transmissible diseases continued throughout most of the twentieth century and appears to dismiss discourses of inadequacy of end-of-life care. As observed in the emergence of the academic discipline ‘international health’ in the US, this field was primarily constituted by interests in addressing health needs in low-income countries primarily through what industrialised countries assumed was best for medicine and public health (Brown and Fee, 2011 in Cueto, 2018). In this sense, although there are some international developments in ideas of inadequate terminal care, these were not deemed an ‘international health’ concern as demonstrated through the absence of this discourse both academically and within the WHO.

Yet, while inadequacy was absent within the WHO, the European Union considered the effects of medical technology on the care for the dying in 1976. The Parliamentary Assembly in the European Union recognised the effects of medical technology, as evidenced in statements such as: “considering that the rapid and continuing progress of medical science creates problems, and may even pose certain threats, with respect to the fundamental human rights to the integrity of sick people” Assembly debate on 28 January, 1976)., indicates that ideas of inadequate care and the poor quality of life of dying patients were officially recognised by government authorities.

The Council recommended at the time that governments of the member states: “take all necessary action, particularly with respect to the training of medical personnel and the organisation of medical services, to ensure all sick persons, whether in hospital or in their own homes, receive the relief of suffering as effective as the current state of medical knowledge permits”; to allow patients to be fully informed if they do so wish and to give them “opportunity to prepare themselves psychologically to face death” (Assembly debate on 28 January, 1976). Despite not mentioning ‘palliative care’, the Assembly illustrates how ideas of inadequacy are associated to medical technology and hospital care to which the recommended solution refers to ideas of the relief of suffering, awareness and psychological dying similar to what was proposed by Saunders and others in the late 50’s and 60’s.

While ideas of inadequacy gained official governmental support in Europe, there was still no official engagement from the WHO (see Clark 1998; Clark 2016). Brown, Cueto & Fee (2006) describe how the WHO, in the years between 1960’s and 70’s, was facing political struggles. For instance, political and economic changes along with civil rights movement forced changes within the WHO from strengthening healthcare infrastructure towards a Primary Healthcare approach which included “training of community health workers and the solution of basic economic and environmental problems” (Brown, Cueto & Fee, 2006, p.66). The approach was considered “unrealistic” and “unattainable” for many agents involved in the provision of healthcare (ibid).

Moreover, the emergence of the World Bank as an investor in population health in the late 70’s began to gain influence among governments with more liberal approaches becoming dominant among international health agencies, especially after the publication of the report Investing in Health in 1993 (Cueto, 2018). During the 1980’s the World Bank contributed to the emergence of ideas of health as an accelerator of economic growth which allowed the

Bank to offer loans for health services favouring free market instead of national governments as main providers of healthcare (Brown, Cueto & Fee, 2006). Given the World Bank's increasing authority, the 1980's represented a troubled time for the WHO, with weakened authority and increasing competition and WHO's reputation as a leading authority in population health was questioned (ibid). Amid political struggles and disputed approaches to 'health care', Jan Stjernswärd became the Chief of Cancer at the WHO in this same period. With proposals aiming to increase coverage for cancer care, it was the first sign of problematising end-of-life care within the WHO (Stjernswärd, 2013; Teoh & Stjernswärd, 1990). According to Stjernswärd (2013), at that time, WHO's campaigns did not acknowledge 'cancer' as a global health problem.

In a paper entitled *Personal Reflections on Contributions to Pain Relief, Palliative Care and Global Cancer Control* (2013) Stjernswärd highlights how the WHO did not seem to acknowledge that the differences in healthcare between 'developed' and 'developing' nations would be problematic for those near death. A challenge that Stjernswärd replied with "there cannot be one future for the developed world and another for the developing. Either it is one common future or none" (Stjernswärd, 2013 para). He observed that resources towards cancer control were limited and unequally distributed leaving developing nations at a disadvantage: "almost all cancer patients in the developing world suffered severe pain, so pain relief and symptom control would have to be one of the priorities" (WHO, 1981). Stjernswärd (2013) worked alongside Vittorio Ventafridda, a trained anesthesiologist from the EAPC to develop the WHO's Cancer Pain Relief programme (Clark & Centeno, 2006).

Meanwhile, the Council of Europe in 1999 through the Protection of the Human Rights and Dignity of the Terminally Ill and the Dying echoed ideas of inadequacy when it states that medical progress should be made possible to postpone death "as a result, the quality of life of the dying is often neglected, and their loneliness and suffering ignored, as is that of their caregivers" (see Recommendation 1418, Council of Europe, 1999). From the previous recommendation in 1976, the Assembly added that the "prolongation of life should not in itself constitute the exclusive aim of medical practice, which must be concerned equally with the relief of suffering" (ibid), thus establish palliative care as a right of terminally ill or dying persons. Not long after the publication of Recommendation Rec of 2003 that focused on the organisation and development of palliative care within the European Region, palliative care galvanised support from the European Federation of Older Persons (EURAG). These developments were favourable conditions for the publication in the same year of the series of booklets by the WHO Regional Office for Europe arguing for palliative care implementation and policy development (Clark & Centeno, 2006).

Changes in the care for the dying are frequently assumed to have been prompted by the emergence of the hospice movement and Cicely Saunders, yet this genealogy demonstrated that these changes also relate to the variations in the epidemiological order that forced changes in medical practice by allowing the inclusion of other types of knowledges into medical practice. The intensification of technology prompted changes in how death is conceptualised, creating a new form of dead bodies raised debated over the quality of life through artificial prolongation. Such challenges have been addressed not only by palliative care but by other institutions such as the Vatican.

Moreover, while Europe was developing a clear understanding that dying under medical care could be seen as problematic, the WHO was focused on vertical campaigns aimed to eradicate diseases in developing nations. With the emergence of the World Bank, political struggles took place over the understanding of health as a social medical problem and health as economic issue. While the WHO aimed to promote reforms in order to protect the health of populations from epidemics, the World Bank promoted the perspective that international health could be a tool that could lead to economic growth. Aiming to reduce the gap between the ‘developed’ and ‘developing’ world, the WHO adopts palliative care as a tool to protect developing nations from the effects from economic disadvantage. An idea that is far different than the perspective adopted by the European Regional Office, where the promotion of reforms was largely based on the notions of the problems caused by medical technology and an aging population

5.4. Silences of ‘Inadequacy’ problematisation (Q4)

Having examined how the problematisation ‘inadequate care’ is constituted and the processes that made this form of thinking possible, this section will identify the silences ‘healthcare inadequacy’ creates. As proposed by Bacchi (2009), this examination aims to understand “what fails to be problematised?” (Bacchi, 2009, p. 12). The previous sections offer some insight into what is being silenced in thinking about the problem in this manner. First, by constituting the problem as ‘inadequacy’ the WHO draws attention to ‘healthcare provision’ such as training professionals, ensuring opioid availability, managing resources effectively and coordinating health and social care in a way that allows patients to have their preferences met. However, the guidelines fail to problematise the influence of culture in health care, especially considering end-of-life.

5.4.1 Culture

The literature suggests that ‘palliative care’ is not a universal concept. As evidenced by Radbruch et al. (2020), the definition provided by the WHO is not universally adopted. Some palliative care organizations have their own definitions of palliative care. Other disparities regard variance on how and when palliative care is implemented in the care continuum (Radbruch et al., 2020). Others refer to the scope and the possibility for self-determination as it is the case in the Netherlands (see Janssens & Have, 2001). Or the perception of end-of-life suffering not as a medical problem but as a social problem as it is the case in Macao (Tam et al., 2021). As such, there is a variety of interpretations of key concepts such as ‘palliative care’ or ‘hospice’ which can have different meanings for different nations, leading to multiple ways of organising and delivering palliative care services as a result (Seymour & Cassel, 2017). These concerns seem to conflict with WHO proposals for palliative care, which are based on ideas of freedom from pain and meaningful and individualised dying.

Likewise, in the Middle East, Weng et al. (2021), found that the term palliative care is understood as the provision of pain relief to a limited group due to differences in cultural and religious background that shapes how 'end-of-life' care is offered which require significant cultural adaptations. Moreover, even in countries where palliative care is developed such as the US and the UK, differences can be found in the meanings attributed to palliative care as well as differences in the targeted population (Seymour & Cassel, 2017).

As demonstrated in the genealogy conducted in section 5.3, end-of-life care practices have been profoundly shaped by societal developments in the US and Europe, where ideas of the relief of suffering were associated to appropriate 'end-of-life' care and were not equally developed in 'developing' nations. Consequently, another silence 'inadequacy' creates refers to the assumption that the answers created to respond to problems in the 'developed' world will be equally appropriate for 'developing' nations. As argued elsewhere in this thesis (chapter 3, section 3.10), one way to conduct the analysis proposed by question 4 is to engage with a comparative analysis to find alternative problematisations (Bacchi, 2009; Goodwin, 2011) following section will be dedicated to conduct a case study to understand how the problem can be thought differently.

Differences in how palliative care is conceptualised and delivered suggests that contrary to WHO's proposals, integration of palliative care may not be related to inadequate care, but to different ways of understanding what 'end-of-life' that is premised on social and cultural grounds. In this sense, interpreting the problem as 'inadequacy' constricts the room for change into the realms of patient care and professional relationships rather than wider societal attitudes and beliefs surrounding death and dying. Transforming the problem into a clinical rather than a societal problem prevents the development of palliative care beyond the spheres of pain relief, symptom management and patient choice, ultimately constricting what ‘palliative care’ should look like. By favouring ideas such as freedom from pain and other distressing symptoms, individualised care and agency, WHO guidelines create a very particular model of care that may create silences on other factors influencing palliative care implementation, such as culture, modes of funding and national laws.

5.4.2. How Problems can be thought differently: Colombia

The case study that follows aims to identify alternative problematizations. As discussed in Chapter 3 (Section 3.9.4), this step of the WPR analysis involved applying question 1 of the WPR framework to national guidelines in support of palliative care. The goal was to identify how the problem is represented, allowing for comparison with the WHO’s problematization of the inadequacy of care. Furthermore, the case study will discuss the identified problematization within the context of research literature on the development of palliative care strategy in Colombia.

Development of Palliative Care Strategies in Colombia

Research into national laws supporting palliative care has demonstrated that, although palliative care services may have increased, there is still a lack of national laws supporting palliative care (Clark et al., 2020; Clelland et al., 2020). However, Colombia was one of the first countries in Latin America to ensure palliative care strategies through national laws and is currently developing its national plan for palliative care (Observatorio Colombiano de Cuidados Paliativos, 2021; Pastrana & De Lima, 2021). Recognised as the first country in Latin America to acknowledge palliative care as a medical specialty (Pastrana et al., 2021), Colombia currently hosts 79 palliative care teams (ALCP, 2021) and is classified as a category 3b generalized provision in the most recent map of palliative care development worldwide (Clark et al., 2017). Countries classified in this category are characterized as having activism activities in several locations and multiple sources of funding. There is morphine availability and several hospice-palliative care services as well as training and education initiatives by hospice and palliative care organisations (D. Clark et al., 2020). Category 3b reflects much of the PHS model where development of palliative care in national contexts depend on education, policy formulation and implementation and opioid availability (Callaway et al., 2018).

According to the latest Atlas of Palliative Care in Latin America (ALCP, 2021), palliative care services in Colombia date back to the 1980s, with the creation of a Clinica de Dolor y Cuidados Paliativos by the University of Antioquia. A decade later, the first association in support of palliative care, the Asociación Colombiana de Cuidados Paliativos (ACCP), emerged in the early 1990s, focusing on education for palliative care specialists. In 2014, the ASOCUPAC (Asociación Cuidados Paliativos de Colombia) was created to include members beyond academic settings (Pastrana et al., 2021). Compared to other Latin American countries, Colombia stands as a significant example of efforts made by both national and international organizations in alignment with the WHO to develop national palliative care strategies (Hernández-Rico & Ballen-Vanegas, 2021; Leon et al., 2011; Pastrana et al., 2021). Yet, the number of services per capita, lack of appropriate education for healthcare workers, and disparities in the consumption and availability of opioids suggest that the Colombian palliative care strategy is far from achieving the expected results proposed in the WHO’s guidelines (Observatorio Colombiano de Cuidados Paliativos, 2021; Pastrana et al., 2021; Vargas-Escobar et al., 2022).

Palliative care in Colombia is supported by the federal government through the Social Security Health System (Rosa et al., 2022), indicating political efforts to secure access to palliative care for the Colombian population. The provision of palliative care services in

Colombia is ensured by Law nº 1384 of 2010, which states that palliative care should be available for cancer patients and their families, primarily focusing on the availability of opioids (Rosa et al., 2022). In 2012, Colombia's Ministerio del Salud y Protección Social (MSPS) published a document, namely, the 10-Year Public Health Plan, which included palliative care for the aging population (Pastrana et al., 2021).

In 2014, Law nº 1384 was updated to Law nº 1733, which included patients with other illnesses such as "chronic, terminal, degenerative, and irreversible illnesses" (Colombia, 2014; Rosa et al., 2022). The extension of palliative care coverage to include other illnesses besides cancer is a clear reference to the shift from the Cancer Pain Relief and Palliative Care (WHO, 1990) and the National Cancer Control Programmes (WHO, 2002), recommending palliative care for people with illnesses other than cancer. Furthermore, it is observed that the WHO's views on palliative care have influenced the conceptualisation of 'palliative care', as evidenced by the referred Law nº 1733 of 2014, where palliative care is understood as (translated):

> The appropriate care measures for patients with a terminal, chronic, degenerative, and irreversible illness, where pain and other symptoms require not only medical but also social, spiritual, and psychological support for patients and their families during illness and bereavement. Palliative care aims to achieve the best possible quality of life for patients and their families. Palliative medicine affirms life and views dying as a natural process (Law nº 1733, article 4, Colombia, 2014).

The text above echoes both the definition and one of the principles of palliative care established in the Cancer Pain Relief and Palliative Care (WHO, 1990), which situates palliative care as the 'appropriate care' for patients and families during and after illness and death. Hence, the implication is that previous ways of caring for people with chronic and other illnesses may no longer be appropriate.

To further support palliative care, the Colombian government issued a second law (Law nº 100 or the Statutory Health Law) to ensure access to essential medicines such as opioids for those in palliative care (De Lima & Radbruch, 2018; Pastrana et al., 2021; Pastrana & De Lima, 2021). This law also introduced a model for health care delivery, namely the Modelo de Atención Integral en Salud, which replicates much of the directives presented in the WHO’s National Cancer Control Programmes (WHO, 2002). The model focuses on the promotion of healthy behaviors, prevention of illnesses, treatment, rehabilitation, and palliative care (Pastrana et al., 2021). Shortly after the publication of *the Modelo de Atención Integral en Salud*, Colombia’s government, through their Health Ministry (MSPS), published national guidelines directed at health professionals in support of palliative care: the *Guía de Práctica Clínica para la Atención de Pacientes en Cuidado Paliativo* and *Lineamientos para la Atención Integral en Cuidados Paliativos* (León, 2014; Nossa & Sánchez, 2016; Pastrana et al., 2021). In 2018, Colombia recognized patients' rights to write living wills and to reject futile treatments through advance directives.

The brief history of palliative care developments in the Colombian context only tells half of the story. It demonstrates that Colombia is a country committed to the development of palliative care measures and indicates some level of overlap between Colombia’s government and WHO publications such as the Cancer Pain Relief and Palliative Care (WHO, 1990) and the National Cancer Control Programmes (2002). This aligns with Sturdy, Freeman, and Smith-Merry’s (2013) argument that the WHO’s power to influence member states relies heavily on its reputation as a source of reliable knowledge, which can be used to mobilize political will within countries. Moreover, Colombia’s case can serve as an illustration of the wide array of mechanisms in place to consolidate the influence of expert knowledge on national governments and the limitations of these when it comes to implementation. The next section will address the overlap in their problem representations as well as discuss their differences. Then, attention will turn to current research literature to discuss the implications of these problem representations.

What's the problem represented to be? (Q1)

There are two documents from the Colombian Ministry of Health and Social Protection (MSPS) that recognise palliative care as an important public health theme and offer guidance to implement and strengthen palliative care services across the country. They are *Lineamientos para La Atención Integral en Cuidados Paliativos* and *Guía de Prática Clínica para la atención de pacientes en Cuidado Paliativo.*

Starting with *Lineamientos para La Atención Integral en Cuidados Paliativos* (Nossa & Sánchez, 2016), the expressed aims and goals of the referred guideline are to "provide guidance to implement and strengthen palliative care assistance" (Nossa & Sánchez, 2016, p. 9). Implementation of palliative care is considered to be needed: "(…) due to the fact that they currently constitute an important topic in public health; advocating for the dignity and non-suffering of the person affected by a highly threatening or incapacitating, chronic, terminal, degenerative, irreversible disease, or in the final stages of life" (Nossa & Sánchez, 2016, p. 9).

In *Guía de Prática Clínica para la atención de paciente en Cuidado Paliativo (GPC)* (Ministerio de Salud y Protección Social, 2016) the guideline expresses a concern with the quality of life of patients facing chronic and life-threatening illnesses, especially in their final stages of life. According to this document: "[…] the impact in the quality of life of patients affected by these conditions determine the urgent need for guidance on clinical practice to inform decisions regarding palliative care, with the goal of improving quality of care and the efficient use of resources" (Ministerio de Salud y Protección Social, 2016, p. 26) Since the palliative care strategy in Colombia can be seen to be influenced by the WHO and the IAHPC, (De Lima & Radbruch, 2018; Pastrana et al., 2021; Pastrana & De Lima, 2021) it is unsurprising to find that at a first glance they share the same concerns.

The alignment with the WHO's Cancer Pain Relief and Palliative Care report (WHO,

1990) is explicitly demonstrated by structuring the argument for palliative care through the WHOs data on the need for palliative care each year, as presented in the following: “The WHO estimates that around 40 million people need palliative care each year, with approximately 80% living in low - and - middle income countries, and about 67% being 60 years or older” (Nossa & Sánchez, 2016, p. 7). This overlap is further evidenced by Colombia’s clinical guidelines where there is an explicit concern with the quality of care for patients facing a chronic illness to which, it says: “the chronicity and the rise of treatments aimed at prolonging life, as well as the limited response to treatment, demand special attention that involve the physical, mental and emotional aspects of care” (Ministerio de Salud y Protección Social, 2016, p. 27). The WHO is even explicitly mentioned to reinforce the alignment between Colombia’s palliative care and the WHO recommendations for palliative care: “Palliative care should be provided from the moment of diagnosis of the illness, adapting to the progressive needs of the patient and family, and offering support to the family in their grieving process, as suggested by the WHO” (Ministerio de Salud y Protección Social, 2016, p. 37).

The association of palliative care with illness-related suffering echoes the main rationale behind the ‘inadequacy problematisation’ which is, that without palliative care, people will suffer due to inadequate care. However, differences can be found on the representation of ‘inadequacy’. Inadequacy is represented within the WHO guidelines based on ideas that other forms of care are not sufficient or are harmful to the quality of life of patients (see chapter 5 Q2). In Colombian guidelines however, the idea of inadequacy is presented to include the lack of capacity to respond to palliative care needs everywhere: “most healthcare systems inadequately respond to this need. It is estimated that 42% of countries lack palliative care services, and in 30% of countries with such services, only a percentage of the population in need actually receives them” (Nossa & Sánchez, 2016, p. 7) . Similarly to the WHO guidelines (see chapter 5, section 5.2), the language of statistics is used to create a sense of urgency and to support the argument for palliative care as the appropriate response to the 'problem'. This is further evidenced by statements such as: "Only 15% of countries in the world have integrated palliative care in their health care systems according to the International Observatory of End-of-Life. In general, countries have some form of palliative care, but they are characterized by fragmented services and limitations in access" (Ministerio de Salud y Protección Social, 2016, p. 27). A problem that the *Guia de Prática Clínica* states that the Colombian government has responded to through Law nº 1733 from 2014 which established palliative care for patients facing life-threatening, chronic or degenerative illnesses at any given time (Ministerio de Salud y Protección Social, 2016).

Other systemic issues were described in both the Colombian guidelines such as the status of training in palliative care and the lack of opioid analgesics to the majority of the population in need (Ministerio de Salud y Protección Social, 2016; Nossa & Sánchez, 2016). Thus, we can see a different premise underlying the inadequacy representation. Rather than focusing on symptom control and patient care, these guidelines seem to represent the problem as an issue of preparedness to respond to palliative care needs. That is, the problem is represented as a social-political problem.

The different premises underlying Colombia's guidelines may be due to the fact that Colombia is a LMIC. As expressed in the statement that follows:

> The demographic and epidemiological changes that have occurred in the world in recent centuries have led to an increase in the incidence and prevalence of chronic, disabling diseases with prolonged convalescent phases. These conditions create difficult social and economic circumstances, particularly in low – and- middle income countries, which add to the existing social vulnerability of the population (Nossa & Sánchez, 2016, p. 7).

That is, the lack of preparedness to attend to palliative care needs is seen to result in an increased social vulnerability which is another problem palliative care measures are proposed to address. This understanding provides a different reason as to why palliative care should be available, not just because patients are suffering at the end-of-life, but because of the economic impact that increases the social vulnerabilities of an already vulnerable population. In this sense, this guideline gives insight into aspects that have been neglected in the WHO's publications examined in this chapter. Although it has been noted that there are continuities between Colombia and the WHO, the rationale provided in the Colombian guidelines problematises healthcare systems' neglect of palliative care needs rather than the suffering caused due to inadequate protocols of patient care. In addition, this publication also shows how the economic status of a country such as in Colombia – a low-middle-income country – can affect what is understood as problematic. In this case, I argue that the issue of social vulnerability is argued as a key aspect of palliative care delivery, something that has been silenced in guidelines from the WHO.

Having identified the ways in which the problem of inadequacy has been represented, Colombia can be thought as an illustration of how expert knowledge can reach and influence national governments efforts to support palliative care measures. Yet, as will be described below, it also demonstrates that the WHO original guidelines leave out important social and political aspects, which in turn, can contribute to maintaining the gaps in provision rather than addressing them.

For instance, Colombia's development of palliative care measures has been a result of national and international efforts(De Lima & Radbruch, 2018). Colombia was home to several workshops from the International Association for Hospice and Palliative Care (IAHPC). The IAHPC is an important non-governmental organisation (NGO) in a formal relationship with the WHO, and it is committed to the development and improvement of palliative care internationally (De Lima & Radbruch, 2018). Their advocacy feeds into the

WHA resolution 67.19 (WHO, 2014) which establishes that palliative care provision should be an obligation of health care systems (Rosa et al., 2022). Its views of integration of palliative care into health care are aligned with the WHO's PHS strategy: health policies, education, access to opioids and service implementation (De Lima & Radbruch, 2018). Countries are invited to participate in the IAHPC workshops which are done in collaboration with health authorities such as the Ministry of Health and representatives of other institutions such as the Pan American Health Organization which is a regional WHO office for the Americas (*Ibid*). This poses a direct relationship between non-governmental organisations such as the WHO and national governments to support the development of palliative care strategies at the national level.

In 2007, a pilot workshop was conducted in Colombia (De Lima & Radbruch, 2018), a few years before the first national law supporting palliative care was introduced. According to De Lima & Radbruch's (2018), the pilot workshop resulted in an "effective elimination of barriers in most of the countries" (De Lima & Radbruch, 2018, p. 598). In fact, Colombia's *Statutory Health Law*, mentioned previously in this section represents an effort to ensure that patients would have access to opioids. In addition, as described by Pastrana et al. (2021), the *paquete basico* proposed in this law includes all medicines that are proposed in the Essential Package of the Lancet Commission on Palliative Care and Pain Relief. A commission that "provides policy pathways and recommendations to drive systemic change" (Knaul, Rodriguez, et al., 2018, p. 5). The list of essential medicines provided by the Lancet Commission on Pain Relief was specifically designed with the conditions of LMICs in mind, focusing much of the attention on the disparity in opioid consumption between HICs and LMICs (Hannon et al., 2016; Knaul, Rodriguez, et al., 2018).

Research conducted on this topic demonstrates systematically that there is a great disparity in consumption of morphine between countries according to their resource level (Hannon et al., 2016; Knaul, Farmer, et al., 2018), a disparity that is reflected in Colombia where the average consumption of controlled opioids is 556.1 kg which translates to 11.2mg per person (Vargas-Escobar et al., 2022). That is, having laws in place to ensure opioid availability as per PHS indicators do not translate into adequate access for those in need (Pastrana et al., 2021; Rosa et al., 2022; Vargas-Escobar et al., 2022).

Additionally, in 2014 Colombia was home to another IAHPC project, *the Palliative Care Competencies for Undergraduate Medical and Nursing Schools* (De Lima & Radbruch, 2018) which aimed to change the curricula in universities to include palliative care. This project was funded by international partners such as Atlantic Philantropies from the US and the DAAD Foundation from Germany (De Lima & Radbruch, 2018). The meetings were followed by a workshop in Bogota, to assess competencies which resulted in recommendations for change. This was followed up with workshops on teaching methods to health care educators, an initiative done with the collaboration of Foundation FEMEBA (Argentina) and the University of Aachen (Germany) (De Lima & Radbruch, 2018). Yet, lack of education of health workers is another barrier to palliative care integration in that country. As demonstrated by Pastrana et al. (2021), only five out of 55 medical and nursing schools currently offer palliative care in the undergraduate curricula. To Pastrana et al. (2021), using the PHS indicators as to assess the status of palliative care development in Colombia revealed a greater gap in professional education. However, Rosa et al. (2022) indicates that there are gaps in the official opioid consumption reports which do not include the opioids imported by the private sector. The failure to account for the prescribed opioids by pharmacies in the private sector create an erroneous estimate of population need (Rosa et al., 2022) thus making Pastrana's et al. (2021) argument, that the greatest gap lies in education, questionable.

Moreover, despite having two national palliative care organisations, Colombia's official reports of palliative care development come from the Colombian Palliative Care Observatory (Observatorio Colombiano de Cuidados Paliativos [OCCP]). These reports are based upon PHS criteria (Observatorio Colombiano de Cuidados Paliativos, 2021; Vargas-Escobar et al., 2022)which once more reinstates the dominance of the PHS indicators as a reliable, stable measurement of palliative care development in any given region. The alignment with the WHO PHS has been discussed in the literature as an important measure to advance palliative care service and policy development as well as to map out the progress of palliative care between countries (J. Clark et al., 2018; Pastrana & De Lima, 2021; Rosa et al., 2022): it becomes important for countries to be aligned with PHS model to gain *legitimacy* in their national programmes. Yet, the case presented here demonstrates how limiting the indicators can be when trying to understand the complex nature of palliative care development in a LMIC country.

In addition, considering the findings from Vargas-Escobar (2022) who identified that the reports from the OCCP do not include regional stakeholders' perspectives, we can then argue that there is a lot more to the 'problem' than the 'inadequacy' representation is able to address. Their study conducted with a qualitative, rather than the traditional quantitative methods brought visibility to the challenges faced by those who work in palliative care in Colombia, such as medical professionals, representatives of patient and caregiver organisations, health insurance companies, regulatory authorities and regional health secretariats, community representatives and the media (Vargas-Escobar et al., 2022). The study found that rather than focusing on opioid inequality, the participants were concerned with working conditions, administrative processes, and the low economic conditions of patients and caregivers (*Ibid*). Thus, it is not just that patients cannot access opioids, but that they rarely have the conditions to even access the health care services. This indicates that beyond the PHS indicators, social vulnerability plays an important role in palliative care services in Colombia. Vargas-Escobar et al., (2022) study also revealed that patients in rural areas and other areas with a low income may not have access to palliative care services due to poor allocation of resources. The fact that health insurance companies have not taken actions to ensure the provision of palliative care also plays an important role, affecting many patients who would otherwise have access to care. Finally, the lack of knowledge about palliative care within health care circles and professionals continues to be a barrier to consolidate palliative care in the country(Vargas-Escobar et al., 2022).

This case study identifies alternative problematisations to the ‘inadequacy’ problematisation identified within the WHO guidelines and discusses how particular forms of representing the problem may contribute, rather than respond, to gaps in palliative care provision. Although international collaboration can be thought to have helped Colombia’s development of palliative care in their national health system, the discussion above supports Walter’s (2020) argument that we need to question the idea that a single model of palliative care allows enough scope for countries to develop their own strategies. Rather, it seems that countries could gain more insight into what needs to be prioritised by considering their own particular circumstances and conditions.

5.5 Effects of ‘Inadequacy’ problematisation (Q5)

The application of the WPR framework began with the rationale for the recommendations established in this group of guidelines. I have addressed the meanings that have to be in place in order for this problematisation to be made intelligible (section 5.2). I also provided the historic and social processes that allowed the emergence of ideas of ‘inadequacy’ and how they reached WHO publications (section 5.3), followed by cross-country comparisons to identify how palliative care implementation is shaped by cultural and social conditions more than through implementation of protocols for patient care (section 5.4). To continue the examination, this final section will critically reflect upon the effects of this form of thinking. First considering discursive effects and then to discuss the subject positioning (subjectification effects) that are created in this representation of the problem.

5.5.1 Discursive effects

In relation to the inadequacy problematisation, the problem is not that people are dying, but how they are being cared for. The WHO therefore establishes that the lack of palliative care access is a problem for individuals and healthcare systems: failure to provide access to palliative care will produce poor outcomes such as a death in suffering. Thus, instead of contributing to a widespread establishment of palliative care globally, the largely professional and ethnocentric representation of 'dying' may prevent culturally diverse groups and countries independently constituting their own 'good dying'. Moreover, this model associates 'suffering' as the struggle of 'dying' and the lack of palliative care services, which overrides the real 'dying' experiences in favour of a normative and idealised 'model' of death (see Lawton, 2000; Pollock & Seymour, 2018).

5.5.2 Subjectification Effects

5.5.2.1 The 'sufferer'

Starting from the 1990 Cancer Pain Relief and Palliative Care guideline, the expressed goal of palliative care implementation for 'cancer patients' is to increase the patient's quality of life with alleviating and preventing 'suffering' (WHO, 1990, 2002). The guideline invokes thinking about the patient in terms of 'pain' and 'suffering' and not being able to 'enjoy' life without palliative care as discussed in section 5.2. This identity of the dying patient as the personification of 'suffering' is central to confer meaning to an impending crisis: end-of-life demands will surpass healthcare capacity. For instance, still regarding the 1990 publication, 'cancer' is articulated as an urgent and 'world problem': "the number of cancer patients and overall cancer mortality are increasing" and "cancer mortality can be expected to rise in nearly all regions of the world" (WHO, 1990, p. 13). Increasing numbers associated with issues such as resource allocation, little training on palliative care and preference for therapies that have limited effects (WHO, 1990, p. 15), creates a scenario that emphasises the scale of the suffering as a way to engage stakeholders and Members States to adopt 'palliative care' strategies worldwide.

It becomes important therefore to know what is this 'suffering' that patients are assumed to have due to the lack of proper healthcare strategies. Thus, the knowledge of ‘suffering’ is central to constituting the aims and goals around which healthcare and in this case, palliative care, should be organised. This includes monitoring the population’s pain and establishing trends against which ‘normality’ can be established:

> Pain was controlled (judged as absent or slight on a 4-point scale) in 75% of patients treated in centres trained in the use of the (WHO) method. A similar level of pain control was obtained in only 50% of patients treated in the centres not previously exposed to the method. One reason for better results was a significantly greater use of orally administered morphine and related drugs. Adverse effects were infrequent in both groups. These results indicate that professional and public expectations about the successful management of cancer pain can be raised considerably (WHO, 1990, p. 22).

The guideline promoted the idea that for “freedom from pain should be seen as a right of every cancer patient and access to pain therapy as a measure of respect for this right” (WHO, 1990, p. 8) suggesting that the ideal outcome for cancer care should be ‘freedom from pain’. This constitutes ‘freedom from pain’, and by extension ‘freedom from suffering’, as a mutual goal between the patient, who is assumed to want this pain relief, and healthcare systems.

In addition, ‘freedom from pain’ is embedded in psychological discourses in which ‘psychological factors’ are believed to “influence the severity of pain in patients with cancer” (WHO, 1990, p. 20) and “unless these receive recognition and response, good pain control and symptom relief may prove impossible” (WHO, 1990, p. 44). These psychological needs are regarded as “common to cancer patients in all cultures” (WHO, 1990, p. 44), and as such it implies a universal patienthood that is measurable and intelligible to healthcare workers.

Just as biomedical knowledge and practice constitute 'illnesses and 'disease' as their field of practice, the inadequacy problematisation constitutes the patient's subjectivity as a territory. For instance, we can note the inseparability of the patient's subjectivity to the logics of 'treatment' and 'care' via claims that "a sense of hopelessness and the fear of impending death add to the total suffering of patients and exacerbate their pain" (WHO, 1990, p. 44). These claims insert the emotional needs of the patients as an object for professional intervention in the name of relief. As expressed in the 1990 guidelines, the patient should be reassured that "everything will be done to relieve distressing symptoms" (WHO, 1990, p. 43) in order for the patient to have a 'goal' and remain 'hopeful' (ibid).

> One of the essential elements of a "good death" is freedom from pain that dominates consciousness and may leave the patient physically and mentally incapable of reaching *whatever goals he or she may want to achieve before death* (WHO, 1990, p. 52 emphasis added).

It is embedded in the sufferer's identity that achieving goals before death and pain relief is desired by patients at the end of life and that this should be enabled by healthcare professionals. Similarly, as the patients' 'family' is promoted as the patient's main source of psychological support and should be aware of 'common reactions' to 'life-threatening' illnesses (WHO, 1990, p. 52), families are expected to be willing and able to care for a dying patients and to promote the same outcomes as healthcare workers. This indicates that the patient is at simultaneously articulated as an atom of self-interest, such as in the intent to remain 'hopeful' and to 'achieve goals', and as a relational self in which the condition for its emotional wellbeing is a consensual understanding and agreement by the family of the patient's needs and desires: "Few things are more damaging to the patient's self-esteem than to be disregarded in discussions concerning treatment" (WHO, 1990, p. 43).

The 'family' is welcomed to be involved in the care of their loved ones so as long as they comply with the ‘patient-centred’ approach in which they have now to relate to their loved ones in terms of their patienthood: they should be informed about the patient’s needs and be trained in performing tasks previously carried out by a health professional such as ‘skin care and the prevention of bedsores, how to lift a paralysed patient and how to cope with incontinence’ (WHO, 1990, p. 46). This imposes a new type of relationship with a loved one, in which the previous history of the family’s relationships is ignored as well as the possible conflicts that may arise from this type of relationship. Yet, although families are involved, are considered ‘particularly important’ and their ‘active participation is essential’, it is important ‘not to let relatives “take-over”’ (ibid).

This positioning of the family reveals a paradoxical discourse whereby the family are both active and engaging but at the same time ‘constricting’. In this way there is a hierarchy in palliative care that needs to be observed and respected as part of the patient-centred approach. The paradox of the ‘family’ is that they are understood to be perfectly capable with the appropriate support to care for their loved ones at home and guarantee a ‘good death’ but at the same time are also ‘problematic’ as they are a ‘precipitating factor in the admission to hospital of a dying patient’ (WHO, 1990). The knowledge of the patient’s ‘needs’ and their ‘suffering’ articulated through palliative care urged families to gain responsibility for their dying and allowed the insertion of healthcare into the family domain.

5.5.2.2 Prevention of suffering: the ‘risk’ discourse

Following the 1990 Cancer Pain Relief and Palliative Care guideline, the 2002 National Cancer Control Programmes emphasises the ways of avoiding ‘the sufferer’ through control, continued assessment, and professional care. In this sense, ‘palliative care’ is not articulated as a way to alleviate end-of-life suffering common to cancer patients, rather, it is understood to be an “exercise in prevention – prevention of ultimate suffering” (WHO, 2002, p. 85). It is understood that since patients with such conditions have “problems similar to those commonly encountered in cancer patients” (WHO, 2002, p. 86), palliative care should be extended across disease groups. That is, there is an understanding that dying patients regardless of illness will have similar needs to those of cancer patients that will require professional assistance, rendering all chronic patients ‘at risk’ of potentially becoming the ‘sufferer’.

This comes as the notion of ‘palliative care’ promoted by WHO in the 1990 guideline became inadequate as it is recognised that poor outcomes at the end-of-life (i.e., dying in suffering) are a consequence of a lack of symptom management at an earlier stage of the illness trajectory. The idea is that professional intervention from early stages of disease, in the form of palliative care, could become a technology of improvement, in which the patient’s quality of life is articulated as the outcome of appropriate healthcare services and professional expertise. However, quality of life is intrinsically associated to professional control of the patient’s experience of ‘illness’. In order to do so, the patient’s experience is spatialised into different types of ‘needs’ that require professional attention:

> Care of the dying extends beyond pain and other symptom relief. It also supports the social, psychological and spiritual needs of the patients and their families. Therefore, it is important to assess these needs and be able to respond with a holistic approach (WHO, 2002, p. 87).

An increase in professional gaze into the patient’s ‘needs’ is only possible through the patient’s expression of such needs. For instance, to address psychological distress, communication is articulated as a key component of psychological support. ‘Good communication’ is described in this context as open, honest, sensitive and compassionate in which: “the level of information and pace at which it is given should be appropriate for an individual’s ability, needs and culture” (WHO, 2002, p. 90). Patients are assumed as wanting to be informed and that practices of ‘silence’ and withheld information is understood to possibly add to the patients’ suffering (WHO, 2002). As such, open awareness of the impending death underlies the condition of ‘wellbeing’ in palliative care in which ‘acceptance’ is the result of optimum care. Expression’ therefore is constituted as a ‘relief’ of personal anxieties and fears of death and dying and, in this sense, the ‘informed patient’ becomes the pathway to the ‘acceptant patient’ whereby we can observe an effort to make the experience of dying as docile.

5.5.2.3 The dying entrepreneur

The previous guidelines articulated ‘palliative care’ in terms of relief and prevention of ‘the sufferer’ that comes because of life-threatening illnesses in which palliative care is the solution. Meanwhile, the guidelines promoting palliative care in Europe promotes the notion of ‘choice’ and ‘accomplishment’ to mitigate suffering. In the guidelines developed between 2004 to 2011 the ‘individual’ is not articulated in terms of their suffering, but in terms of their individuality.

According to the *Palliative Care the Solid Facts* (Davies & Higginson, 2004), palliative care “begins from the understanding that every patient has his or her own story, relationships and culture, and is worthy of respect as a unique individual” (p.7). This includes making a rational use of their time: “This respect includes giving the best medical care and making the advances of recent decades fully available, so that all have the best chance of using their time well” (Saunders, in Davies & Higginson, 2004, p. 7). In this sense, the optimal palliative care would not only avoid the ‘sufferer’ by successfully managing total pain but would require individuals to choose how to make the best use of their remaining life.

Engaging with decision-making would be “an important contributor to their satisfaction with care at the end of life” (ibid). Statements such as these reveal that the ‘success’ of end-of-life care would be satisfying individual preferences. Patients are therefore positioned as the dying entrepreneurs, with a task to decide, choose and actively be engaged with the last years of their lives and healthcare systems with a duty to attend to these preferences. This engagement and decision making involves a certain calculation of risks and benefits given the reality and awareness of death in order to make ‘a rational use of their time’.

In the 2004 to 2011 guidelines, ‘palliative care’ is also aligned with a ‘client orientation’ approach in which healthcare systems are centred around the individual preferences. A client orientation approach acknowledges that “concerns and interpretation of terms such as “quality of life” are highly individual” (Davies & Higginson, 2004, p. 12). A client-oriented approach requires healthcare systems to direct attention and have in place a system that embraces the ‘divergent’ patient, i.e., those who do not see themselves as ‘entrepreneurs’ or ‘clients’. However, the individual differences appear to be accommodated by the “willingness and ability to talk openly about their illness or its prognosis, the needs they wish to acknowledge, the level of symptom control they find acceptable, the interventions they will consider, and whom they wish to care for them” (Davies & Higginson, 2004, p. 16). As such, while there is acknowledgment of variant degrees of willingness to expression, most practices of ‘palliative care’ rely on the patient expressing themselves to health professionals. Similarly, as ‘the sufferer’ is scrutinised in their subjectivity, the ‘client’ or the ‘entrepreneur’ is territorialised through their wishes:

> Policymakers should monitor the wishes of seriously ill people concerning place of care and death; policy-makers should routinely monitor place of death as one interim measure of success of the system of palliative care provided; policy-makers should encourage the health services to inquire of people their preference for place of care and death. Meeting individual preferences should be the ultimate measure of success (Davies & Higginson, 2004, p. 17).

Territorialising wishes redirects the attention from the governments and health professionals from the ‘sufferer’ to scrutinise the patients’ preferences. The same can be argued for families. In 2004, the guideline expressed the concern with attending to the preferences of caregivers, as expressed in the statement: “further work is needed to explore the priorities of caregivers and what it is realistic for services to achieve for them” (WHO, 2004, p. 28). The task at hand thus, refers to anticipating what the preferences will be. As expressed in the statement:

> We all die, and although this reality is as much a part of life as birth, thinking about it is not easy. Individually we may plan the treatment we would wish to have towards the end of life or anticipate the comfort we might find in cultural and religious beliefs, but most of the time we choose to avoid thinking too much about it. Healthcare systems, however, do not have the option of prevarication. Many people already need better care towards the end of life. As well as providing this, healthcare systems must plan now for the care we all need in the future (Davies & Higginson, 2004, p. 9).

Such statements give insight to the mentalities that constitutes the WHO approach to palliative care in Europe. The palliative care promoted within the WHO guidelines for Europe problematises their territory to the target population’s wishes and preferences. This change in the ‘mentality’ of palliative care, from relief and prevention of the ‘sufferer’ to attending individual preferences of ‘the entrepreneur’, involves a change in the forms of subjectivity desired for ‘palliative care’.

5.6 Summarised analysis and closing arguments

Through examining the conceptual premises that sustains particular ways of thinking ‘implementation’ of palliative care, this study revealed how WHO guidelines produced rationalities that allows specific forms of intervention. For instance, it was revealed that in representing the problem as inadequate protocols for patient care, ‘palliative care’ meant addressing symptoms of suffering (Q2). Thus, countries who do not offer the appropriate conditions such as opioid availability, efficiently managing resource allocation and meeting patients preferences are, as a consequence, contributing to poor end-of-life care outcomes (Q2).

Interrogating the historical and social processes that allowed this representation of the problem to emerge revealed how despite claims of a ‘global’ public health problem, ideas of inadequacy were shaped by multiple events occurred in America and Europe rather than the natural result of cancer care (Q3). The recommendations for palliative care in this sense, proposed as a solution for ‘global health problems’ through what industrialised countries assumed was best for medicine and public health. Additionally, the genealogy revealed how ideas of inadequacy were largely shaped by social processes rather than by the emergence of palliative care (Q3). As such, it is no surprise that as a consequence, ideas of ‘inadequate’ care failed cross-cultural comparisons (Q4). Importantly, the section highlighted how patients’ needs are culturally and socially shaped rather than a consequence of symptoms. As observed in this chapter, especial attention was given to multi-ethnic perspectives of palliative care. The findings revealed the varied ways in which palliative care can be defined and practiced (Q4). This point was better illustrated by the case of palliative care provision in Colombia (Q4), where both literature and guidelines for that country focused on national context rather than patients’ symptoms.

Without the ideas of ‘pain’ and ‘suffering’ at the basis of the claim of inadequacies in patient care there is no need for palliative care (Q2). It is through these ideas that guidelines produce codes of conduct both for governments and professionals. For instance, this chapter demonstrated how guidelines set out social relationships between the patient and the family, health worker, and the patient (Q5), upon which social roles are delegated. Patients are expected to want to have pain relief and want to express their suffering to health professionals and make choices (Q5). Families are positioned as caregivers, responsible for maintaining the patients’ well-being and participating in the decision process, at the same time, they are also constricted in the type of decisions they are allowed to make (Q5).

Ideas of neglect in addressing pain and suffering allows health professionals to codify, spatialise and interpret individuals in terms of ‘total pain’ (Q5). ‘Symptoms’ in this sense represented more than just a manifestation of biological misfunction. They are rather, intrinsic to the patients’ personality and the healthcare worker’s responsibility to address (Q5).

In this light it was possible to consider that thinking the problem as ‘inadequacy of care’ favours normative understandings of ‘end-of-life’ (Q5) that does not include cultural or ethnic diversity (Q4). Moreover, while favouring standardised end-of-life care, the problematisation then obscures the wider social, political, and economic aspects of palliative care as illustrated by the Colombian case study (Q4). Without which ‘care’ continues to be operationalised as ‘addressing’ individual ‘needs’ in the same logic as ‘addressing symptoms’ (Q5). As a result, the inadequacy problematisation favours a depoliticised, ahistorical, and technicist understanding of palliative care that conflicts directly of the experiences with providing palliative care in other countries (Q4).

In summary, thinking the problem as inadequate care becomes a key indicator of securing the appropriate care for people at the end-of-life in the guidelines from 1990 to 2011. In focusing on ‘healthcare provision’, the problematisation allows new forms of professional power over a new territory, guiding Member States to constitute apparatuses of surveillance and control of ‘suffering’ and ‘preferences’. In this sense, attention is redirected from social and political issues, such as presented in the case study (Colombia) and into patient outcomes as measures of success. This summarised analysis shows an overall view of the analysis conducted above on the ‘healthcare inadequacy’ problematisation and what the implications of this problematisation may be. The next chapter will discuss the ‘healthcare capacity’ problematisation.

Chapter 6. Problematising Capacity

The previous chapter discussed how WHO guidelines constitute the problem of ‘inadequacy’ as a problem of patient care. Having examined the meanings in place that allows notions of adequacy and inadequacy and contextualised the historical and social processes that led to this form of thinking, the previous chapter also concentrated on providing insight into the silences this problem creates and on the type of subject the ‘capacity’ problem requires. In this chapter, attention will be dedicated to the ‘capacity’ problematisation identified in WHO’s guidelines concerned with access to palliative care services (chapter 4).

In this chapter, the WHO guidelines from 2004-2011, 2016, 2018, will be examined in light of the problematisation identified as ‘capacity’. To further investigate the ‘capacity’ problematisation, this chapter begins with an examination on the premises, categories and assumptions that constitute the problem as a ‘capacity’ problem. This will be followed by a genealogical perspective on the emergence of this form of thinking about the problem, that is, contextualising the social and historical processes that converged into thinking about the problem in this manner. Having established how the problematisation is constituted and established the origins of this form of thinking, the chapter then identifies the silences that this interpretation of the problem creates. Lastly, the chapter will identify how the problem of ‘capacity’ requires specific subjectivities, that is, creating subjects of a specific kind.

6.2 Examining the conceptual premises of ‘capacity’ problematisation (Q2)

As observed in the previous chapters, the guidelines are constituted in a system of meanings that shape the problem as a specific type of problem. Concerned with increasing coverage of palliative care services, the capacity problematisation is based upon an underlying assumption that there is a lack of access to palliative care. This assumption is in turn is articulated through categories of developed and developing ‘places’ to indicate which ‘places’ are in greater need for palliative care. Thus, in order to demonstrate both assumptions and categories that constitute the ‘capacity’ problem, the next section will first examine the assumption of ‘lack of access’ and will follow on how this assumption is structured around particular notions of ‘places’.

6.2.1 The assumption of ‘Lack of Access’

Beginning with *The Solid Facts* (Davies & Higginson, 2004) it is recognised that palliative care services are varied: “the organisation and delivery of palliative care services varies in different countries, depending on historical norms and national policies and patterns of funding” (Davies & Higginson, 2004, p. 18). In some countries services are provided through primary care and hospitals while others focused on inpatient services or home care (ibid). The assumption that there is a lack of access to palliative care services is therefore not demonstrated by forms of organisation and delivery of care but is mostly associated with notions of equitable distribution: “despite progress in developing palliative care, in several countries there are some evidence that some groups in society are excluded from the best of these services or have special needs that are not well met” (Davies & Higginson, 2004, p. 20). Likewise, the WHO asserts:

> They (variation in access to palliative care) may reflect untested assumptions about the desire and ability of different groups to cope without the special form of help available, discrimination, lack of skills in detecting concerns, or more general problems with the way that healthcare is structured (Davies & Higginson, 2004, p. 20).

This statement identifies how the WHO problematises the lack of equity within palliative care services to suggest that some groups have been marginalised over others. One of the groups that have been assumed to be excluded from palliative care services is ‘older people’. This is argued to be because traditionally palliative care has been offered mostly to cancer patients and as such fails to include other serious illnesses: "traditionally palliative care has been offered most often to people suffering from cancer, partly because of the course of illness has been more predictable making it easier to recognise and plan for the needs of patients and their families" (Davies & Higginson, 2004, p. 14). In this sense, the WHO argues that a new concept of palliative care must be developed to include more people in care:

> The concept of offering palliative care only at the end of life clearly does not fit many common situations, whereby people need palliative care after diagnosis and continue to benefit from treatments that alter the progress of disease until the end of life. New concepts of palliative care try to match the service more closely to what is understood about the course of illness (Davies & Higginson, 2004, p. 15).

Lack of access to palliative care by specific groups therefore underpins much of the arguments being made for changing the perception of palliative care from cancer care and end-of-life care to "an intervention that can be offered alongside potentially curative treatment" that is expected to "meet the needs of the ageing population, as well as those of younger people and children who experience life-threatening illness" (Davies & Higginson, 2004, p. 15). That is, concerns over equitable access to palliative care services structure the argument that an expanded concept of palliative care must be developed within healthcare settings and health policies in order to improve coverage.

In the same year, following the publication of *The Solid Facts* (Davies & Higginson, 2004) *Better Palliative Care for Older People* (WHO, 2004) was published which reproduced the argument for implementing palliative care services, assuming that some groups have lacked access to palliative care because programmes failed to recognise their needs:

> In spite of existing welfare programmes, very often the real needs of older people –

> for pain relief, to feel involved and listened and to enjoy a certain degree of autonomy – are not taken into consideration. Pain, physical suffering, helplessness, loneliness and marginalisation can too often become part of everyday experience in the final phase of life (WHO, 2004, p. 7).

Considering the statement above and how it was followed by: “This booklet from the Regional Office for Europe of the World Health Organisation arises from a project aimed at increasing awareness among policy- and decision-makers in healthcare about the needs of older people and how to promote innovative programmes of care” (WHO, 2004, p.7) the guideline reinstates that capacity in palliative care must be built to meet the needs of ‘older people’. Moreover, the underpinning assumption of lack of access is also at the basis of claims that palliative care programmes have not been able to reach all populations in need:

> One reason for older people not receiving palliative care is that they suffer more often from many chronic illnesses such as heart failure and dementia, which have not traditionally been the focus of specialist palliative care and where models of palliative care are only just beginning to be applied (WHO, 2004, p. 22).

Once more, the WHO expresses that issues with how palliative care has been conceptualised is the reason why older people are not receiving the care they need: “one consequence of this has been the perception that palliative care is only relevant to the last few weeks of life and can be delivered only by specialized services” (WHO, 2004, p. 17). This argument is central to the claim that palliative care must be integrated broadly into health care:

> The idea that palliative care support and care should be offered alongside potentially curative treatment, although obvious to patients and families, appears a radical idea for some health professionals. In addition to supporting people with a clearly terminal

> illness, healthcare systems must find ways of supporting people with serious chronic illness or multiple chronic problems over many years and allow for an unpredictable time of death (WHO, 2004, p. 18).

In *Palliative Care for Older People Better Practices* (WHO, 2011), the WHO states that: “palliative care is an important public health issue due to population ageing, the increasing number of people in most societies and insufficient attention to their complex needs” (WHO, 2011, p. 1). To this matter, WHO argues: “in the past palliative care was mostly offered to people with cancer in hospice settings. It must now be offered more widely and integrated more broadly across healthcare services” (ibid). Continuing to reproduce the notion that because palliative care was understood as something to be offered only for cancer patients, other groups such as ‘older people’ are not included: “palliative care services urgently need to be developed to meet the complex needs of older people. These services need to be available for people with diseases other than cancer and offered based on need rather than diagnosis or prognosis” (ibid). However, the lack of access in this instance is not represented as a problem of service provision, it is attributed to misconceptions regarding the nature and scope of palliative care as reflected in the Catalonian Project (WHO, 2011).

The Catalonian project involved revising legislation regarding opioids; training all healthcare professionals in palliative care; developing a model for funding; integrating basic palliative care services throughout the healthcare system; developing standards and developing a monitoring and evaluation system (ibid). The outcomes of this project are presented by the WHO as “full integration into national health plans, changes in relevant legislation governing and providing high quality, culturally sensitive, consistent and equitable services to all those in need, the project meets the requirements of the WHO whole-system approach” (WHO, 2011, p. 12). The Catalonia example indicates that the WHO equates building capacity to increasing coverage, as expressed in the following statement: “after 15 years, more than 95% of Catalonia was covered by palliative care services" (WHO, 2011, p. 13).

In England, the End-of-Life Care Strategy (WHO, 2011) is another example of how increasing services are expected to improve coverage. According to the WHO (2011), this strategy involved among other measures government investments of £88 million in 2009/2010 and £198 million in 2010/2011 (ibid). In comparison, in 'Eastern' Europe, services are "unevenly distributed, uncoordinated and poorly integrated across the wider healthcare systems" where "significant barriers to the development of palliative care in these countries have been reported" which included: "financial and material resources; problems relating to the availability of opioids; lack of public awareness and government recognition of palliative care as a specialty; and lack of palliative care education and training programmes" in which the lack of financial and material resources reported as the most significant barrier to palliative care implementation (WHO, 2011, p. 15). Therefore, in 2011, statements that indicate the lack of access to palliative care services are associated to notions of places such as 'eastern' more than 'western' Europe.

In publications regarding low and middle-income countries (2016 and 2018), it is important to observe some differences in the constitution of the 'lack of access' assumption. In *Planning and Implementing Palliative Care Services* (WHO, 2016), the guideline expresses concern with the lack of access to palliative care. It reminds Member States of their commitments towards implementation in the WHA67.19 that calls to "improve access to palliative care as a core component of health systems" (WHO, 2016, p. 1). With the aim of "contributing to providing equitable access to good palliative care in the context of Universal Health Coverage" (WHO, 2016, p. 1), the underpinning assumption of lack of access is explicitly expressed in this guideline. Other statements, such as the one below, also remind Member States of their commitments to improve access to palliative care:

> In the WHO Global Action Plan for the Prevention and Control of Noncommunicable Diseases (NCDs) 2013-2020, palliative care is explicitly recognised as part of the comprehensive services required for the noncommunicable diseases. Governments acknowledged the need to improve access to palliative care in the Political Declaration of the High-Level Meeting of the UN General Assembly on the Prevention and Control of Noncommunicable Diseases in 2011, and access to opioid pain medicines is one of the 25 indicators in the global monitoring framework for NCDs (WHO, 2016, p. 6).

Moreover, ensuring access in this guideline is described as “an ethical obligation of healthcare systems” and as “an obligation under international human rights law” (WHO, 2016, p. 6) reminds countries of their responsibilities in ensuring access to palliative care, not as an option, but as an essential element of healthcare systems. A similar rationale can be found in the 2018 Integrating Palliative Care and Symptom Relief into Primary Healthcare (WHO, 2018), where palliative care is introduced as a response to global health commitments, such as the WHA 67.19. Reminding countries that “the integration of palliative care into public healthcare systems is essential for the achievement of the Sustainable Development Goal on Universal Health Coverage” (WHO, 2018, p. v). The lack of access in LMICs therefore is not discussed as something that happens to particular groups of people, such as ‘older people’, but are expressed as a systemic issue: “inequality of access to palliative care and symptom relief is one of the greatest disparities in global health care” (WHO, 2018, p. 1).

This section examined the WHO’s assumptions about a lack of access to palliative care and explore how this assumption is expressed differently between the guidelines from the WHO Regional Office for Europe (2004-2011) and those targeting low-and middle-income countries (2016-2018). In the first group, lack of coverage to palliative care services are understood as an ‘equity’ problem, highlighting how some groups have more access than others. In the second, guidelines discuss disparities in accessing palliative care as a systemic problem across the globe.

The assumption of lack of access to palliative care underlies the argument for palliative care provision and is constitutive of the claim that capacity for palliative care requires attention from governments. The lack of coverage assumption in the European guidelines suggests issues with equity, where specific groups are excluded in healthcare systems and therefore their needs are not met. Meanwhile, in the 2016 and 2018 guidelines the WHO reaffirm commitments to global health goals of Universal Health Coverage and commitments under human rights law and assume disparities in accessing palliative care as a global problem. In all instances, building capacity is indicated as a way to improve access to palliative care services. To continue examining how the ‘capacity’ problematisation is constituted, the next section will demonstrate how this notion of increasing capacity relies upon categories such as ‘places’.

6.2.2 Key Category ‘Places’

The idea of lack of access and consequently the notion that capacity must be increased is articulated through the key category of ‘places’ such as ‘western’ and ‘eastern’ or through ideas of ‘developed’ and ‘developing’ nations. The ‘places’ category, in association with epidemiological data and along with notions of social problems such as health disparities, constitutes some ‘places’ in greater need of palliative care than others. In this section therefore, I will examine the category of places and its relation to the ‘capacity’ problematisation.

Beginning with *The Solid Facts* (Davies & Higginson, 2004), ideas of developed/developing countries appear in statements such as: “people in developed countries have lost the familiarity that previous generations had with death and dying” (Davies & Higginson, 2004, p. 26) which gives insight to assumptions of cultural attitudes towards death and dying in countries assumed as ‘developed’. Statements such as: “populations in European and other developed countries are ageing, and more and more people are now living with effects of serious chronic illnesses towards the end-of-life. Meeting their needs presents a public health challenge” (Davies & Higginson, 2004 abstract), presents general ideas of ‘developed’ nations and the type of problems they face and indicates that this is a shared problem. In the publication that followed, the same ideas are observed when the WHO states: “across the world- and particularly in developed countries – the number of older people is increasing, raising many pressing issues for health policy as well as important financial and ethical questions” (WHO, 2004, p. 7). Thus, continuing to reproduce that population ageing is a problem of ‘developed nations’.

The 2011 guideline is a publication written in collaboration with the European Association for Palliative Care (EAPC) (WHO, 2011, p. 2), the examples provided aim to illustrate how services can be developed in different countries, thus aiming to “help those involved in planning, funding or developing services most appropriately and effectively” (ibid). One of the examples used to illustrate successful palliative care programmes came from ‘western’ countries such as Spain (see the Catalonia project discussed in the previous section) and the United Kingdom (WHO, 2011, p. 12). In comparison, in ‘eastern’ Europe, services are presented emphasising the barriers to development of palliative care in these countries (see WHO, 2011, p. 15). Therefore, there is an implied classification of ‘western’ and ‘eastern’ Europe as developed or underdeveloped in terms of palliative care programmes.

The argument for increased coverage is structured through a binarism where ‘service provision’ signals the level of palliative care development of a given country. Thus, relying on the premise that increased services would lead to increased access to palliative care, the category of places is operationalised to indicate ‘where’ coverage is most needed. Countries with higher service provision are positioned on the positive pole of the binarism, meaning that countries that lack service provision are positioned on the negative pole.

In 2016 low-and-middle income countries are represented as 'places' in greater need for palliative care services. Taking the 2016 *Planning and Implementing Palliative Care* services as illustration, the greater need for palliative care provision is due to the increasing rates of cancer. As the guideline states, 20 million people are expected to need palliative care in their last year of life, 78% of them are in low and middle-income countries (LMICs) (WHO, 2016). The type of palliative care recommended for these places is also articulated through levels of development. For instance, since these are 'places' with lower levels of resources, strategies such as community-based and home-based care are emphasised.

As illustration, the guideline demonstrates the successful implementation of palliative care in South Africa, where "trained community care workers" is key to delivering care to the population. Described as "empowering" families and members of the community to care for patients at home "relieving the health system of the burden of care" (WHO, 2016, p.21), palliative care implementation in LMICs is shaped through notions that while these are places with low levels of resources, "empowering" the community serves as a resource.

Another example given comes from Kerala, India, and is an initiative developed by civil society, which attracted the support from local government, political parties, and religious organisations (WHO, 2016). The Kerala Neighbourhood Network for Palliative Care (KNNPC) is used to illustrate how programmes can ensure "local ownership" a principle that is at the centre of community-based initiatives (WHO, 2016). Empowering local communities are presented in a positive light and associated with places such as South Africa and Kerala, which continues to indicate how palliative care services could be available in low resourced places. These services are mainly determined by 'trained' professionals, volunteers, and family members rather than specialised institutional care:

Primary care and community care are essential to provide palliative care services to

> the large majority of people in need. Much of the care of dying persons has to occur in the community and in all health-care settings, mainly conducted by health professionals who are generalists and not specialist practitioners. Most people with advanced chronic conditions with palliative care needs are living in the community and, with the right training, primary care professionals should be able to identify them (WHO, 2016, p.59).

As observed above, coverage of palliative care should be largely provided by primary care and community-based care, making healthcare settings less needed. The successes of South Africa and Kerala are used as an example of how programmes can succeed through “empowering communities” rather than investing in more healthcare infrastructure. For these ‘places’, palliative care benefits healthcare systems by helping address their gaps, reducing costs and improving coverage.

In the 2018 guideline, *Integrating Palliative Care and Symptom Relief Services into Primary Care* this idea of coverage is further developed. Statements such as the one below clearly express a shift in the gaze away from individuals and into the health system itself:

> It is neither possible nor necessary that palliative care specialists provide most palliative care and symptom relief. Primary healthcare providers with basic training in palliative care and symptom relief and respond effectively to most palliative care needs and arrange for transfer to a higher level of care when necessary (WHO, 2018, p.v).

Considering that both guidelines (2016 and 2018) target LMICs for service development, the guidelines are embedded in ideas of LMICs as ‘places’ of community resources and primary health care. Ideas of LMICs are also associated to problematic conditions: “people in LMICs often endure less healthy conditions” (WHO, 2018, p.5) and comparisons with more developed countries emphasises what LMICs lacks in terms of health infrastructure: “they also have typically less access to disease prevention, diagnosis and treatment, to social support, and to specialists and specialised services of many kinds than people in high-income countries”. For these ‘places’: “palliative care can help fill these needs” (WHO, 2018, p.6).

Data on morphine consumption in HICs and LMICs are articulated as to confer the “enormous disparity” between countries (WHO, 2018, p. 9). Data from the International Narcotics Control Board (INCB) indicate that 91% of morphine was consumed in HIC while LMICs which accounts for 81% of the world’s population consumed only 9% (ibid). The use of comparison between countries therefore is structural to the argument that palliative care is needed in LMICs. This use of evidence contributes to ‘localising’ the greater need for palliative care services in LMICs by emphasising what they lack in terms of health infrastructure, morphine availability and epidemiological data.

What this section has demonstrated is that there is a clear association between the level of financial resources and the need for palliative care. As such, there is an important shift in the system of meaning in place that constitutes the WHO’s argument for palliative care - from benefits to patients to benefits to healthcare systems. Additionally, this section also demonstrated that ‘places’ are discussed comparatively: ‘eastern’ European countries as well as LMICs, are presented in contrast to ‘western’ European countries and HICs. In this sense, what this category implies is that there will be places in greater need to build capacity for palliative care than others.

6.3 Contextualising the ‘healthcare capacity’ problematisation (Q3)

This section will be dedicated to tracing the heterogeneous processes that led to the emergence of ‘capacity’ to be thought as a problem. The genealogical perspective aims to highlight the assemblage of practices that converged into this understanding of the problem.

It is not uncommon to find examples in the literature concerned with international palliative care development (Callaway & Foley, 2018; J. Clark, Gardiner, et al., 2018; de Lima & Radbruch, 2018; Kastenbaum & Wilson, 1997; Stjernswärd, 1997b). Yet, Clark (2012) observes that this was not always the case. He argued that there was a lack of systematic understanding regarding palliative care development in the global context prior to the year 2000, which suggests that the problem of 'capacity' was not yet formalised.

At that time, as Sepúlveda and colleagues (2002) argued, 'palliative care' was not yet considered a public health priority. Despite some successes in located services, the notion of a collaborative effort for policy and service development as well as research promoting palliative care internationally were at the margins of debates (Clark, 2012). In Clark's (2012) account of global development for palliative care, the turn of the millennium represented important changes in this field.

Institutions for palliative care began to emerge at the end of the 20th century, such as the European Association for Palliative Care (EAPC) in 1988 and the International Association for Hospice and Palliative Care (IAHPC) in 1980 (see chapter 2). In 1990 St. Christopher's Hospice established its international newsletter gathering information on development around the world. Not long after that, in 1990 Eastern and European Task Force contributed to a systematic understanding of palliative care development in the region (Clark, 2007). In 1998 the International Palliative Care Initiative was established aiming to "serve as a catalyst" towards the integration of palliative care into public health policies (Callaway & Foley, 2018). In the following year, the Foundation for Hospices in Sub-Saharan Africa emerged, the Latin America Association for Palliative Care in the year 2000 (Clark, 2008), and the Asia Pacific Hospice Palliative Care Network in 2001 (Clark, 2007) facilitated the emergence of 'international development' for palliative care as a field of study.

Experts from all over the world gathered to share their experiences with palliative care development in several international conferences at the beginning of the years 2000 (Clark, 2008, 2012; Clark & Graham, 2011). In 2003, the first summit on the subject was held in The Hague, followed by another in Seoul in 2005, Nairobi in 2007 and Vienna in 2009 which led to the emergence of the Worldwide Hospice and Palliative Care Alliance (WHPCA) a year later (Clark & Graham, 2011). The WHPCA's mission of "universal access to high quality palliative care" (Connor & Gwyther, 2018, p. 113) suggests the beginnings of ideas of global capacity for palliative care.

Moreover, mapping out levels of palliative care development became an important theme in the literature produced by organisations such as the EAPC (see chapter 2 for more details). The EAPC was the first organisation publish an Atlas of Palliative Care in Europe, where for the first time, there was "valid data for comparison of the state of palliative care across European countries" (Radbruch & Payne, 2009, p. 278). The Atlas revealed "considerable heterogeneity of service provision in different countries" (Radbruch & Payne, 2009, p. 280).

At the same time, a study commissioned by the WHPCA from the International Observatory on End-of-Life Care (IOELC), provided the first "world map" of hospice and palliative care development aiming to "contribute to the debate around the growth and recognition of palliative care services" (Wright et al., 2008, p. 470). The study observed, amongst other things, that palliative is prerogative of high-income countries (Wright et al., 2008). Studies on levels of development largely contributed to systematic understanding on the status of palliative care internationally and to ideas of 'lack of capacity' throughout the globe (see Clark, 2012).

Ideas of lack of capacity are at the centre of the WHO' Public Health Strategy (PHS), where 'implementation' became a criterion for palliative care development in 2007. The PHS proposed by the WHO includes four elements which must be provided: appropriate policies;

adequate drug availability; education of healthcare workers and the public; implementation of palliative care services at all levels (Stjernswärd et al., 2007a, 2007b). This approach was considered to demonstrate ‘an effective strategy for integrating palliative care into a country’ (Stjernswärd et al., 2007b, p. 492). Given the appropriate tailoring for each individual country, this strategy was expected to increase population-based coverage as a result (Stjernswärd et al., 2007a; WHO, 2002). However, despite the WHO’s PHS, other mapping efforts such as the Quality of Death Index (The Economist Intelligence Unit, 2010) commissioned by the Lien Foundation, ranked palliative care development in 40 countries, reproduces notions that there are ‘huge gaps’ in provision: “too often such care is simply not available: according to WPCA, while 100m people would benefit from hospice and palliative care annually, less than 8% of those in need access it” (EIU, 2010, p. 5). As such, the index reinstated the unequal provision of palliative care to a majority of the people in need. With major concerns on access to palliative care, the WHA 67.19 called all Member States to develop palliative care services (Connor & Gwyther, 2018; WHO, 2014, 2016a). Therefore, what the literature demonstrates is that ideas of ‘building capacity’ were not a prerogative from the WHO, but rather the culmination of the emergence of systematic knowledge developed from international organisations.

6.4 Silences in ‘healthcare capacity’ problematisation (Q4)

As section 6.2 demonstrated, problematising ‘healthcare capacity’ suggests that there are problems with access to palliative care in the world. As also discussed in section 6.2, the categories of ‘places’ reveal how the ‘need’ for palliative care services is articulated for some countries more than others and is used to highlight how palliative care can contribute to healthcare services rather than patients. Section 6.3 traced back the emergence of ideas of ‘capacity’ where it became clear that this problem took shape only after the emergence of international palliative care development as a field, where multiple studies indicated the great disparities in provision converged in global health developments such as WHA 67.19. Having established the constitution and the origins of the ‘capacity’ problem, this section will be dedicated to examining silences created by this problematisation.

To recap this step of the WPR approach, identifying silences according to Bacchi (2009) involves uncovering the alternative ways in which the problem can be thought about. To this effect, comparisons with other guidelines may contribute to bring visibility to other ways palliative care implementation can be problematised (Goodwin, 2011). Moreover, as Bacchi and Goodwin (2016) described, going back to questions 2 and 3 can give insight into the silences imposed.

Considering what has been discussed so far, it is possible to infer that problematising coverage does not allow us to acknowledge of the possible implications of home-base care and community care for the financial stability of households. In countries such as Brazil and Canada, the shift towards home base palliative care highlighted issues of increased financial burden on family caregivers. In a study conducted in Canada in 2015, the shift in policy towards community provision revealed that home-based caregivers had twice the amount of unpaid time for caregiving activities than those caring for hospitalised patients (Gardiner et al., 2020). In Brazil, the shift towards community-based care allowed the discharge of seriously ill patients from hospitals to their homes without any financial support (Cordeiro & Kruse, 2019). Moreover, this problematisation also fails to problematise that increasing coverage does not necessarily equate to quality of care and to equitable services. To understand this argument further, as discussed in chapter 3 section 3.10, England will be used as a case study will to examine how the ‘problem’ is represented to in palliative care guideline, The End-of-Life Care Strategy (EOLCS) (Department of Health, 2008).

6.4.1 How problem can be thought differently: England

The case study that follows aims to identify alternative problematisations. As discussed in Chapter 3 (Section 3.9.4), this step of the WPR analysis involved applying question 1 of the WPR framework to national guidelines in support of palliative care. The goal was to identify how the problem is represented, allowing for comparison with the WHO's problematisation of the inadequacy of care. Furthermore, the case study will discuss the identified problematisation within the context of research literature on the development of palliative care strategy in England.

It is a widely recognized across the research literature on palliative care development that those countries in high-income settings have better access to palliative care services, opioids, and education in comparison to those in low-and-middle income (Hannon et al., 2016; Knaul, Farmer, et al., 2018; Knaul, Rodriguez, et al., 2018). The *Lancet Commission on Palliative Care and Pain Relief* report (Knaul, Farmer, et al., 2018) recently stated that palliative care and pain relief is one of the most inequitably distributed health interventions (Knaul, Farmer, et al., 2018; Knaul, Rodriguez, et al., 2018; Sleeman et al., 2019). The WHO also acknowledged that the world faces great disparities in palliative care provision, emphasising the differences between HICs and LMICs (WHO, 2018, 2020). Much of the debate on inequalities focuses on the asymmetries in global health where statements such as "the abyss is broad and deep, mirroring relative and absolute health and social deprivation"(Knaul, Farmer, et al., 2018, p. 1391) which seems to direct attention to the need for change in global health disparities, positing an argument structured by a dichotomy between HICs vs LMICs.

As argued elsewhere in this chapter (chapter 6, section 6.2), the discourse of inequalities within the WHO's publications are constituted by statistical data such as mortality rates, epidemiological trends, and opioid availability. The data is used in a way to 'localise' where palliative care is most needed, consequently drawing attention to the lack of palliative care in LMICs. Thus, I argued that problematising the lack of coverage for palliative care feeds into the dichotomy between HICs and LMICs. Access to palliative care services would then be mitigated by increasing capacity to respond to palliative care needs according to the WHO guidelines analysed in this chapter. The capacity discourse echoes through other reports such as *The Lancet Commission Report*, where the issue of equity is once more proposed in a HICs vs LMICs structure, drawing attention to the needs of the ‘poor’ (Knaul, Farmer, et al., 2018). Yet, as this section will demonstrate, problematising lack of coverage obscures, more than addresses, the issue of inequality in palliative care. To further analyse the silences imposed by the problematisation identified in this chapter, this section will draw attention to England’s EOLC Strategy (Department of Health, 2008), but first it is important to understand the context in which English palliative care development is situated.

Historically the UK has been regarded as having the best quality of death in the world, as evidenced across all of the Quality of Death Indexes to this date (Finkelstein et al., 2022; Kong et al., 2010; The Economist Intelligence Unit (EIU), 2015) . The most recent survey on palliative care development categorises the UK as a group 4b country (WHPCA, 2020), which category represents countries where palliative care services are at an advanced stage of provision. This includes:

> The development of a critical mass of palliative care activism in a wide range of locations; comprehensive provision of all types of palliative care by multiple service providers; broad awareness of palliative care on the part of health professionals, local communities, and society in general; a palliative care strategy that has been implemented and is regularly updated; unrestricted availability of morphine and most strong pain-relieving drugs; substantial impact of palliative care on policy; the existence of palliative care guidelines; the existence of recognised education centres and academic links with universities with evidence of integration of palliative care into relevant curricula; and the existence of a national palliative care association that has achieved significant impact (WHPCA, 2020, p. 53).

The UK therefore represents an example of the WHO’s Public Health Strategy with advanced stages of palliative care integration, medicine availability, policy development and education. Yet, despite higher levels of capacity for palliative care provision, the UK can serve as to illustrate how service provision at the country level may not translate to equitable coverage and quality care. That is, where you live does not guarantee high-quality end-of-life care experiences (Finkelstein et al., 2022). Consequently, it can be argued that increasing coverage does not equate to quality of care and equitable distribution of services. For example, Finkelstein et al., (2022) argue that even in HICs people die in pain and suffering without having their needs met. Their work also raises important questions on the reliability of the quality of death indicators when these are mainly based on data availability and often do not include patients and families’ perspectives for assessing the quality of end-of-life care (Finkelstein et al., 2022).

As such, if we take the UK’s rankings and classifications at face-value, then the challenges faced to provide consistent EOLC experiences is obscured. For instance, The National End of Life Care Intelligence Network (NEoLCIN) revealed in 2015 an estimate of 92000 people that would have unmet palliative care needs per year, a number that is likely to rise due to population projections of increasing diversity, which, as previously argued, have systematically had less palliative care support over the years (Calanzani et al., 2013; Finkelstein et al., 2022; Lancaster et al., 2018). Thus, it seems logical to assume that the healthcare capacity problematisation is limited as it constricts our understanding of inequality to countries with the most capacity for care, rather than equity.

It is also important to note how the ‘UK’ is often represented in guidelines, cross-national studies and reports as one homogeneous group. Since 1999 Scotland, Wales and Northern Ireland have developed their own national health systems, which translates into “distinct policies, strategies and delivery mechanisms in place” (Marie Curie, n.d., p. 2)

There are also geographical and demographic differences that makes access to palliative care a particular challenge to each of these nations (Dixon et al., 2015; Hospice UK, 2021) Despite their differences, equity in end-of-life care can be seen as a central concern, as argued by Borgstrom (Borgstrom, 2013, 2016) In Scotland, the *Scottish Government's Strategic Framework for Action on Palliative and End of Life Care*, aims to make palliative care accessible to "all who can benefit from it, regardless of age, gender, diagnosis, social group or location" (Scottish Government, 2015, para 1). England's *Ambitions for Palliative and End of Life Care (2021-2026)* (National Palliative and End of Life Care Partnership, 2021) equally positions health inequalities as a remaining 'problem'. In Northern Ireland, the *Palliative Care in Partnership Mandate*(Palliative Care in Partnership Programme, 2023) , is a document that describes the commitment to deliver quality palliative and end-of-life care across Northen Ireland. Although the document does not mention the term 'equity', the concern with equitable coverage is implied in the aims of the programme where it states that: their goal is to "provide regional direction so that everyone identified as likely to benefit from a palliative care approach" (Palliative Care in Partnership Programme, 2023, p. 5) can be supported.

The same can be argued for Wales, where the Welsh government proposed a broader spectrum of health and social care rather than focusing on specialist palliative care to:

> […] ensure that equity of palliative care and end of life access is provided for those people who have faced inequality such as ethnic minority communities and the LGBQT+ communities and some pathways will need to be reimagined to incorporate more flexibility and innovation to deliver this (Welsh Government, 2022, p. 2).

More recently, Hospice UK, a charitable organisation in support of hospice and palliative care, released a report on equality in hospice and palliative care in the UK which places 'equity' as a central priority for all nations within the UK. The document states that health inequalities are disproportionately distributed, echoing a similar dichotomy between affluent areas and deprived areas (Hospice UK, 2021). In doing so, the report offers insight on the groups more likely to have access to palliative care, and the groups who are often excluded from accessing services, which demonstrates how the distribution of services may favour some groups more than others (Hospice UK, 2021). That is, the fact that the UK is continuously referred to as an example of successful implementation for palliative care programmes (WHO, 2011), it becomes increasingly necessary to not assume such affirmations as taken-for-granted.

Of the four nations that constitute the UK, England certainly has a historical role in palliative care development. Besides being the place of birth to the modern palliative care movement, England was also a pioneer when it refers to policies in support of end-of-life care (Borgstrom, 2016). England was one of the first countries in the world to have a specific policy towards end-of-life care, namely the End-of-Life Care Strategy (EOLCS) (Department of Health, 2008). This policy is recognised worldwide as the first national policy to offer an integrated approach to care (Borgstrom, 2016; Hunter & Orlovic, 2018). Thus, making the EOLCS an important starting point to identify alternative problematisations and to compare it to those found in this chapter (section 6.1).

As demonstrated through the ‘capacity’ problematization (see chapter 6 Section 6.1), the discourse of health inequalities within the WHO guidelines highlights social disadvantage as a ‘problem’ to which service-building is proposed as a solution. That is, the ‘capacity’ problematisation fits into a technocratic solution to a social problem. That favours the establishment of normative standards for health provision. These standards are subsequently represented as universally applicable to be readily applied by member countries, rather than uncovering the uncomfortable debate of privilege that permeates global palliative care provision.

English EOLCS: *what’s the problem represented to be?*

In response to demographic changes in the population and place of death, the End-of-

Life Care Strategy (EOLCS) from the English Department of Health aimed to meet the needs and preferences of patients and their families (Department of Health, 2008). The idea promoted in this programme was that palliative care could reach equitable coverage irrespective from prognosis, location, and preference for place of death (Clark et al., 2015). According to Hunter & Orlovic (2018), the EOLCs had two main interests: to further improve care at the end-of-life and to reduce costs of end-of-life care. In this policy, the *location* of end-of-life care gains relevance and it is thought to reduce hospitalisations while attending to people's preferences (Department of Health, 2008; Hunter & Orlovic, 2018). The discourse of choice is also a key aspect of this policy which includes where patients would like to die, how they would like to plan their care, i.e. choosing what treatment they find acceptable and who they wish to care for them (Borgstrom, 2013; Borgstrom & Walter, 2015; Department of Health, 2008).

Before 2008, palliative care and end-of-life care services were restricted, mainly provided by specialists or volunteers (Borgstrom, 2016) something that is also mentioned in the EOLC Strategy as a "variable" quality of care within health and social care services (Department of Health, 2008). The use of the word 'variable' offers insight on what was considered as problematic with EOLC in England at the time, and to propose the appropriate ways to respond to the problem through creating normative standards to EOLC provision. In this case, the Strategy set out key areas of improvement, such as changing attitudes to death and dying; identifying those who are reaching the end-of-life, which in turn, requires health and social care workers to be trained in identifying those who are approaching the end of life; planning, that is, discussing wishes and preferences about care; coordinating care and delivering high quality services in all locations (Department of Health, 2008). These areas for improvement all indicate the need for systemic change, and as such, imply that the ways of responding to death and dying may be insufficient and/or inadequate.

In Borgstrom's (2016) analysis of English EOLC policies, offers insight on how the issue of ‘equity’ is represented to be within this policy. She argues that there are two main issues about equity addressed in this policy: one refers to access of specialist services based on diagnosis and the other refers to differences in care across health and social care settings (Borgstrom, 2016). Thus, it could be argued that underlying the issue of ‘equity’ is a biomedical approach to health differences, where the issue lies on the types of illnesses being supported by EOLC and the technical standardisation of provision. In this light, the socio-economic circumstances associated with health inequalities are obscured. As proposed by Richard (2022), people’s socioeconomic conditions are an important determinant of many factors of healthcare, such as housing, income and education, all of which have an impact on health across the lifespan, even before people are born. Thus, while representing the problem of equity through a biomedical framework and standardisation of provision may be more readily achievable, it fails to produce ways to effectively address the structural health inequalities that determines access to any health care in the first place.

As illustration of ?, the English palliative care programme *Liverpool Care Pathway* (LCP) aimed to establish high-quality care for dying patients. According to Walter (2020), this ‘pathway’ worked well in high-resourced settings but faced challenges in establishing ‘high-quality’ care in a less resourced settings where ‘quality’ of care had become a “tick-box exercise” (Walter, 2020). Further, the LCP was withdrawn in 2013 due to claims by families that care was conducted inappropriately, with multiple cases of inadequate use (Al-Benna, 2013). The programme became associated with instances of inadequate end-of-life care, poor communication and hastening of the dying process (ibid). The independent review panel concluded that the LCP had failed to provide high-quality care and the programme was discontinued. This suggests/shows?

In 2014, the *Dying Without Dignity* report identified different areas of concern on the quality of EOLC in England such as: issues around recognising when someone is dying;

poor symptom control where patients were argued to have died in pain or in agitated state; poor communication; inadequate out-of-hours services; poor care planning and delays in diagnosis or referrals for treatment (Dying without Dignity Investigations by the Parliamentary and Health Service Ombudsman into Complaints about End of Life Care, n.d.). Additionally, a survey conducted with palliative care practitioners in the UK revealed that only 19% of participants believed to have sufficient capacity to deliver high- quality end-of-life care while 66% felt that there was insufficient capacity for high-quality care, with many reporting difficulties in providing home base care (ibid). 86% of practitioners reported late referrals to palliative care services due to late diagnosis and an overwhelming majority of them (93%) reported that they felt unsure about whether or not there will be enough capacity to deliver palliative care in 10 years' time (Association of Palliative Medicine and Marie Curie Survey of Palliative Care Practitioners 2021). All of which indicates that a biomedical approach to EOLC, in detriment of a social-economic approach, tends to maintain inequalities in health despite having 'capacity' for palliative care provision.

Furthermore, the discourse of choice and preferences identified in EOLCS (Department of Health, 2008) also restricts the understanding of the problem to the 'individual', which also obscures the asymmetries that constitute health provision in the first place. In the document *Ambitions for Palliative and End of Life Care (2021-2026)* by the National Palliative and End of Life Care Partnership (2021), quality and accessibility to end of life care and palliative is regarded as a priority. The language of a 'collective' effort is employed to make palliative and end-of-life care a shared responsibility: "palliative and end of life care requires collaboration and cooperation to create the improvements we all want" (National Palliative and End of Life Care Partnership, 2021, p. 4). Collective effort implies collective responsibility at the same time that obscures accountability. Considering that as argued by Borgstrom (2016) palliative care in England has been largely provided and funded by charitable organisations, the premise of a ‘collective’ effort continues to obscure the lack of governmental funding as one of the reasons why reports and investigations of care are so frequently identified as “poor care”(National Palliative and End of Life Care Partnership, 2021, p. 9).

The document *Ambitions for Palliative and End of Life Care (2021-2026)* draws from the DoH Strategy for End-of-Life Care (Department of Health, 2008) and introduces the COVID-19 pandemic as an illustration for the need to improve support for “people of all ages including those bereaved, and to drive down health inequalities. Nobody must get left behind” (National Palliative and End of Life Care Partnership, 2021, p. 4). The framework calls for a collective response to palliative care needs and proposes new ways of working together to achieve a more integrated way to deliver care. This framework provides insight to the types of people who have been left behind: those from black and minority ethnic communities (BAME); people living in rural and deprived areas; the homeless and the imprisoned; and lastly, “those who are more vulnerable or less able to advocate for their own care” (National Palliative and End of Life Care Partnership, 2021, p. 21). That is, those who have been historically marginalised and excluded from palliative care services (Monroe et al., 2011).

The analysis so far indicate that despite having a EOLCs that problematises ‘equity’, care continues to be delivered differently depending on *who* you are, for example, structural racism may play an important part in how end-of-life care is provided and who has access to it. As such, the so called ‘equity turn’ in palliative care and end-of-life care urge governments and other health authorities to recognise that the poor EOLC outcomes is shaped by wider societal issues such as “colonialism, racism, sexism, homophobia, ableism, all of which intersect with poverty and deprivation” (Rowley et al., 2021 in Richards, 2022, p.3).

To summarise, examining English EOLCS helps us to reflect that problematising capacity as proposed in the WHO guidelines silences two main issues: first, that inequality is not a problem exclusive to LMICs as exemplified in this case study, and second, that without acknowledging how social and economic factors plays a key role in the types of care people are able to access, the policies may continue to maintain inequitable social relations. As such, the discourse of capacity as analysed in this chapter, mainly focused on service-building, fails to acknowledge that health inequalities play a key factor in how a country can structure, organise and deliver culturally sensitive care.

English end-of-life care and the WHO guidelines: an enmeshed relationship?

The EOLCS (Department of Health, 2008) is a document that echoes a similar narrative of the death-denying literature (see chapter 2), stating that in the past, people died mostly of acute illnesses and a higher proportion of deaths occurred in infancy with most people dying in their own homes. These changes led to a loss of familiarity with death has decreased over the centuries (Department of Health, 2008). The same arguments can be seen in Ariès (1974) death-mentality theory where death was previously considered ‘tamed’, a scenario drastically changed by modernity. The influence of death-denying theory is further evidenced in the EOLCS by statements such as: “as a society, we do not discuss death and dying openly” (Department of Health, 2008, p. 9). That is, in modern English society death remains a ‘taboo’, a premise that has been disputed by authors such as Mellor (1993) and Walter (1991; 1994; 2003; 2017) and by the latest report on the *Lancet Comission* on the value of death (Sallnow et al., 2022).

The EOLCS (Department of Health, 2008) document also draws from the ‘good death’ discourse where good dying is defined through symptom control and place of death. Despite recognition that these may vary, a ‘good death’ has been defined as: “being treated as an individual, being without pain and other symptoms, being in familiar surroundings; and being in the company of close friends and families” (Department of Health, 2008, p. 9). England’s EOLCS therefore poses several similarities with the WHO series of booklets for

Europe, namely *Palliative Care the Solid Facts* (Davies & Higginson J., 2004) and *Better Palliative Care for Older People* (WHO, 2004) For instance, the first guideline states that "palliative care begins from the understanding that every patient […] is worthy of respect as a unique individual"(Davies & Higginson J., 2004, p. 7). In the second guideline mentioned above, ideas of autonomy and choice are promoted as a human right and a "core ethical value for society and health services" (WHO, 2004, p. 18). Both resonates with the EOLCS's (Department of Health, 2008) discourse of individuality and choice. In addition, the EOLCS places emphasis on the place of death and presumes an individual that is willing and wanting to be involved in decision-making, rationales that can also be found in the WHO's guideline for Europe: "there is increasing research evidence concerning the decisions that people would prefer to make about care at the end of their life. Most studies have found that around 75% of respondents would prefer to die at home." (Davies & Higginson J., 2004, p. 16). Statistical data is used to urge health authorities to consider place of death as a key aspect of health care, which is also a priority of England's EOLCS (Department of Health, 2008)

As discussed elsewhere in this thesis (chapter 5, section 5.3), the series of booklets published by the WHO is a collaboration with the European Association for Palliative Care (EAPC), which demonstrates, as proposed by Littoz-Monnet (2022) a mechanism of circularity, that is – how knowledge is produced and disseminated in circularity by an enmeshed group of organisations, individuals, and research clusters. Consequently, the analysis conducted in this section feeds into her argument that there is no strict separation between expert knowledge and policymaking (Littoz-Monnet, 2022). The enmeshed relationship between the WHO booklets in support of palliative care in the European Region and the English EOLCS (Department of Health, 2008) demonstrate how the circularity of knowledge dissemination make expert claims hard to disrupt, even when there are competing knowledge claims (Littoz-Monnet, 2022).

6.4.3 Summary

This section aimed to identify the silences created by the capacity problematisation. Identifying silences invites the analysts to consider cross-country comparisons in order to examine the alternative ways problems can be thought about (Bacchi, 2009; Goodwin, 2011). Using England as an illustration, I argued that the issue of capacity does not allow thinking other problems such as quality of care and equitable distribution. Other systems such as the Canadian and the Brazilian reported increased poverty among caretaking households which in the Brazilian case prevented them from receiving care. As such, for these countries, an alternative way of thinking about palliative care could be thought of as a welfare problem rather than healthcare capacity.

6.5 Effects of the 'healthcare capacity' problematisation (Q5)

6.5.1 Discursive effects

The 'capacity' problematisation as observed in this chapter reveals that the problem is understood to be improving access to palliative care by building capacity in existing health services and extending services to the home and community care. This section will examine the discursive effects that results from this form of interpreting the problem.

As discursive effects aim to identify the ways in which problematisations can 'close off' other possible avenues for analysis (Bacchi, 2009), this section will build on the silences identified above. In the previous section, I demonstrated through multiple cross-country examples how capacity building could be thought otherwise. Considering the English case presented above, what follows is that one discursive effect is that 'capacity' constricts palliative care into the realms of healthcare , closing off opportunities to conduct sociological analysis on the structural inequalities that continue to shape access to healthcare services.

The English case also allows us to think how measurements such as levels of palliative care development fail to represent accurately how palliative care is being conducted in the national context, while continuing to favour a classist understanding of 'provision' (i.e., higher levels of resources equal higher levels of palliative care provision). Moreover, the discourse of provision for LMICs was centred around ideas of filling the voids of healthcare provision which attributes responsibility to the 'people' for the care rather than institutions. Thus, redirecting attention away from the lack of funding, international cooperation and political power to influence global health policies.

6.5.2 Subjectification effects

I have argued in the previous chapter that the guidelines from 2004-2011 produced patients as 'dying entrepreneurs', where ideas of individualised care and meeting preferences required a specific kind of subject – the individual as the atom of self-interest, willing and wanting to make choices to achieve a good end-of-life. For this reason, this group of guidelines will not be included in subjectification effects as they have already been presented in chapter 5. Thus, the discussion that follows will cover subjectification effects from guidelines from 2016 and 2018.

6.5.2.1 Agents of care

The first subjectification effect identified in the 2016 guideline refers to the transformation of individuals into 'agents of care'. There are multiple instances where the WHO draws attention towards individual agency as the primary source for service development. For instance, home-care services should be initiated by the "local health authorities" (WHO, 2016a, p. 20). indicates how palliative care is being thought about as 'something that people do', thus focusing on the agency of those involved in care provision. This can be seen in statements such as how health authorities should follow "planning processes used in the local health system" (ibid, p.20) focus on individual behaviours rather than on systems of government or policy formulation. Agency is also emphasised for the development of community services: "in any area there will be people interested in helping others. The first step is to hold an awareness meeting/discussion for people *who are likely to be interested in helping*" (WHO, 2016a, p. 23, emphasis added), thus reinforcing ideas that services will develop depending on people’s agency towards palliative care.

Individuals may vary in terms of the roles they are expected to perform in healthcare as expressed in the following statement: “before a palliative care service is established there must be clarity on what mix of paid staff and volunteers is best and which professional staff will be needed and with what level of expertise” (WHO, 2016a, p. 36); however, the idea still is that palliative care development is made by ‘people’. Focusing on people shifts responsibility away from ‘governments’ and ‘institutions’ as the main agents of this service. ‘Governments’ are mentioned as a source of ‘funding’ (WHO, 2016a, p. 37) which revels an interesting positioning of institutions as collaborating agents rather than ‘providers’.

6.5.2.2 Trainable Subjects

The comparison between places shapes the way we die as more or less likely to be ‘positive’ that is: more chances of survival in the case of an incurable disease; more chances of support; access to specialised services such as palliative care; and with less chances of dying in suffering. These statements serve to highlight the deficits in healthcare provision in LMICs: “many people around the world have limited or no access to cancer chemotherapy, radiation therapy or surgery, to effective chemotherapy for multidrug resistant tuberculosis, or to neonatal intensive care” (WHO, 2018, p. 5). The assumption of a deficient healthcare structure requires feasible cost-effective services which in turn invites individuals to become ‘trainable subjects’.

The idea of trainable subjects reflects the positioning of any individual as a prospective agent for palliative care. This notion is reflected in statements such as: “inexpensive, safe and effective medicines and equipment prescribed *by any physician,* clinical officer or assistant doctor with basic palliative care training” (WHO, 2018, p. 13, emphasis added). Considering that in 2018 the WHO is arguing for palliative care in primary health care, trainable subjects become central to development of such programmes:

> It is neither possible nor necessary that palliative care specialists provide most palliative care and symptom relief. Primary healthcare providers with basic training in palliative care and symptom relief can respond effectively to most palliative care needs and arrange for transfer to a higher level of care when necessary(World Health Organization, 2018, p. v).

The notion of trainable subjects is also associated with notions of deficiencies in healthcare systems: "in countries where pain medicine does not yet exist as a specialty and where prevention and relief of pain from trauma or burns or surgery are inadequate, clinicians trained in palliative care can filled this therapeutic void" (WHO, 2018, p.6). As 'trainable subjects', those who have been trained, can contribute to palliative care by transforming their peers into trained subjects, they are positioned both as trainees and trainers: "clinicians trained in palliative care can intervene either by training colleagues in symptom control, by providing direct symptom relief, or both" (ibid). Trainable subjects also include those in non-official roles such as community health workers and volunteers: "community health workers can provide frequent emotional support for the patient and family and report to a clinician at CHCs" (WHO, 2018, p. 6). Training once more is the necessary condition for any community health worker to become an agent of care:

> With as little as three to six hours of training, CHWs not only can provide important emotional support, but also recognize uncontrolled symptoms, identify unfulfilled basic needs for food, shelter or clothing or improper use of medications, and report their findings to a nurse-supervisor at a CHC. In this way, they can accompany patients in need of palliative care and help assure their comfort by serving as the eyes and ears of their clinicians (WHO, 2018, p. 24).

Trained individuals, therefore, are expected to provide care at primary health level. Through clinicians trained in palliative care, community care becomes feasible because they can train community health workers to perform various tasks including those that were previously performed by healthcare professionals: “bereavement support should also be made accessible. This may consist of bereavement support groups led by adequately trained personnel. Some interventions can be provided safely by CHWs with basic training” (WHO, 2018, p.25). Thus, with more people ‘trained’ in palliative care, palliative care programmes can be integrated into primary care which eventually leads to “reducing costs for the healthcare systems and reducing dysfunctional overuse of hospitals and non-beneficiary interventions” (WHO, 2018, p.45). In this sense, the subjectification effects within the 2018 guideline refers to creating ‘trainable subjects’ for palliative care, which is central to the expansion of coverage believed to be able to reduce the burden of care away from healthcare systems.

6.6 Summarising arguments

The constitution of capacity problematisation is sustained by ideas that some countries have a greater need for palliative care services due to their lack of health infrastructure (Q2). Patients are left to suffer not because of the inadequacies of current protocols of care, but because of geopolitical, social, and economic conditions that are at the basis of ideas of an ‘overwhelmed healthcare system’ or having ‘less access to health conditions’ (Q2). Rather than directing attention to the structural inequalities that makes the healthcare deficient, guidelines direct attention to the expansion of coverage through training professionals, volunteers, community health workers in palliative care (Q5). ‘Palliative care’ in this case meant filling the voids of healthcare provision and providing a cost-effective alternative instead. ‘Coverage’ in this sense, is represented not as a systemic problem, but its transferred to the individual sphere, attributing responsibility to the very people affected by health disparities (Q5).

The disparities in accessing palliative care in LMICs is not a reflection of wider global problems (Q2). Rather, ‘coverage’ becomes a local problem that can be addressed through the mobilisation of individual agency to assume responsibility for the implementation and operationalisation of care (Q5). Paradoxically, while trying to address the lack of access to palliative care in LMICs, the rationality presented through the ‘capacity’ problematisation continues to represent LMICs as ‘problematic’, thus highlighting what they lack (Q2).

Through genealogical tracing (Q3) of the capacity problematisations, it was possible to widen the scope of our understanding on the emergence of the WHO guidelines not as the natural result from perceived global health problems, but as a product of the relationship between the WHO and other international organisations in support for palliative care (Q3). Indicating as a consequence, the direct influence of expert knowledge (´technocracy´) shaping how ‘palliative care’ is to be perceived at the global level (Q3). Thus, the genealogy conducted here allowed raising questions on the implications of expert knowledge in what is perceived as problematic especially regarding LMICs. For example, as observed in this chapter, the capacity problematisation localises the ‘problem’ in countries that lack infra-structure and trained personal to provide care leaving capacity in HIC unproblematised (Q4). Thus, the English case serves to illustrate that issues of ‘capacity’ assumed in guidelines as a product of socioeconomic and geopolitical disadvantages (i.e., LMICs) is just as problematic in the ‘developed’ world (Q4). As a consequence, the cross-country comparison conducted in this chapter allowed questions to be raised on the claim that capacity is a LMIC problem.

First, the claim that capacity is a problem mainly in LMICs is problematic because at the basis of this claim is the notion of disadvantages (Q2). Because they suffer disadvantages, they are deemed less capable to offer high-quality care and equitable coverage (Q2). This is the reason why palliative care is operationalised for these countries as something ‘easy to apply’ and ‘cost-effective’, redirecting attention from issues such as funding; political power to influence global health agendas (Q5). In addition, redirecting attention away from structural issue allows to transfer the responsibility for care provision to the people as identified in the subjectification effects (Q5). In constricting palliative care into the realms of healthcare provision, the ‘capacity’ problematisation obscures the articulation of healthcare provision and other systems such as social care and welfare and contributes to transferring social problems to the individual sphere (Q5).

Chapter 7. The Creation of End-of-Life Care ‘Problems’

This thesis sought to explore problematisation within the WHO ‘palliative care’ guidelines. The findings presented in chapters 4, 5 and 6 indicated that WHO guidelines foster two dominant interpretations of ‘problems’ to which ‘palliative care’ is recommended as a solution. Conceptualised as ‘inadequacy of care’ and ‘healthcare capacity’, each problematisation represents a particular rationale underpinning palliative care programmes within WHO guidelines from 1990 to 2018.

In this chapter I will discuss how the problematisations examined in this study contribute to existing literature on palliative care, and more generally, to death and dying studies. To this end, the section What’s the Problem Represented to Be Again? will begin by revisiting and summarising the findings from chapter 4 in order to reiterate how the problematisations were identified. This will be followed by a summary of findings from chapters 5 and 6 in order to situate the discussion that will follow.

The second part of the chapter will focus on how the findings contribute to existing literature. In the section identified as Different Problems Different ‘Palliative Care’, I will go back to Bacchi’s (2009) debate on how problematisations are constituted, to understand how the problematisations identified in this study foster different meanings to what ‘palliative care’ is, the type of care that should be offered and who is being empowered to offer them. In the first section I will argue that this study contributes to understanding the conceptual implications of problematisations to ‘palliative care’.

In the second section identified as Governing Through ‘Inadequacy’: Palliative Care as a Strategy for Administration, I will return to the literature on palliative care as a form of ‘care’ for the dying. As the literature review pointed to a reformist intent underpinning the emergence of ‘palliative care’ (see Chapter 2) this chapter will revisit the argument of palliative care as an opposition to traditional medicalisation. In doing so, I will argue that through problematising ‘inadequate’ forms of care, guidelines empower healthcare professionals to the administration of the dying. In this sense, the section raises questions on whether the interpretation of ‘palliative care’ within WHO guidelines may be favouring the professionalisation of death. This will be followed by the section Problematising Capacity: Homogenising End-of-Life Care Interventions where I discuss that problematising capacity allows maintaining westernised palliative care perspectives. Moreover, this problematisation allows us to see how guidelines favour homogenising end-of-life care instead of pluralistic views. The sections on both problematisations led to a debate on the constructed nature of the perceived problems. In the section entitled The Making of ‘Global Problems’ I reflect back on the historical and social processes that led to the constitution of ‘capacity’ and ‘inadequacy’ as global health problems to indicate how they reinstate ethnocentric values that overrides cultural specificities.

In the third section identified as Governing Through Palliative Care Implementation: Contributions of the WPR, I focus mainly on the contributions of this study to palliative care in helping bring visibility to the forms of governing embedded in the proposed palliative care programmes by the WHO. In doing so, I argue that rather than promote alternative ways of caring and allowing multiple perspectives of palliative care to be created, guidelines shape normative expectations on how ‘care’ is to be performed and to what end. Thus, the section will reflect on the empirical, methodological and theoretical contributions to palliative care studies.

7.1 What’s the Problem Represented to Be Again? Revisiting How Guidelines Constitute ‘Problems’

Going back to Bacchi’s (2009) understanding of policy ‘problems’ and how to investigate them, analysing policies should begin by interpreting what is proposed as change.

Proposals for change implies what is being considered problematic and hence, gives insight on how the problem is being represented (Bacchi, 2009). In this study, Chapter 4 Identifying Problematisations, provided a detailed account on what guidelines proposed as change for end-of-life care from 1990 to 2018 (for a summary of proposals see table 3).

From 1990 to 2011 I observed that the guidelines proposed changes to protocols for patient care for cancer patients and older people, I argued that in this group of guidelines the ‘problem’ was being shaped as a clinical problem. If the problem is clinical, the obvious interpretation is that the ways patients were treated for from 1990 until 2011 were deemed problematic. Hence, the conceptualisation as ‘Inadequacy of Care’. I also observed that although guidelines are complex and can offer overlapping interpretations of ‘problems’ the identification of dominant problematisations was based on the expressed goals within the guidelines forward and introduction chapters. This way, the guidelines ‘problems’ were shaped by the very goals they aimed to achieve.

In turn, the problematisation ‘Healthcare Capacity’ was shaped by the guidelines expressing concern with the current status of access to palliative care services. In this sense, I argued that they interpreted the problem as a ‘capacity’ issue where attention is directed to strategies to increase coverage of palliative care services. This was predominantly identified within the guidelines from 2016 and 2018. However, the guidelines from 2004 to 2011 also problematised coverage in the European Region, for this reason they were also included as to represent the ‘capacity’ problematisation.

In order to examine each problematisation separately the above chapters have been separated into two. This is not the same as saying that the problematisations themselves are separate, as one problematisation is a discontinuity from the previous. Bacchi (2009) clearly states that ‘problematisations’ can often be nested within each other or overlap. The table below represents a summary of findings from Chapters Problematising Care and Problematising Coverage - Chapters 5 and 6 respectively:

	Chapter	Problematising Care	Problematising Capacity
2.	Examining premises, assumptions concepts and binaries (Q2)	Established upon the premise that palliative care will improve quality of life and comfort before death. The assumption being that without palliative care patients will die in suffering. The 'problem' is constituted by people categories: 'cancer patients' and 'older people'; and disease categories 'life-threatening illness'; 'advanced cancer'; 'frailty'; 'dementia' The categories are articulated as 'suffering' understood in terms of 'total pain'. Imposes binarism appropriate vs inappropriate care, where palliative care is on the positive pole. Each guideline from this group will set out what is expected from national governments in order to achieve appropriate care. This was identified as opioid availability, adequate patient prioritisation and meeting patients' preferences.	Established upon the premise of that increased capacity will lead to increased access to palliative care services The assumption being that more coverage of palliative care equals more quality of 'care' The problem is constituted by 'places' categories: 'HICs'; 'LMICs'; 'eastern Europe'; 'western Europe'. The categories of places are understood in terms of 'levels of palliative care development' This structure imposes a binarism developed vs developing where developed countries are placed on the positive pole The structure therefore sustains that coverage is a problem of LMICs and sets out 'coverage' as a goal governments must aim to achieve.
3.	Contextualising Problematisations (Q3)	Ideas of inadequacy appeared in the decade before the emergence of the hospice movement. Mostly shaped by social processes occurred in Europe and North America, such as the development of transplants and changes in the criteria to certify death from interruption of heart and breathing to 'brain death' Inadequacy of care was first problematised by the Vatican and then by European Council before reaching WHO. Campaigns for palliative care implementation through ideas of 'inadequacy' came as a product of personal decision from the Chief for	Ideas of capacity are a development from the systematisation of knowledge produced by organisations in support of palliative care international development. Studies mapping levels of palliative care development shaped ideas of uneven distribution The influence of international organisations in support of palliative care led to collaborations with WHO such as the publication Palliative care for Older People Better Practices (WHO, 2011). This indicates that ideas of capacity are a product of the enmeshed relationship between WHO and the knowledge produced by international organisations for such as the EAPC and the WHPCA.

		Cancer Care for WHO at that time and not the outcome of care reform.	
4.	Silences (Q4)	Problematising care as 'inadequate' does not allow to see how different ideas of death and dying may indicate different understandings of what is 'appropriate' or not at the end-of-life. Culturally specific studies reveal that ideas of what constitutes appropriate end-of-life care is culturally shaped rather than a lack of appropriate medical/professional care. Inadequate care does not allow to see how the national context will shape the country's need for palliative care as demonstrated by the Colombian case.	Problematising 'coverage' fails to recognise that increased coverage does not equate to equitable distribution or quality of care. Because coverage serves as a criteria to classify countries as more problematic or less problematic, this problematisation fails to recognise that HICs also face issues with coverage, equitable access and quality of care as demonstrated by the English case. Countries such as Brazil and Canada faced increased economic challenges with the policy shift towards community and home base care hence, although increases capacity does not allow to see other impacts of extended coverage.
5.	Effects of Problematisations (Q5)	Discursive effects: Palliative care becomes constricted to patient care. Inadequate care equates knowledge and training in palliative care to quality of end-of-life. Subjectification effects: inadequacy creates specific types of subjects: the sufferer and the dying entrepreneur.	Discursive effects: Palliative care is constricted to the realms of training/education preventing analysis of how it relates to wider societal problems. Capacity equates service provision to development which contributes to the continued classist understanding of international palliative care development. Subjectification effects: Capacity requires specific type of subjects: Agents of care and trainable subjects identified.

Table 4. Summary of findings

The table above offers insight into how 'problems' became problems of a particular kind. It also offers the possibility to make comparisons on how they were constituted, the different origins of the problematisations and the silences that they impose. It is most important to observe that the way guidelines constitute 'problems' have implications to the meanings attributed to the concept of 'palliative care'. This will also have implications to particular kinds of subjectivities and discourses. The next section will consider how these findings contribute to our existing knowledge on 'palliative care' and death studies. It is to this discussion that I now turn.

7.2 Different Problems Different ‘Palliative Care’

As demonstrated elsewhere in this thesis (chapter 2) the field of ‘global’ palliative care is constituted by ideas of unrelieved suffering on a global scale to which ‘palliative care’ is positioned as a response. The literature demonstrated a progressive narrative where the WHO’s support to palliative care was based upon concerns with the increasing rates of cancer, AIDS and population ageing (Sepulveda et al., 2002; Stjernswärd, 1997a, 2013b; Teoh & Stjernswärd, 1990). Currently, with the burden of life-threatening illnesses likely to increase in the world (WHO, 2020), global health debates have been largely focused on palliative care as a *response* to alleviate suffering (Abel & Kellehear, 2016; Connor & Gwyther, 2018; de Lima & Radbruch, 2018; Knaul et al., 2018; WHPCA, 2020). Yet, this study brings visibility to the ways in which guidelines, in the form of expert knowledge, can *produce* end-of-life care problems.

Looking closer into the constitution of ‘inadequacy’ of care indicated that the creation of strategies constricted to healthcare delivery, transforms dying into a symptom management problem. This argument will be further developed in the next section. For now, what we need to observe is that the very ‘problem’ of ‘how we die’ is constituted in palliative care terms. For instance, as evidenced in this study, ideas of appropriate care (chapter 5, section 5.2) are constituted by particular conditions governments must ensure within health systems. In 1990 this debate was constituted through ideas of ‘pain relief’ which in turn required availability of pain relief medicine. In 2002, I observed how appropriate care was articulated as intrinsic to the prioritisation of patients, thus equating earlier intervention to better palliative care outcomes. And lastly, in 2004 to 2011 in referring to ‘older people’ focus was given to ideas of patient choice and preferences for care. All of which are shaped by ‘palliative care’ principles such as freedom from pain, early intervention and patient choice (Clark, 2016; Saunders, 2003).

Clark (2016) had alerted that using the principles of palliative care is not the same as promoting the original purposes of ‘palliative care’. He argued that ‘palliative care’ can be framed as ‘medical solutions’ and that the emphasis on symptom relief can contribute to dissipating the holistic ideals that underpinned the original purposes of this form of care (Clark, 2002, 2016). This study thus demonstrates that the WHO guidelines *contribute* to the conceptualisation of palliative care as a ‘medical solution’, by problematising the lack of appropriate care framed in terms of poor symptom management. Thus, whilst on the one hand it is argued that the WHO is a catalyst for palliative care development internationally (Sepulveda et al., 2002), the WHO can also be considered a catalyst for a biomedical approach to palliative care. This thesis revealed that rather than ‘solving’ problems in palliative care provision, the WHO publications analysed in this thesis simultaneously produced global health ‘problems’. In this sense, the thesis has demonstrated how expert knowledge can be used to justify palliative care interventions that favour HICs and leave issues relating to coloniality, marginalization, and power asymmetries unresolved.

In an examination of global palliative care development within end-of-life care policies, Clark (2012) noted that more needed to be done to demonstrate how palliative care could be associated to primary healthcare and its role in reducing poverty, promote social cohesion “and to examine how palliative care can reduce social, economic and gender inequalities” (p.225). Building on Clark (2012), this study demonstrated that guidelines should be considered an important window from which one can see how the WHO can actively contribute to problems it aims to address. Revealing that professional guidelines that constitutes ‘palliative care’ as a clinical problem, challenges claims that the WHO is a “neutral” base from which governments can draw to build their own services (Stjernswärd et al., 1996). Instead, his study suggest that the WHO guidelines are rather *political* as they circumvent problems of social integration, cultural adaptation, and conflict of values, which favour the constitution of pain relief and symptom management *as palliative care*.

Moreover, promoting symptom management and pain relief as palliative care produces problems for politics. For example, they are insufficient to give insight on how ‘care’ is to be offered within health systems, how principles of palliative care could be integrated within different cultures and how ‘palliative care’ relates to wider aspects that shape healthcare provision. As observed by Walter (2020, p.43): “(…) the degree of commodification in the healthcare system profoundly affects people’s experiences of, and access, to care at the end-of-life”. That is to say economic policies within the health system will shape to a great extent the experience of caring, which are aspects of healthcare circumvented by the interpretation of the problem as ‘inadequacy of care’. Moreover, responsiveness to cultural specificities is central to palliative care delivery (Monroe et al., 2011; Zaman et al., 2017).

It seems as thus, that the interpretation of ‘palliative care’ offered in the guidelines from 1990 to 2011 prompts standardised forms of care designed to fit western expectations of ‘good dying’ as a managed and controlled experience. The research conducted in this study thus suggests that the ‘palliative care’ model proposed by the WHO guidelines reproduces what experts on palliative care think is best for end-of-life care rather than build on the voices of local communities on the types of care they wish to receive. These are important indicators of a technocratic tendency that has implications especially considering how ‘palliative care’ has been recommended for LMICs.

In problematising the lack of palliative care coverage, the guidelines from 2016 to 2018 positioned palliative care as means of helping LMICs reduce the impact of social disadvantages. As demonstrated in the literature, the global landscape of palliative care is one of great disparities (Clark, Gardiner, et al., 2018; Knaul et al., 2018; Lynch et al., 2013). With estimates that 45% of countries do not have access to palliative care (Knaul et al., 2018), the concern with the lack of palliative care provision is one that has received a great deal of attention. As expressed in 2018 by the Lancet Commission on Palliative Care and Pain Relief: “no other important health intervention is as lacking or inequitably distributed as pain relief, the pillar of palliative care” (Knaul et al., 2018, p. 883). Increasing rates of people dying from life-threatening, prolonged illnesses, especially in low resourced scenarios poses concerns over the capacity of health systems to cope with such demands (Clark, Gardiner, et al., 2018). Yet, very little attention has been directed to the ways in which the guidelines targeting increasing palliative care coverage paradoxically reproduces a classist classification of countries, emphasising their problems rather than their potentialities.

Guidelines actively engage in what Foucault understood to be dividing practices (Foucault, 1984 as cited by Bacchi & Goodwin, 2016). Diving practices refers to processes that separates the subject inside himself or divided from others: “the mad and the sane, the sick and the healthy, the criminals and the good boys” (Foucault, 1994b, p. 208). Dividing practices become accepted, naturalised and justified through scientific claims and through the power the social group attributes to them (Foucault, 1994b). In problematising coverage, dividing practices separates LMICs from HICs through discourses that reinstate their perceived social and economic disabilities which combined with epidemiological data naturalise LMICs palliative care provision as problematic. Statements such as the one expressed by the WHPCA that “every year, 40 million people need palliative care, 20 million at the end-of-life, yet only about three million are able to access the care they need. As a consequence, 18 million people die with *avoidable pain and suffering*” (Connor & Gwyther, 2018, p. 112, emphasis added), serves to moralise government action, regardless of their economic position and power to influence global health agendas.

In this sense, the guidelines problematising coverage while highlighting social and economic problems that are at the basis of the claims of lack of access to palliative care, contribute to an understanding of palliative care as an ‘easy’ solution to end-of-life care demands regardless of potential cultural, social, and economic differences (Clark, 2012b; Walter, 2020; Zaman et al., 2017). Add to that, the available evidence points to economic gains through palliative care provision, such as reducing costs and saving money for healthcare systems (Clark, Gardiner, et al., 2018; Knaul et al., 2018), can be operationalised to individualise responsibility for the lack of palliative care provision. Since palliative care is thought to benefit healthcare systems in LMICs by avoiding hospitalisations, filling the gaps in healthcare provision, and saving money, then there is very little excuse for the lack of palliative care provision in these countries.

In this sense, this study argues that despite the fact that socio-economic inequalities are accompanied by poorer health status and access to services (Hanratty & Holmes, 2011), the focus of the guidelines on community and home-based care strategies produced a simplified and reductionist understanding of the issue. For instance, the interpretation that increasing capacity for palliative care services will lead to an increased access to care ignores how market forces influence healthcare systems (Walter, 2020). Additionally, this premise also ignores the role of structural inequalities due to gender, sexuality, ethnicity in shaping access to services (Hanratty & Holmes, 2011; Monroe et al., 2011). In producing a simplified 'solution' to such a complex problem, interpreting the problem as a problem of lack of capacity obscures the political aspects of healthcare provision.

Transferring 'care' from institutions to communities is a model of palliative care welcomed in the literature focused on New Public Health approaches to end-of-life (Sallnow & Paul, 2018). In this proposal 'care' is a shared responsibility between community and 'palliative care' teams (Abel & Kellehear, 2016). This model is critical to approaches of palliative care that emphasise professionalised care over community empowerment (ibid). The New Public Health approach to palliative care proposes an interpretation of death and dying as "social experiences" (Sallnow & Paul, 2018, p. 2). Abel and Kellehear (2016) argued that issues such as dying, caregiving and loss should be seen as “a social problem with medical aspects to them rather than a medical problem with social aspects” (p.25), thus echoing the need to rethink the concepts and values underpinning forms of care. Yet, as identified in this study, the emphasis on community and home-based care referred more to an expansion of the workforce rather than the articulation of palliative care within existing networks or the engagement with other sectors of society.

This section aimed to discuss how particular interpretations of ‘problems’ shapes what is understood by ‘palliative care’ within the guidelines. To further expand on how palliative care can be used to direct efforts to some directions and not others, the next section will discuss the political implications of professional guidelines, especially considering how ‘palliative care’ operates as a ‘programme of conduct’ (Dean, 2010). As programmes of conduct are used to “attempt to regulate, reform, organise and improve what occurs within regimes of practices in the name of a specific set of ends articulated with different degrees of explicitness and cogency” (Dean, 2010, p. 43), the next section will focus on the ways the study of problematisations allows visibility on the programmes of conduct within the WHO guidelines.

7.3 Governing Through ‘Inadequacy’: Palliative Care as a Strategy for Administration of the Dying

In chapter 5 the ‘inadequacy’ problematisation claimed that dominant protocols for patient care were insufficient to address patients’ needs. In doing so, the guidelines paradoxically reproduced much of the criticisms on the management of dying widely established in the literature of the 20th century. The management of the dying was central to criticisms regarding dying within medical institutions as hidden in inaccessible locations submitted to routine, hospital order and medical expertise (Aries, 1974; Illich, 1975; Walter, 1994; Hart et al., 1998; Seale, 1998). Yet, while the criticism of medicine is widely established in the literature (see chapter 2), the same routine, order, and expertise are proposed for palliative care. Thus, while the literature places palliative care as an alternative to medicalisation, this study argues that the palliative care proposed by the WHO in guidelines from 1990 to 2011 produced new discourses of death and dying while maintaining the very power relationships palliative care emerged to oppose.

7.3.1 Controlling suffering or constricting choices?

It is not uncommon to find tensions at the core of the concept of ‘palliative care’. Kearney (1991 as cited by O’Brien, 1993, p.34), for example, claims that attitudinal changes are necessary towards cancer patients:

> Patients with incurable illness must no longer be viewed as medical failures for whom nothing more can be done. They need palliative care, which does not mean hand-holding second-rate soft option, but treatment, which most people will need at some point in their lives, and many from the time of diagnosis, demanding much skill and commitment as is normally brought into preventing, investigating, and curing illness.

The author criticises the functionalist perspective of ‘patient’ where the patient is valued only when it comes to the Doctor’s ability to perform, by another equally performative argument: that the same performance that is required to cure illnesses is to be applied to the end-of-life through palliative care. Armstrong (1987) argues that rather than transforming practices, the opposition rhetoric serves to reconfigure the rules upon which death and dying can be discussed. Likewise, the use of ‘palliative care’ by Kearney (1991) is to criticise attitudes towards patients and is therefore not transformative of the power relations in place, but rather a reconfiguration of professional power. In the WHO guidelines, palliative care was used to problematise professional conduct toward the dying, reconfiguring the rules upon which professionals must behave, rather than transform the power relations in place.

As I argued in chapter four, this suggested that current protocols of patient care are

> not adequate. Other forms of end-of-life care, besides palliative care is denied. As expressed in 1990, governments must resist requests for euthanasia and offer palliative care instead (WHO, 1990, p. 55). Additionally, treatments such as chemotherapy are referred to as having limited effects, denying patients of the possibility of "enjoying life "(WHO, 1990, p. 18).

> Thus, if other forms of care are deemed 'inadequate', dying through palliative care measures in this sense is made the only option available.

Instead of a range of possibilities of care, adequate care for cancer patients becomes restricted to palliative care. The literature demonstrates how the concept of hospice care was deeply rooted in ideas of a 'good death', that is a death without pain and other distressing symptoms (Howarth, 2007; Seale, 1998). The idea of a 'good death' as a death without pain and suffering is significantly associated with the WHO guidelines associated with inadequacies of care. In these guidelines, providing death without suffering is the very purpose of palliative care within healthcare systems (see WHO 1990, 2002). Positioned as something to be offered for patients whose disease is no longer curable, the choice for palliative care is already made for them. Thus, rather than allowing patients to choose how they want to live their lives until death, there are important constraints on the available choices for preferred end-of-life care.

Palliative care publications problematising protocols for patient care engage in the 'good death' typologies where death, and hence the dying, are subjected to professional care in order to achieve a death without suffering. This raises another problem as it implies that a death without suffering, managed through palliative care, is something that patients are *assumed to want*. Dying with palliative care support, promoted as the appropriate, moral, and humanistic way to die (Davies & Higginson, 2004, WHO, 1990), avoid having to consider the possibility of patients choosing to die in any other way.

This section therefore demonstrates that the way 'inadequacy' is constituted within guidelines inhibits other forms of care, allowing palliative care to be the only option. In doing so, the guidelines replace one death typology: that without palliative care dying means to die in suffering for another death typology: that through palliative care patients will have their needs correctly assessed, their wishes respected, and they will be free from pain and other distressing symptoms (Davies & Higginson, 2004; WHO, 1990, 2002, 2004, 2011). It is thus that patients' may choose some aspects of their care, but the choice for other forms of care beyond palliative care are not available. This gives insight to the exercise of professional power, where the 'choices' available to patients are determined by those in power (Borgstrom & Walter, 2015).

7.3.2 New discourse, new powers

The discussion above reflects concerns over the medicalisation of palliative care widely discussed in the literature, where scholars have questioned the extent to which the original ideology of a 'good death' had become another form of medicalisation of death (Clark, 2002). This study builds on this debate by suggesting that the WHO framework for palliative care is less a return to 'medicalisation' of the dying, and more to the professionalisation of death (Walter, 2020). This point requires elaboration.

The section above demonstrates how ideas of 'inadequacy' require that governments and health authorities create palliative care strategies. This section will look into the inclusion of a wide range of professionals that will respond to the needs of the dying. This is reflected in the first guideline published in 1990: "palliative care requires a team approach, which recognises that all health workers have a role to play" (WHO, 1990, p. 12). The guideline also states that because "treatment of multiple symptoms is demanding, therapeutic efforts must consider the interaction of symptoms, the casual factors involved and maintenance of the delicate balance between relief, adverse drug effects, and patients' expectations" (WHO, 1990, p. 42). Because 'dying' is demanding, the guideline states, "this task" that is, the task of managing dying, is "best carried out by a palliative care team working with the patient – family group and other involved professional healthcare workers" (ibid). Dying, therefore requires the expertise from multiple professionals.

In 2002, the very definition of ‘palliative care’ highlights the active role health professionals will have in the care of the dying. As ‘palliative care is understood to prevent and relieve suffering “by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2002, p. xvi) the dependency on healthcare expertise is made rather explicit. In 2004, the dependency to healthcare professionals is expressed as “using a team approach, palliative care addresses the needs of patients and their families including bereavement counselling if necessary” (Davies & Higginson, 2004, p. 14, emphasis added). That is, it is the team who is deemed capable to address the needs of the patients and their families.

If problematising ‘inadequate’ care leads to the limit of choices that patients will be able to make, it also paves the way for the emergence of new experts that are being empowered to intervene on the dying process. This process refers to what Walter (2020) identified as ‘professionalisation’. He argues that rather than the medicalisation of death, modern societies now manage their dying through “an increasing range of health professionals” (Walter, 2020, p. 28). There is an intrinsic association between those who hold knowledge and the exercise of power (Foucault, 1994c), that requires attention. The dependency on healthcare professionals is associated with the presumed knowledge and expertise these professionals hold on the needs of the dying. This relationship of power can be seen in the types of subject patients are invited to become.

As previously observed, in WHO guidelines from 1990 to 2011, the problem of ‘inadequate care’ is shaped by ideas of ‘total pain’ (chapter 5, section 5.2). This was due to limitations of previous concepts of pain that were focused mainly on the physical aspects: For most patients, suffering is not purely physical, and pain is only one of the several symptoms. As exemplified in the statement that follows: “pain relief should therefore be seen as part of a comprehensive pattern of care which encompasses the physical, psychological, social and spiritual aspects of suffering and which has come to be known as *palliative care*" (WHO, 1990, p.11, emphasis in the original). The ideas of pain that were found in the guidelines from 1990 were reproduced in the guidelines published in the years that followed (see chapter 4 for more details). However, as demonstrated by the literature, ideas of 'total pain' nevertheless are a concept intrinsically associated with symptom control:

> In attempting to relieve total pain, hospice has produced a model of care that assumes that the reduction of physical pain will assist in alleviating the distress of other symptoms of pain. In other words, if physical pain can be controlled, this will reduce the emotional and spiritual suffering and therefore, improve quality of life for dying people (Howarth, 2007, p.141).

Saunders conceptualised 'total pain' as a way to 'understand and respond to patient's needs in order to free the patient from pain and to find their own journey until death (Davies & Higginson J., 2004; Saunders, 1993). Despite the noble intent, Clark (1999) argued that a consequence of 'total care' is the emergence as a new form of medical gaze that empowers health professionals to rationalise patients. Hence the use of 'total pain' reveals a paradoxical picture where the constant control of pain can be extended to constant control of the patient (Clark, 1999). The hospice approach thus, extends professional power beyond physical symptoms to the patient's social relations and emotions (Walter, 1994).

On one hand the use of 'total pain' within WHO guidelines can indicate forms of patient control by authorising professionals to gaze upon patients. On the other, it invites patients to think of themselves as people in 'need' of intervention. The creation of particular kinds of subjects such as the 'sufferer' and 'the dying entrepreneur' (chapter 5 section 5.5) gives insight into the ways in which guidelines produce governable subjects. Establishing palliative care as the moral, appropriate way of death, guidelines invite patients to welcome professional intervention in their dying process. Alternatively, the creation of patienthood as a 'dying entrepreneur', invites patients to think themselves as subjects of preferences, as atoms of self-interest wanting and willing to make decisions about their care (chapter 5 section 5.5). The relationship that is formed in this context attributes particular roles to specific actors: professionals will offer the 'appropriate' care and patients must want to be 'appropriately' cared for.

The hospice movement is embedded in typologies of a 'good death' (Hart et al., 1998; Howarth, 2007; McNamara, 2004; McNamara et al., 1994; McNamara et al., 1995; Seale, 1998). It becomes important to enquire, as observed by Heart and et al. (1998), whether a death typology can operate as an "ideology that constructs a socially approved form of dying and death with powerfully prescribed and normalised behaviours and choices" (Hart et al., 1998, p. 72). Given that this section discussed how problematising 'care' imposed a rationale that restricts choices to 'palliative care', authorise new professional powers to manage dying and invites patients to think themselves as subjects of suffering and preferences, it is possible to see how guidelines prescribe normalised forms of dying.

7.3.3 Normalising dying through palliative care

The particular set of relationships created through problematising 'inadequate' care reinforces dependency on the expertise of healthcare professionals expertise and encourages people to welcome professional intervention. Thus, it is worth questioning whether the forms of 'palliative care' prescribed within WHO guidelines are contributing to what Illich (1975) regarded as social iatrogenesis:

> Social iatrogenesis is at work when healthcare is turned into a standardized item, a staple; when all suffering is "hospitalized" and homes become inhospitable to birth, sickness and death; when bodies is turned into bureaucratic gobbledygook; or when suffering, mourning, and healing outside the patient role are labelled as a form of

> deviance (Illich, 1975, p. 41 emphasis added).

The concept of social iatrogenesis refers to the social implications of the societal dependency of medical care. In this case, palliative care is being promoted as the ‘adequate’ care which necessarily imposes a classification of other forms of dying as ‘inadequate’. This form of standardisation and classification is aligned with Illich’s (1975) understanding of medical authority, which has the power to determine “what is normal, proper or desirable” (Illich, 1975, p. 45). In relation to the hospice movement, similar efforts to normalise and standardise a particular form of death was identified by Lofland (1978).

Lofland (1978) observed multiple strategies directed to create a new ‘craft of dying’. The ‘happy death’ movement as she called it, tried to promote change in three different ways. First was the intent to promote structural reform by engaging in discussions of death and dying to counter the perceived ‘taboo’. The second strategy created forms of care for the dying person as an alternative to hospitalised and medicalised dying. Lastly, by promoting legislative change to regain control over the dying process away from medical establishments and into the hands of the dying person (Lofland, 1978).

Drawing from Lofland (1978) observations of the happy death movement, guidelines made other forms of care ‘inadequate’ by associating poor outcomes at the end-of-life to the lack of palliative care. Thus, in order to counter the medicalisation of the dying, palliative care becomes associated to positive terms. Secondly, they set out the need for structural reforms to care for the dying by engaging governments into setting out the appropriate conditions to operationalise ‘palliative care’. Thirdly, the problematisation silences ‘diversity’ in constricting the possibility of choice. Lastly, it promotes rationalities of patients’ needs from which professionals can draw interventions to achieve symptom control.

As such, investigating ‘inadequate’ care brought visibility to how the ‘new order of life relative to death' (Lofland 1978) is constituted within palliative care guidelines. This can be argued to create new forms of care dependency and social iatrogenesis, risking transforming all dying needs into objects for 'palliative care' intervention. As observed throughout this chapter, discourses produced by inadequacy produces a particular form of dying.

7.4 Problematising Capacity: Homogenising End-of-life Care Interventions

The disparities of palliative care provision have been widely debated in the literature (Chapter 2). Commonly framed in global health debates as an inequality problem, the lack of access to palliative care services is frequently attributed to a lack of engagement from health authorities in recognising 'palliative care' as a 'public health problem' (Sepulveda et al., 2002; Stjernswärd, 1997b; Stjernswärd et al., 1996). Yet, this study identified that in the attempt to respond to inequalities of palliative care provision within public health in LMICs, guidelines reproduced a classicist classification by associating lack of provision to socio-economic development. In this section I will discuss how discourses of disparity, inequality and 'capacity' within 'palliative care' can serve as a means to obscure power relationships shaping global health.

The association between palliative care and public health has been largely seen in positive terms (Whitelaw & Clark, 2019). However, it has been perceived that the number of countries with integrated palliative care services within public health strategies is modest (Clelland et al., 2020; WHPCA, 2020). Going further, they also indicate that the majority of those with a national strategy to palliative care services had higher levels of economic resources (Knaul et al., 2018; WHPCA, 2020). Despite varying levels of provision, there seems to be a general idea that palliative care is something predominantly available in the countries classified as High-Income (Clelland et al., 2020).

Since the publishing of the Public Health Strategy (PHS) (Stjernswärd et al., 2007a), the disparity in palliative care provision has been associated with the lack of policy development, making ‘policy development’ one of the fundamental aspects of ensuring palliative care globally (WHPCA, 2020). The second edition of the *Global Atlas of Palliative Care* (WHPCA, 2020) also illustrates a lack of policy formulation towards palliative care:

> Without policies that support the provision of palliative care it is quite difficult for any palliative care to develop. In some countries there is no government support whatsoever for palliative care. In others, such as Romania and Zimbabwe, charitable palliative care services have developed. But even in these cases permission to operate has to be granted. Policy is therefore seen as the fundamental component, because without it other changes cannot be introduced (WHPCA, 2020, p. 33).

Without policies, the provision of palliative care services may be limited to localised initiatives that reach only part of those in need. However, while the lack of policies is a central argument to promote changes in the provision of palliative care globally (Clelland et al., 2020; WHPCA, 2020), policies themselves are only one part of a wider system. The challenges involved in implementation of policies refer to wider aspects of societal administration such as “political, psychological, financial and social barriers” (Clelland et al., 2020, p. 188). Additionally, the statement above from WHPCA (2020), largely ignores global health debates especially referring to how palliative care is predominantly shaped by western perspectives.

It is known that the narrative of medicalisation of death and the concern with the way patients were being treated within modern hospitals has been profoundly shaped by ‘western’ scholars (see Ariès, 1974; Elias, 2001; Glaser & Strauss, 1965; Sudnow, 1967). The literature in chapter two demonstrated how little we know on the death perspectives in other parts of the world, and how much of what we know about palliative care provision has been shaped by the ‘west’ (Borgstrom & Ellis, 2017; Pastrana et al., 2010). The field of palliative care research has been found to reflect predominantly anglophone perspectives, where very little is known on the attitudes and beliefs towards death and dying in other cultures (Borgstrom & Ellis, 2017; Pastrana et al., 2010; Zaman et al., 2017). For instance, while the opening of St Christopher's hospice in the UK represented the beginning of an international network of practitioners, supporters and volunteers in support of hospice care for the dying (Saunders, 2003), these were limited to English-speakers (Walter, 2020).

Furthermore, the early stages of palliative care dissemination were premised on a belief that, as expressed by Kastenbaum & Wilson (1997, in Saunders, 1997),: "that palliative care concepts and techniques are not limited to any one type of sociotechnological structure, any one level of economic development, or any religious system" (p.286). Cultural beliefs on death and dying, however, have appeared in the literature concerned with palliative care development as an 'obstacle'. Recently, the WHPCA (2020) indicates that 'human factors' are a barrier towards development. Issues such as the association of palliative care with "the end of life and dying" (WHPCA, 2020, p. 38) are considered an additional barrier, thus reproducing theories of 'taboo of death' (Lamers, 2012). As expressed in the statement below:

> Psychologically most people fear and avoid anything relating to death. There is often a belief that even acknowledging the possibility that one may die soon is harmful (…). Many cultures have expressly prohibited informing patients of their diagnosis and prognosis when life-threatening. Previously this had been the case in most cultures, but views have been changing in the past several decades to the point where there is now some acceptance of the idea that patients themselves should be given the choice as to whether to receive this information (WHPCA, 2020, p. 38).

The idea being that while in "many cultures" death is 'taboo', and therefore must be silenced, implies that accepting "death" would facilitate the development of palliative care. However, palliative care is premised upon individualistic values, and implementing palliative care was facilitated in countries that shared similar individualistic values rather than an accepting attitude towards death (Clark, 2016; Howarth, 2007; McManus, 2013). This understanding clearly contradicts what Jan Stjernswärd had argued for developing nations.

As discussed elsewhere in this thesis, Stjernswärd played a key role in introducing palliative care into global health. In 1997 he stated that the future of palliative care in developing countries depended more on strategies to preserve cultural attitudes towards death and dying than “technomedical advances” (Stjernswärd, 1997a, p. 15). In this sense, instead of changing cultural attitudes to death and dying in order to accommodate ‘palliative care’, palliative care should be accommodated to cultural attitudes towards death and dying in different cultures. Yet, as observed in this study cultural attitudes towards death were left largely unproblematised in the guidelines from the WHO, which reveals a tendency to maintain the existing ‘technomedical’ models of palliative care.

According to Walter (2020): “in sum, western palliative care practices have spread around the world, benefiting millions. To maximize their benefits however, the practices may need modification to such an extent that they become entirely different species of care” (p. 253). The findings from this study builds on this perspective. Instead of cultural integration, the guidelines problematising coverage as a lack of capacity to provide palliative care services focused on the expansion of trained workforce (WHO, 2016a, 2018). Transforming people into possible agents of care redirects the focus from specialised care to anyone with palliative care training. In this study, the findings suggest that the focus on individual agency in order to increase coverage serves the purpose to circumvent the need for governmental action and cultural adaptation.

Overall, problematising capacity in terms of increasing services contribute to obscure how healthcare provision is socially shaped. It also contributes to thinking coverage as both a technical and an educational issue creating a network for patient care that involves health professionals but extends professionalised care to volunteers, community health workers and family members (chapter 6, section 6.5). The guidelines allow homogenising end-of-life care strategies rather than including pluralistic perspectives.

While I agree with the statement introduced above - that policy development is an important component to introduce better end-of-life care (WHPCA, 2020), this study reveals that focusing on policy development alone is insufficient. We need to rethink the way in which intervention in national healthcare systems in poor and developing countries are justified within WHO guidelines. This leads to a consideration on the historical, cultural and epistemological dominance of 'western' perspectives of palliative care being promoted to LMICs.

7.5 The Making of 'Global Problems'

The literature had suggested that 'palliative care' has been largely shaped by ethnocentric values (see chapter 2). In this study, tracing back the social and historical processes that gave shape to ideas of 'inadequacy' and 'capacity' allowed us to see how they were transformed into 'global' problems. In doing so, the study builds on the lack of pluralistic views within global palliative care debates. The findings revealed in this study echoes Lizzot-Monnet's (2017; 2022) perspectives on the politics of expert knowledge, where a technocratic approach to knowledge production can be seen to justify the WHO guidelines as a technical tool rather than political product. Such an approach tends to obscure the mechanisms of exclusivity which are embedded in knowledge production (ibid). The genealogical analysis conducted in this study also indicates that the technical and consensual frame in which palliative care is positioned in the WHO guidelines was consolidated through mechanisms of circularity, whereby there is no clear distinction between research clusters, other international organisations and the WHO. Moreover, the study revealed how epidemiological data has been used to justify *who* and *where* palliative care is most needed from a top-down perspective that has implications for maintaining issues of equity and marginalization unresolved.

In contextualising the problematisation at hand, it was interesting to note that discourses of inadequacy reached other institutions outside of medical care such as the Vatican and the European Council before reaching the WHO (Council of Europe, 1999; Pius XII, n.d.). At that time, debates on the quality of care for the dying was not a concern, as the WHO had concentrated its efforts in eradicating infectious diseases in LMICs (Brown et al., 2006). Palliative care was included in global health debates through a personal decision from the WHO Chief of Cancer Care in the 80's Jan Stjernswärd, who considered that the best way to address disparities in pain relief was through the dissemination of palliative care programmes (Stjernswärd, 2013b).The detailed account on how 'inadequacy' came to be presented in guidelines, suggested that while the WHO was concerned with increasing awareness and mobilisation of governments in adopting healthcare strategies, one consequence of standardising protocols for pain relief and palliative care could be framing the inclusion of 'palliative care' into healthcare systems as a managerial and technocratic problem (chapter 5, section 5.3).

In promoting protocols for the 'adequate' care of patients, the doors to consider different interpretations of adequacy are closed. As evidenced in the examination of the silences imposed by problematising inadequate care (chapter 5, section 5.4), 'palliative care' proposals from the WHO are not universally adopted. The literature had already indicated that there is a variety of interpretations of palliative care that leads to multiple ways of organising and delivering palliative care services (Seymour & Cassel, 2017). There are also differences in the definitions of palliative care adopted and, on the ways, palliative care is implemented (Radbruch et al., 2020). It has been argued that problematising inadequate care therefore while drawing attention to important aspects of healthcare provision such as training professionals, ensuring opioid availability, managing resources effectively and prioritising patients, the problematisation fails to recognise the influence of culture in health care, especially considering end-of-life (section 5.4).

Meanwhile, tracing back the historical and social processes that led to the emergence of the ‘capacity’ problematisation, it was observed that once more, the problems were not identified by the WHO directly, but reached the WHO through multiple organisations in support of palliative care. As suggested by Sepúlveda and colleagues (2002) ‘palliative care’ was not understood as a public health problem in the year 2000. Services at that time were dispersed with no collaborative efforts being made to promote palliative care internationally (Clark, 2012). Efforts to conduct comparative studies to map out levels of provision within Europe marked a change in the field, where standards to palliative care programmes were first drafted (Radbruch & Payne, 2009). Organisations such as EAPC and WHPCA played an important role in publishing studies denouncing the lack of provision of palliative care in the world, which markedly led to the WHA 67.19 resolution from WHO (Connor & Gwyther, 2018; de Lima & Radbruch, 2018). In this sense, ideas of building capacity were also largely shaped by western perspectives (chapter 6 section 6.3). This way, guidelines proposing ‘palliative care’ programmes to LMICs, made it difficult think how palliative care could be adapted to different values. As a result, the findings suggest we need to rethink how ‘palliative care’ is framed within ‘global’ advocacy (Abel & Kellehear, 2016; Clark, Barnes, et al., 2018), in order to prevent the perpetuation of anglophone values being disseminated *as* palliative care values.

In this sense, it is important to rethink how palliative care is prescribed WHO guidelines. Especially considering how little we know about end-of-life perspectives in the world, it is important to question how expert *knowledges* is used to produce WHO’s recommendations. For instance, palliative care recommendations, especially those directed at

LMICs could be based on social aspects of death and dying such as cultural attitudes, beliefs, values, religion as well as epidemiology. Moreover, focusing on the lack of policy in order to push for palliative care development disregards how policy development does not necessarily lead to more services. As demonstrated in this study, even in countries with high coverage such as the UK, challenges remain in providing equitable services and quality of care.

7.6 Governing 'dying' through palliative care: contributions of an WPR analysis of palliative care guidelines

The discussion so far has focused on how the findings from this study both sits within and expands existing literature on palliative care. Given that the WHO's approach to palliative care has never been problematised through an WPR framework, this study contributes to debates on international palliative care development. Beginning with a methodological contribution, developing a WPR framework to interrogate WHO guidelines uncovered the ways in which guidelines could be objects for systematic investigation.

Drawing from Bacchi's (2009) theoretical and methodological approaches to problematisations, I developed a framework to be applied to guidelines rather than policies. Following a series of analytical steps, the framework to analysing guidelines were organised following the same analytical steps to Bacchi's (2009) WPR. However, because guidelines are often complex and offer more than one interpretations of 'problems', adaptations had to be made in order to systematically apply the guiding questions from the WPR. The five analytical steps developed in this research - identifying problematisations; examining premises, concepts, categories and binaries that gave shape to the 'problematisations'; contextualising the emergence of problematisations; identifying silences; identifying discursive and subjectification effects - allowed to uncover the systems of meanings in place that justifies particular 'palliative care' interventions. As such the research satisfied the premise of analysis in the WPR approach: to uncover how we are governed through problematisations rather than 'problems'. With a broader scope than most approaches to policy analysis, an WPR analysis means to:

> This broad focus on ‘rule’ means incorporating, but also looking beyond, the state in order to identify other forms of influence on governing conduct. We are trying to understand *how society is managed, with what repercussions to different groups of people*, including ‘citizens’ and those positioned outside ‘citizenship’ (Bacchi, 2009, p. 25, emphasis added).

Bringing the WPR analysis to palliative care studies contributes to our understanding on how ‘dying’ is proposed to be managed within WHO guidelines, to expand our understanding on the implications of the expert knowledge governing palliative care publications and to theorise on the repercussions guidelines may have for different groups such as patients, families and workers. Moreover, this study required me to theorise on the repercussions of forms of governing death to countries classified as LMICs and to offer alternative perspectives such as redirecting focus from epidemiology and socioeconomic status to the cultural and social aspects shaping death and dying in these countries.

The empirical contributions brought by this study, refers not only to the ways in which forms of rule takes place through WHO guidelines, but also on the discourses, institutions and organisations shaping the management of end-of-life care practices on a global level. The kind of analysis this study produced indicated that through problematising inadequate care, the guidelines established a particular set of relationships. Professionals are empowered with a new knowledge on the needs of the dying, who in turn become objects for professional care. Dying in guidelines is something to be improved due to the complexity of needs and symptoms to which only palliative care is the ‘adequate’ form of care. Through ideas of suffering and sustained by knowledge on ‘total pain’, patients are once more fragmented and subjected to professional control.

In problematising capacity on the other hand, allowed the expansion of healthcare roles to ‘individuals’ by making them ‘trainable’ or ‘agents’ of care. In doing so guidelines attributed responsibility for the coverage of care instead of governmental institutions. Additionally, the same strategy allowed to maintain the premise of feasibility unproblematised, which continues to favour ‘westernised’ perspectives of palliative care. In this sense, with focus on training and educating ‘people’ in palliative care, strategies proposed within WHO continues to undermine local culture and existing death practices.

Taking the concept of government as assumed in the WPR, as “not a definite uniform group of institutions” but “an inventive, strategic, technical and artful set of assemblages” (Dean and Hindess, 1998, p.8 as cited by Bacchi, 2009, p.25), the study brought deeper understanding on the way ethnocentric values, historical and social processes on the management of death and dying and the professionalisation of end-of-life, converged into discourses of management of ‘patient’ and ‘individuals’ within healthcare systems. In summary, the study allowed to gain insight on the following:

1. How, for whom and for what purposes palliative care was being recommended.
2. Which concepts, knowledges and assumptions gave shape to WHO guidelines for palliative care and to theorize how they introduced binary forms of thinking.
3. The contingent nature of guideline problems, I sought to offer an alternative way of thinking guidelines as a *cultural product.*
4. The ways in which guidelines authorise forms of intervention on death and dying.
5. How guidelines establish power relationships between professionals and patients, and between HICs and LMICs.
6. The production of normative expectations for end-of-life care.

As the literature on global development of palliative care has focused on policy development as the way to increase service provision (Clelland et al., 2020; Knaul et al., 2018; WHPCA, 2020), this study suggests that palliative care provision must not be ‘offered’, but *co-constructed*. In this sense, it supports Zaman et al. (2017) argument that the future of palliative care lies within “finding the particular within the universal” (p.77) for the end-of-life. In order to do so, it would require structural changes within WHO’s proposals for palliative care.

As this study revealed the reproduction of similar values that shaped end-of-life debates in the mid-twentieth century, such as the opposition rhetoric (Zimmermann & Rodin, 2004) and ideas of a good death from the hospice movement (Howarth, 2007) this study indicate that it might be time for us to assume that ‘good’ death and dying holds many faces (Walter, 2020). In this sense, I argue that this study brought visibility to the perseverance of WHO to maintain a restrictive concept of ‘palliative care’ rather than promote a pluralistic view. In doing so, WHO guidelines favour standardised care and the engagement with traditional medicine by the continued association of palliative care to ‘illnesses’, rather than *societies*.

Furthermore, as this chapter aimed to demonstrate the contributions of an WPR analysis to palliative care guidelines, I turn to the concept of governmentality to direct attention to the final theoretical contributions from this study. Foucault uses the term governmentality to direct attention to the forms of conduct of conduct (Rabinow & Rose, 2003; Turner, 1997). The definition as ‘conduct of conduct’ requires clarification.

As addressed in Bacchi (2009) and Dean (2010), this is term with varied meanings. To conduct, says Dean (2010) refers to directing, guiding and implies a level of calculation on how something should be done. It can also mean individual behaviours. They presume norms of conduct through which ‘behaviour can be judged, and which act as a kind of ideal towards which individuals and groups should strive' (Dean, 2010, p.18). The WPR framework developed in this study therefore, allowed to make visible the governmentality of technical frameworks that empower some to intervene and invites groups to welcome professional intervention. The problematisations 'inadequacy' and 'capacity' were argued to allow forms of conduct that contributes to the maintenance of power relations within healthcare settings and between countries. In this sense, the WPR allowed to see how problematisations within WHO guidelines favour those who hold power such as healthcare professionals, palliative care experts and HICs.

Yet, it is important to reinstate the need for further studies informed by Foucauldian scholarship. As palliative care scholars have already suggested the power relations that shape understandings of palliative care, such as the debate promoted by New Public Health scholars (Abel & Kellehear, 2016; Murray et al., 2015; Paul, 2015; Sallnow & Paul, 2018), the Foucauldian scholarship allows to make visible how discourses produce forms of subjectivities and empowers some forms of care over others. The contribution of a Foucauldian stance on palliative care is revealing that the field of 'palliative care' is not exempt from forms of governmentality. Hence, they can bring visibility to the ways in which 'palliative care' discourses invites us to think ourselves as particular kinds of people, how we are invited to act upon ourselves and others and who is empowered to intervene in our lives and deaths.

The application of WPR to the WHO guidelines also has its limitations. While the WPR contributed largely to understand how 'technical frameworks' such as guidelines often promoted as 'evidence-based' can be understood as a cultural product with important political implications to the groups it aims to support, more needs to be done to understand how these forms of rule influence practice in palliative care settings. Although it is known that WHO frameworks for palliative care are adopted in national policies (Clelland et al., 2020), not much is known about the perspectives of patients and families regarding the ‘care’ they received or whether or not WHO’s proposals are aligned with their wishes for care. It also does not allow understanding what healthcare professionals think about WHO guidelines and how (or if at all) they are incorporated into practice.

7.7 Summarising arguments

This chapter discussed the findings of an WPR analysis of the WHO guidelines aimed at palliative care development. Rather than assuming WHO’s activity as ‘neutral’, this thesis identified WHO’s activity in the form of publications, such as guidelines, as contingent and productive. That is this study identified that WHO’s guidelines are cultural and historically bounded and are *productive*, rather than *responsive*, in producing specific kinds of subject, object and places.

In applying the WPR framework to WHO’s ‘palliative care’ guidelines from 1990 to 2018 I examined the “unexamined ways of thinking” in which they rely, thus challenging their assumptions and premises, bringing visibility to their history and to question their silences and implications which contributes to an original perspective on technical guidelines. The findings suggest that, despite changes in *discourse*, the rationale underlying WHO’s advocacy remains centred on symptom-management focused on the realms of health institutions and professional knowledge. Ironically given the establishment of palliative care as a reform on the medicalisation of dying, guidelines continued to empower healthcare professionals to intervene and patients to think themselves as in need of professional care. Thus, questions have been raised on the possible social iatrogenesis of recommending palliative care as a form of managed, controlled socially accepted form of dying.

As such, the WPR analysis brings visibility to the social construction of the rationale underlying practical guidelines which allows us to see them as product of cultural, social, and political arrangements rather than a biomedical phenomenon. While being informed by epidemiological and clinical studies on pain relief and symptom management may favour engagement with mainstream health care, the form of ‘palliative care’ constituted within guidelines had significant implications for what we can understand by ‘palliative care’, and how it should be offered and to whom. Moreover, both problematisations imposed silences on social aspects of death and dying such as cultural beliefs, healthcare provision and structural inequalities which suggests the dominance of a medical rather than a social approach to ‘care’.

This research therefore proposed new ways of thinking palliative care guidelines. It challenged WHO’s self-proclaimed neutrality and indicates the implications of forms of thinking embedded in professional frameworks. Moreover, the approach taken to guidelines as a meaning-making agent requires considering the how forms of thinking can have material consequences. It is in this light that we can now think of the implications of this study to be discussed in the next chapter.

Chapter 8. Conclusion

This study aimed to explore the concept of ‘palliative care’ within WHO guidelines. It has identified the ways in which ‘palliative care’ has been problematised within WHO guidelines. In doing so, it uncovered the reasons given, the aims and goals to be achieved through palliative care intervention, the strategies required to achieve them and the role of guidelines in creating particular patient identities. The study also sought to understand the role of guidelines in creating forms of administrating end-of-life care, the values, premises and assumptions that give shape to the ‘problems’ palliative care is supposed to address. This chapter will be dedicated to revisiting the research objectives, the research questions and to theorise on the implications of this study to palliative care studies.

The theoretical literature on global development of palliative care highlights the role of WHO as a catalyst of global agreements towards palliative care. Through the WHA 67.19 and the inclusion of palliative care within UHC, WHO has recommended palliative care strategies for healthcare systems everywhere. One of WHO core functions is in disseminating knowledge and publishing guidelines from which governments can draw to build their own proposals. However, the literature on WHO approach to palliative care is inconclusive on vital questions regarding the role of palliative guidelines in promoting particular models of ‘palliative care’. The study aimed to answer the questions: How guidelines problematise palliative care? What are their implications for the goal of Universal Health Coverage? And for the people involved in palliative care?

In order to address these questions, this chapter will first draw attention to the research questions. In the section Addressing *the Research Questions* I will discuss how the findings from this study answers the questions on how palliative care has been problematised within WHO guidelines, the implications for Universal Health Coverage and to the people involved in palliative care.

Entitled as *Governing through Palliative Care: Implications for Research, Practice and Policy,* this section will discuss how the problematisations identified in this study has developments for palliative care research, policy and practice. I have argued elsewhere in this thesis that WHO guidelines are both productive (of rationales for palliative care intervention) as well as they are a product, that is, contingent to social and historical processes. This argument develops into two main considerations. First, that in considering guideline as *product* we need to keep questioning the premises and knowledges informing them rather than accepting them uncritically. Second, considering guideline as *productive* of particular forms of conducting 'palliative care', I will propose that WHO guidelines can be harmful rather than informative. As such they have important implications for policy development. Lastly, in *Reflecting back on the PhD journey,* the chapter begins with a reflexive discussion on the research objectives and what was accomplished with this research

In proposing how guidelines produce particular meanings to 'palliative care', the policies adopting WHO's framework have implications on how 'care' is to be organised, delivered and prioritised. They give credibility to certain forms of end-of-life care over others, and they hold normative expectations to what 'good' end-of-life care should look like. Moreover, since guidelines are *productive*, they create forms of rationalising patients, their needs and the roles they must assume in the final stage of their lives. In addition, considering that dominance of western values shaping WHO proposals for palliative care, this study also proposes that palliative care policies in the global level feeds into the power relations existent between HIC and LMICs.

Lastly, given how guidelines themselves have been neglected as a research topic, I raise possibilities for further research. Although the comprehensive analysis provided in this study provides insight on the implications of problematisations within guidelines, there are many aspects of guidelines that the escaped the scope of this research, and as such, require further investigation. In this sense, the last section will consider the implications for future research.

8.1 Addressing the Research Questions

8.1.1 Research Question 1: How is ‘implementation’ of palliative care problematised within WHO guidelines?

To answer this question, I refer back to chapter 4 *Identifying Problematisations* where I offered a detailed account of what WHO’s guidelines for palliative care service implementation aimed to achieve. In this chapter, I observed that despite sharing a common goal, that is, implementation of palliative care into mainstream health care, the reasons why countries should implement palliative care changed throughout the years.

From 1990 to 2011, I observed how palliative care guidelines emphasised the *suffering* patients were under without palliative care measures. Statements indicating the need of palliative care measures were articulated through ideas of ‘improving quality of life’ and ‘providing comfort before death’ within guidelines aimed at cancer care (WHO, 1990, 2002). With an increasing older population with multiple healthcare needs, things such as frailty are expected to become increasingly common within European societies (Davies & Higginson, 2004; WHO, 2004, 2011). Because ‘palliative care’ is deemed as something frequently associated to end-of-life care for cancer patients only, WHO guidelines targeting Europe emphasised how ‘older people’ have been neglected within healthcare systems (ibid).

Emphasising the need for better assessment of pain and other symptoms, the individualisation of care and the possibility to make choices about their care, palliative care is recommended to be broadly implemented within healthcare systems in order to incorporate the increasing demand for end-of-life care for older people. From 1990 to 2011 thus, it has been observed the emphasis on the perceived problem of lack of adequate responses to end-of-life care demands, to which ‘palliative care’ is recommended as a solution. Hence, the problematisation conceptualised as ‘inadequacy’ of care reflects to the implied ‘inadequacy’ of current patient care protocols.

From 2004-2018, I observed a shift in discourse in the reasons given, the motives and values shaping recommendations for palliative care. As guidelines aimed at European societies have also emphasised, there is an increasing demand for palliative care services that health systems must prepare for, and hence the reason why palliative care is deemed necessary refers to the perceived lack of *capacity* to offer the necessary coverage. The perceived lack of capacity was even more emphasised within guidelines aimed at LMICs (2016-2018). This is because countries classified as LMICs are deemed to have an already overwhelmed health system, and in this sense, the cost-effective alternative that is palliative care would contribute to relieve systems from being burdened with the care for the dying.

In the empirical chapters that followed (*Problematising Care* and *Problematising Capacity*), I examined how these problematisations were constituted. Common to all guidelines examined within this study, was the predominance of westernised values of ‘good dying’. In guidelines from 1990 to 2002, the study suggested to be underpinning by the concept of ‘total pain’ articulated with goals to provide better quality of life and comfort before death, the guidelines associate palliative care to symptom relief. Within guidelines from 2004 to 2011, ideas of appropriate end-of-life were largely shaped by values such as autonomy and choice. Thus, palliative care was associated to meeting patients’ needs and preferences for care.

In guidelines problematising capacity, the guidelines from 2004 to 2011 aimed at European countries were shaped by a classificatory system where a country is deemed more or less problematic depending on their level of palliative care provision. It engaged in dividing practices such as separating eastern vs western Europe, highlighting the successes of *some* places rather than others. It is important to observe that while from the first problematisation WHO guidelines created types of patients with particular needs, the second problematisation allowed the production of ‘places’. Within guidelines from 2016 to 2018, these places mainly LMICs are considered as in particular need for palliative care measures, as they are considered as having less healthy conditions, these are the places in need of intervention. Given the exposed palliative care has been thought about as a symptom management strategy and as a cost-benefit strategy to avoid overwhelming health systems with the burden of caring.

8.1.2. Research Question 2: What are the implications of such problematisations to the goal of universal coverage?

The question regarding universal coverage is a development of the first question concerning how palliative care has been problematised within guidelines. The aforementioned empirical chapters (chapters 4, 5 and 6), problematising end-of-life care both as a lack of adequate care and as a lack of capacity, constricts ‘palliative care’ into the particular ways of conducting ‘care’ within the realms of healthcare provision. Going back to Bacchi (2009) to shed light on this argument, she proposes that we are governed through problematisations that attempt to shape or conduct our behaviours. Drawing from governmentality studies, Bacchi offers ways to see how order is maintained and how societies are administered (Bacchi, 1999, 2009, 2010, 2012b). Within this study, I drew attention to instead of seeing guidelines as neutral and benign, I proposed seeing them as proposals to govern aspects of end-of-life care such as setting priorities, goals and prescribing normative behaviours for patients and professionals.

The proposals examined described how palliative care as shaped end-of-life care as a clinical and an economic strategy reflect an underpinning agenda to normatise professionalised deaths and to homogenise cultural understandings of death and dying in favour of cost-effectiveness instead of quality of care. These programmes for end-of-life care simplifies palliative care, reducing it to simple management strategies to control pain and other symptoms and facilitate coverage. The premise of Universal Health Coverage is defined as “ensuring all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship” (WHPCA, 2014, p. 2). Achieving total coverage of palliative care while maintaining quality of care and preventing financial hardship is yet to be achieved.

This study provided insight into the challenges local governments faced within their palliative care programmes. While the intent to provide care for all seemed to be a shared goal between national governments and WHO guidelines, the examples of national palliative care programmes illustrated here (*Identifying Silences*, chapter 5, section 5.4 & chapter 6, section 6.4) indicate how there is far more than policies and well-developed programmes to secure universal coverage. The case in Colombia illustrated how whilst adopting WHO palliative care framework in a national law and into palliative care programmes did not suffice to overcome other barriers in healthcare provision (Pastrana et al., 2021). Universal coverage in that country will depend on how ‘palliative care’ is articulated with wider societal aspects such as poverty and civil conflicts (ibid). Conversely, the palliative care programme in England – a well-developed programme considered one of the best in the world (EIU, 2010; EIU, 2015) faces ongoing challenges with equitable provision and quality of care. Moreover, the findings also highlighted the differences in end-of-life care priorities.

End-of-life care priorities are largely shaped by cultural values (Abel & Kellehear, 2016; Sallnow & Paul, 2018; Walter, 2020; Zaman et al., 2017) rather than symptom management. This was demonstrated by examples such as Turkish immigrants whose priorities were to be under curative treatment until the end of their lives (de Graaff et al., 2010), as well as to development of palliative care programmes in Macao, where the cultural norm is to maintain life rather than to pursue care until death (Tam et al., 2021). These findings all seem to support Zaman et al. (2017) that in order to reach a ‘universal’ coverage we need to open the way for *multiple* forms of palliative care. Additionally, the case studies explored in this thesis suggested that the PHS indicators may be inadequate to demonstrate the level of palliative care development in local context. It draws attention to ‘equity’ and ‘social vulnerability’ as important indicators for palliative care provision.

8.1.3 Research Question 3: What are the implications of such problematisations to the people involved in ‘palliative care’?

WHO guidelines are premised upon several assumptions regarding ‘patients’. In problematising care, guidelines are shaped through ideas of patienthood that are premised on an individual self. This individual is assumed to be willing and wanting to be submitted to palliative care intervention in order to be free from suffering. It presumes that dying without suffering is a universal value to all cancer patients independently from culture, transforms ‘patients’ into governable subjects.

If we take how ‘suffering’ functioned as a governing mechanism, the subjectification effects identified in this study (chapter 5, section 5.5) teased out “the forms of knowledge that made it thinkable” (Dean 1999:178). Epidemiology for instance, was used to confer meaning to the urgency of palliative care measures and to create the sense of the scale of the problem. However, patient identities were largely shaped by clinical symptoms chronic and life-threatening illnesses that are at the basis of their ‘suffering’ which allows professional intervention, the expansion of the professional gaze from the patients’ and into their subjectivity.

In 2002, WHO requires healthcare professionals to deploy strategies for assessment of symptom control on a regular basis, and as such made ‘measuring’ symptoms an intrinsic part of palliative care practice. In this sense, positioning patients as sufferers allowed a continuation of a fragmented idea of patienthood. Therefore, from 1990 to 2002 ‘people’ are understood and rationalised by their illness and the severity of their symptoms, while ‘care’ is replaced by symptom relief. Thus, problematising care allowed to create strategies to govern ‘suffering’ at the end-of-life. It requires people to think themselves as in need of professional support at the end-of-life while inviting healthcare professionals to see themselves as holding the knowledge and skills to relieve suffering at the end-of-life.

Alternatively, the second patient identity identified as ‘dying entrepreneurs’ referred to guidelines for European countries from 2004 to 2011. This patient identity displaces the concern with symptom relief and pain control to meeting choice and preferences, where attention is being directed at the patient’s wishes. Thus, making choices and having preferences met is the main strategy being deployed to address suffering at the end-of-life. The success of palliative care measures is transformed into satisfying individual preferences which signals how patients are being constituted as ‘*dying entrepreneurs*’ with a task to decide, choose and actively be engaged with the last years of their lives. In turn, healthcare systems have a moral duty to attend to these preferences.

This study also enquired on the type of relationships established through guidelines aimed at LMICs where significant differences were found from previous subject positionings. It was identified here while ‘people’ identities discussed previously created particular kinds of subject positioning. When patients are understood according to their symptoms or their choices they are positioned as *receivers* of ‘care’. Meanwhile the types of identities created in guidelines from 2016 to 2018 are shaped by ideas of compassion and relational selves is aligned with goals to expand palliative care coverage in the community.

Identified as ‘agents of care’ and ‘trainable subjects’ the focus on agency of ‘carers’ displace attention from the receivers of care to the *carers*. That is, ‘palliative care’ is no longer being positioned as something to be offered by healthcare institutions but by the ‘people’ involved in care (i.e., paid professionals, community health workers and volunteers). This allows the responsibility of care to shift from healthcare institutions and governments and to be placed on individuals. Therefore, positioning individuals as ‘agents of care’ and ‘trainable subjects’ transforms them into *providers*. While returning power to the people may be welcomed

(Kellehear, 1984), the type of ‘carers’ they are invited to become is based on professional knowledge. For example, in 2018 the identified ‘trainable subjects’ emphasised how education and training in palliative care could transform how care is provided in low resourced settings. Training in palliative care is expected to suffice to allow professionals and individuals to respond to peoples’ needs effectively, thus inviting people to become agents of professionalised care.

8.2 Implications and Recommendations for Research, Practice and Policy

8.2.1 Research

Palliative care research concerned with global development is an emerging research field (Borgstrom & Ellis, 2017; Clark, 2012b). Throughout this study I have indicated the dominance of ‘western’ perspectives in this field which has been predominantly shaped by European studies in English language (Borgstrom & Ellis, 2017; Pastrana et al., 2010). Despite the language limitation, this research has adopted a wide perspective which included literature on how the concept of ‘palliative care’ was established, how it reached global health debates and the dominant issues within the literature concerned with global palliative care development.

Regarding international development of palliative care, there is a predominant focus on policy development, levels of development and on the disparities of palliative care provision between HICs and LMICs (chapter 2. *Integrating Palliative Care Globally: mapping WHO strategies towards global palliative care*). Without questioning the implications of discourses of disparities associated to economic development and to cultural diversity. Thus, in order to move forward in our understanding of ‘palliative care’ internationally, the findings in this study supports Zaman’s et al. (2017) argument to redirect attention away from ‘global’ perspectives. Global perspectives such as levels of service provision, status of policy development and integration to health care, do not give insight on how palliative care provision is socially determined. In this study, ‘global’ perspectives revealed a technocratic tendency to reduce ‘problems’ something professionals or trained individuals would be able to respond. In doing so, it provides a de-politicised view of palliative care, one that is exempt from power relationships.

In the previous chapter, I discussed the contributions for this study. The list of contributions ranged from the ways in which palliative care is recommended within the WHO guidelines to the production of normative expectations for end-of-life care. In this section I will return to the list of empirical contributions to discuss their implications for research. First, to remember the list presented in the previous chapter (chapter 7, p. 205) :

1. How, for whom and for what purposes palliative care was being recommended.
2. Which concepts, knowledges and assumptions gave shape to WHO guidelines for palliative care and to theorize how they introduced binary forms of thinking.
3. The contingent nature of guideline problems, I sought to offer an alternative way of thinking guidelines as a *cultural product.*
4. The ways in which guidelines authorise forms of intervention on death and dying.
5. How guidelines establish power relationships between professionals and patients, and between HICs and LMICs.
6. The production of normative expectations for end-of-life care.

The first empirical contributions that have particular implications for research, refers to numbers 2 and 3 of the list above. The opportunity offered by the application of the WPR framework on WHO guidelines, distinctively separates this research from other studies. For instance, the research conducted here challenged ‘evidence-base’ guidelines and offered ways of thinking them as contingent to historical and social contexts. Moreover, the analysis provided here brought visibility to what is left at the margins of ‘palliative care’ which in turn indicates the types of knowledges, values and premises are shaping WHO's proposals (contribution 2). Thus, more critical attention should be directed to the *implications* of WHO's palliative care proposals rather than impact.

Moreover, considering how this study revealed guidelines as discursively constituted, it proposed two forms of thinking 'technical' guidelines. First as a *product*, and second as *productive* (contribution 3). The first proposition - that guidelines are produced - indicates the contingent nature of expert knowledge and how they are embedded in particular social and historical contexts, indicates that perceived 'global' problems need to be questioned rather than accepted. Since it was observed multiple times that 'global' problems were *created* though an assemblage of individuals, institutions and organizations that converged into shaping 'palliative care' as a global health problem, focus should be given in situating how perceived problems came to be.

The second proposition put forward in this study, revealed that guidelines are productive in creating problems as problems of a certain kind. As such, discourses of palliative care 'problems' fostered rationalities for administrating particular aspects of 'palliative care'. Largely shaped by western values and technocratic tendencies it can be argued that the guidelines themselves impose obstacles to alternative ways of thinking palliative care.

In this sense, the propositions put forward by this have implications to research concerning international palliative care development. It invites research to focus on the non-western perspectives of death and dying rather than on global perspectives. Second, it redirected focus from impact to implications. Lastly, it proposes a critical attitude towards the constitution of global health problems that may contribute to the maintenance of power relationships shaping end-of-life care knowledge.

8.2.2 Policy

The literature concerning 'global' palliative care suggest a wide range of fields interested in understanding both the gaps in provision with a main focus on ‘disparities’ between countries and to point to solutions in order to address them. One of the main arguments established in this study referred to challenging the claimed neutrality in WHO guidelines. While it is important to recognise the relevance of WHO in establishing global health agendas, it is also important to recognise that ‘evidence-base’ does not mean ‘neutral’. Evidence, data, and expert knowledge can be used to create particular forms of *reality*. Three of the empirical contributions presented in the previous section have implications for policy developments. They are:

1. How, for whom and for what purposes palliative care was being recommended.
2. How guidelines establish power relationships between professionals and patients, and between HICs and LMICs.
3. The production of normative expectations for end-of-life care.

Taken as the ‘truth’ rather than ‘in the true’, the ethnocentric aspects of guidelines could influence, to a certain extent, what palliative care *means* in end-of-life care policies in many countries adopting WHO’s guidelines. In addition, guidelines foster rationalities, they set out goals to be achieved, they foster particular patient identities and prescribe social roles (contributions 1 and 6 above). In this sense, ethnocentric perspectives of palliative care may favour practices that undermines local cultural end-of-life care practices and restrict patient choices within national healthcare systems (contribution 1).

Moreover, in shaping palliative care according to WHO’s frameworks may contribute to maintaining the gaps in palliative care provision and policy development between countries. As ‘palliative care’ adopted in WHO’s proposals were revealed to be ethnocentric, the debate on policy development at the global level must redirect attention from efforts to homogenising end-of-life care policies (contribution 5). Lastly, this study has implications for policy end-of-life care policy development where more focus should be given to cultural and social aspects of death and dying and quality of care rather than increasing the number of service provision.

8.2.3 Practice

One goal this research sought to achieve was to gain a better understanding on the prescriptive role WHO guidelines have in the creation of ‘approved’ social roles such as the ‘patient’. As argued in the previous chapter (Chapter 7, section 7.3), examining proposals for palliative care within guidelines can shed a light on how they shape our conduct and behaviours (contribution 4). As such, two of the empirical contribution this study (see previous chapter for more details) have implications for practice:

1. How, for whom and for what purposes palliative care was being recommended.
2. The ways in which guidelines authorise forms of intervention on death and dying.

Positioning patients as someone who is in pain and someone who is actively being neglected in healthcare systems are premised on a dying trajectory that is commonly attributed to cancer, which fails to represent the experiences of patients suffering from other illnesses (contribution 1) (Pollock & Seymour, 2018; Walter, 2017). Yet, as demonstrated in the guidelines from 2002, the subject positioning of patients as ‘sufferers’ is extended to patients with other forms of illnesses (chapter 5, section 5.5). The inclusion of other patient categories within the ‘sufferers’ identity allowed guidelines to call for surveillance of symptoms and needs (contribution 4).

Establishing the patient as a ‘sufferer’ the idea of ‘care’ could implicate in moralising end-of-life care (contribution 1). As identified by Pollock and Seymour (2018) ideas of ‘good’ and ‘bad’ deaths are morally charged creating what they called ‘good’ patients and ‘bad’ patients. In this sense, the identity of patients as ‘sufferers’ could be operationalised to create new forms of profissionalisation of death; reducing ‘palliative care’ to symptom relief and contributes to a fragmented idea of patienthood at the end-of-life (contribution). Because it clearly imposes a binarism of what is desirable to achieve at the end-of-life (i.e., a death without suffering), the rationale proposed in guidelines from 1990 to 2002 could lead to classification of dying as ‘good’ or ‘bad’ and in doing so, dying with palliative care support becomes moralised.

Despite a discourse of end-of-life profoundly shaped by ideas of individuality, power is still placed on the hands of professionals and healthcare workers who will then *allow* the patient to make choices. In addition, as argued previously, while patients are required to make choices, the choice for palliative care is already made for them. The constitution of ‘choice’ as an *offer* signals to the type of relationship established through the entrepreneurial identity.

Considering how people are constituted within policies contributes to theorising on how they may shape people’s end-of-life (contribution 1). With a system directed at responding to people’s suffering, emphasis is placed on managing symptoms (of any kind) which necessarily leads to the ‘othering’ of non-conforming subjectivities. Constituting patients in this manner excludes from palliative care the instances that are not available such as euthanasia or inpatient or ICU unit. In this sense, the implications for people involved in palliative care can be thought as: the constrains on the roles individuals must perform, the subjectivities they are invited to assume and constrains on the possibility of making any choice other than palliative care (contribution 4).

8.3 Future developments

As discussed previously in this thesis (Chapter 3), ‘problematisation’ is a concept with disputed meanings and analytical traditions and therefore there is no single ‘correct’ way of thinking about problematisations as they ‘have no fixed meaning’ (Bacchi, 2015, p. 2). While the findings from the application of Bacchi’s framework may contribute to our existing knowledge on the implications of WHO guidelines for palliative care, these findings must be understood in a non-essentialist way, thus rejecting any attempt to constitute them as an ‘entity’ or the ‘truth’ regarding palliative care guidelines. Instead, they should be seen as part of an ongoing process of discursive constitution and reconstitution of problems, subjects, and objects. Nonetheless, the Foucault-influenced perspective adopted in this study revealed the importance of challenging the premises upon which recommendations for practice were established within guidelines and as such, more research is required in respect to the social implications of WHO’s recommendations for palliative care.

One possible future development refers to exploring how discourses of palliative care within guidelines may favour men more than women. Being socially constructed as a ‘female’ role in many cultures, WHO’s guidelines promoting the shift to home-base care and community base care may be contributing to further increase gender inequalities. There were also cultural aspects of palliative care that the guidelines failed to acknowledge. In the guidelines examined, ‘culture’ became something to overcome through professional training and education for the general population, rather than being integrated into palliative care. In this sense, another possible implication for research is paving the way to rethinking professional guidelines entirely. This way, the findings in this study pave way for further developments on the social and cultural implications of guidelines.

8.4 Reflecting back on the PhD journey

As reflected in the opening of this thesis, this research emerged from concerns with professionalised discourses of palliative care in my own country. Back in 2016 when I was practicing psychology within palliative care facilities, it occurred to me that palliative care professionals seemed to agree on the type of dying considered as desirable for the Brazilian population. A type of death that were mostly resisted by the many families I have encountered. Moreover, as palliative care practice and policies in Brazil are predominantly informed by WHO, healthcare policies towards palliative care reproduce the view that WHO’s approach to palliative care is feasible and culturally appropriate for the Brazilian context of healthcare provision. However, Brazil is a nation of diversity. Here, everything is plural. Colours, religion, values, differences, inequalities, disadvantages… In a country with such a plural constitution, the idea that a single model of palliative care based on a single model of 'good dying' had always concerned me.

I began to wonder whether our job as 'palliative care' professionals, aiming to provide a 'good death', was to completely reject the possibility that maybe that form of death was not what people wanted to receive. Maybe, I wondered, because our practice as palliative care professionals *require* us to listen and stand by families and patient's wishes, we should think about ways to be inclusive on the other forms of caring for the dying. Were we replacing one death typology for another? These were the questions that led to this thesis. At the beginning of my PhD journey, I found out that many of my concerns were shared by many scholars. Questioning the predominance of particular discourses of end-of-life care (Borgstrom, 2013), the lack of cultural inclusivity in WHO palliative care frameworks (Zaman et al., 2017) and the extent to which 'palliative care' constructed particular form of 'dying' (Seale, 1998; Walter, 1994, 2020), the objectives I set out to achieve through this research was both inspired and shaped by the questions these authors have raised.

As introduced in opening chapter of this thesis, I was interested in understanding how the concept of 'good death' shaped what we understand by 'palliative care' and sought ways to consider the implications of these ideas to different cultures. However, in looking closely to the questions scholars have been raising in the literature redirected my attention from the 'good death' to 'palliative care' itself. Thus, I began to raise questions on how such an important global health actor, such as WHO interprets, shapes, recommends palliative care to other countries. I wanted to know how the interpretations of palliative care within WHO guidelines were associated to particular goals and how they allowed power relations to be established. Thus, raising questions on the ways guidelines *produced* forms of governing end-of-life care and what the implications of these are for countries with significant less power to influence global health agendas, or that have different attitudes to death and dying than those promoted within WHO publications.

The examination of guidelines as demonstrated by the previous chapter made it visible guidelines are productive, carrying interpretations of problems that justified forms of palliative care intervention. It also demonstrated that these problematisations had implications for different groups of people. For patients, problematising 'care' established patient identities aligned to the goal of professionalising death. These identities invited people to think about themselves as subjects in need of professional help. Whether was in order to alleviate suffering or having their preferences met, patients were invited to welcome palliative care practice as the 'appropriate' care. For professionals, the adequate conduct was identified as one that sought to alleviate suffering and facilitate 'choices' to be made regarding their care. Shaped by the concept of total pain and relief of suffering, dying through palliative care having their needs assessed and addressed, engaging in decision-making, this is what perceived to be 'adequate' end-of-life care. As such, I argued that while emphasising one form of 'dying' as 'adequate' guidelines do not allow any other choice to be made as it is assumed that this is the care patients will want to receive if given the option.

Considered particularly important in health settings where diagnosis and treatment are largely absent palliative care is not a 'choice', but the only possibility for many. In problematising the lack of 'capacity', professionals are invited to assume the responsibility for training and educating others in order to expand the available workforce. This form of thinking allowed the creation of identities as 'trainable' and 'agents' of care which transform anyone willing to help into a potential carer. Problematising capacity disregarded how care is mostly culturally and socially shaped rather than a product of 'trained' abilities, knowledge and skills. In this view, the 'palliative care' people were expected to 'learn' is assumed as universal to all cultures, thus reflecting the predominance of monolithic perspectives. The dominant 'palliative care' within WHO is highly restrictive on possibilities for *change*.

From the exposed, the findings and analysis conducted in this study as indicative that

I have accomplished the objectives set out for this research. They demonstrate how WHO guidelines are productive of ways of administrating death. How they create particular identities aligned with goals that directs intervention to some aspects of dying and not others. It also creates forms of institutionalising the WHO approach to palliative care which demonstrates the tendency to homogenise end-of-life care by circumventing cultural as societal aspects of death.

8.5 Final Message

This study demonstrated that palliative care guidelines are a key aspect of global end-of-life care debates as it provides a rationality for palliative care provision, patient care, community care and home-base care. It recognises the importance of WHO guidelines for global development of palliative care practices. Yet, if we are to achieve UHC, this study establishes that the role of guidelines in promoting palliative care is concerned with homogenising and professionalising care; offering socially approved forms of dying; and empowering individuals to assume responsibilities for structural problems. This understanding indicates the need to reorientation of palliative care advocacy to build on plurality; recognising the potentialities of countries rather than their deficiencies and to reorganise the proposals for care from ‘illnesses’ to culture.

Appendix 1

Searched Terms

Searched terms in relation to death and dying
Death or Dying and Attitudes Death or Dying and Taboo Death or Dying and Sociology
Searched terms in relation to Hospice and Palliative Care
Death and/or Dying and Hospice Hospice and Sociology Palliative care and History Palliative care and/or development Palliative Care and models New Public Health and Palliative care Public Health and Palliative care
Searched terms in relation to WHO/Global Development
Global and Development and Palliative Care WHO and Palliative care Levels of Development and Palliative care

Appendix 2

Sampling results

Searched Terms: Palliative care **Filters: WHO authorship; Guideline; English Language**
Integrating palliative care and symptom relief into primary health care: a WHO guide for planners implementers and managers
Integrating palliative care and symptom relief into paediatrics: a WHO guide for health-care planners, implementers and managers
Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises: a WHO guide
Home care for patients with suspected or confirmed COVID-19 and management of their contacts: interim guidance, 12 August 2020
Community-based health care, including outreach and campaigns, in the context of the COVID-19 pandemic: interim guidance, May 2020
Guidelines on the management of chronic pain in children
Abortion care guideline
Persisting pain in children package: WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses
WHO recommendations: intrapartum care for a positive childbirth experience
Guideline: nutritional care and support for patients with tuberculosis
WHO guideline on self-care interventions for health and well-being
Updated recommendations on service delivery for the treatment and care of people living with HIV
Pocket book of hospital care for children: guidelines for the management of common childhood illnesses
WHO guidance for climate resilient and environmentally sustainable healthcare facilities
Home-based long-term care: report of a WHO study group
Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations
Public-private mix for TB care and control : a toolkit
Patient monitoring guidelines for HIV care and antiretroviral therapy (ART)
Nutrition counselling, care and support for HIV-infected women : guidelines on HIV-related care, treatment and support for HIV-infected women and their children in resource-limited settings
Hand hygiene in outpatient and home-based care and long-term care facilities: a guide to the application of the WHO multimodal hand hygiene improvement strategy and the “My Five Moments For Hand Hygiene” approach
Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations
Compendium of WHO guidelines and associated standards: ensuring optimum delivery of the cascade of care for patients with tuberculosis
National AIDS programmes: a guide to monitoring and evaluating HIV/AIDS care and support
WHO consolidated guideline on self-care interventions for health: sexual and reproductive health and rights
WHO self-care interventions for health: sexual and reproductive health and rights: web annex: global values and preferences survey report
IMAI district clinician manual: hospital care adolescents and adults: guidelines for the management of illnesses with limited-resources
Consolidated guidelines on HIV prevention, testing, treatment, service delivery and monitoring: recommendations for a public health approach
WHO guidelines for the pharmacological and radiotherapeutic management of cancer pain in adults and adolescents

WHO guideline for screening and treatment of cervical pre-cancer lesions for cervical cancer prevention
WHO guideline for screening and treatment of cervical pre-cancer lesions for cervical cancer prevention, second edition: use of mRNA tests for human papillomavirus (HPV)
Ethics and governance of artificial intelligence for health: WHO guidance
WHO guideline on school health services
Policy and advocacy
Comprehensive cervical cancer control: a guide to essential practice
Diagnosis and treatment
Guidelines for the management of symptomatic sexually transmitted infections
Narcotic and psychotropic drugs : achieving balance in national opioids control policy : guidelines for assessment
WHO guidance on research methods for health emergency and disaster risk management
National cancer control programmes : policies and managerial guidelines : executive summary
National cancer control programmes : policies and managerial guidelines
WHO technical guidance and specifications of medical devices for screening and treatment of precancerous lesions in the prevention of cervical cancer
Early detection
World Health Organization model list of essential medicines: 21st list 2019
Costing guidelines for tuberculosis interventions
WHO guidelines on tuberculosis infection prevention and control: 2019 update
Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines
Guidelines for malaria vector control
Management of physical health conditions in adults with severe mental disorders: WHO guidelines
Prevention
WHO model list of essential medicines : 16th list (updated) March 2010
Companion handbook to the WHO guidelines for the programmatic management of drug-resistant tuberculosis
WHO model list of essential medicines : 17th list, March 2011
WHO model list of essential medicines, 20th list (March 2017, amended August 2017)
The selection and use of essential medicines : report of the WHO Expert Committee, 2007 : (including the 15th model list of essential medicines)
WHO guideline on health policy and system support to optimize community health worker programmes
Clinical management of patients with viral haemorrhagic fever: a pocket guide for front-line health workers: interim emergency guidance for country adaptation
Clinical management of patients with viral haemorrhagic fever: a pocket guide for the front-line health worker: interim emergency guidance - generic draft for West African adaptation 30 March 2014
Guidelines for managing advanced HIV disease and rapid initiation of antiretroviral therapy, July 2017
Guidance note on the integration of noncommunicable diseases into the United Nations development assistance framework
WHO model list of essential medicines : 16th list, March 2009
The use of essential drugs: ninth report of the WHO Expert Committee (including the revised Model list of essential drugs)
Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach
Palliative care: the solid facts
Consolidated guideline on sexual and reproductive health and rights of women living with HIV
Antiretroviral therapy of HIV infection in infants and children: towards universal access: recommendations for a public health approach - 2010 revision

WHO guidelines on hepatitis B and C testing
Guide to producing reproductive health subaccounts within the national health accounts framework
WHO Expert Committee on Drug Dependence : thirty-fifth report
Guidelines for the management of conditions that are specifically related to stress"
Guidelines on post-exposure prophylaxis for HIV and the use of co-trimoxazole prophylaxis for HIV-related infections among adults, adolescents and children: recommendations for a public health approach: December 2014 supplement to the 2013 consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection
WHO model list of essential medicines for children : 1st list, October 2007
Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV
WHO model list of essential medicines for children : 3rd list, March 2011
The use of essential drugs: seventh report of the WHO Expert Committee (including the revised Model list of essential drugs)
WHO model list of essential medicines for children : 2nd list, (updated) March 2010
WHO model list of essential medicines : 18th list, April 2013
Guideline on HIV disclosure counselling for children up to 12 years of age
Guidelines on the treatment of skin and oral HIV-associated conditions in children and adults
WHO model list of essential medicines for children : 2nd list, March 2009
Integrating collaborative TB and HIV services within a comprehensive package of care for people who inject drugs: consolidated guidelines
HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV : annex 9 : review methods
Management of the child with a serious infection or severe malnutrition : guidelines for care at the first-referral level in developing countries
Sexual and reproductive health of women living with HIV/AIDS : guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings"
Preparation of national health-care waste management plans in Sub-Saharan countries : guidance manual / Secretariat of the Basel Convention and World Health Organization
Operations manual for delivery of HIV prevention, care and treatment at primary health centres in high-prevalence, resource-constrained settings : edition 1 for fieldtesting and country adaptation
WHO guidelines for safe surgery 2009: safe surgery saves lives
Updated recommendations on treatment of adolescents and children with chronic HCV infection, and HCV simplified service delivery and diagnostics
Community needs, perceptions and demand: community assessment tool: a module from the suite of health service capacity assessments in the context of the COVID-19 pandemic: interim guidance, 5 February 2021
WHO recommendations on antiplatelet agents for the prevention of pre-eclampsia
WHO guideline on health workforce development, attraction, recruitment and retention in rural and remote areas
Guidelines for implementing collaborative TB and HIV programme activities / prepared by Nicola Hargreaves and Fabio Scano on behalf of the Scientific Panel of the Global TB/HIV Working Group of the Global Partnership to Stop TB
Brief sexuality-related communication: recommendations for a public health approach
Planning guide for the health sector response to HIV/AIDS
Cancer pain relief and palliative care : report of a WHO expert committee [meeting held in Geneva from 3 to 10 July 1989]
Global health-sector strategy for HIV/AIDS : 2003-2007 : providing a framework for partnership and action

National AIDS programmes: a guide to indicators for monitoring and evaluating national antiretroviral programmes
Cancer pain relief and palliative care in children
Cancer pain relief
Access to pain relief and essential opioids in the WHO South-East Asia Region: challenges in implementing drug reforms

Appendix 3
List of codes

Codes

Name	Description
Aims and goals	Statements that indicate the expressed aims and goals of a guideline
Binaries	the creation of relationship A - not A
Categories	Statements that express people categories or disease categories - 'cancer patient' for example
Disease categories	Statements that make reference to symptoms, illnesses
People categories	Statements about ‘people’ – i.e. patients, families, workers
Places	HICs, LMICs, West, East
Cause of the problem	What is assumed as the root of the problem
Concepts	Key concepts that support the aims and goals of the guideline
Context	Statements that indicate the context in which the guideline was produced
Knowledge	Statements that indicate 'evidence support'
Epidemiology	Usage of epidemiology
Gaps	Gaps in knowledge
Medicine	Statements based upon clinical or medical knowledge
Psychology	References to psychological knowledge
Society	References to knowledge on 'social' problems
Spirituality	References to knowledge of spiritual needs

Name	Description
Measurements	tools used to calculate palliative care needs, trends, etc
Desirable conditions	Statements expressing what is desirable
Education	Statements that express desirable education
Behavioural change	Statements expressing desired behavioural changes
Information to change cultural beliefs	Statements expressing desired cultural changes
Cost-effectiveness	Statements on the cost-effectiveness of palliative care
Dissemination	Forms of dissemination, developments from the guidelines
Ethical and moral considerations	discussions on what is right or ethical in providing palliative care
Government	The role 'government' - attributions and responsibilities of the 'government' towards palliative care
NGOs	Role of NGOs
WHO	Attribution of responsibility
Impending crisis	Statements that express the notion of an impending crisis
Inequalities	Statements expressing the inequalities of palliative care access
Inequalities as a lack of knowledge	Discussions on the lack of expert knowledge as the reason for lack of coverage
Inequalities as an economic problem	Discussions on economy as the reason why access to palliative care is inequal
Inequalities as lack of engagement	Discussions on lack of engagement as a reason for inequalities
Inequalities as social gradient	The use of 'social gradient' discourses as to explain the inequalities in palliative care

Name	Description
Neglect	Discussions on 'health problems' that are deemed ignored by public health
Obstacles to implementation	Statements that describe the elements that prevent successful implementation
Ignorance	Statements discussing lack of knowledge as an obstacle
Lack of engagement	Discussions on lack of engagement (from policymakers and health professionals) as an obstacle
Poor management	Discussions on the inefficient management of healthcare resources
Resistance	Discussions on how palliative care measures were met with resistance
Palliative care definitions	Statements that define what 'palliative care' stands for
Community	Statements expressing the role of 'community' within palliative care
Expected outcomes	statements that indicate what is the expected outcome from palliative care implementation
Family carers	Statements that express the place of family members within palliative care practice - attributions, responsibilities and needs
Palliative care target	Statements that indicate who is to be benefited from palliative care
Patienthood	Statements that express assumptions on palliative care 'patient' - behavioural, emotional, spiritual and physical needs
Agency	Discussions on agency and decision-making
Control	Discussions on the importance of control
Empowerment	Discussions on how to empower patients
Informed patient	Discussions on informed decision-making

Name	Description
Lifestyle	Discussions on lifestyle and health
Palliative Care workers	Statements that indicate how professionals are expected to perform - attributions and responsibilities
Reasons for palliative care	Statements express the 'need' for palliative care
Policy changes	Statements indicating recommendations for policy change
Good death - Dying without suffering	Discussions on palliative care to promote a good death - dying without suffering
Health promotion	Discussions on how to promote palliative care to achieve health promotion goals
Wellbeing	Discussions on palliative care as to promote wellbeing
Success	Discussions on the successful palliative care programmes
Requirements	Statements that express what is being required from Member States - what they need to do to implement palliative care
Equality	Discussions on how to promote coverage
Equality as engagement	Discussions on how to mobilise policymakers and professionals towards palliative care implementation
Risk	Discourses on what is at risk without palliative care
Surveillance	Statements that indicate what countries should pay attention to - what needs to be under 'surveillance'
Universality or Generalisation	Statements indicating the feasibility of palliative care in different contexts

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