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Exploring Chinese Bioethics Through the Practice of Palliative Care

By

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A dissertation submitted to the University of Bristol in accordance with the requirements for award of the degree of Master of Science by research in the Faculty of Population Health Sciences.

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Abstract

This research explores the ethical challenges arising in palliative care in the Western (Anglo-Saxon) context and the Chinese context. In each context, the history, key values, terminology, care delivery models and training schemes of palliative care are traced. Both the East and the West apparently confront similar difficulties regarding conceptional tensions and inadequate resourcing. However, palliative care has a shorter history in China, and these difficulties appear most pronounced in Chinese contexts.

Similarities and differences can also be detected in the palliative care ethics that underpins practice in each context. In the West, palliative care ethics is firstly shaped by Christian ethics and then guided by the dominant ethical theory of 'principlism', which is particularly committed to respect for individual autonomy. In contrast, a distinct 'palliative care ethics' is less detectable in Chinese contexts. Nevertheless, the indigenous philosophy of Confucianism appears to be relevant and applicable to the practice of palliative care. In apparent contrast to principlism, Confucianism is distinctive by virtue of its relational nature and commitment to familism and thus family autonomy.

Although the ethical underpinnings vary, common ethical challenges nevertheless appear to arise in palliative care practice in both contexts. Ten common challenges are identified from the literature, with two – medical futility and truth-telling – investigated in-depth. To address such challenges, healthcare professionals in the West and East are trained under homogeneous pedagogies and adopt similar bioethical deliberation tools and clinical responses.

Irreconcilable ideological differences nevertheless remain. Confucianism' s family autonomy cannot be neatly squared with the individualistic orientation of Western principlism. Such fundamental variations, in turn, cast doubt on what counts as an 'ethical challenge' in these different contexts. This project concludes that, in order to identify the actual ethical challenges arising in palliative care in China (and responses thereto), 'empirical bioethics' research is now needed.

Covid-19 Statement

Due to the COVID-19 pandemic, the planned element of face-to-face, semi-structured interviews was removed from this research. Ideally, this project would have gathered data from healthcare professionals working in palliative care in China. However, the pandemic resulted in stricter visiting policies in hospitals. Individuals were not allowed to attend a medical facility unless absolutely necessary. Given this, face-to-face interviews were not feasible, although the ethics approval was received (Appendix A). While the alternative of online video interviews was explored, potential participants reported difficulties with this due to surging workload. Given also the time frame of a MSc by research (two years maximum), the empirical element was removed from this project.

However, as this dissertation argues, empirical research (specifically qualitative research) is needed in this area. Had interviews been possible in the current project, I would likely have received valuable insights into:

- How Chinese healthcare professionals define ‘ethical challenges’, and what kinds of difficulties they perceive as ‘ethical’ challenges;
- How Chinese healthcare professionals solve these perceived ethical challenges; whether there are any commonly used methods, and why these in particular;
- What kinds of training, focused on addressing ethical challenges, Chinese healthcare professionals have received, and how effective such training might be; and
- What kinds of ethical training is most needed, and why; and, if this has not yet been provided, the possible reasons for this.

As I argue in section 4.3 of this thesis, qualitative research is needed, as part of an ‘empirical bioethics’ project. I have accordingly planned a follow-on PhD study. This appears to be an appropriate next step since:

- A PhD project allows more time for data collection and analysis (up to 4 years, including a writing-up year); and
- It is hoped that the pressures of the pandemic will be alleviated and I will have the opportunity to access medical facilities and interview their staff in person.

Details of this planned follow-on plan can be found in section 4.3.

Author's Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's Regulations and Code of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

SIGNED: .... DATE: ....

Dedication and Acknowledgements

This journey of Master by research is more than pleasant and enjoyable to me. I have gained so much through these two years. The unprecedented pandemic has inevitably reshaped this research, yet the challenges and fun brought by these changes have made this experience unique and unparalleled.

Firstly, I owe my sincere gratefulness to my parents. They always have my back, even from thousands of miles of away. With their love and care, I am empowered and able to overcome the self-doubt, the tiredness and all the difficulties along the road.

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Finally, I want to express my great appreciation to Wellcome Trust. With their generous funding, I am able to complete this brilliant project and meet all these fabulous people.

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List of Abbreviations

ADL activities of daily living.

CNKI China National Knowledge Infrastructure.

CPR cardiopulmonary resuscitation.

DNACPR Do Not Attempt Cardiopulmonary Resuscitation.

DNAR Do Not Attempt Resuscitation.

DNR Do Not Resuscitate.

EIU Economist Intelligence Unit.

GPs general physicians.

IAHPC International Association for Hospice and Palliative Care.

LCPC Lien Centre for Palliative Care.

LWPA Beijing Living Will Promotion Association.

NCHSPCS National Council for Hospices and Specialist Palliative Care Services.

NHC the National Health Commission of the People's Republic of China.

NHS National Health Services.

PUMC Peking Union Medical College.

QELCA© Quality End of Life Care for All.

SAR Special Administrative Region.

WCSPH West China School of Public Health (attached to Sichuan University).

WHO World Health Organisation.

Chapter 1

Introduction

From the side, a mountain range; from the end, a single peak;
Far, near, high, low, no two parts alike.
Why can't I tell the true shape of Mount Lu?
Because I myself am in the mountain.

– Su Shi (Song Dynasty)

This is a literature-based study concerning the construction of 'bioethics', and 'ethical challenges' in palliative care, in the world and with a particular focus on China. Using a narrative review, I screened and analysed recent bio/ethical literature. The study firstly examines the practice of palliative care. This is a young medical specialty, with only a few decades of development. Originating in the UK, palliative care has become common in European and North American countries (Economist Intelligence Unit (EIU), 2010; 2015). Within this mature system, palliative care is well-supported by specialists from multiple disciplines including and beyond the field of medicine, such as psychologists, lawyers, social workers, the clergies and so on (World Health Organisation (WHO), 2018). However, in China, palliative care is not only immature, but also resisted due to certain cultural traditions. The taboo of death and an expectation that the end of life will and should be medicalised are deeply rooted in Chinese people's minds, which creates additional barriers for the provision of palliative care (于世英 (Yu), 2020). In general, there is still a significant gap between China and high-income countries in terms of the availability, accessibility and quality of palliative care.

The research then turns to the conception of 'bioethics', particularly and specifically 'palliative care ethics'. While the field of bioethics is also rather in its youth, there are clear differences and divergences revealed between Western – predominantly principlist – and Confucian (bio)ethics. It seems that the two (bio)ethics are built on quite different grounds. Palliative care ethics in the West has its roots in the religious world yet it has gradually integrated a modern, liberal, secular ethics – principlism. The notions of personhood derived from this ideology thus appears to be quite individualistic. In contrast, Confucianism is more of a complex of religion, philosophy and political ideology. The Confucian idea of personhood contains more collectivist features, which entails a relational moral self-cultivation procedure which begins within the family (邱仁宗 (Qiu), 2012; Wong, 2020). Such differences inevitably lead to different interpretations of ‘ethical challenges’.

Finally, combining these two ideas, (bio)ethical challenges and palliative care, I identify the common ethical challenges that appear to arise during palliative care provision. It is not surprising to find that similar challenges have been encountered around the world wherever palliative care is practised (Li and Wen, 2010; 鄢思佳 (Yan), 2018). However, there are different interpretations of the specific challenges, as well as of the best interests of patients, which arise from different causes and invite different solutions for addressing them. My ultimate conclusion is that, instead of the practices themselves (e.g. around truth-telling, or medical futility), it is the conception of ‘family autonomy’ that appears to be incompatible with the Western construction of individual autonomy and privacy.

This reflection raises fresh questions about the identification of ‘ethical challenges’ – specifically whether challenges in China (and Chinese contexts in general) are defined and classified differently from the mainstream Western thinking. As depicted in the poem above, different interpretations can be reached while standing at different positions. Therefore, further research is needed, which steps away from view presented in the prevalent Western ideology, and towards the view(s) seen in Chinese contexts. I end with a prospective plan for qualitative ‘empirical bioethics’ research that explores how Chinese healthcare professionals approach the concepts of ‘bioethics’ and ‘ethical challenges’, and aims to develop ethically justified responses to such challenges. Through such a follow-on project, it should be possible to resolve the questions presently left unanswered in the current research.

1.1 Research Aim

This research aims at:

- Critically exploring and comparing the ethical challenges arising in palliative care in the West and East, with a focus on China, and considering their implications.

In seeking to fulfil this aim, this research further seeks to meet three objectives:

- To investigate the history, nature and provision of palliative care, reflecting on its development in the West (specifically in the UK) and the current position in the East (specifically in China);
- To critically explore palliative care ethics and the ethical challenges arising in palliative care in China and the West;
- To critically compare the ethical challenges arising in palliative care in China and the West and explore their implications.

The researcher will seek to meet these objectives in the order given. Starting from the investigation of the origins of palliative care, this thesis will illustrate how ethical challenges are understood and dealt with in palliative care in different cultural contexts.

1.2 Research Methods

To address the research question, this project undertakes a critical comparative analysis to examine the commonalities and differences in palliative care provision, and the ethics of palliative care, in different cultural environments, with a particular focus on China. The main parameters of the comparison include the definition of the term ‘palliative care’ (or other synonyms that are needed to accommodate translation and differing cultural backgrounds), the major services provided, training and education schemes, and the ethical challenges arising in this field of practice. By critically interrogating these aspects, it is anticipated we can access and understand the localised interpretation of ethical challenges and identify relevant ethical theories which may offer a response to those challenges.

This was intended to be an empirical ethics study, including data collection in China, but that was prevented by the arrival of the COVID-19 pandemic. As a result, this is a desk-based project, therefore, the analysis is built on a literature review undertaken via the method of narrative review. Narrative reviews aim at *‘identifying and summarising what has been previously published, avoiding duplications, and seeking new study areas not yet addressed’* (Ferrari, 2015, p. 230). Narrative reviews are capable of capturing both breadth and depth. A primary goal of this research (e.g., captured in the first objective, above) is to explore how certain key concepts, such as ‘ethical challenges’, are interpreted in various cultural contexts. The ability of narrative reviews to screen massive literatures and identify commonalities and differences makes it particularly suited to this goal (Denzin, 2001). Narrative reviews can also help to establish a broad and solid foundation for the subsequent development of innovative ideas and concepts (Jones, 2004). The technique of analytic induction deployed in a narrative review also allows for a critical approach to be taken, rather than merely uncritically amassing the existing literature (Jones, 2003; Bolderston, 2008). Indeed, as I will discuss (section 4.3), critical reflection on the findings reported here suggests that this review provides a theoretical foundation for a follow-on project.

Other research methods, such as critical interpretive synthesis or a more systematic review, were considered, but these were judged not to be suited to the current project. Systematic review is a well-developed research method with a clear, linear procedure (Dixon-Woods *et al.*, 2006). Recognised for its rigor and transparency, the prominent characteristics of systematic reviews include a pre-defined, highly focused question(s), explicit searching strategies, and specified appraisal of data quality determination (Egger *et al.*, 2001). This rationalist method is usually applied to evaluate the effectiveness and efficiency of healthcare interventions (Higgins *et al.*, 2019). Since each research step of a systematic review is recorded in order and in detail, such reviews are commonly believed to be reproduceable for verification (Gysels *et al.*, 2012). Notably, the approach of systematic reviews is more widely used in quantitative research. In particular, the design of randomised controlled trials is more compatible with the evidence selection criteria of systematic reviews (Dixon-Woods *et al.*, 2006; Higgins *et al.*, 2019). Neither the procedure nor the characteristics of systematic reviews appear to match the nature of the current research, hence this method was ruled out.

In contrast to systematic reviews, critical interpretive synthesis seems to be more suited to handling large mixed data sets, including both qualitative and quantitative data (Dixon-Woods *et al.*, 2006; Kazimierczak *et al.*, 2013). Given its ability to capture such breadth, this method was initially considered. However, this approach can be more time-consuming than a narrative review, and unfortunately the progress of this research was significantly interrupted due to the unexpected pandemic. Therefore, considering efficiency, the decision was made to undertake a narrative review (although critical interpretive synthesis may be re-considered in the follow-on project that this study recommends).

It needs to be highlighted here that, while narrative review is chosen as the most suitable method, two of its potential weaknesses (relative to other approaches) have also been recognised. First, since narrative reviews do not require a pre-set searching protocol, there is a risk of personal bias during literature screening (Demiris *et al.*, 2019). To minimise the potential bias, in the following section, a series of keywords are listed which were used to define the scope of searching. Second, questions may also arise about the assessment criteria to be applied when determining whether or not to include the identified literature (Collins and Fauser, 2005). Although no formal quality assessment tool was used, this project sought to reduce the risk of including low-quality outputs by restricting searches to reputable databases, as indicated below.

1.3 Literature Searching Strategies

To conduct a comprehensive review of the literature, the following databases were searched for papers published in English: Medline, Social Care Online, PubMed and Google Scholar. The China National Knowledge Infrastructure (CNKI), one of the most well-known Mandarin databases, was also screened because the focus of this project is on China. The researcher is native in Mandarin therefore no translation issues arise. Citation tracking was also used while searching these databases to find related literature.

Three categories of keywords were used interactively:

- "Palliative care", "hospice care", "cancer care", "terminal care", "continuing care" and "end-of-life care" and their Mandarin equivalents;
- "Ethics", "bioethics", "medical ethics", "healthcare ethics", "ethical challenges", "ethical training/education" and their Mandarin equivalents;
- Given prominent cultural features of China, the terms "Confucianism", "familism" and "filial piety" and their Mandarin equivalents were also included to explore their influence on the understanding of ethics and morality.

The criterion of time frame was considered. As palliative care ethics is a young field, only limited literature has been published, thus any literature published after 1955 was included in analysis process. The time point of 1955 captures the earliest publication of the pioneer of modern hospice movement, Dame Cicely Saunders – *Dying of Cancer*. Since then, research on palliative care has flourished.

Following this lead, the next chapter traces the history of palliative care, starting from 1955. In this chapter (Chapter 2), key values, frequently used terminology, the mainstream care delivery model and educational programmes of palliative care are briefly introduced. Chapter 3 then turns its attention to palliative care ethics. The dominant thinking in the West and the East – namely principlism and Confucian bioethics – are depicted respectively. In Chapter 4, a comparative analysis between the Anglo-Saxon and Chinese contexts is presented. Firstly, the common ethical challenges arising in palliative care delivery are illustrated. Key similarities and differences between the two contexts are exemplified by two particularly challenging cases, which respectively focus on medical futility and truth-telling. Western and Chinese approaches to addressing these challenges are explored in greater depth. Both convergence and divergence can be observed during (Western) principlist and (Chinese) Confucian analysis. Moreover, the dynamic evolution in the field of bioethics also reveals a trend of confluence between these two kinds of palliative care ethics. In practice, Western and Chinese professionals seem to adopt similar bioethical deliberation tools, pedagogies and clinical responses. Such features stimulate further reflections on the relationship between principlism and Confucian bioethics, and reveal the need for further research, which is proposed.

CHAPTER

2

The Origin, Nature and Provision of Palliative Care

This chapter introduces the history and the construction of palliative care in the two contexts of the West, mainly the UK, and the East, mainly China. It should be clarified at the beginning that this project focuses on modern palliative care, which was officially established after the modern hospice movement in the 1960s. As a field originating from the UK, palliative care offers a blueprint of a holistic care plan for the dying (Baines, 2011). Dame Cicely Saunders (2004), the founder of modern palliative care, was inspired by the spirit of Christianity. She sought to bring mercy to those approaching the end of their lives who were still treated, or more accurately, 'tortured' by advanced medical technology intent on life preservation (Stolberg, 2017). In a unique approach, palliative care prioritises quality of life rather than quantity of life, or life expectancy. Decades later, palliative care has been imported into mainland China, where it has been considered a necessary response to – as well as a welfare benefit for – the rapidly growing aging population. Yet, the distinctive Confucian cultural background in China seems to require transformation of this Western-born service.

2.1 Palliative Care in the West

In the first half of this chapter, I will explore the history and the construction of modern palliative care in the Western world. Notably, most of the literature reviewed concerns the UK and the US, which appear to be the countries investing most in palliative care research. While papers written in English and focusing on other European or Oceanian countries are also included, the amount is proportionally less than the two dominant countries. Language can be a potential reason for this imbalance. The bias brought by the concentration on English-speaking countries is recognised. However, considering that the UK and the US are two of the countries with the most advanced palliative care systems in the world, such bias does not seem to significantly undermine the precision and comprehensiveness of the following analysis.

This section opens with the historical background of palliative care (section 2.1.1). Then, common terminology in this field is analysed to investigate the definitions and any conceptional confusion related to them. In the final part, the mainstream services provided and the corresponding training and education schemes are explored.

2.1.1 The History and the Spirit of Palliative Care

In the Oxford English Dictionary (2022), the verb 'palliate' means *'to alleviate (a disease or its symptoms) without effecting a cure; to relieve or ease (physical or emotional suffering) temporarily or superficially; to mitigate the sufferings of'.* In this research, the focus is on 'palliation' of or for a particular group – the dying. Such care has its own technical name in modern medicine: 'palliative care'.

The idea of palliative care has its prototype in Christianity (Saunders, 2004). In the mid-nineteenth century in Western Europe, the term 'hospice' stood for the facilities supported by the religious orders which care for the chronically ill and the dying, or in general, the disadvantaged (Saunders, 2004; Portenoy, 2021). Later, such places, which were heavily influenced by Christianity, gradually redirected their focus to dying patients with incurable diseases (Saunders, 2004). In 1967, the first modern hospice, St Christopher's, was founded by the pioneer of palliative care, Dame Cicely Saunders. In St Christopher's, patients were cared for not only by the will of God, but also by healthcare professionals. According to Dame Saunders herself, St Christopher's was a place that offers comprehensive general care for primarily cancer patients in the terminal stages of illness. The services provided included *'home care, family support throughout illness, and bereavement follow up,* [leading] *to several different systems of offering care'* (Saunders, 2004). The goal of St Christopher's is no longer curation or medical (over)treatment, but relief and comfort. Saunders' unprecedented approach to caring for the dying had a revolutionary impact on the construction of such facilities as 'hospices', which thus signified the beginning of the modern hospice movement. Later, similar institutions were established around the Europe, Oceania and North America (Saunders, 2004).

Dame Saunders had developed a series of innovative concepts that underpinned the modern hospice development, which have been adopted and built upon by modern palliative care. At their core is the concept of 'total pain', which expands the scope of care from solely physical symptoms to also mental distress, social problems and spiritual dimensions (Miccinesi *et al.*, 2020). Correspondingly, during the provision of palliative care, practitioners were (and are) required to prioritise patients' overall quality of life over the quantity of life in the pursuit of a 'good death'. Looking through these beliefs, it is apparent that simply symptom-driven medical treatments are not enough to adequately address total pain and improve the patient's quality of life. Support from psychiatrists, psychologists and social workers is also demanded (WHO, 2018). Therefore, facilities that are able to provide modern palliative care usually consist of multidisciplinary teams (ten Have and Clark, 2002), a distinction developed much in advance of modern medicine.

Ideologically, the provision of palliative care appears to be committed to individualisation. Thinking of patients' various socio-economic, cultural and spiritual backgrounds, it seems obvious that the meaning of a 'good quality of life' and a 'good death' can vary dramatically between different patients and families. To address such individual variations, in palliative care, patients' autonomy has been prioritised to facilitate better communication about, and understanding of, their wishes (Woods, 2007*c*). A brief definition of autonomy this research refers to is the liberty of independence and self-determination (Pastrana *et al.*, 2008). In addition, further reflections on the conception of individual autonomy are provided in section 3.1. For now, what is emphasised is that to better fit individuals' wishes, any resulting care plan in palliative care inclines to reject the standardised procedures of modern medicine. Instead, a patient-centred, personalised plan is preferred and welcomed in palliative care (Portenoy, 2021).

2.1.2 The Terminology of Palliative Care

At the beginning of the modern hospice movement, this service was first named 'hospice care', as it was solely provided in hospices. In 1973, the term 'palliative care' was then proposed by a Canadian doctor, Balfour Mount, who established a palliative care unit within a hospital. Palliative care was firstly considered equivalent to hospice care (Clark, 1999, 2002). However, later, it seemed that by referring to 'palliative care', the values and principles upheld in hospices could be transferred from certain physical facilities – hospices – to other and broader contexts (Woods, 2007*c*). Therefore, the umbrella term for this service, at least in the UK, was changed from 'hospice care' to 'palliative care', so as to be more inclusive of the different locations in which such care was provided. The change of umbrella term can be seen as offering implicit support for the integration of palliative care into hospital settings (ten Have and Clark, 2002). The timing of palliative care has also shifted, with recognition that the service should be included early in disease trajectories (Woods, 2007*c*). This permeation process has nevertheless been criticised as 'medicalising' palliative care, which risks shifting the emphasis from holistic care back to medical treatments (Illich, 1976; Clark and Seymour, 1999).

Another commonly mentioned difference between palliative and hospice care is the target subject. The recipient of hospice care will not additionally receive any curative treatments (Hui and Bruera, 2020; Marie Curie, 2022). In contrast, palliative care appears to be more active (Woods, 2007*c*), which welcomes the interventions for symptom control and still aims at prolonging life expectancy and improving body functions if these are possible (Kurita and Larkin, 2021).

In modern times, both terms – ‘hospice care’ and ‘palliative care’ – are still in use. In line with the aforementioned distinctions, hospice care now normally stands for the care provided in particular settings – the (home-like) hospices or care homes (Saunders, 2004; Hui *et al.*, 2016). Palliative care, in contrast, can be provided in multiple places, including but not limited to hospitals, care homes/hospices, and the patient’s home (Woods, 2007*c*; Portenoy, 2021). In this sense, hospice care is part of palliative care.

Another term frequently used in the early development of this field of practice is ‘terminal care’. This was considered the synonym of ‘hospice care’ at the beginning of the establishment of St Christopher’s (Woods, 2007*c*). Indeed, this facility was built as a sanctuary for the *dying*. The recipients were mostly cancer patients in the terminal stages of the illness (ten Have and Clark, 2002; Saunders, 2004). Nonetheless, the subject of palliative care has been gradually expanded from solely cancer patients to others with chronic life-threatening conditions. The term ‘terminal’ does not appear appropriate or applicable to these new conditions. Consequently, this term has been seldom used in recent years to avoid exclusion or imprecise descriptions of the potential recipients. Another reason proposed is that the pessimistic connotations of the word ‘terminal’ do not appear to be easily acceptable to the patient and their family. Thus, the currently more common term, ‘palliative care’, is chosen as a euphemistic alternative to emphasise the focus on aiming ‘to *palliate*’ (Pastrana *et al.*, 2008). This change has nevertheless been criticised as it undermines the clarity of this service, since it removes both the most prominent feature of the recipient and the specific timing of provision from the name (Doyle, 1993).

To some extent, ‘terminal care’ means the same as another interchangeably used term in palliative care – ‘end-of-life care’. Both terms are introduced only at the last phase of a patient’s life. This phase is depicted as a limited, specific amount of time, usually weeks or months of life (National Council for Hospices and Specialist Palliative Care Services (NCHSPCS), 1995; NHS, 2018). Palliative care, on the other hand, places more emphasis on the relief of distress and improvement of patients’ overall wellbeing, regardless of their life stage (WHO, 2019). While, normally, palliative care is provided in the last six to twelve months of a patient’s life, early referral and integration of palliative care has been proposed to maximise its efficiency (Aldridge *et al.*, 2016; Hui and Bruera, 2020; Hannon *et al.*, 2021). However, the absence of timing in the definition of palliative care raises the question of when the service should be introduced and provided to the patient.

It needs to be highlighted here that a consistent definition of the relationship between, and the scope of, ‘palliative care’, ‘end-of-life care’ and ‘hospice care’ is lacking. While all three terms are considered broadly synonymous, this is not always the case in the literature. For instance, palliative care is considered part of ‘end-of-life care’ (Guo *et al.*, 2012; NHS, 2022), part of ‘hospice care’ (Clark and Seymour, 1999), or the other way round (Bruera and Hui, 2012). The interchangeable use of these synonyms and unclarified relations among them reflects the lack of solid consensus regarding the meaning of ‘palliative care’, or of any of these related terms. The absence of such consensus is argued to be a major barrier to palliative care development (Guo *et al.*, 2012; Radbruch *et al.*, 2020).

Other synonyms for ‘palliative care’ include ‘supportive care’ and ‘continuing care’. Both of them have been used interchangeably with ‘palliative care’ in the literature. This project nevertheless uses the term ‘palliative care’ throughout. The primary reason for this is that this is the more frequently used concept among international organisations (e.g., WHO, European Association for Palliative Care, International Association for Hospice and Palliative Care (IAHPC), Asia Pacific Hospice Palliative Care Network, etc.). Since this project aims at a cross-country comparison, a concept recognised worldwide provides a common starting point for further discussion. Nonetheless, a differentiation of these further terms is needed to remove potential misunderstanding and confusion.

‘Supportive care’ also refers to distress relief management but is commonly used in oncology (Radbruch *et al.*, 2009). The avoidance of this term can minimise the confusion of palliative care with oncology, rather than seeing it as a separate specialty. However, such a similarity raises questions about the specialty of palliative care: if similar interventions are provided in an existing speciality, is it necessary to establish another? The question appears to be pertinent because the majority of palliative care recipients are cancer and cardiovascular patients (WHO, 2019).

‘Continuing care’ had been used in conjunction with palliative care as ‘palliative and continuing care’. Here continuing care seems to refer to the long-term, ongoing care provided by a multidisciplinary team (Walsh, 1990; Konietzny and Anderson, 2018). The recipients of such care are those with complex conditions that require constant attention (Konietzny and Anderson, 2018). One way to differentiate ‘continuing care’ from ‘palliative care’ focuses on the providers of each: continuing care is often addressed by a nurse, yet the need for palliative care is often addressed by social workers (Newall and Matthew, 1997; Bliss and While, 2003). Yet, it seems that there are several overlaps between the service scopes of continuing and palliative care. Nevertheless, nowadays, continuing care appears to refer to something quite distinct from palliative care, at least in the UK context. Firstly, the focus of continuing care is now solely placed on the feature of consistency – i.e. ‘on-going’ care – and little link is made to palliative care in current uses of this term (AgeUK, 2017). Secondly, continuing care is now frequently used interchangeably with continuing *healthcare*. According to the definition of NHS (2021*a*), continuing (health)care means a care package including National Health Services

(NHS) support and social services that is offered to people with complex conditions. This term, so understood, therefore seems to be less relevant to the current project.

At the institutional level, the undefined meaning of ‘palliative care’ can raise uncertainty and challenges as healthcare professionals need to specify the subject, the services and the time frame of palliative care provision in practice (Hui and Bruera, 2020). Furthermore, lack of agreement on the procedure(s) of care delivery can impede the standardisation of this service on a local and national level (Aldridge *et al.*, 2016). Moreover, the variation in use of terms and understanding of service content can be an obstacle to communication and cooperation in both research and practice. Especially globally, communication between countries may lack the essential basis for conceptional consensus on goals and tasks and may confront additional obstacles when socio-cultural factors are involved and mapped onto the multiple interpretations of ‘palliative care’.

Efforts have been made to reconcile the gaps between these various terms. One frequently cited definition of ‘palliative care’ is proposed by WHO (2020):

> *‘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, 2020).

Another definition by Radbruch *et al.* (2020) also attempts to conclude an inclusive summary of the ethos of palliative care:

> *‘The active holistic care of individuals across all ages with serious health-related suffering (suffering is health related when it is associated with illness or injury of any kind. Health-related suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social, spiritual, and/or emotional functioning) because of severe illness (severe illness is a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress.) and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers.’* (Radbruch *et al.*, 2020, p. 761)

In contrast to the definition by WHO (2020), Radbruch *et al.*’s (2020) conception aims at a more detailed explanation of ‘life-threatening illness’. The original term is decoded to ‘health-related suffering’ caused by ‘severe illness’, alongside thorough descriptions of these new words.

Looking at both of these definitions, it can be clearly observed that the improvement of quality of life is the well-recognised goal of palliative care. The recipient of this service is not limited to the patient, but also the family and the caregiver. Nevertheless, the key criteria for judging 'quality of life' or 'health-related suffering' appear to remain content-thin and may not be amenable to standardisation. Consequently, these definitions may appear less practical in real-life scenarios, especially at the point of referral from other departments to palliative care. In the next section, I will describe how this vagueness of definition influences the construction and delivery of palliative care services.

2.1.3 Major Palliative Care Delivery Models

The common components of palliative care include symptom control (NHS, 2018; WHO, 2020), advance care planning (Hui and Bruera, 2020), spiritual and social care (Marie Curie, 2018), and support for bereavement and grief (NHS Inform, 2018; WHO, 2020). These services are offered by a multidisciplinary team consisting of general physicians (GPs), palliative care and other medical specialists, nurses, social workers, and other healthcare professionals including psychiatrists, psychologists, nutritionists, etc (WHO, 2018).

The models of palliative care delivery can be classified according to the providers or the locations of care, although the models captured under these two types of classifications are correlated. In terms of providers, palliative care can be divided into generalist and specialist services. Generalist palliative care refers to the care provided as *'an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team'* (Higginson, 2021, p. 113). The potential providers are usually primary care professionals, residential home care staff and medical professionals from non-palliative care teams, such as oncology and intensive care (Shipman *et al.*, 2008). Accordingly, generalist palliative care can be commonly found in communities, hospices and outpatient clinics (Hui and Bruera, 2020). The responsibilities of generalist palliative care are basic symptom management, educating the patient and the family, close monitoring, as well as advance care planning (Hannon *et al.*, 2021; Higginson, 2021). The major recipients of generalist care are patients with life-threatening conditions who show low-to-moderate symptom burden (for outpatient clinics) and/or have limited mobility (for community-based and home care) (Hui and Bruera, 2020).

The most prominent advantage of generalist care is that practitioners are able to give timely attention to recipients (Hannon *et al.*, 2021). In addition, the patient, the family and the healthcare professionals can have opportunities for in-depth and follow-up meetings and discussions. These features are particularly beneficial for personalised care planning, which can seek to ensure that patients' autonomy (further explained in section 3.1) is respected during care provision.

Another benefit of generalist care, particularly community-based and home-based care, is that it can effectively increase the rate of home death (Gomes *et al.*, 2013; Shepperd *et al.*, 2016). This benefit seems to better respond to patients' preferred place of dying, as home is often ranked as the most desirable place (Ali *et al.*, 2019). This preference has been considered unrealistic in the broad context of the medicalisation and hospitalisation of death. The medicalisation and hospitalisation of death means that dying patients are usually submitted to acute care units in hospitals for life-preserving treatments, where they then remain until they die (Driessen *et al.*, 2021). A primary reason for many people dying in hospital is that life-sustaining treatments require multiple specialists and advanced equipment, which cannot be provided at home. Thus, under the conception of medicalised dying, the home setting is incapable of caring for patients in their last stage of life, regardless of their wishes to die at home. However, generalist palliative care can offer necessary medical support to patients and their families, while minimising the potential physical and emotional suffering brought by life-preserving treatments and unachieved last wishes (Abel *et al.*, 2013; Saurman *et al.*, 2022). In this sense, (generalist) palliative care can better address patients' needs and provide holistic care.

Specialist palliative care, on the other hand, is provided by experts who have undertaken specific training or accreditations on the subject and are integrated as part of the inter-/multi-disciplinary team (Luyirika *et al.*, 2017; Higginson, 2021). The common place for specialist care is usually an inpatient unit and inpatient consultation (Hannon *et al.*, 2021; Higginson, 2021). This care is suitable for patients with more complex conditions and higher levels of distress (Hui and Bruera, 2020). In a sense, an inpatient palliative care unit parallels intensive care, yet with more emphasis on symptom management and spiritual support. In addition to routine care, palliative care specialists are also responsible for research and education (Luyirika *et al.*, 2017).

From the literature, generalist and specialist palliative care can appear to be running in parallel, without sufficient mutual interaction. Palliative care specialists are required to guide generalists in practice, yet despite such mentorship, communication and cooperation in case management tends to be inadequate (Quill and Abernethy, 2013). The segregation of these two types of services exposes and worsens the weakness of them. Specialist palliative care is commonly located within tertiary hospitals in major cities, as they are rich in both medical and human resources (Bayly *et al.*, 2021). Nevertheless, this location implies that residents in rural areas may have limited access. While generalist palliative care is normally based in the community or at home, practitioners are reported to receive little professional training in palliative care and sometimes lack the resources required (Kurita and Larkin, 2021). In addition, it appears to be infeasible to build a multi-disciplinary team that includes specialists in each outpatient clinic (Bayly *et al.*, 2021). Consequently, generalist palliative care can only provide treatments at a baseline level, and is reportedly unprepared for patients with complicated conditions (Hui and Bruera, 2020). In general, access to palliative care is significantly restricted due to the reportedly insufficient cooperation between generalist and specialist palliative care.

In this circumstance, a new model – ‘integrated palliative care’ has been proposed in the US to ensure collaboration between the two types of services to maximise their utility (Quill and Abernethy, 2013; Bayly *et al.*, 2021). Nevertheless, this model appears only to be a proposal, which has not been widely adopted, and which requires further clarification regarding how the interaction between the two services should function.

2.1.4 Training and education in the West

Training and education are considered to be especially important facilitators to the advancement of palliative care. They are also essential to the specialisation of palliative care. Training for physicians, nurses, social workers and chaplains can be observed in, for example, British and American medical schools. For medical professionals, palliative care has been integrated in both undergraduate and postgraduate curricula. At the undergraduate level, palliative medicine is considered a basic skill for all medical students, regardless of their ultimate specialisation (Forbes and Gibbins, 2021). Postgraduate courses, meanwhile, cover advanced knowledge as well as the specialised skills required in specific roles. In addition to formal education, there are also continuing professional development training programmes available for healthcare professionals as well as policymakers and caregivers who are interested in the topic (Li, Chhabra and Singh, 2021).

Nevertheless, these schemes are still deemed inadequate. Firstly, while most medical schools in Europe and North America include palliative care in their curricula, the course design is sometimes criticised as lacking an experiential element. The format of the course often involves lectures and case studies delivered in a couple of hours (Forbes and Gibbins, 2021). Students are seldom exposed to patients and frontline clinical work (Gibbins *et al.*, 2011). The knowledge learnt from class then appears to be isolated from practice and students can find it difficult to apply these theories in real life scenarios (Kawaguchi *et al.*, 2017). Secondly, there is little evidence of standardised textbooks or teaching materials (Li, Chhabra and Singh, 2021) or of national competency frameworks (Forbes and Gibbins, 2021). The absence of these components inevitably raises questions about the assessment of healthcare professionals’ skills and the credibility of their certification. In addition, without a consensus, the content of these programmes is suspected of failing to address non-medical skills. For instance, students report feeling unprepared particularly in terms of the skills of communication, bereavement care and social/spiritual support (Forbes and Gibbins, 2021). Another critical weakness of contemporary curricula setting is its neglect of inter-/multi-disciplinary collaboration. The training and education commonly take place within medical schools; other practitioners within a palliative care team – for example, social workers, psychologists and chaplains – are rarely involved (Fineberg *et al.*, 2004). Excluding these professional perspectives and the essential skill of multidisciplinary working from the curriculum may present additional challenges when specialists are required to cooperate in a multidisciplinary team in practice. The efficacy of overall care delivery may also be undermined since the specialists are not fully aware of the strengths of, and appropriate time point to begin, care other than curative medical treatments.

Other existing systematic training includes courses for social workers and chaplains. Palliative care social workers are considered to occupy an independent specialty (Glajchen *et al.*, 2021). In accordance, there are certified continuing education programmes available to both medical professionals and social workers. Chaplaincy care has not been officially integrated into medical education yet. Chaplains' training is commonly provided by faith community leaders instead of schools (Swift *et al.*, 2012). A potential problem is that such self-developed training is not nationally recognised. The lack of accreditation can unavoidably raise questions about the credibility of the provider and efficacy of the care provided (Glajchen *et al.*, 2021).

Finally, training for other common players in the multidisciplinary palliative care team – volunteers, dieticians, physiotherapists and psychologists – remains underreported. This gap implies that the training system for palliative care is still underprepared to instruct professionals across disciplines. A foreseeable consequence of unsatisfactory training schemes is the increasing shortage of specialist staff in palliative care delivery. The shortage seems to be most significant in the construction of the multidisciplinary team and provision of high-quality holistic care.

2.2 Palliative care in China

Compared to European and American countries, palliative care has a comparatively shorter history in mainland China. According to the *Blue Book of Palliative Care Development in China 2019-2020* (name translated by the researcher), the development of palliative care in China officially began in the 1980s. In 1988, the first care home for the elderly was built in Shanghai (于世英 (Yu), 2020). In the 1990s, the central government started to develop national policies and guidelines, establishing academic institutes and a specialist committee to support the growth of palliative care (Ning, 2018). The development of palliative care has accelerated since the 2010s and China has been included in several international rankings of the quality of palliative care – for instance, the two *Quality of Death Index* reported by the EIU (2010; 2015). Its inclusion partially confirms that the efforts China has made are being recognised by other countries. Nevertheless, the services provided in China were considered unsatisfactory due to limited availability, accessibility and geographical coverage (Clark *et al.*, 2019). The quality of palliative care in mainland China was initially ranked 37th out of 40 countries in 2010 (EIU,

2010) and then, in 2015, 71st out of 80 (EIU, 2015).

Having briefly introduced the history of palliative care in China, this section next introduces the frequently used terminology in Mandarin, the mainstream care delivery model, and then outlines the existing training programmes in comparison with its Western counterpart(s).

2.2.1 Terminology: The Translation of Key Terms

After exploring the conceptional tensions surrounding palliative care in the English-language literature (section 2.1.2), this section aims at further investigating how linguistic and cultural factors can amplify such tensions. The term 'palliative care' has no precise synonym in Mandarin. Therefore, this term needed to be translated into an indigenous phrase before it could become established in the Chinese context. However, common translations of 'palliative care' carry more or less negative or discouraging connotations in China. Such connotations tend to deter people from using palliative care, and inevitably prevent its development in China. Palliative care was first translated as '*Lin Zhong Guan Huai* (临终关怀)' in 1988 (史宝欣 (Shi), 2020), which literally means *'caring for a person approaching death'* (Gao, 2012, p. 1000e113). This term seems to echo the term 'terminal care', which was widely used in the first phase of the modern hospice movement. However, this translation fails to differentiate palliative care from end-of-life care, especially after the abandonment of the term 'terminal care' (as distinguished in section 2.1.2). Moreover, the word '*Lin Zhong* (临终)', namely 'dying', triggers Chinese people's cultural taboo of death. An imprecise implication that accepting palliative care equals waiting for death had prevailed under the use of this term. Therefore, the phrasing unavoidably results in reluctance to engage with the service by the public (于世英 (Yu), 2020).

Another common translation, '*Gu Xi Zhi Liao* (姑息治疗)', which resonates with the more clinical aspects of palliation and sedation in symptom management, also generates resistance from patients and families. The word '*Gu Xi* (姑息)' literally means indulgence or tolerance, which has a strong connotation of compromise. Such a connotation can mislead the family into gaining the (wrong) impression that accepting palliative care means giving up on the patient (Wang *et al.*, 2004; Wu *et al.*, 2016). Therefore, the translation appears to depict 'palliative care' as a medical concession, a passive, hopeless substitute to active, curative treatment, a placebo to comfort, if not deceive, those who are abandoned (Li, 2013; Silbermann, 2017).

To clarify and minimise such misconceptions, new translations have been developed. However, the interchangeable use of the terms 'palliative care', 'hospice care' and 'end-of-life care' in English has been passed to Mandarin, which creates further confusion in translation. According to Ning (2018, p. 200), a new translation, '*An Ning Liao Hu* (安宁疗护)', was officially adopted in 2016 for the term 'hospice care' to emphasise the element of holistic care. However, 于世英 (Yu) (2020) insists that '*An Ning Liao Hu* (安宁疗护)' not only represents hospice care but also end-of-life care in Mandarin. For ‘palliative care’, it should be interpreted as ‘*Huan He Yi Liao* (缓和医疗)’ to replace the misleading ‘*Gu Xi Zhi Liao* (姑息治疗)’. Together, ‘hospice and palliative care’ are translated as ‘*An Ning Huan He Yi Liao* (安宁缓和医疗)’ (Ning, 2018; 2019). Among all these phrases, ‘*An Ning Liao Hu* (安宁疗护)’ is the one recognised by the National Health Commission of the People’s Republic of China (NHC). In multiple documents, announcements and national policies, it is ‘*An Ning Liao Hu* (安宁疗护)’ which has been consistently used (中华人民共和国国家卫生健康委员会（原国家卫生计生委）(NHC), 2017). Nevertheless, no clear definition has been given to clarify the meaning of ‘*An Ning Liao Hu* (安宁疗护)’, nor the differences between ‘hospice care’, ‘end-of-life care’ and ‘palliative care’ in the Chinese context.

Following the national policy, the terms used within mainland China have been gradually unified to ‘*An Ning Liao Hu* (安宁疗护)’. However, apart from mainland China, there are other Mandarin-speaking areas and countries which have their own interpretations. For example, there are Mandarin terms directly used in the studies and papers from the Hong Kong Special Administrative Region (SAR), Taiwan and Singapore. In Hong Kong SAR, it is called ‘*Ning Yang Fu Wu* (宁养服务) or ‘*Shan Zhong Fu Wu* (善终服务)’ (史宝欣 (Shi), 2020). In Taiwan, palliative care is translated as ‘*Shu Huan Liao Hu* (舒缓疗护)’ or ‘*An Ning Zhao Gu* (安宁照顾)’ (史宝欣 (Shi), 2020). The Lien Centre for Palliative Care (LCPC) (2015) offers the officially recognised translation of palliative care in Singapore as ‘*Ci Huai Liao Hu* (慈怀疗护)’. In fact, all these phrases seem to have very similar meanings. The different use of Chinese characters is only a matter of habit, or dialect. Nevertheless, using these many terms simultaneously appears to be confusing and troublesome for communication. As a proposal, it can be more helpful to the development of palliative care in mainland China, and eventually the whole Mandarin-speaking area, if a single translated term can be used consistently.

2.2.2 Palliative Care Delivery in China

It needs to be highlighted here that the healthcare delivery system in China operates quite differently from the Western one. In China, the concept of ‘primary care’ is largely absent. Primary care is a common component for Western healthcare systems and plays a crucial role in generalist palliative care (Hui and Bruera, 2020). The definition provided by the UK NHS offers more detail:

> *‘primary care services provide the first point of contact in the healthcare system, acting as the “front door” of the NHS. Primary care includes general practice, community pharmacy, dental, and optometry (eye health) services’* (NHS, 2021*b*).

In short, in the West, primary care is the gatekeeper and the entry point of palliative care, or any other care (or treatment) (Hui and Bruera, 2020). However, in China, it is the tertiary and secondary hospitals which play roles similar to that of primary care in the West (Jin, 2014). Procedurally, specialists, rather than GPs, are the first point of contact in healthcare delivery in China. Patients can make an appointment with specialists directly, regardless of the severity of their conditions (Ma, 2019). Partially, the reason for this is that, in China, patients are not required to register with a GP before attending outpatient services in medical institutions (Fang, 2020). In fact, using GPs as gatekeepers is very rare in China. The concept of a ‘family doctor’ is also uncommon in Chinese medical contexts. Occasionally, a village doctor may be considered a ‘family doctor’ since most family members visit this same doctor for reasons of convenience and familiarity. Nevertheless, these kinds of doctors often play a lesser role in formal healthcare delivery.

Coming back to palliative care, most palliative care services in China are provided in inpatient units and inpatient consultations in tertiary and secondary hospitals (赵耀辉，张泉，王梅 (Zhao, Zhang and Wang), 2020). There is also one outpatient clinic attached to the Peking Union Medical College (PUMC) Hospital. These facilities are usually equipped with more funding and resources (罗峪平，张正，李雯 (Luo, Zhang and Li), 2020). Hospices and care homes are largely underdeveloped in Chinese contexts due to cultural traditions. In Confucianism, the most dominant philosophy in Chinese cultures, a morally good, or a ‘filial’ child should serve and care for their parents *in person*. While more in-depth discussion on filial piety and familism featured in Confucian ethics is developed in section 3.2, at this point a quick highlight of the relationship between elderly care in Chinese contexts and Confucian ethics is that: leaving older parents in hospices/care homes implies children are absent from the delivery of most daily care, which is thus equal to a moral failure (Li, 2013).

The hospital, in contrast, mainly provides medical treatments which are beyond non-professional people’s caring abilities, so submitting older patients to the hospital is not condemned on a moral level. In addition, the concept of death is highly medicalised in China. Even at the end of life, the pursuit of survival is still the leading demand in care planning. Thus, dying patients are commonly submitted to the emergency department or intensive care unit for the purpose of life-prolongation (赵可式 (Zhao), 2016). Following such thoughts, in China, services like palliative care are mostly provided within the tertiary and secondary hospitals, to which most dying patients are submitted. The formal providers of palliative care consist of medical professionals from oncology and geriatrics (宁晓红 (Ning), 2020), (medical) social workers and volunteers. While there have been attempts to build multidisciplinary palliative care teams, psychologists, therapists and spiritual support providers remain underrepresented (Ning, 2018; 宁晓红 (Ning), 2019; 于世英 (Yu), 2020; 秦苑 (Qin), 2020). Lacking such input, the majority of work is borne by physicians and nurses – and especially the latter. In addition to routine nursing care, nurses in the palliative care unit are also responsible for emotional support and spiritual support, which are normally provided by other specialists in the West

(Silbermann, 2017).

The palliative care units in China primarily provide symptom control, yet rarely offer advance care planning and bereavement support (赵可式 (Zhao), 2016; Ning, 2018). In general, unlike in the West, there has been no similar tradition of advance care planning or bereavement support in Chinese history. Thus, medical professionals reportedly lack confidence when asked to provide such services (刘霖, 徐燕, 袁长蓉 (Liu, Xu and Yuan), 2009).

(Medical) social workers and volunteers are two other pillars of palliative care provision in China. Nevertheless, data on their contribution appears meagre. It currently appears that, since there is no well-organised and well-supervised social work system established in China, there are few qualified medical social workers in Chinese hospitals. Moreover, it has not been confirmed yet whether these social workers are specialised in palliative care or if they are responsible for all patients in the wards. Volunteers are, however, another important group, which appear to be undertaking the responsibilities of those missing providers (罗峪平, 张正, 李雯 (Luo, Zhang and Li), 2020). The main tasks of volunteers are providing emotional comfort, spiritual support and sometimes musical therapies and aromatherapies if they are appropriately certified. In this sense, the participation of volunteers appears to boost the diversity of disciplines to some extent. However, since there are no national guidelines or standardised professional training courses for these volunteers, their caring roles tends to vary and lack monitoring.

Another major informal provider of palliative care is the family, which is considered a unique feature of the Confucian care model (Chung *et al.*, 2020). The family is mainly responsible for the activities of daily living (ADL), which include eating, bathing, dressing, toileting and travelling (Zhang and Li, 2005; Zhang *et al.*, 2019). The responsibilities of the family derive from the special cultural tradition – familism – in China (discussed further in section 3.2). Familism suggests that children owe the moral duty, required by filial piety, to take care of the elderly (Zuo *et al.*, 2014). A more practical reason for this deep involvement of the family is the financial cost. Hiring other carers can impose additional costs (刘晓惠等 (Liu *et al.*), 2015). Besides this, the Chinese welfare system does not offer the free caring programmes or home care that most Western countries offer. Considering the financial burden induced by medical treatments, most families prefer to provide daily care by themselves to avoid these extra costs.

The substantially hospital-based model nonetheless reveals problems that can significantly impede the development and prevalence of palliative care. Firstly, the financial charges imposed by hospitals can be rather higher than those imposed by primary care facilities, and most palliative care treatments are not (yet) included in the Chinese national medical insurance schemes. Therefore, as just mentioned, receiving palliative care can become financially unbearable to those socio-economically deprived patients (于世英 (Yu), 2020). In addition, similar to the Western countries, hospitals are mostly concentrated in major cities. The geographical inconvenience can then further restrict the access of residents in rural areas (谌勇毅 (Chen), 2020). Moreover, the operation of hospitals does not appear as appropriate to non-intensive long-term care. In the Western models, inpatient unit is available to patients with the most complicated conditions and that require closest monitoring in the short term (Hui and Bruera, 2020). In contrast, the majority of palliative care needs are long-term, with low to moderate symptoms. If the inpatient palliative unit were to be amenable to providing long-term care, this delivery model would only be able to receive a very small number of patients due to the limited resources and facilities (Ning, 2018).

To address these problems, China is revolutionising its healthcare delivery. Minister Ma Xiaowei, the head of NHC, has announced the aim for a new referral system in medical care in *Healthy China 2030*. It is perceived that the primary clinics and health centres appear to be more suitable and more accessible for long-term, daily care. Particularly for older people, the major recipients of palliative care, a community-based facility usually involves shorter travelling distances and lower costs (韩铮铮, 金琳 (Han and Jin), 2020). Therefore, in *Healthy China 2030*, an official proposal is made to establish a functional primary care system. More new GPs will be appointed as gatekeepers to boost the energy of clinics (Ma, 2019). Moreover, cooperation between tertiary, secondary hospitals and primary care clinics is strongly encouraged and recommended. With support from more advanced hospitals, it is believed that patients will be more willing to attend primary care (Ma, 2019). This proposed change seems to further align Chinese and Western healthcare delivery systems. If this proposal is adopted, experiences and reflections from the West may prove useful when developing this more integrated healthcare delivery system in China. Similar benefits might also apply to the development of palliative care, since this service originated from the West, too.

2.2.3 Education and Training

In China, palliative care has been gradually considered a specialist discipline and integrated into higher education and occupational training schemes. The majority of these programmes were developed in the 2010s, by which time palliative care had become a widely debated topic among the public (Ning, 2018).

In higher education, most courses on palliative care are optional units for postgraduate students. The PUMC based in Beijing is the only university which includes palliative care as a compulsory unit in the curriculum of clinical sciences (Master of Medicine/MMed) (王戎津 (Wang), 2021). PUMC is also the only institution which offers specialist palliative care teaching modules to all levels of students, from undergraduates to post-docs (宁晓红 (Ning), 2020). In terms of discipline building, West China School of Public Health (attached to Sichuan University) (WCSPH) is the only university which considers palliative care an independent discipline at the postgraduate level (罗峪平，张正，李雯 (Luo, Zhang and Li), 2020).

Compared to the number of courses available in higher education curricula, there are reported to be more occupational training schemes. Most of these training schemes are hosted by tertiary hospitals and the local governments and provided via seminars and workshops (谌勇毅 (Chen), 2020; Li Kai Shin Foundation, 2020). In addition to the regional-level courses, in 2017, there were also two national capacity-building events held in Beijing and Shanghai. The national training schemes were designed to offer equal opportunities to healthcare professionals from less developed areas (in terms of both economy and palliative care) in China. The aim is to train selected mentees, so that, when they return to their local institutions, they can provide mentorship and deliver further specialist training in the region. Notably, participants in these events usually come from the departments of geriatrics and oncology (宁晓红 (Ning), 2020; 赵耀辉，张泉，王梅 (Zhao, Zhang and Wang), 2020).

In terms of long-term training programmes, the only known scheme is the Quality End of Life Care for All (QELCA©) training, which originated in St Christopher's (UK), the pioneer institution of palliative care (Christopher's, 2021b). This course has been imported to China by the Beijing Living Will Promotion Association (LWPA) since 2016 (北京生前预嘱推广协会 (LWPA), 2016).

Since volunteers are also crucial providers of palliative care in China, there are also courses for volunteer training. These courses are often hosted by charities and foundations in cooperation with palliative care units. After successful completion, volunteers will have opportunities to enter these units under supervision. However, these courses primarily use self-developed online lectures, with little professional assessment. Therefore, there currently seems to be little evidence of their efficacy.

After reviewing the training and education in palliative care available in China, it seems that this country is facing some similar challenges to those encountered in the Western world. The number of programmes available appears to be far less than the demand (罗峪平，张正，李雯 (Luo, Zhang and Li), 2020), and the outcome of such training seems not to have been measured. Moreover, the specialisation of palliative care (徐仲煌 (Xu), 2013; Wang *et al.*, 2018a) and the integration of multidisciplinary roles (罗峪平，张正，李雯 (Luo, Zhang and Li), 2020; 史宝欣 (Shi), 2020) in education are largely neglected in course design. Overall, an overarching guideline or framework for the designation and assessment of these courses is lacking.

In spite of these shared difficulties, there is a unique (or, at least, particularly acute) challenge confronted by China: geographical inequality. Most of these training schemes are concentrated in provincial capitals and municipalities in middle and eastern China, which have more advanced socio-economic conditions (谌勇毅 (Chen), 2020). The less developed areas, such as Western China, do not appear to have any recorded training. Such geographical inequalities may significantly impact upon the development of the service at regional levels. The suburban areas might not be able to provide this specialist service due to professionals' inexperience and inability to improve their skills. As a predictable result, with no effective intervention, the gap between the quality of care in developed and developing areas will remain and might continue to widen.

Overall, inadequate training for palliative care in China tends to limit its sustainable development. As a direct result, significant shortages of human resources in palliative care provision have been a key issue faced by the Chinese government in the 2010s (EIU, 2015; Ning, 2018). The shortage of human resources can further restrict the availability and accessibility of the service, preventing the integration of palliative care into primary care (Chung *et al.*, 2020). As an effective response, more long-term training – with broader coverage, structured content, well-balanced integration of theory and practice, and a consistent regime of supervision – is required in China in order to boost the growth of palliative care specialists.

In overview, this chapter has described the development and current status of palliative care in the West and China. It seems that Western countries have a longer history and offer better quality of care. Nevertheless, both sides confront similar difficulties regarding conceptional tensions, unbalanced resource distribution and inadequate training. The unique healthcare delivery system in China seems to further exaggerate the difficulties. Similar pattern appears to be mirrored in palliative care ethics: the topic appears to be better researched and more systematically established in the West, as the longer history of development can generate richer experiences. In China, or Chinese cultures in general, little literature focused on mainly or solely palliative care ethics has been found. In this case, the coming chapter aims at further investigating the composition of palliative care ethics in these two cultural settings. The investigation can not only build a theoretical foundation for the analysis in Chapter 4, but also represent an attempt to enrich the research on palliative care ethics in Chinese contexts.

Chapter 3

Ethics in the West and the East

Having outlined the development and delivery of palliative care, this chapter turns its focus to the ethical issues arising in palliative care. There are variations in the development and provision of palliative care in the West and the East, but it is in the realm of ethics that we see particularly significant differences between these cultural contexts. Cultural analysis has long distinguished the Western and Eastern worlds, with the Chinese culture usually depicted as the exotic 'other' in comparison to the West. This chapter provides a description of both Western and Chinese (bio)ethics, specifically in relation to palliative care, which provides the background to the comparative analysis in Chapter 4. The chapter begins with the construction of palliative care ethics in the West, which provides a reference point for the subsequent investigation of the Chinese context. The latter discussion mirrors the structure of its Western counterpart, whilst additionally providing an introduction to the mainstream philosophical thinking in China: Confucianism.

3.1 Palliative Care Ethics in the West: Principlism

According to Woods (2007*c*), the palliative care approach can represent a philosophy of care. In his work *Death's Dominion: Ethics at the End of Life*, he quotes the definition given by the NCHSPCS to better describe the principles and core values of this approach:

> '*Palliative care is the active total care of patients and their families by a multi-professional team when the patient's disease is no longer responsive to curative treatment*' (NCHSPCS, 1995, p. 5)

The two more recent definitions mentioned in section 2.1.2 (WHO, 2020; Radbruch *et al.*, 2020) also resonate with this description. Here the 'philosophy' of care is not to be understood in technical academic terms; instead, according to Randall and Downie (2006), the phrase has ideological implications. All these definitions reflect the beliefs, values and principles held by a particular group of people – palliative care providers. This philosophy is formulated in normative terms, presenting a general action guide to any such provider. Such normative guide is primarily originated from the religious world and now underpinned by Western ethical theories.

As aforementioned in section 2.1.1, palliative care ethics appears to be a unique synthesis of Christian ethics and modern bioethics. The service of palliative care had grown out of Christianity. The home of the dying was originally an altruistic community inspired by Christ's help and kindness (Saunders, 2004). The first modern hospice, St Christopher's, was initially *'defined as a religious foundation based on the full Christian faith in God'* (Clark, 2018, p. 153). Thus, the ethos of palliative care is inevitably distilled from Christian ethics (Woods, 2007*b*). A resulting feature of palliative care is that, primarily, the service is morally motivated (ten Have and Clark, 2002). In addition to their professional credentials, providers of palliative care are also expected to be morally virtuous. Another key theme of palliative care, which is inherited from Christian ethics, is the commitment to the sanctity of life. The 'good death' was depicted as a natural death in the first stage of the modern hospice movement, as well as for many palliative care specialists nowadays (Woods, 2007*c*). Accordingly, the precepts of palliative care are based on a strong opposition to euthanasia and physician-assisted suicide, since they are contrary to life running its natural course (ten Have and Clark, 2002; Clark, 2018). Nevertheless, the impact of Christian ethics has gradually faded along with the medicalisation of palliative care. To tailor this service to a wider group of patients, especially those with different or no religious beliefs, the altruistic characteristics of Christianity have been gradually transformed into those more philosophical concepts of caring, compassion and empathy (Cherny and Portenoy, 2021). The sanctity of life has been expanded to include the pursuit of a good quality of life (ten Have and Clark, 2002). The resistance to euthanasia and physician-assisted suicide is still built upon the commitment to the sanctity of life, but rarely recognised as a religious reflection (Randall and Downie, 2006).

The integration of palliative care with modern medical institutions also makes the principles of bioethics become increasingly pertinent. Randall and Downie (2006, p. 220) note that the content of palliative care needs to *'be consistent with the aims, values and assumptions of health care in general'* for its better integration with other medical services. Woods (2007*b*) further argues that contemporary medical ethics, and bioethics in general, is underpinned by secular liberal ethics.

Before proceeding, two aforementioned concepts – healthcare ethics, medical ethics and their umbrella term bioethics – should be explained. These terms have been used interchangeably, which can result in confusion and conceptional tensions. In outline, all three fields share ethical goals and seek to provide normative ethical guidance, particularly for professionals (Callahan, 1973; Brannan *et al.*, 2012; Fieser, 2020). Nevertheless, there are important differences between these fields.

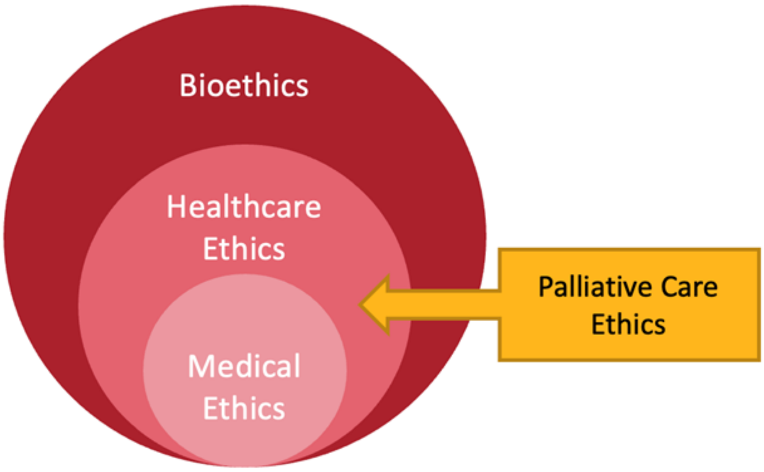

Figure 3.1: The Scope of Medical Ethics, Healthcare Ethics and Bioethics

As shown in Figure 3.1, medical ethics has the narrowest scope, which concerns issues arising in clinical practice (Campbell, 2013). The interests of medical ethics almost exclusively focus on doctors and their relationship with patients (Brannan *et al.*, 2012; Gordon, 2020). In recognition of the other healthcare professionals and practices also involved, medical ethics has also been extended to the more inclusive 'healthcare ethics'. Compared to medical ethics, healthcare ethics engages with *all* healthcare providers, including nurses and ancillary healthcare staff who are frequently neglected in medical ethics (Sommerville, 2013). Bioethics, on the other hand, suggests much broader interests. Both medical ethics and healthcare ethics are essentially anthropocentric, only concerning human beings (Gordon, 2020). The subjects of bioethics, it has been suggested, cover multiple forms of life in the biosphere. The goal of bioethics is to promote not only the wellbeing of humanity, but the greater good of this planet (Potter, 1971).

Bioethics – and the related, narrower fields – is distinctive as it encompasses a wide range of disciplinary areas, including philosophy, sociology, law, and public policy (Steinbock, 2007; Singer and Viens, 2008). Bioethicists accordingly also explore potential social and legal implications related to clinical practice (Singer and Viens, 2008; Kuhse and Singer, 2009). Bioethics is an applied field, which aims to integrate the application of these multidisciplinary perspectives with daily clinical practice. By doing so, bioethicists hope to provide a more comprehensive and sound account of decision-making in various contexts (Talbot, 2012). As such, bioethics is an interdisciplinary field, whose advancement requires in-depth understandings within, between and across all these various areas (Kuhse *et al.*, 2016).

Relating these observations to palliative care, it has been construed as a holistic approach to address patients' and their families' wellbeing, including not only physical but also psycho-social and spiritual aspects. As we saw in section 2.1, the palliative care team comprises multidisciplinary specialists (Luyirika *et al.*, 2017; Higginson, 2021). Therefore, it is sensible to locate 'palliative care ethics' under the category of 'healthcare ethics' as shown in the diagram (Figure 3.1).

While deliberating the ethical challenges within the realm of healthcare ethics, there are various theories that can be applied. For instance, the classic trio of normative ethical theories are deontology, consequentialism and virtue ethics (Fieser, 2020). The dominant ethical framework in both medical ethics and bioethics, nevertheless, appears to be principlism. Principlism is a theory proposed by Beauchamp and Childress (2013). This theory contains four components: the principles of respect for autonomy (respect for patients' wills and wishes), nonmaleficence (avoidance of harm), beneficence (maximisation of benefits) and justice (for example, focusing on allocating medical resources fairly among patients) (Beauchamp and Childress, 2013). Thus, it is also called the four-principles approach.

Principlism appears to be well adapted into the clinical environment, as well as other disciplines of social sciences. For healthcare professionals, the content of the principles is drafted in (arguably) familiar moral language, therefore making the approach more accessible to practitioners (Sommerville, 2013). Moreover, assessing the relevance of these principles can act as a gateway to considering a complicated case, which offers a good starting point for developing a justification for what ought to be done or decided (Arras, 2010). In addition to the philosophical aspect, principlism can also be integrated with diverse theories in legal, social and religious belief systems (Rauprich, 2012). Such integration can effectively generate a more comprehensive response than might be reached through purely philosophical deduction. Therefore, this approach seems to be better received by professionals from multi-disciplinary backgrounds. As a subsection of bioethics and, more specifically, healthcare ethics, palliative care ethics is also heavily informed by this theory. The following discussion then aims at briefly introducing how principlism can underpin the core values of palliative care ethics.

The conception of principlism reflects the profound influence of liberal secular ethics on the construction of modern medical and healthcare ethics (and, more broadly, the anthropocentric aspects of bioethics). In detail, secular liberalism emphasises the conception of negative rights (Woods, 2007*b*). For example, the most pertinent rights to this research would be freedom from non-consensual intervention, which reflects respect for (patient) autonomy, and freedom from harm, which reflects nonmaleficence. The importance of respect for autonomy in principlism makes most explicit its correlation with liberalism.

The principle of respect for autonomy is given top priority in principlism. Gillon (2003, p. 310), who defends principlism, sees *'autonomy as primus inter pares – first among equals – among the four principles'*. This principle is also held at the heart of palliative care ethics. The idea of autonomy, as well as the freedom from intervention in liberalism, originate from the Greek political theory of self-governance (Woods, 2007*b*). Moreover, respect for autonomy is also instructed by Kant's conception of liberty – the liberty to choose to do the right thing (Kant, 1786). Summarising from these premises, autonomy has two key elements: independence and self-determination (Pastrana *et al.*, 2008). In the practice of palliative care, to fulfil the goal of enhancing the quality of care, the principle of respect for autonomy is then interpreted as the acknowledgement and best possible fulfilment of a patients' wishes about their care (Miccinesi *et al.*, 2020). Whenever there is a conflict between patients' free choices and medical treatments that can maximise patients' wellbeing, respect for autonomy is entitled *'greater moral weight than advancing their welfare'* (Woods, 2007*b*, p. 80).

In addition to this commitment to respect for autonomy, there are other qualities and duties deemed essential to palliative care ethics. For instance, the duty of candour and open awareness are central to what is expected of a qualified palliative care specialist (Woods, 2007*c*; Cherny and Portenoy, 2021). These characteristics facilitate the gathering of key information of the patient's wishes, needs and the family's opinions. Only with this information can a care plan be best tailored in terms of approaches to symptom management and pain control, the choice of place of death and other services in palliative care (Pastrana *et al.*, 2008). Nevertheless, in terms of moral significance, the duty of candour and open awareness are placed as secondary to the four principles. Therefore, the application of these qualities should be aligned with principlism, otherwise they might be overridden.

In a nutshell, palliative care ethics in the West is underpinned by individualism and the prioritisation of autonomy in decision-making. Although it might appear that the principle of respect for autonomy might be dominant, it is claimed all four principles proposed by Beauchamp and Childress (2013) should be equally weighed in moral justification. However, these principles can aim at different, sometimes irreconcilable ends. (This phenomenon also recurs in the forthcoming discussion of 'ethical challenges' in section 4.1.)

3.2 Ethics in Palliative Care in the East: Confucian Bioethics

Having examined Western palliative care ethics, in this section, the rich ground of Chinese thinking will be explored. The title of this section is intentionally not named as *'Palliative Care Ethics in the East'* for two reasons. Firstly, the spirit of palliative care is unprecedented in Chinese cultures. Unlike Western peers, Christianity has little influence on the construction of ideology in the greater China region. The dominant role has been taken by Confucianism, which inspires a rather different morality (Fan, 2006; Nie, 2011). Accordingly, the key values and principles in palliative care philosophy, which are inherited from Christian ethics, appear only to be faintly echoed in this distinctive context. Secondly, as we have seen (in section 2.2), palliative care has an even shorter history in the greater China region, and is therefore neither well established nor well researched (于世英 (Yu), 2020). There is insufficient data on palliative care delivery from which to deduce insights into ethical challenges and any justifications for addressing them in particular ways. Given this situation, this section aims at identifying ethical insights relevant to palliative care from the existing mainstream philosophical thinking in Chinese cultures.

It initially needs to be clarified that the greater China region is pluralistic, as it includes various countries, cultures and areas. There has also been discussion about cultural identity (or identities) beyond nationality – for example, regarding Chinese immigrants in the UK, US or other Western countries (Chan *et al.*, 2012). This group may share broadly similar (Chinese) cultural backgrounds, but their worldviews and moralities are simultaneously shaped by the local cultures as well. Both phenomena indicate that neither Chinese culture nor Chinese ethics is singularly united (for example, under one set of principles). Mindful of this background, this research does not intend to engage with whether there is or should be a Chinese ethics. Instead, this project keeps its focus on the most influential school of philosophy in Chinese cultures, Confucianism (Fan, 2002; Goldin, 2015).

3.2.1 Confucian Ethics

Confucianism is considered the most revered philosophy in Chinese cultures, and still has significant impact in and on modern society (Wong, 2020). From a Western perspective, the nature of Confucianism appears to be multi-layered: it can be a religion (Weber, 1951), a school of thinking (Goldin, 2015) or a political ideology (Wong, 2020). Each of these perspectives is not wrong, yet any one of them is not comprehensive enough to depict this complex thinking. Looking through Chinese history, Confucianism has been deeply embedded in the moral, cultural and political realms. Such connections derive from the Confucian conception of the destiny of individuals. In Confucianism, a clear image of the ideal agent – *Jun Zi*[1], or the gentleman[2] – is vividly depicted. The gentleman is expected to excel in every aspect, including

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[1] It needs to be highlighted that, due to the challenges of translation, the use of terms can be tricky. Some Mandarin characters may have multiple English translations, and some may be impossible to translate directly or precisely into English. Given this, in the following analysis, the corresponding Chinese phonetic alphabet (*Pinyin*) of the key concepts will be provided alongside each proposed translation. The *Pinyin* will be marked in italics.

[2] The most straightforward translation of *Junzi* is the gentleman, which indeed is a very gendered concept. The sole focus on males is due to the dominant patriarchy in ancient China as well as in Confucianism. Since no other suitable alternatives are observed, the pronouns used here remain male, which aligns with original Confucian texts. Notably, at this point, Confucianism is frequently criticised for gendered prejudice. And, nowadays, this term, *Junzi*, refers to morally superior individuals, making no particular reference to gender.

moral excellence (*Ren*) (Goldin, 2015). To become such a 'perfect' person, individuals need to undertake a life-long process of self-cultivation (Fan, 2002; Chen, 2013).

This conception of the ideal (self-cultivating) agent is built on the relational nature of Confucianism. As an anthropocentric ethics, Confucianism suggests that a human being is different from and superior to other kinds of animals. The decisive proof of such superiority is humans' capacity to master various kinds of interpersonal relationship (Hui, 2002). Therefore, instead of the individual personhood familiar in the West, Confucius introduces 'social personhood'. A Confucian society is essentially an other-regarding one. Individual identities only become morally significant when their social roles and the corresponding duties to others are simultaneously recognised (Wang, 2002; Cong, 2004; Fan, 2006). In other words, undertaking obligations are essential to the fulfilment of individual (social) identities and moral progress. This other-regarding principle is also believed to serve the greater good. When individuals improve their moralities in a relational manner, they can also promote a more harmonious relationship among the wider social communities (Wong, 2020). This perspective reflects the point that welfare is assessed on a collective level in Confucian society. Confucianism envisions that the collective welfare is prior to individuals' welfare (Wang, 2002). Actions only benefiting individuals can be regarded as morally insignificant – or even unacceptable if they threaten to hamper the collective wellbeing.

The relational manner in the self-cultivation process is reflected in the acquisition of the virtues and the polish of them. In the Confucian view, individual moral self-actualisation should be triggered and accomplished via interpersonal relationships (Chan and Tan, 2004; Chen, 2013; Ivanhoe, 2013). The advancement of moral characteristics in Confucianism is progressive. Confucius believes that a person should first learn and exercise basic moral characteristics – such as '*benevolence, righteousness, propriety, wisdom, trustworthiness, forthrightness, courage, and unbending strength*' – within the family (Chen, 2013, p. 21). Only if someone treats their family properly can that person then practice these characteristics more broadly – for example, in the neighbourhood, the community, the society and eventually the whole world (Fan, 2002; Wong, 2020). During the cultivation of these characteristics, individuals are required to constantly attend the practice of rituals (*Li*) – a form of collective activity (Wang, 2002; Chen, 2013). Rituals (*Li*) are designed to offer a role model for how to practice these virtues correctly. By participating in such activities, individuals are consistently trained and guided towards the right end.

The relational nature of Confucian thought, together with the progressive actualisation process, can explain why the family plays such a central role in Confucianism, and – by extension – in Chinese cultures. Confucius indicates that the family should be seen as the basic unit of a society since it is the *'first school of virtues'* for individuals (Wang, 2002, p. 249).

Correspondingly, the parent-children[3] dyad is the most fundamental relationship in morality (Hui, 2002). A good parent-children relationship can be achieved by the fulfilment of filial piety (*Xiao*). Filiality (*Xiao*) requires the individual to preserve *'an emotionally viable relationship with one's parents'* (Wong, 2020). In detail, *Analects* 2.5 states that

> *'When your parents are alive, comply with the rites in serving them; when they die, comply with the rites in burying them and comply with the rites in sacrificing to them'.*

It needs to be highlighted that such compliance is not synonymous with blind obedience, a common misunderstanding and criticism of Confucianism (Wang, 2002; Chan *et al.*, 2012; Goldin, 2015). The proper virtue while caring for parents can be better expressed by the term 'reverence (*Jing*)', with an emphasis on genuine respect (Wang, 2002). By genuinely respecting one's parents, Confucius himself explains that children should correct their parents' wrongdoings instead of supporting them. Otherwise, obeying parents' unethical requests is considered as a moral failure on the part of children.

Based on such a conception, filial piety (*Xiao*) is regarded as the *'root of humanity and morality'* in Confucianism (Wang, 2002, p. 250). The fulfilment of filial piety (*Xiao*) is therefore considered a mandatory prerequisite of good citizenship (*Analects* 1:2). Confucian reasoning appears to be a kind of 'analogical reasoning' in this case (Lau, 1970). In detail, filiality is often related to loyalty. If one can build a harmonious relationship with one's parents, then one is believed to be capable of serving the ruler well (Chan and Tan, 2004). This reasoning then unites everyday life in a family, the politics of the nation and the culture and moral norms shared by the society together under the name of Confucianism. After centuries of immersion, Confucianism has – unsurprisingly – intervened in almost every aspect of Chinese societies.

In summary, relationality and collectivism feature strongly in Confucian ethics. Individuals are required and expected to discipline themselves through interpersonal interactions. Such self-discipline is desirable, not only because it makes the individual a better person, but also because it makes for a better community. As a knot between the individual, the community and the nation, the family is the key to achieving all these betterments. By giving people their very first lessons on morality, the family is seen as the pioneer of moral education in Confucianism. Held up by the family, Confucianism has had a significant influence on the construction of Chinese cultures, Chinese philosophies and Chinese moralities.

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[3] The original word used in *Analects* and other Confucian classics is father-son relationship. As explained in footnote 2, the concepts in traditional Confucianism are quite gendered and patriarchal. Nevertheless, their use nowadays appears to be increasingly gender neutral. Therefore, to avoid any sexist implications, in this research, this term is replaced by parent-children relationship, making no specific gender reference.

3.2.2 Confucian Biothics

The above description of Confucian ethics aims at providing a theoretical background to the Chinese contexts. Nevertheless, questions might arise about whether Confucianism is relevant to bioethics, or more specifically, healthcare ethics. As a response and a clarification, this section looks to those concepts in Confucianism which can closely coincide with the Western philosophy of palliative care.

First of all, Confucianism offers a holistic conception of personal health. In Chinese etiology, there are *'seven mental factors (delight, anger, sadness, pleasure, grief, fear, and fright) together with six natural factors (wind, cold, heat, humidity, dryness, and fire) as the most common causes of diseases'* (Fan, 2002, p. 7). Any imbalance of these factors – whether excess or insufficiency – can cause health problems. Confucianism aims at the promotion of the inner world: via self-cultivation, individuals can possess more virtues and become more at ease with such intense emotions. Thus, individuals are able to remain peaceful and can distance themselves from diseases. In Neo-Confucianism, the individual body is also seen as a totality consisting of *Qi*. *Qi* is commonly translated as 'vital energy', although it can include both the material and the spirit (Tu, 2002; Fan, 2002). Confucianism believes *Qi* is dynamic in format, which can transform from material to spirit and vice versa. Therefore, both are crucial to the promotion and maintenance of *Qi*. The self-cultivation process can guide individuals to exercise and advance their moralities, and moral advancement can then in turn nourish the *Qi* (Fan, 2002). In this manner, not only is Confucian ethics concerned with personal health status, but it also offers an approach to improving individual health.

Another implication of the Confucian holistic view on personal wellbeing is related to care for the ageing. Since Confucianism considers both the mental and physical realms equally essential to individual health, care for the ageing should not be simplistically interpreted as caring for their physical health and helping with burdensome chores (Fan, 2002; Chan *et al.*, 2012). In contrast, while taking care of one's elderly parents, namely when practicing the virtue of filial piety, children should not only pay attention to their physical suffering but also to their spiritual needs (Wang, 2002). Confucius explicitly refers to the ultimate ideal world, in which '[t]*he elders* [have] *a happy ending*' (*Li Yun Da Tong*[4]). Therefore, the practice of filial piety is commonly considered as a form of emotional support and relief, even in contemporary context (Engelhardt, 2006; 刘晓惠等 (Liu *et al.*), 2015).

The holistic conception of individual health seems to echo the innovative idea of 'total pain' proposed by Cicely Saunders. While Confucianism does not specifically refer to the idea of pain and suffering, it does consider a person's physical and mental well-being as a whole. This shared conception implies that Confucianism can fit in the practice of palliative care, even

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[4] In English as *'The Great Together'* from the chapter *'The Operation of Etiquette'* in *Li Ji.*

though this form of care appears to have an exotic origin.

In terms of clinical practices, there is also explicit moral rule proposed by Confucianism. The headline principle is ‘do no harm’. This principle is clearly documented in Confucian classics: *‘To do no harm is the art of benevolence (Ren)’* (*Meng Zi*, chapter on King Lianghui I, paragraph 7). This principle can be equivalent to the combination of the principle of nonmaleficence and beneficence in principlism (Qiu, 2011). Such commonality seems to imply that there are shared precepts between Confucian bioethics and the dominant Western thinking.

Confucianism also shapes a rather distinctive care delivery model in the greater China region: familism. Derived from the tradition of filial piety, elderly care in Chinese cultures is considered a family business (Zuo *et al.*, 2014; Li, Singh and Keerthigha, 2021).

Taking care of one’s elderly parents *in person* is considered ethically necessary and socially expected. The main caregivers are family members, mostly the daughters and/or one of the sons (Chan *et al.*, 2012). The content of care normally refers to assistance in eating, bathing, dressing, toileting and travelling (Zhang and Li, 2005; Zhang *et al.*, 2019). The company of family members is also an important emotional support to the elderly (刘晓惠等 (Liu *et al.*), 2015). Historically, to fulfil this filial duty usually implies co-residency across generations (Fan, 2006). Yet, modernisation has brought increasing labour, especially female labour, into the market (Sung, 2013). This phenomenon tends to weaken the family’s capacity for providing care. In addition, rising housing prices also limit the possibility of co-residency (Fan, 2006). Consequently, instead of in-person care at home, sending elderly parents to care homes while still supporting them financially has become more prevalent in Chinese societies (Chan *et al.*, 2012). However, the inability to care for parents in person can constantly stimulate shame and regret among children, as it is regarded by Confucianism as a failure to fully exercise filial piety.

This sole-provider care model appears to lead the development of palliative care in China to a path throughout the thorns. The long history of home-based elderly care has planted among Chinese people a deep attachment to the family. Consequently, admitting one’s elderly parents to care homes or hospices – the main providers of palliative care in the West – is considered, morally, less than ideal or even inappropriate (Chan *et al.*, 2012; Li, 2013). While, under the influence of the ‘medicalised death’, admission to hospitals appears to be more acceptable (Li, 2013; Silbermann, 2017; 于世英 (Yu), 2020), limited resources and infrastructures in hospitals make this choice unrealistic. Given these challenges, and individuals’ aforementioned decreasing capacities to provide home-based care, it is not clear how palliative care can reasonably be delivered in Chinese contexts.

Despite the care delivery model, familism in Chinese contexts provides a distinctive decision-making model. As previously introduced, the family is seen as the basic moral entity in Confucianism. Family members have shared rights, duties and benefits (Fan and Li, 2004; Fan and Tao, 2004). The welfare of the family is correspondingly assessed on a collective base (Hui, 2002). Individual benefits, on the other hand, are negligible compared to the greater good. These ideas are described in terms of 'family autonomy' by Western researchers, and positioned in contrast with the dominant 'individual autonomy' in Anglo-Saxon contexts (Cheng *et al.*, 2012; Raposo, 2019). Family autonomy applies to all kinds of decision-making, and medical decisions are no exception. During medical decision-making, the family is also regarded as the 'spokesperson' of the patient. Healthcare professionals usually start by seeking the family's opinions, rather than the patient's. Especially in care planning and information disclosure, the family – instead of the patient themselves – is vested with decisive power. It has been considered legitimate (and even required) in Chinese contexts that the family withholds a poor diagnosis/prognosis from the patient or even makes up an unreal yet less severe one in order to avoid their psychological collapse (Zhang *et al.*, 2021). The intention behind such decisions is essentially protective, which is therefore considered morally acceptable (Chan, 2004). Nevertheless, this concept appears to be incompatible with the autonomy-led decision-making model in the West.

Familism (and those other aspects of what we might call Confucian bioethics) remains pertinent in and to modern Chinese cultures. For instance, this moral duty is reinforced in the Chinese Marriage Law, according to which parents are granted the right to be financially supported by their children (Section 3, Article 15). In the Hong Kong SAR, individuals are incentivised for caring for the elderly (Fan, 2006).

In sum, it is evident that Confucianism (and, by extension, Confucian bioethics) remains prevalent and pertinent to Chinese contexts, including in the practice of palliative care. This relational and collectivist philosophy has made the family the centre of care delivery and decision-making. Both features appear to explicitly distinguish Confucian bioethics from the dominant individualistic approach of principlism in the West. However, the following questions arise: do these different ethical theories give rise to different ethical challenges in practice? Do they also provide distinctive responses or solutions? To better address these questions, the coming chapter aims at critically comparing the application of Chinese and Western ethical theories through the case studies of medical futility and truth-telling.

CHAPTER 4

Contrasting Ethical Challenges in the West and East

After chapters 2 and 3 provide the theoretical foundations, chapter 4 then explores the ethical challenges encountered in palliative care practice. This chapter firstly introduces key challenges arising in palliative care delivery, as described in the literature. Section 4.1 primarily adopts a Westernised framework, since Western research appears to be the most systematic and comprehensive in this field. Two specific cases – medical futility and truth-telling – are then further investigated in a comparative manner. With these concrete examples, the divergence and convergence between Confucian bioethics and principlism can be better unveiled. Section 4.2 then explores dominant responses to these ethical challenges and the theories underpinning those responses. Through addressing the theoretical foundations and their practical applications, the relationship between Chinese and Western bioethics is revealed. In the final section (section 4.3), some unfilled gaps are highlighted, including the different conceptions of 'ethical challenges' and 'palliative care'. How Chinese healthcare professionals approach and adopt these concepts in clinical practice appears to be under-researched. Given this, further empirical inquiry is required, which can contribute to the evidence base of research on palliative care in China, Chinese bioethics, and bioethics in general.

4.1 Common Ethical Challenges Arising in Palliative Care

Ethical dilemmas can arise in palliative care at various points, such as when determining a care plan, caring for dying patients, or when patients and families seek nonbeneficial treatments (Macauley, 2018). It is not surprising to find that, even in different countries and cultures, the ethical challenges encountered in practice share some commonalities. Given this, the first part (section 4.1.1) of this section aims at offering a brief summary of these common challenges.

The following two sub-sections – section 4.1.2 and 4.1.3 – then focus more on the distinct challenges arising particularly in Chinese contexts and considers why this might be the case. While there appear to be few unprecedented dilemmas in China, the distinct conception of family autonomy seems to present additional challenges.

4.1.1 Common Ethical Challenges among the East and the West

Although palliative care ethics is related to and interacts with (at least the aforementioned) wider fields of applied ethics, distinct ethical challenges appear to arise in palliative care. While the term ‘ethical challenges’ is widely used in bioethical literature, consensus on what this term means in theoretical and empirical contexts is lacking (Schofield, Dittborn, Selman and Huxtable, 2021). For some, ‘ethical challenges’ may refer to difficulties that individuals confront in practice when at least two competing values require conflicting actions (McCartney and Parent, 2015). Moral agents cannot fulfil both moral injunctions simultaneously and must choose to comply with only one of them. Nevertheless, whichever action an agent chooses to perform, the other moral precept will be violated, resulting in moral failure (McConnell, 2018). In other words, actions in ethically challenging situations are both required and forbidden (Shafer-Landau, 2010).

There is, however, already a term that can be used to describe this phenomenon: ‘moral dilemma’. Yet, this is distinctly philosophical terminology (Tessman, 2014; McConnell, 2018; Apay *et al.*, 2020), while this research also seeks to explore the practical, empirical side of applied ethics. In order to accommodate both theoretical and empirical perspectives, this research adopts a broader account of ‘ethical challenges’, drawing on the work of Schofield, Dittborn, Selman and Huxtable (2021).

According to Schofield, Dittborn, Selman and Huxtable (2021), there are four common accounts of ‘ethical challenges’:

- *As defined through concepts (e.g. ‘ethical dilemmas’, ‘moral dilemmas’, ‘moral challenges’, ‘ethical issues’, and ‘ethical conflicts’)*;
- *Defined by reference to moral conflict, moral uncertainty or difficult choices*;
- *As defined by participants*;
- *Challenges linked to emotional or moral distress.*

While more than one of these approaches may be simultaneously employed in one study, no research has covered all four of them (Schofield, Dittborn, Selman and Huxtable, 2021). During literature searching, all the aforementioned terms and approaches were included to enhance the thoroughness of this research.

We can now turn our attention to the concrete ethical challenges arising in palliative care practice. The following ten topics are frequently mentioned in the relevant ethics literature and textbooks (Chiu *et al.*, 2000; Schwartz *et al.*, 2002; ten Have and Clark, 2002; Randall and Downie, 2006; Dickenson *et al.*, 2010*a*; Macauley, 2018; Cherny *et al.*, 2021). Here, only a brief introduction of each challenge is provided; further details about each can be found in Appendix B.

1. **Advance decision-making**
   This category includes challenges related to advance care planning and advance directives (or decisions). Primarily, ethical challenges may present when:
   a) Patients' preferences as stated in advance directives are in conflict with families' wishes;
   b) The enduring validity of patients' previously stated preferences cannot be affirmed.
2. **Communication**
   This category includes challenges related to truth-telling, breaking bad news and informed consent. While withholding information from the patient is usually deemed morally unacceptable, absolute honesty can induce additional anxiety, depression and stress in the patient. This potential consequence seems to breach the principle of nonmaleficence, challenging the assumed morality of truth-telling.
3. **Confidentiality**
   In the field of healthcare, there is an ethical obligation to maintain patients' confidentiality (and privacy), but there may be limits to this obligation, for example, if respecting confidentiality might endanger others. The balance between protecting patients' rights and interests and protecting others can present ethical challenges, including in palliative care.
4. **'Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)'**
   DNACPR was originally stated as 'Do Not Resuscitate (DNR)', and thereafter 'Do Not Attempt Resuscitation (DNAR)', but nowadays more specifically refers to not attempting cardiopulmonary resuscitation (hence DNACPR). Patients may consent to this for the purpose of preserving quality of life at the very end and avoiding unnecessary suffering. Yet, even if the patient does consent, their family might have conflicting views. In addition, challenges may arise because forgoing cardiopulmonary resuscitation (CPR) inevitably ignores the chance of survival it might offer (however slim), which sometimes is regarded as a violation of the principle of the sanctity of human life.
5. **Euthanasia and physician-assisted suicide**
   This category seems to be the most widely and hotly debated of all these ethical chal-

lenges. Proponents of euthanasia and physician-assisted suicide typically justify these practices by reference to a patient's autonomous choice. Nevertheless, such active termination of life is an explicit violation of the sanctity of human life, which, given its Christian heritage, is apparently contrary to the ethics of palliative care. In this situation, the moral status of euthanasia and physician-assisted suicide cannot be settled.

6. **Family participation in decision-making**
   Family participation in medical decision-making is quite common, regardless of cultural backgrounds. Close family members are commonly regarded as best knowing a patient's preferences and wishes, which is particularly relevant if the patient lacks the competence of capacity to be involved in decision-making at the time. Despite this, patients' and families' opinions can contradict, which can leave healthcare professionals in an ethically challenging situation.

7. **Pain relief and symptom management**
   Pain relief and symptom management are located at the core of palliative care services. However, these two treatments can cause side effects, including (even if only in rare cases) death. In such a case, challenges can arise concerning how best to balance the need for symptom management against possible harms.

8. **Palliative sedation**
   Palliative sedation – in which a patient's consciousness is minimised – is a specific form of symptom relief, which is usually considered as a last resort at the end of life. This can potentially cross the fine line between relieving distress and hastening death. Also ethically challenging is the apparent lack of convincing evidence that the induction of palliative sedation can affirmatively reduce, rather than induce, patients' suffering.

9. **Requests for futile/inappropriate/nonbeneficial treatments**
   Requests for unnecessary treatments can be made by either the patient or their family, including in palliative care. Problems arise, firstly, in efforts to define 'futility' and 'inappropriateness'. Secondly, overriding patients' requests arguably means that healthcare professionals are violating the principle of respect for autonomy.

10. **Withholding and withdrawing (life-sustaining) treatment**
    Often classified as 'omissions', withholding and/or withdrawing life-sustaining treatments can be justified as ethical by reference to (for example) the ethical obligation to avoid harm or distress to the patient. Yet, withholding or withdrawing life-sustaining treatment might sometimes, firstly, be contrary to a patient's wishes and, secondly, might even cause additional suffering for the patient as well as the family.

In addition to these 10 topics, paediatric palliative care ethics and research ethics in palliative care are also common venues of ethical challenges. However, this research primarily focuses on clinical (rather than research) practice in relation to adult patients, including older adults. Accordingly, these two topics will not be discussed further.

Although some of these topics (for example, confidentiality and communication) may arise in other areas of healthcare practice, many of these topics are distinctive to palliative care, providing a straightforward snapshot of the ethical challenges arising there. While this appears to be the most common way to categorise different kinds of ethical challenges, particularly in textbooks that cover palliative care ethics (Dickenson *et al.*, 2010*a*; Macauley, 2018; Cherny *et al.*, 2021), it is not the only way of doing so. Schofield, Dittborn, Huxtable, Brangan and Selman (2021, p. 315) further indicate that ethical challenges may also occur during healthcare professionals' *'application of ethical principles,* [engagement] *with institutional structures and values,* [and navigation via] *societal values and expectations and philosophy of palliative care'.*

It should be emphasised that the sorts of 'ethical challenges' discussed here derive primarily from the Western (English language) literature. The reason is that these challenges are comparatively better documented and more systematically defined in this literature (Schofield, Dittborn, Selman and Huxtable, 2021; Schofield, Dittborn, Huxtable, Brangan and Selman, 2021). Yet, similar challenges have also been frequently identified in Chinese contexts (Chiu *et al.*, 2000; Li, 2013; 陈小鲁，罗峪平 (Chen and Luo), 2020). In relevant Chinese research and reports, these Westernised accounts and definitions are explicitly cited and employed, so it seems appropriate here to adopt such accounts and definitions. Nevertheless, this move does not attempt to ignore the differences that can arise in distinctive cultural contexts. While both Chinese and Western healthcare professionals may share an understanding of major 'ethical challenges', they may differ in their responses to such challenges. To draw out these differences, in the following sections, two specific examples of ethical challenges – requests for futile treatments and withholding information – are deliberated, making reference to (Western) principlism and (Chinese) Confucian bioethics.

4.1.2 Case Study 1: Medical Futility/Inappropriate Treatments

Requests for futile or inappropriate treatments are a common challenge arising in both Chinese and Western contexts. The challenging point lies in the conceptualisation of 'futility' and 'inappropriateness'. In the West, the main venue of ethical challenges tends to be the justification for overriding the patient or the family's requests, which is essentially based on the likelihood that the patient will not benefit from the provision (or continuance) of treatment (Kon, 2021). The requests are commonly autonomous choices made by either the patient or the family. The treatments requested are therefore believed to be at least emotionally supportive and encouraging to the patient. While the side effects of treatments requested can induce a breach of the principle of nonmaleficence, overriding such decisions nonetheless risks undermining the patient's autonomy. In addition, neglect of the potential spiritual and psychological support that the provision of such treatment might bring may also be contrary to the principle of beneficence.

However, in Chinese contexts, request for additional 'futile' treatments is well accepted if not demanded. The challenging point, on the other hand, might be how to ethically legitimise the possible adverse impacts on the patient which are brought up by these treatments. Although such a perspective might be criticised as over-medicalisation, for Chinese families, a hospitalised death with all possible treatments applied has become increasingly normalised (Schubauer *et al.*, 2018; 于世英 (Yu), 2020). One possible reason is that Confucian bioethics places a high regard upon humans' physical bodies (Hui, 2002). When a patient is diagnosed as unconscious or incompetent, s/he indeed loses an important part of their overall humanity. However, the remaining physical body still represents the existence of his/her personality. Accordingly, the patient cannot be reduced to *'some portion of the patient's anatomy, physiology or chemistry'* (Schneiderman *et al.*, 1990, p. 950) for which *'all medical treatments would predictably yield "qualitatively poor results"'* (Hui, 2002, p. 144). Therefore, the requests for clinically futile treatments in this sense can be translated as a recognition of and respect for the patient as a human-being. This view can contradict the mainstream Western view of medical futility and quality of life. Since these treatments can only bring little – but potentially no – medical benefit, they are deemed unnecessary in the West (Hui, 2002). Furthermore, the intrusive intervention can cause additional harms to the patient, which inevitably lowers the patient's quality of life (Huang *et al.*, 2014). Nevertheless, the Western conception of 'futility' tends to be poorly accepted in Chinese cultures.[1]

In addition, the obligation of filial piety requires children to invest full efforts while serving their parents – exhausting medical treatments for recovery affirmatively falls into this scope (Wang, 2002). Therefore, not requesting additional applicable treatments can be deemed as a moral failure in fulfilling the filial duty. From the patient's point of view, less active requests from the family can imply a sense of abandonment and compromise (Li, 2013; Silbermann, 2017). To avoid moral flaws and the patient's disappointment, requests for such clinically less effective treatments seems to be morally obligatory for the family, and expected by the society.

While there are sound reasons to justify a request for less physiologically effective treatments as morally appropriate, this does not mean that Chinese healthcare professionals ignore the suffering these treatments can cause (Huang *et al.*, 2014). In contrast, the suffering is clearly recognised as an under-fulfilment of the principle of 'do no harm' (Qiu, 2011). In this vein, the ethical challenge presented in Chinese contexts appears to be competition between

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[1] For example, the specific diagnosis like 'permanent vegetative state' is not perceived as a strong argument for the removal of life-sustaining treatments or the withdrawal of any aggressive operations (Hui, 2002).

the recognition of humanity, the duty of filial piety and the baseline of nonmaleficence. Moral distress can be experienced by Chinese healthcare professionals, as well as the family, if they feel morally obligated to provide and request nonbeneficial, potentially harmful, treatments for the patient.

In sum, the ethical challenges provoked by requests for futile or inappropriate treatments show intrinsic differences between the Western and Chinese contexts. The ethical challenge for Westerners is to justify the provision of the treatment, when the principles of respect for autonomy and nonmaleficence conflict. In contrast, for Chinese, the provision of treatment is justified (indeed, required) by respect for humanity and the duty of filial piety. The ethical challenge arises at the point that Chinese healthcare professionals must attempt to justify the inevitable harms induced by these treatments. Such differentiation displays how healthcare professionals in distinct cultural backgrounds interpret and respond to the same ethical challenge in distinct ways.

4.1.3 Case Stuy 2: Truth-telling

Truth-telling – or, more specifically, withholding information from the patient – might be the ethical challenge that shows the greatest differences between the East and the West. In the Western world, open communication is regarded as the foundation of high-quality palliative care (Woods, 2007*c*). In the US and the UK, provision of *'complete truthful information'* is deemed as the *'gold standard'* of clinical practice (Emanuel *et al.*, 2021, p. 1151). In addition, the duty of candour is also part of healthcare professionals' occupational moral codes (Beauchamp and Childress, 2013). In this situation, withholding information from the patient is generally deemed unethical (and may also be illegal), since it primarily breaches the patient's autonomy. While there are considerations regarding the possible negative feelings brought by truth-telling in the West, they are not considered as sound justifications for the action of not telling a patient or even lying to the patient (Dickenson *et al.*, 2010*b*).

In the East, there appears to be the opposite moral expectation. The common picture of information disclosure in Chinese cultures is that the family requires bad news to be withheld from the patient (Huang *et al.*, 2014; Fan *et al.*, 2019; Pun *et al.*, 2020). In some situations, the family may make up a false, less severe diagnosis to tell the patient (Chin, Dunn and Wong, 2017). The initial motivation for these moves is to avoid the significant psychological suffering that might be caused by the bad news (Zhang and Min, 2020). Referring back to Confucian bioethics, a balanced emotional status is essential to individual health (Fan, 2002). Thus, not being aware of the negative information is believed to be helpful to maintain a stable health status for the patient. Moreover, talking about death or death-related topics is a taboo in Chinese culture. There is a common superstition that mentioning death in a conversation can hasten the patient's death (Pun *et al.*, 2020). Therefore, the diagnosis at the end-of-life phase is usually hidden from the patient for their own good.

Such justification of withholding the truth inevitably incurs criticisms, especially from the West. Yet, arguably, what makes Western scholars more uncomfortable is the family's dominant role in medical decision-making (Raposo, 2019). Confucian bioethics gives the family greater power over the individual in decision-making. Even in the patient's last stage of life, the family is still regarded as the culturally legitimate final decision-maker (Zhang *et al.*, 2021). Correspondingly, in contrast to the patient-doctor relationship in the West, the care relationship in Chinese contexts appears to be a triad of the patient, the family and the healthcare professional (Cong, 2004). Furthermore, compared to the complementary role of the family in Western countries, the family in Chinese contexts is always the first contact point and the final approver regarding information disclosure. Such perceptions are fundamentally contradictory with the prima facie principle of respect for autonomy, which is so highly valued in Western palliative care. At this point, it seems that the ethical challenge of truth-telling in Chinese contexts is not about information disclosure. Instead, the challenge is visible only when the Chinese approach is examined from a Western perspective. Chinese and Western practices clash at this philosophical or cultural level since the Confucian bioethical principle of familism is accorded a similar respect in China to autonomy in Western principlism.

4.2 Approaches to Address Ethical Challenges

In this section, the responses to ethical challenges from both the East and the West are evaluated. Beginning with the inherent variation embedded in both principlism, the representative of the West, and Confucianism, the representative of the East, how these ethical approaches intersect and depart from each other are unveiled. Following this, the practical toolkits commonly used in clinical practice to address ethical challenges are elaborated: i) deliberation tools; ii) pedagogy and; iii) clinical responses.

4.2.1 The Theoretical Base: Western Ethics vs Chinese Ethics

Theoretical thinking is primarily the battlefield of ethicists and social scientists, rather than medical or other health professionals. If the action guide might be considered the 'methods' to seeking solutions to challenges, then the theoretical reflections might be considered the 'methodology'. In other words, theoretical reflections can support and justify the applicability of suggested practical solutions. In the field of palliative care ethics, there is less consistency between the East and the West in the theoretical realm. This section begins with some areas of consensus or commonality, but then moves to consider the areas of difference and their ethical implications.

4.2.1.1 *Convergence*

While comparing principlism and Confucian bioethics, it appears that there are some key values and principles shared between them. First and foremost, it is commonly agreed that patients' interests should be placed at the core of all clinical practices. Patient-centred care, or person-centred care, is increasingly promoted as a central theme of healthcare worldwide, regardless of societal context (Pelzang, 2010). This trend is not something innovative but has a long history in Confucian (bio)ethics (see section 3.2). The cornerstone of Confucianism – benevolence (*Ren*) – primarily requires healthcare professionals, mainly physicians at that time, to cherish the value of life. Physicians should make maximal efforts to save patients' lives and relieve their suffering (Guo, 1995; Hui, 2002; Li and Wen, 2010). Yet, Confucian bioethics does not solely focus on curing patients. Instead, the holistic conception of individual health status requires great compassion and empathy and that there be comprehensive care for every aspect of a patient's life (Fan, 2002; 鄢思佳 (Yan), 2018). This doctrine resonates within the philosophy of palliative care, which also requires healthcare professionals to alleviate symptoms and improve quality of life at the same time (Beauchamp and Childress, 2013; MacDonald *et al.*, 2021). Similarly, the character of benevolence (*Ren*) is also consistent with the core values of palliative care. Both beliefs uphold a holistic view of personality and the value of life, which are not merely directed towards a concern with the physical symptoms of diseases (Baines, 2011; 赵可式 (Zhao), 2016; 宁晓红 (Ning), 2019; 陈小鲁, 罗峪平 (Chen and Luo), 2020; Christopher's, 2021a).

The principle of benevolence (*Ren*) also implies both the (Western) principles of beneficence and nonmaleficence. Confucian bioethics holds that individuals should treat others in a way that they themselves would want to be treated, and that they should avoid behaviours towards others that they themselves would not wish to be subject to (Guo, 1995; Li and Wen, 2010). Within clinical practices, physicians should aim at doing good but also avoid inflicting harm, since to do otherwise would risk causing inharmonious conflicts, which are contrary to Confucianism. This stance broadly aligns with the principles of beneficence and nonmaleficence, which prevail in Western bioethics (Dickenson *et al.*, 2010*a*; Macauley, 2018).

Moreover, the relational nature of Confucianism seems to have an implicit connotation of the principle of justice. As an other-regarding philosophy, Confucianism assesses well-being in a collectivist manner (Wong, 2020). The greater good is therefore emphasised over individual benefits (Wang, 2002). Since healthcare is an essential component of a well-functioning society, Confucian bioethics indicates that it should be equitably distributed to each citizen to ensure the high-quality operation of the society. The responsibility of each physician is then to treat patients equally. According to Simiao Sun, the 'King of Medicine' in ancient China:

> *'If someone seeks help because of illness or on the grounds of another difficulty,*

> *a great physician should not pay attention to this person's status, wealth, or age, neither should he/she question whether this person is an enemy or friend, whether this person is a Chinese or a foreigner, or finally, whether this person is educated or uneducated. He/she should meet everyone on equal ground; he/she should always act as if he/she is not to ponder over his own fortune or misfortune and should thus preserve life and have compassion for it'* (Sun, 1995, p. 18).

While, in the West, such ideas tend to be underpinned by consequentialism , the ultimate goal is still to promote the greater good (Dickenson *et al.*, 2010*a*; Beauchamp and Childress, 2013; Li, 2013; Macauley, 2018). Therefore, it can be concluded that both principlism and Confucian bioethics share a common pursuit of justice in the area of healthcare.

In short, while Chinese cultures and Confucian bioethics have been constantly deemed as 'the exotic other', convergences can be identified between them and their Western peers. The mutual support of these underlying principles might challenge the dichotomisation of the East and the West, which can then inspire innovative thinking in cultural-bioethical research.

4.2.1.2 *Divergence*

Despite such shared values, there are fundamental differences revealed between Chinese and Western bioethics as they relate to palliative care. The most outstanding one is the role that the family plays in medical decision-making in Confucian cultures. The involvement of the family in Chinese environments appears, particularly, to challenge more Western notions of the principle of respect for autonomy (Cong, 2004; Li and Wen, 2010; Li, 2013; Raposo, 2019). In this section, critiques and refutations from both sides are described to evidence the gaps in thinking.

As noted above (section 4.1.3), the idea of 'family autonomy' can generate ethical challenges in relation to truth-telling. The common situation in Chinese contexts is that, before talking to the patient, the healthcare professionals reveal to the family the diagnosis, prognosis and any necessary discussion regarding treatment selection and care planning. The patient, on the other hand, will typically only receive tailored or even false information about his/her condition, with the family's permission (Fan and Li, 2004; Li, 2013; Zhang *et al.*, 2021). As an extension, obtaining informed consent in Chinese contexts does not seem to fit the Western 'standard', which is underpinned by respect for autonomy. Especially in mainland China, while a signed informed consent form is required before treatment may be given, healthcare professionals usually seek the signature from a family representative (Li and Wen, 2010; Cheng *et al.*, 2012). Unlike the West, informed consent provided and signed by the patient him- or herself is still rare in mainland China.

It has been thoroughly argued in section 3.2 as well as section 4.1.3 that the legitimacy and authority of the family in Chinese cultures is founded upon Confucian familism. The relational nature prioritises the family over the individual in decision-making. In addition, the family has a duty as well as a privilege to speak for their unwell member. This feature is vastly different from the individualistic conception of rights and relationships. The image of an agent in principlism, or more generally within liberal secular ethics, is independent, if not isolated (Woods, 2007*b*; Raposo, 2019). While construing individual rights, the focus appears to be mainly concentrated on the agent's own benefits and capacity to make decisions (Pastrana *et al.*, 2008). Such a conception therefore inspires criticism of the collectivist decision-making model in Chinese cultures.

On the foundational level, this familial duty of filial piety is questioned as invalid. Primarily, familist care has its root in children's filial obligations towards their parents (Fan, 2002), but this ground cannot be well-justified from an individualistic perspective. The relationship between parents and children is construed as asymmetrical (Daniels, 1988). In other words, parents' duty to care for children is 'self-imposed', while children do not have such self-imposed obligations to care for their parents. In addition, Jane English (1979) argues that, in a parent-children relationship, informed consent is largely absent: children are not asked for their consent to enter this relationship; accordingly, they do not give their consent to care for their parents in the future (O'Neill and Ruddick, 1979). Confronting such criticisms, it needs to be re-emphasised that such an obligation should be justified within its original context. As explained in section 3.2.1, the social roles in Confucianism, including those of parents and children, are attached to normative action requirements (Fan, 2002; Wang, 2002). The fulfilment of a social role therefore requires individuals to comply with the moral duties it imposes. Therefore, the duty of filial piety can be ethically justified in Confucian ethics, and still be relevant to this research.

Turning our attention to the field of palliative care ethics, the 'overinvolvement' of Chinese families has been strongly criticised by Western bioethicists. As stated by Raposo (2019, p. 26), *'the "cultural excuse" cannot override core values at this stage of the development of mankind and there are indeed core basic values that should be universally respected'.* The deception and exclusion of patients in such contexts are alleged to violate one of the most fundamental of human rights – the right to respect for autonomy (Beauchamp and Childress, 2013; Nie and Fitzgerald, 2016; Raposo, 2019). Notably, it needs to be emphasised that such criticism is not ethically neutral but, rather, is essentially Westernised. The denial of family autonomy is rooted in the (Western) conviction of individual autonomy. Notwithstanding that this project has adopted theories and definitions from the West as its points of reference, Western theories should not be automatically adopted as the appropriate normative rules for Chinese contexts. Before judging the native Chinese ethical principles by Western standards, one needs firstly to justify the Westerner's right to judge another culture or ethics. Otherwise, these blunt critiques may risk Western scholars exhibiting *'bioethical imperialism'* (Solomon, 2006, p. 336).

Bioethical imperialism refers to the prevalence, if not invasion, of liberal secular bioethics into other cultures. Solomon (2006, p. 338) remarked that *'Western culture was developing a cult of authenticity, a focus on individualism and autonomy, and a privatisation of religious views'*, while ignoring and distorting the uniqueness of other cultures. As part of the long-lasting universal-ethics-versus-local-ethics debate, it has been emphasised that bioethics is culturally sensitive, which implies it might display various constructions in different cultures (Wang, 2010). The incompatible twins of individual and family autonomy may indicate that Confucian bioethics is something unique or distinctive, which is independent of the dominant individualistic bioethics in the West (Chan, 2014). In this case, the fallacious assumption of principlism as a universal rule should be abandoned. A more delicate examination of the relationship between principlism and Confucian bioethics, or of bioethics in the West and the East in a broader sense, is needed.

Nevertheless, such a relativist claim does not – conversely – mean that we must reject all critical questioning from the West. There are other arguments which cautiously avoid such risky premises and raise thoughtful questions about the efficacy of the family itself. For instance, it has been suggested that the duties regarding love and care are built on the basis of a *well-functioning* family (Chan, 2004). Only a well-functioning family can always come to a consensus that will maximise both individual and familial benefits. Unfortunately, this is not always the case in reality. Healthcare professionals find additional ethical challenges when caring for those elderly parents who have lost their only child. With no surviving children, such parents lack a legitimate surrogate. While individuals in this group are allowed to make decisions on their own, it is considered less morally or socially satisfactory since the entity of the family is impaired or absent.

Furthermore, there are also questions regarding the justification of family autonomy. It has been suspected that, in the modern age, the decisive role of the family is not solely legitimised by Confucian (bio)ethics. In detail, the requirement for harmony (*He*) in Confucianism proposes a primary rule of avoiding conflicts in interaction (Li, 2013). In hospital settings, a harmonious relationship is also expected between healthcare professionals, the patient and the family. While preservation of a harmonious relationship is still demanded amongst stakeholders, it has been argued that this move is not driven by virtues, but by self-preservation. Raposo (2019) claims that the reason the patient is obedient to the family's calls in decision making is due to a concern about costs. At present, it is usually the family, and primarily the spouse and adult children, who pay the bill for any treatments (Tsai, 2008; Hui, 2008). The patient may therefore worry about losing familial financial support if he or she disagrees with the family (Ding, 2010). Moreover, there appear to be increasing cases of litigation (Ding, 2010) and violent attacks (Xu, 2014; Jiang *et al.*, 2014) against healthcare professionals in China. These unpleasant events are usually stimulated by families' dissatisfaction regarding a poor prognosis or the low cost-effectiveness of treatments (Wang, 2009; Liebman, 2013). To avoid such hazards, healthcare professionals can be inclined towards honouring families' opinions and consequently overlooking what the patient might want or need.

In general, it seems that the Confucian conception of family autonomy has still not been well accepted in the Western world. Some of the criticisms appear to be driven by the assumption of the universality of principlism and liberal secular ethics, for which further justification of their premise is required. Other questions regarding the composition of the family and the underlying motivation of family autonomy tend to be pertinent and useful. If these questions can be soundly addressed, the role of the family as a decision-maker can be further affirmed.

4.2.1.3 *A Trend of Confluence?*

After the critical comparison, it seems that, while there are considerable commonalities identified between the East and the West, distinctions persist. At this point, it needs to be highlighted that bioethics has always been dynamically evolving, and any analysis should account for this. In this section, some important changes in both Confucian bioethics and principlism are indicated to show there might be a trend of confluence.

Firstly, familial participation is not unique to Confucian cultures. On the contrary, it is routine worldwide that patients and healthcare professionals consult family members for advice and support (Nie and Fitzgerald, 2016; Raposo, 2019). In European countries, it is strongly encouraged to consider and balance the family's attitudes and opinions equally to the patient's, especially when caring for dying patients (Metselaar and Stolper, 2015). Supported by Hegelian theories (Hegel, 1976), the unique intimacy and natural bond of love between the patient and the family can justify the family's 'equal' position during information gathering at least (Birchley, 2015). However, in Anglo-Saxon models, there is a limit to familial power and participation in medical decision making. A medical decision cannot be made entirely on the basis of families' perspectives, since their perspective may not be in the patient's best interests (Horn, 2015).

Furthermore, the prominent individual(istic) personhood embedded in principlism has also been transformed into a more relational conception. However independent an individual can be, the fulfilment of his/her identity and rights cannot be separated from the social environment in which s/he resides (Kymlicka, 1990). Therefore, sole self-determination in decision-making seems to be incomplete, as it would inevitably undermine the social relations and networks underpinning individual interpretations of a 'good life' and a 'good death' (Woods, 2007*b*,*c*). As an alternative to individualistic personhood, a communitarian stance is sometimes suggested in Western bioethics. Only by giving emphasis to shared knowledge and societal backgrounds, can the practice of individual autonomy be properly understood (Woods, 2007*b*). Furthermore, the awareness of social conditions can also help healthcare professionals to better demarcate the content of a 'good life' (MacIntyre, 1981). Such a conception is aligned with the spirit of palliative care proposed by Saunders (1995). Primarily, in Saunders' vision, the hospice, and palliative care delivery in general, should be a community that is bound by *'shared values and common purposes'* (Woods, 2007*b*, p. 94). The interpersonal relationships of patients should be taken into account in order to arrive at a more precise understanding of their best interests. As Saunders wrote:

> *'Our choices do not take place in a purely individual setting ⋯I believe we can and should constantly reiterate that this is the way to respect patients' and families' true needs. Their autonomy must be seen in the context of society as a whole'* (Saunders, 1995, p. 44).

This turn in Western bioethics seems to be more compatible with the familist personhood constructed in Confucian bioethics. The mutual concern with relationships and social networks, centred on the patient, may be able to accommodate and unite these two distinctive philosophies.

In addition to such adjustments in the West, there are also changes occurring in Chinese societies. Taking mainland China as an example, there has been significant Westernisation in the overall field of medicine in China. Modern medicine in China is a Western import. Dating back to the 19th century, there was a wave of revolutions, which attempted to stimulate social development in China by imitating the contemporary, more 'advanced' Western societies. The overall realm of hard sciences, including modern medicine, was constructed on this basis (Nie and Fitzgerald, 2016). Thus, the ideas underpinning the administrative structure, care delivery models and protocols operating today in Chinese hospitals largely have a Western root. Related to this project, the setting up of palliative care services in mainland China can be seen mainly as an adaption of the Western hospital-based model.

Furthermore, medical education and training in China has also been increasingly coloured by Western ideas. Chinese textbooks and curricula are usually designed with reference to their American counterparts (Weng *et al.*, 2011; Qian *et al.*, 2018). On graduation from Medicine, there is a commonality with (at least some countries in) the West in that Chinese medical students also take the Hippocratic Oath before receiving their licences (Zheng and Shi, 2016). Moreover, increasing numbers of medical graduates have experience of overseas training and education. This group inevitably absorbs such cornerstone concepts as 'autonomy' and 'quality of life' as understood in Western philosophy as well as medical or healthcare ethics (Chan and

Chan, 2006). Such concepts therefore influence the professionals practising in China. Gradually, such Western ideas are imperceptibly becoming embedded into Chinese contexts.

It has also been argued that concealing information from patients is not part of traditional Confucian bioethics. In the past, Chinese doctors were generally required to disclose an authentic diagnosis to the patient (Nie, 2011; 罗秉祥. 陈强立，张颖 (Luo, Chen and Zhang), 2013). The turn occurred in the importation wave in the mid-19th century, when paternalism from the ancient West was imported into China, alongside modern medical technology (Nie and Fitzgerald, 2016). The importation of paternalism led to nondisclosure of information to patients. Yet, the origin of withholding information may inspire a solution derived from the Western philosophy. After the transition to patient-centred care in the West, the awareness of patients' rights has also grown in China (Pelzang, 2010). To adapt to such transitions, a modified version of familism – moderate familism – has emerged. Moderate familism suggests that individual autonomy and family integrity can be achieved simultaneously (Fan and Tao, 2004; Cheng *et al.*, 2012). In addition, moderate familism has justified the deception of patients by reference to utilitarianism, rather than the Kantian position on lies, which sees deception as absolutely wrong. Instead, the nature of a lie should be assessed by reference to the underlying motive behind what is (not) said and the results of such (non-)disclosure (Zhang *et al.*, 2021). The argument then runs that, if providing limited or unreal messages to patients can effectively reduce patients' mental distress, then such deception should be considered ethically acceptable (Meyers, 2021). While moderate familism has not been thoroughly examined, its proposal suggests a new direction, which may further facilitate the convergence of Western bioethics and Confucianism.

By preserving a dynamic view of bioethics, it seems that the relationship between principlism and Confucianism has been developing into a more harmonious, cooperative one. It seems plausible that these two kinds of ethics can not only work in parallel, but also complement one another. Moreover, the new changes can also inspire unprecedented methods to address these commonly confronted yet variously experienced and resolved ethical challenges. Such a possibility indeed leads bioethics toward an exciting and hopeful future.

4.2.2 The Practical Toolkits

Moving from the theoretical to the practical realm, in this section, more practical methods for addressing challenges in clinical practice are explored. Unlike the theoretical base, a high(er) level of consistency has been identified in this section. Three aspects – respectively: the deliberation tools; the orthodoxy; and the clinical responses – are investigated to exemplify how the aforementioned ethical theories are applied in practice.

4.2.2.1 *Bioethical Deliberation Tools*

The first aspect, deliberation tools, is the one most closely related to ethical theories. While these tools aim at resolving practical challenges, they primarily focus on the theoretical justification of the action to be taken. The best established one seems to be the method of 'reflective equilibrium'. Reflective equilibrium was initially proposed as a way to bridge overarching theories and real-life cases. This term was firstly coined by John Rawls (1971) in his work, *A Theory of Justice*. Reflective equilibrium refers to a state when *'at last our principles and judgments coincide; and it is reflective since we know to what principles our judgments conform and the premises of their derivation'* (Rawls, 1971, p. 21). To reach this state, a thinker needs to examine the situation

> *'by going back and forth, sometimes altering the conditions of the contractual circumstances, at others withdrawing our judgments and conforming them to principle, I assume that eventually we shall find a description of the initial situation that both expresses reasonable conditions and yields principles which match our considered judgments duly pruned and adjusted'* (Rawls, 1971, p. 18).

In essence, this is a process of assigning weight to the competing values and precepts within the given situation. While each value is carefully weighted, the relevant moral principles can be rejected or justified accordingly and properly. Notably, a reflective equilibrium is neither fixed nor permanent. When new information is discovered, another round of balancing and analysis will be needed (Schroeter, 2004). In short, reflective equilibrium is a cycle of specification and balancing (Beauchamp and Childress, 2013). Each time the equilibrium is destabilised by additional conditions, a new cycle will be motivated.

Reflective equilibrium follows the epistemology of coherentism, which pursues a convergence among diverse principles and judgements (Beauchamp and Childress, 2013). However, it would be wrong to consider this a completely coherentist method. At the core of this method, Rawls (1971) suggests a foundationalist element. The theoretical basis of reflective equilibrium, namely 'considered judgements' have to be self-evident to some extent (McMahan, 2000; Nichols, 2012). In addition, reflective equilibrium also contains features of constructivism. As such, the arguments made from reflective equilibrium are not fixed but rather evolve in accordance with any changes in the overall environment. The reflective renewal of the moral justification after new thoughts have arisen implies that context can shape the construction of the final equilibrium (Daniels, 2016).

Reflective equilibrium is now a widespread method of moral justification in bioethics (Dickenson *et al.*, 2010*a*; Brannan *et al.*, 2012; 罗秉祥. 陈强立，张颖 (Luo, Chen and Zhang), 2013; Macauley, 2018). This type of mid-level theorising enables the incorporation of empirical fact into theory as an enhancement of credibility (Stout, 1988). Within the field of bioethics, reflective equilibrium is often adopted as the underpinning theoretical framework for resolving possible ethical challenges. This method aims at providing some systematic instruction to support healthcare professionals when confronting an ethically challenging case. With such assistance, the practitioners can feel more assured during their daily work. However, it needs to be highlighted here that this method is still far from perfect. One potential weakness is that reflective equilibrium does not explicitly illustrate how to decide the relative moral importance of relevant principles (Shafer-Landau, 2010). Furthermore, there is also no way to confirm whether the overall judgement is in a state of equilibrium and fully justified (Beauchamp and Childress, 2013). Consequently, the application of these methods may risk endless questioning.

Turning attention to the Chinese side, a similar practice-oriented approach is offered by 邱仁宗 (Qiu) (2012). It is a four-step paradigm, which looks like a close relative to reflective equilibrium. The first step is to identify the bioethical problems arising in practice. Then, the problems are analysed from a bioethical perspective, namely, by exploring the conflicting moral values. The third and the crucial step is to formalise the advice provided by bioethicists into official documents. In this final stage, 邱仁宗 (Qiu) (2012) urges bioethicists in China to broadly communicate with other disciplines, such as healthcare professionals, lawyers, scientists and policymakers. With such interdisciplinary communication, the bioethical theories can be evaluated by different specialists and, eventually, are capable of being transformed into guidelines, public policies or legislation. Notably, in this method, 邱仁宗 (Qiu) (2012) is inclined to consider bioethicists as the main stakeholders; specialists from other domains, such as healthcare professionals and others, are invited to contribute, but they are not required to bear the responsibilities of resolving bioethical challenges and evaluating bioethical solutions. This feature may differentiate Qiu's approach from reflective equilibrium, which arguably considers all the aforementioned roles to be relevant. Qiu's method is well structured. Nevertheless, how effective it is, and what kind of contribution it has made to the development of Chinese bioethics, is still undermeasured.

In general, two homogeneous approaches can be observed from the Western and Chinese bioethics. At essence, both philosophies recognise the importance of balancing the moral significance of competing principles and values. Referring back to the case studies in section 4.1.2 and 4.1.3, the analysis of both reveals attempts to assess the practical impacts, identify harms and benefits and assign moral significance to each principle (and/or value) on a case-by-case basis. While neither approach comes up with a definitive solution or alters the competition between principles within the equilibrium, the process seems to be a broad fit with the approaches of both reflective equilibrium and Qiu's method. The convergence of such methods may imply there might be more commonalities between principlism and Confucian bioethics than those already identified.

4.2.2.2 *Pedagogy*

Moving closer to palliative care practice, case studies appear to be the primary educational instrument in palliative care ethics (Schwartz *et al.*, 2002; Dickenson *et al.*, 2010*a*; Macauley, 2018; 陈小鲁，罗峪平 (Chen and Luo), 2020). This method is similar to the philosophical method, casuistry, which *'investigates a contemporary phenomenon (the "case") in its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident'* (Yin, 2015, p. 55). In other words, this method often offers a vivid description of a situation at the beginning and invites participants to explore and deliberate the challenges and their potential solutions. Case studies seems to be particularly suitable for palliative care since they derive from real-world practices. The authenticity of cases can encourage participants to be more involved in the discussion and in plotting the solution (Potter, 2015; Hoffmann, 2018). The 'naturalistic' or 'authentic' feature also offers control over the boundaries of the exploration, which can focus more in-depth and encourage critical thinking (Crowe *et al.*, 2011). Furthermore, for participants with little experience, case studies can familiarise them with the real scenarios that can arise, before they have to actually handle them in practice (Schwartz *et al.*, 2002). Such familiarity can then boost practitioners' confidence in practice.

Since ethical challenges arising in palliative care often concern quite sensitive topics, such as DNACPR or withholding and withdrawing life-sustaining treatments, more exposure to 'real' cases is deemed helpful and desirable by both healthcare professionals, medical students and instructors (Fineberg *et al.*, 2004; 陈小鲁，罗峪平 (Chen and Luo), 2020; Chung *et al.*, 2021). Indeed, this method has also been used to some extent in this dissertation (section 4.1.2 and 4.1.3). It seems that this method does not prevent sophisticated theoretical deliberation. Instead, the integration of reflective equilibrium/Qiu's balancing method with case studies can more vividly illuminate the process of ethical justification.

4.2.2.3 *Clinical Responses*

After exploring the theoretical realm, this section focuses on the solutions to ethical challenges that are frequently used in clinical practices. Two common solutions to addressing ethical challenges in palliative care are time-limited trials and family meetings. A time-limited trial is a medical care plan. This method refers to *'instituting a treatment with a clearly defined time frame, at which point its utility would be reconsidered'* (Macauley, 2018, p. 118). Time-limited trials are commonly used when patients and families demand apparently inappropriate, non-beneficial treatment (Macauley, 2018), or when the outcome – and perceived utility or futility – of such treatments cannot be firmly predicted (赵可式 (Zhao), 2016). Time-limited trials act like a buffer, helping (primarily) the family to prepare themselves psychologically and emotionally for the death of the patient. In a Chinese context, the involvement of time-limited trials appears to help settle the moral obligation of filial piety. The introduction of the trial can provide proof of the children's efforts and relieve the sense that they have abandoned the patient. The unsatisfactory outcomes of the first stage of the trial, if there are any, can then legitimate the withdrawal of other aggressive treatments.

The nature of a family meeting is implicit in its name. The aim of a family meeting is to begin and gradually facilitate communications between caregivers (healthcare professionals, family members) and care receivers (patients). Family meetings can offer an opportunity and a platform to build a trustful doctor-family-patient relationship. By doing so, misunderstandings and unrealistic expectations from both the family and the patient can be identified and clarified (赵可式 (Zhao), 2016). Family meetings are particularly pertinent to this research. Firstly, the family plays a crucial role for the patient with a limited life expectancy. Family meetings promote the inclusion of the family within care planning and decision-making, an aim that is widely endorsed (Metselaar and Stolper, 2015). Secondly, family meetings cohere with the family autonomy model prevalent in Chinese contexts. Moreover, in Chinese contexts, the inclusion of both the family and the patient can also encourage the patient to openly express their thoughts, worries and wishes (宁晓红 (Ning), 2020; 秦苑 (Qin), 2020). This may alleviate criticism of family autonomy as undermining patients' opinions.

The efficacy of these two approaches seems to be able to transcend cultural boundaries. At least speaking of reflective equilibrium, literature can evidence its adaption to both the Western and the Chinese contexts (Fan, 2010; Ives, 2014; Davies *et al.*, 2015). The adaptability of this method plus the similarity between reflective equilibrium and Qiu's balancing method may further suggest that the shared perceptions and values between the East and the West are prevalent and might exceed current acknowledgement.

4.3 Implications

As a response to the overarching research question (proposed in section 1.1), ethical challenges in Chinese cultures are partially shared with those of her Western peers. For instance, difficulties regarding truth-telling (Boog and Tester, 2007; Zhang *et al.*, 2015; Katz and Johnson, 2016; Wang *et al.*, 2018a) and requests for nonbeneficial treatments (Macauley, 2018) are reported by healthcare professionals around the world. Nevertheless, it has been argued that the challenging part is not necessarily the legitimacy of care provision, but sometimes the justification of the unavoidable adverse consequences brought by such care. Moreover, the ethical challenges arising from the concept of family autonomy in Chinese cultures seems more fundamental and cannot be neatly squared with the principlist approach of Western bioethics (Cheng *et al.*, 2012; Raposo, 2019). This identification of challenges other than the legitimisation of the provision of care highlights that while considering the 'ought' question – how Chinese healthcare professionals *should* anticipate and address these (Western-defined) ethical challenges, more premises are required to firstly respond to the ‘what’ question, namely what the term ‘ethical challenges’ stand for in Chinese contexts.

At a very basic level, the aforementioned bioethical challenges have been identified and classified using criteria derived from Western bioethics. Modern medicine in China is also heavily Westernised. Thus, the apparent consistency in the application of moral reasoning, education and clinical practice may be fallacious, as the underlying ideology of these aspects can be primarily homogeneous. On the other hand, it is possible that, in the Chinese view, ethical challenges are interpreted in a different way(s). During this project, I was trained and volunteered in palliative care wards in China. In my experience, it turned out that Chinese healthcare professionals were generally unfamiliar with the concept of ‘bioethics’ and with the idea of ‘ethical challenges’. Difficulties were frequently identified, but not under the category of ‘ethical challenges’. The vagueness of definition potentially raises two questions:

1. Are the ethical challenges identified by Western bioethicists regarded as ethical challenges in China?
2. More fundamentally, how do Chinese healthcare professionals define ‘ethical challenges’? Is it even considered necessary for Chinese healthcare professionals to have a clear definition of this concept?

Only by clarifying such basic concepts, can I further investigate whether and how these challenges (if that is the appropriate term) might best be addressed. Since there appear to be relatively few studies which focus specifically on bioethics and ethical challenges arising in practice in China, additional efforts should be made in this field.

Firstly, the literature surveyed regarding family autonomy primarily emerged between 2000s and 2010s, so may be slightly outdated. In addition, the literature is largely written by bioethicists, who explore the relevant practices from primarily theoretical perspectives. According to my experience volunteering on palliative care wards in China, I have yet to see a family participating in medical decision making in the dictatorial manner suggested by the previous accounts of familism. The healthcare professionals also play an active role in listening to patients’ voices and encouraging effective communication between them, the patient and the family (陈小鲁，罗峪平 (Chen and Luo), 2020; 宁晓红，李佳颐 (Ning and Li), 2021). While the term ‘autonomy’ has rarely been mentioned, there appears to be increasing awareness of, and respect for, patients’ wills, wishes and opinions among healthcare professionals.

In reality, harmony (*He*) is no longer a tool to avoid burdensome consequences (Raposo, 2019), but an ideal and a goal of clinical practice in palliative care. Chinese palliative care specialists increasingly value a harmonious familial relationship between the patient and the family. To achieve this goal, it is a compulsory premise of most Chinese palliative care wards that the patient must be informed about their diagnosis. In this case, the ethical challenges related to truth-telling and breaking bad news may be less likely to arise. While arguments are still unavoidable, negotiation via a family meeting is always encouraged. The anticipated outcome is that the patient, the family and healthcare professionals can clarify misunderstandings and differences in their expectations, and eventually reach an agreement. Neither the patient, the family nor the physicians are considered to be dictating the final decision. The family is still an inseparable part of Chinese medical decision making, yet this new model is apparently becoming common. Moreover, the last ten years have also witnessed the rapid development of training on medical ethics and bioethics in China (赵可式 (Zhao), 2016; 谌勇毅 (Chen), 2020). The maturation of training and education implies that new concepts and conceptions may appear. Overall, the situation has changed significantly, but new research is needed to fully understand and explore how, currently, the family engages in the decision-making process at the end of the patient's life.

Secondly, while debate pitting Western bioethics against Confucian bioethics has been running for at least a decade, most of the discussion has been more theoretical than practical or empirical. Bioethics is in essence applied ethics, and the utility of both bioethics should be examined in real-life scenarios. Therefore, in addition to theoretical reasoning, further empirical research is required to assess the relationship between Western bioethics and Confucian bioethics.

Taking all these factors into consideration, a fruitful next step would involve 'empirical bioethics' research. An empirical bioethics project is indicated in this context because it is designed to concretise (bio)ethical theories under specific conditions (Borry *et al.*, 2006). Different from traditional philosophical bioethics, empirical bioethics is not only supported by abstract theories, but also *'has methodological roots in the social sciences and uses methods such as case studies, surveys, experiments, and participatory observation'* (Borry *et al.*, 2006, p. 51). The inclusion of these quantitative and qualitative approaches (and data) implies that conclusions are derived (at least in part) from real-life experiences, which – it is suggested – can produce more pragmatic advice for clinical practice. In addition, the employment of these data also appears to align with the increasing prevalence of an evidence-based approach in medical research (Borry *et al.*, 2006; Ives *et al.*, 2017).

This kind of empirical bioethical research appears to be capable of seeking answers to the previous two questions regarding Chinese healthcare professionals' definition and identification of ethical challenges through the collection of empirical evidence. In essence, a qualitative empirical bioethics project would best enable us to understand and explore palliative care ethics in China. Rich data could be gathered via (for example) semi-structured interviews. Such research could reveal insights into real-life cases, which might support – or indicate revisions to – existing rules and practices (Mbugua, 2012).

Importantly, qualitative research methods, compared to quantitative methods, are more sensitive to context (Mbugua, 2012; Creswell, 2014). Undertaking qualitative research should enable a clear focus on distinct (cultural) approaches in China. It should, accordingly, have the potential to detect nuanced differences derived from the distinct backgrounds of the participants, who might be a range of stakeholders in palliative care. In addition, such research could shed light on how healthcare professionals in China construe the concepts of 'bioethics' and 'ethical challenges'. As perspective-led research, qualitative methods can allow more flexibility and subjectivity, bringing a richness to the findings and subsequent analysis (Gilbert, 2001; Bryman, 2012).

As such, I propose a follow-on, empirical bioethics PhD study as the next step towards fully answering the questions explored in the current project. The follow-on study would initially build on the theoretical findings in the current project. Thereafter, interviews with stakeholders would offer insights into the ethical challenges Chinese healthcare professionals face during their daily practice of palliative care and how these challenges are and should be addressed, for example, in relevant training.

In terms of overall design, the follow-on study could follow the Bristol 'empirical bioethics' research framework. This framework has three phases, which cover the whole process from initial theoretical research to empirical research, to combining all of the findings to issue practical (and ethical) recommendations (Huxtable and Ives, 2019). The first stage is to *map* the existing literature and identify documented problems or theoretical perspectives. The second stage, *framing*, aims to further explore in-depth the findings from the first stage via qualitative research, such as via interviews. For example, approximately 40 healthcare professionals from China could be recruited for one-to-one semi-structured interviews. The possible questions to explore include: how these participants understand the concept of 'ethical challenges'; what kinds of ethical challenges they have encountered; what kinds of training they have received to deal with these challenges; and how do they feel (e.g. prepared, confident, unsure, etc.) when being required to handle these challenges.

This final stage aims at deliberating the findings and *shaping* recommendations for (for example) practice improvement and theoretical development. Some sort of 'bridging' methodology will be needed to bring the theoretical and empirical elements together. This is a complex matter, especially because some argue that, while empirical evidence can offer strong support to the field of bioethics, it cannot necessarily generate normative criteria or any 'ought' claims (Borry *et al.*, 2006). This complexity would be further explored in the proposed follow-on study.

I originally intended this (MScR) project to involve an empirical (qualitative) element, but this was ultimately prevented by the pandemic. This project was therefore desk-based but its findings show that an empirical bioethics project is indeed now needed. Based on the observations above, I have prepared a draft protocol for the proposed follow-on PhD study (Appendix C).

The empirical study planned at the next step aims to complete the research cycle of empirical bioethics. This goes beyond a purely theoretical answer, placing emphasis on how the relevant theory can appropriately inform clinical practice. Only by paying careful attention to theory *and* to practice can bioethics be truly regarded as an ‘applied’ ethics.

Chapter 5

Conclusion

This research has explored the implications of Confucian bioethics in Chinese contexts via comparison with the dominant Western approach to bioethics – principlism. The comparative analysis focused on the practice of palliative care. To provide background, the history, terminology and delivery of palliative care in the two cultures was introduced. It was clearly revealed that, regardless of developmental progress, the conception of ‘palliative care’ is not consistent. The conceptional tension then leads to obstacles in demarcating the scope of palliative care services (Guo *et al.*, 2012; Radbruch *et al.*, 2020). Other common challenges in palliative care delivery include the uneven distribution of resources (谌勇毅 (Chen), 2020; Hui and Bruera, 2020; 于世英 (Yu), 2020), the concentration of the service in specialist, hospital-based institutions (Bayly *et al.*, 2021; Fang, 2020; 赵耀辉，张泉，王梅 (Zhao, Zhang and Wang), 2020), inadequate training for relevant professionals (Chung *et al.*, 2020; 罗峪平，张正，李雯 (Luo, Zhang and Li), 2020; Kurita and Larkin, 2021) and underrepresentation of non-medical disciplines in the palliative care team (Ning, 2018; 宁晓红 (Ning), 2019; 于世英 (Yu), 2020; 秦苑 (Qin), 2020; Bayly *et al.*, 2021). Since palliative care has a shorter history in China, the aforementioned challenges appear to be more significant there, compared to its Western peers.

Against these background observations, the focus then turned to the construction of ethics in these two cultural settings. Palliative care ethics in the West appears to be a synthesis of Christian ethics and liberal secular ethics. The Christian heritage has shaped palliative care as a morally motivated service with high regard for the sanctity of life (ten Have and Clark, 2002). A ‘good death’ in this setting is construed as a natural death (Woods, 2007*a*). In line with the increasing secularisation, secular ethics also now plays a more significant part in

Western palliative care ethics (Randall and Downie, 2006; Cherny and Portenoy, 2021). The most dominant ethical approach in the West – principlism – has been considered as a standard response to the ethical challenges in palliative care, and clinical practice in general (Arras, 2010; Rauprich, 2012; Beauchamp and Childress, 2013; Sommerville, 2013).

In Chinese cultures, by contrast, the mainstream approach appears to be Confucianism. As a complex of philosophy, religion and political ideology, Confucianism has been embedded in every aspect of Chinese peoples' lives. The outstanding features of Confucianism are its relational nature and the familist duty of filial piety (Hui, 2002; Fan, 2006; Chen, 2013; Wong, 2020). These features have given the family a decisive role in medical decision making. In addition, Confucian bioethics adopts a holistic conception of individual health (Tu, 2002; Fan, 2002) and prioritises the principle of 'do no harm' in clinical practice (Qiu, 2011). Notably, this ethos is largely aligned with palliative care ethics in the West.

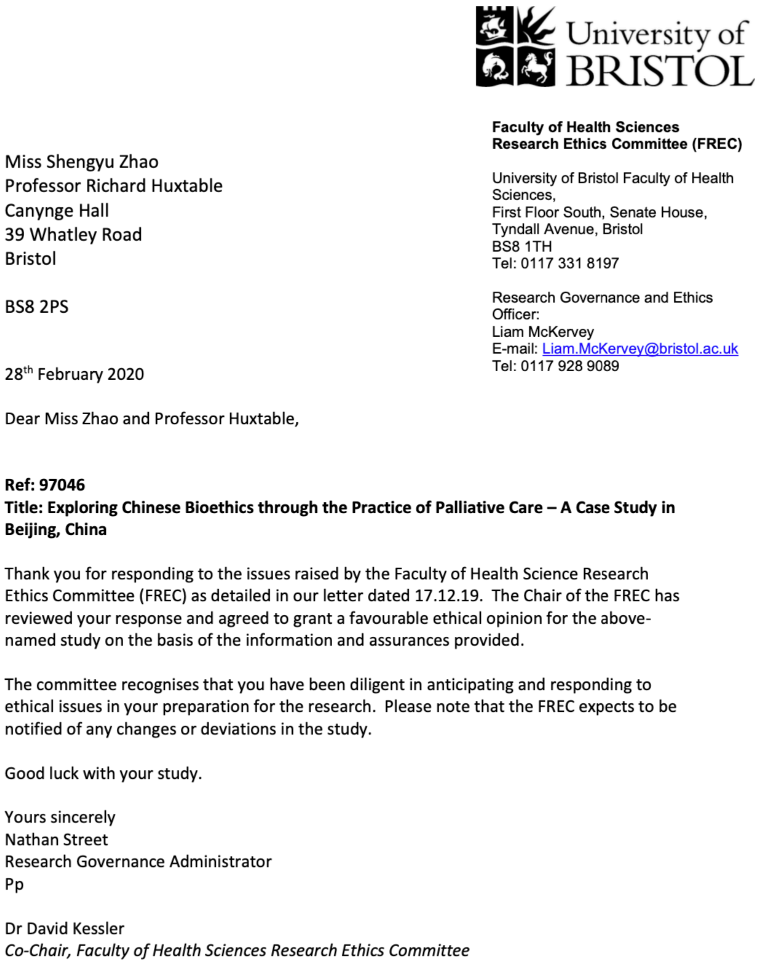
After setting up the background knowledge and theoretical foundation, a critical comparison was undertaken between the two kinds of bioethics and their responses to ethical challenges. Primarily, the challenges arising in practice – and even the responses to them – remain highly homogeneous. For example, the ethical challenges related to truth-telling and medical futility appear to be prominent in both the East and the West (Chiu *et al.*, 2000; Li, 2013; 陈小鲁, 罗峪平 (Chen and Luo), 2020; Schofield, Dittborn, Selman and Huxtable, 2021; Schofield, Dittborn, Huxtable, Brangan and Selman, 2021). Similar moral reasoning procedures – reflective equilibrium and Qiu's balancing method – can also be identified (邱仁宗 (Qiu), 2012; Beauchamp and Childress, 2013). The pedagogy of case studies and clinical responses of time-limited trials and family meetings are also common to both cultural contexts (Schwartz *et al.*, 2002; Dickenson *et al.*, 2010*a*; Macauley, 2018; 陈小鲁，罗峪平 (Chen and Luo), 2020). Moreover, there also appears to be a trend towards the confluence of these two distinct cultures: contrary to the supposed individualism of Western approaches, the role of the family has been promoted and increasingly emphasised in the West (Nie and Fitzgerald, 2016; Raposo, 2019); while, in the opposite direction, Westernisation has extended further into the East (Weng *et al.*, 2011; Qian *et al.*, 2018).

Nevertheless, divergence persists in the theoretical realm. The central role of the family in Chinese contexts has not been entirely accepted by Western scholars. In contrast to the homogeneous responses to ethical challenges, the unsettled role of the family wondering between Chinese cultures and Western philosophy then raises the question that whether the current conception of 'ethical challenges' in China, and in Chinese cultures in general, is incomplete if not imprecise. This research (and much of the literature cited here) used principlism and other Western philosophies as its reference point (Hui and Bruera, 2020; Zhang and Min, 2020). Modern medical services and education in China are also heavily Westernised (Weng *et al.*, 2011; Qian *et al.*, 2018). Therefore, the coinciding solutions might be a result of Westernisation, rather than derived from Confucian bioethics.

The essential question regarding what Confucian bioethics considers to be an ethical challenge(s) – and whether this concept can capture or speak to Chinese healthcare professionals' experiences – is, as yet, unanswered. Since the area is rapidly evolving, existing studies appear quickly to become outdated. New research, particularly empirical research, is needed in order to respond to such questions. As a result, and in conclusion, this project has proposed that qualitative empirical bioethical research is now required to fill the gap that has been identified. Thinking of the poem presented at the beginning, the future research is expected to take a look of the mountain of bioethics from a different angle. With richer experiential data collected, there seems to be a chance to depict the 'real outlook' of the Confucian ethics and its relationship with Western thinking.

APPENDIX A

Ethics Approval Acquired during MSc by Research



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Miss Shengyu Zhao
Professor Richard Huxtable
Canynge Hall
39 Whatley Road
Bristol

BS8 2PS

28th February 2020

Dear Miss Zhao and Professor Huxtable,

Ref: 97046
Title: Exploring Chinese Bioethics through the Practice of Palliative Care – A Case Study in Beijing, China

Thank you for responding to the issues raised by the Faculty of Health Science Research Ethics Committee (FREC) as detailed in our letter dated 17.12.19. The Chair of the FREC has reviewed your response and agreed to grant a favourable ethical opinion for the above-named study on the basis of the information and assurances provided.

The committee recognises that you have been diligent in anticipating and responding to ethical issues in your preparation for the research. Please note that the FREC expects to be notified of any changes or deviations in the study.

Good luck with your study.

Yours sincerely
Nathan Street
Research Governance Administrator
Pp

Dr David Kessler
Co-Chair, Faculty of Health Sciences Research Ethics Committee

Appendix B

Introduction of Common Ethical Challenges in Palliative Care

B.1 Advance Decision-making

In the context of palliative care, advance decision-making, including advance directives or decisions and advance care planning, primarily focuses on the refusal of treatments (Dickenson *et al.*, 2010*a*). In line with the principle of respect for autonomy, a competent (or capacitous) adult is entitled (in the words of an older legal ruling in England) to *'reject any [medical] advice for reasons which are rational, or irrational, or for no reason'* (*Sidaway v Bethlem RHG* [1985] All ER 643). A competent adult is depicted as an individual with sufficient competence or capacity to '*comprehend and retain information, believe in the validity of the information and weigh up the information*' for decision-making (Dickenson *et al.*, 2010*a*, 12). Where the refusal of treatment is made in advance of losing capacity, this might be formally documented in an advance directive, 'living will', or – according to the Mental Capacity Act 2005 in English law – an 'advance decision to refuse treatment'. Such an advance statement (whether in a document or communicated by other means) states a patient's decision(s) regarding certain treatments they would not accept if, at a future date, they are judged to be incompetent (Randall and Downie, 2006). For instance, the patient's requests may concern '*CPR, the preferred place of death, and state preferences for additional medical interventions such as intubation, ventilation, comfort measures, dialysis, and use of antibiotics and other medications*' (Chin, Menon, Berlinger and Chan, 2017). During care planning, healthcare professionals are compelled to follow advance refusals of treatment, where there is evidence of these having been made. Notably, the obligation to follow advance directives is only bound to negative requests, namely *refusals* of treatment. Active requests for additional treatments are not included in this duty and might be rejected (Dickenson *et al.*, 2010*a*, 12).

Making a decision in advance is suggested to have multiple advantages. First of all, it can offer clear instructions to healthcare professionals and therefore facilitate the achievement of patients' wishes in practice (Randall and Downie, 2006). Second, the reduction of unnecessary treatments can prevent the waste of scarce medical resources. Third, advance decision-making can act as a useful guide to the family or other surrogates when they are asked to make a decision for, or contribute to a decision on behalf of, the patient in that person's 'best interests'. An advance directive, for example, can reveal the patient's understanding of their best interests and can therefore relieve the uncertainty and stress experienced by the proxy decision-maker (Macauley, 2018).

The ethical challenges arising in this category concern the time lag of the application of advance directives, the validation of their authenticity and potential conflicts with the wishes of the patient's family. The foundational problem of advance directives and other forms of advance decision-making is that they are made for use in the future. Respect for patients' advance directives and care planning aligns with respect for the principle of respect for autonomy. Yet, when such directives apply, the decision-maker will be incompetent and thus lacks autonomy. At this moment, his/her current thoughts cannot be consulted or confirmed, which raises questions about how healthcare professionals should respond if there is reason to suspect that the patient has changed his/her mind but has not formally expressed this (Dickenson *et al.*, 2010*a*). Moreover, even where patients have made formal expressions, it is very difficult for the healthcare professionals to validate the accuracy of these documents. The patient must be competent at the point of making an advance decision. Nevertheless, there are few tools to verify whether a patient fully comprehends the information they receive and to what level (Randall and Downie, 2006). Consequently, the credibility of advance directives is open to question. What makes it harder to follow patients' advance decision-making is that documents like advance directives are not legally binding in many countries (Macauley, 2018). Healthcare professionals may override them if they are convinced such documents are against patients' best interests. However, if the advance directive is overridden, the practitioners then risk violating the principle of respect for autonomy.

The participation of the family also appears to be problematic, especially when the patient becomes incompetent. When the family discards a patient's choices or proposes contrary opinions, healthcare professionals may find difficulty in determining whose views to follow (Randall and Downie, 2006). This contradiction can be amplified by the lagging application of advance directives. Since patients' wishes cannot be confirmed, following the family's ideas may put practitioners in the danger of unfulfilling patients' wishes.

B.2 Communication

This category includes the ethical challenges presented by truth-telling, especially breaking bad news, and obtaining informed consent. Communication is essential to imparting information, obtaining the patient's opinion and securing their informed consent. A crucial goal of communication in palliative care delivery is to ensure the open awareness among the patient, the family and the professionals. Open awareness is seen as a key feature of palliative care (and, indeed, modern medicine in general). By knowing more pertinent information, it is suggested that the patient is better able to understand his/her current situation, and therefore able to make the decisions best serving his/her interests (Woods, 2007*a*). In addition, the duty of candour is an occupational obligation for healthcare professionals. Failure to fulfil this duty may lead to punishment, stigmatisation or even cessation of one's professional career (Beauchamp and Childress, 2013).

Since telling patients the truth can be both mandatory and beneficial, there has been strong opposition towards providing false information to patients (Dickenson *et al.*, 2010*a*). Initially, lying, or dishonesty, is deemed a moral failure in itself (Widdershoven, 1996). Hiding key diagnostic information is also an explicit violation of the basic healthcare professionals' occupational duty of fidelity. However, as the backbone of traditional medical ethics, paternalism regards withholding diagnosis from patients as common, legitimate and considerate of patients' feelings (Xue *et al.*, 2011). While paternalism has been gradually regarded as inappropriate as the focus has shifted to individual autonomy and patient-centred care, this potential harm still persists. Blunt truth-telling may inflict undesirable mental and spiritual distress upon patients, which can be seen as a breach of the principle of nonmaleficence (Begley, 2008; Zhang and Min, 2020). If addressing this challenge from the perspective of validation theory, the real situations – the truth – is less concerned compared with patients' feeling. Instead of insistence on the fact, what ought to be done, according to the validation theory, is to assist patients to make sense and create meaning of their current lives (Widdershoven, 1996).

The main competing principles in this challenge appear to be the principle of respect for autonomy and the principle of nonmaleficence.

B.3 Confidentiality

To protect patients' confidentiality is one of the elementary occupational duties of healthcare professionals. To have one's confidentiality maintained is also a legally protected human right. This action can be justified from two aspects. First of all, it is in line with the principle of protection of privacy. Related to this, respect for patients' privacy can help them to better practice their autonomy in decision-making (Dickenson *et al.*, 2010*a*). Secondly, the protection of patients' confidentiality is a facilitator of the (ideal) trusting relationship between a patient and the professionals caring for him or her (Schwartz *et al.*, 2002).

Nevertheless, there are exceptions when it is necessary to breach patients' confidentiality. When the confidential information may incur danger to the patient (e.g., self-harm, self-mutilation or suicidal behaviours) or to other people and/or the wider community (e.g., infectious diseases or crimes), the professional concerned either may, must or should pass the information to the relevant authority (Schwartz *et al.*, 2002; Dickenson *et al.*, 2010*a*). The disclosure of patients' private and confidential information can also be justified if such disclosure is ordered by a court. A more contested case would be disclosure within the professional team or to colleagues. Indeed, seeking advice from other specialists is common and acceptable in clinical practice. However, to what extent the patient's information can be revealed needs cautious consideration (Schwartz *et al.*, 2002).

Essentially, the violation of confidentiality can be equivalent to the violation of autonomy. The disclosure of personal information will inevitably undermine the autonomous choice made by the patient. The key to the problem therefore lies in the justification of whether the principle of nonmaleficence and the protection of the greater good can and should override individual rights. This judgement may be extraordinarily difficult to make in the Western world, where the rights and interests of the self-determining individual have particular – even primary – importance (Pastrana *et al.*, 2008).

B.4 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

While DNACPR can be a clinical decision, here it refers to the autonomous decision made by a competent patient or by their surrogate if the patient is incompetent and thus unable to make such a decision (Dickenson *et al.*, 2010*a*; Macauley, 2018; Cherny *et al.*, 2021). By making this decision of DNACPR, the patient can refuse to receive CPR. A common reason to make a DNACPR decision is that the patient or the surrogate believes that the outcome of CPR will not improve the patient's quality of life, and may even worsen it (Dickenson *et al.*, 2010*a*)). This reason is well accepted by many healthcare professionals, and they also consider it a legitimate ethical justification of DNACPR in medical decision-making (Association *et al.*, 2001).

Nevertheless, some proponents of a sanctity of life approach are strongly against such a decision. Firstly, these proponents argue that the 'quality of life' is not clearly defined in the DNACPR. Especially in the situation when the patient falls unconscious, clinical practitioners and the surrogates, usually the family, may have competing ideas of what a life with quality means to the patient (Dickenson *et al.*, 2010*a*). The possibility of maintaining some quality of life is regarded as a credible reason to reject DNACPR. Moreover, CPR might offer a chance, however slim, of survival and recovery. DNACPR as an explicit denial of this chance is therefore deemed a violation of the commitment to the sanctity of life (Randall and Downie, 2006). Another criticism of DNACPR concerns the conceptions of 'unbeneficial', 'inappropriate', 'extraordinary' or 'futile' treatments. These conceptions are quite consequentialist since they mainly focus on the outcome of treatments. Yet, the problem is that there is no rigorous measurement of how the inappropriateness or futility of treatment can be calculated (Dickenson *et al.*, 2010*a*). Accordingly, there is always a risk that the efficacy of CPR is wrongly justified in individual cases, and the acceptance of DNACPR can thus cause harms to the patient.

In this ethical challenge, it seems that the principles of beneficence and nonmaleficence can contradict one another. The principle of respect for autonomy may be prioritised, but it too can still be overridden, if the potential harm of DNACPR is believed to outweigh the benefit of letting the patient die.

B.5 Euthanasia and Physician-assisted Suicide

Euthanasia concerns '*the doctor's action to perform the final, fatal act*', while physician-assisted suicide refers to the doctor's action to '*supply the patient with the means or the information they need to perform that final action themselves*' (Dickenson *et al.*, 2010*a*, 21). Both topics are amongst the most widely debated in bioethical literature (Borry *et al.*, 2006). In the philosophy of palliative care, there is a strong resistance to both euthanasia and physician-assisted suicide (ten Have and Clark, 2002; Woods, 2007*a*). In addition, in many countries worldwide, neither of these two actions are deemed lawful. Nevertheless, euthanasia has been legalised in such countries as the Netherlands, Switzerland and certain states in the US, and the list is growing. Such legalisation then fuels the debate on the legitimacy of these practices.

The case for allowing euthanasia and physician-assisted suicide is mainly based on the principle of respect for autonomy. Indeed, as clearly stated in the Dutch law, euthanasia should and must be voluntarily proposed and well considered by the patient (Janssen, 2002). However, the principle of beneficence may also come into the play. If either euthanasia or physician-assisted suicide is permitted, it should be regarded as the last resort for unbearable conditions with no cure (De Haan, 2002). The right to request these interventions is also considered by some to be an extension of the right to life – a right which, they argue, can be waived (No 2346/02 *Pretty v UK* [2002] 35 EHRR 1).

Nevertheless, euthanasia and physician-assisted suicide involve the active action of killing, which is undeniably unethical according to some, meaning neither can be soundly justified. Even if one believes that the right to life can be waived, this need not ground a right to die that automatically imposes on professionals a duty to kill (Callahan, 1987). Furthermore, the definition of the keywords in the premises are highly subjective and lack consistent assessment criteria. For example, to what extent can patients' choices be judged 'well-considered'? How much information must patients receive? What kinds of symptoms or conditions can be classified as 'unbearable'? Can – or should – these unbearable conditions be addressed by alternative means, such as palliative sedation (discussed further in the following section)? Another question would be whether the symptoms should be limited to physical suffering? Is mental distress a sufficient basis for a request for euthanasia or assisted suicide (Huxtable and Möller, 2007)? Opponents and proponents continue to offer conflicting answers to such questions, which indicates how ethically contested and challenging these practices are.

B.6 Family Participation in Decision-making

Family participation in the decision-making process is not exceptional: healthcare professionals are encouraged to involve the family in care planning and decision-making, and to value their opinions (Pellegrino, 1992; Metselaar and Stolper, 2015; Raposo, 2019). The presence of family members is also believed to be emotionally supportive of, and comforting to, the patient (Nie and Fitzgerald, 2016). However, what induces ethical challenges is the 'overinvolvement' of the family – they may, for example, make a decision to withhold some or all information from the patient (Raposo, 2019; Cherny, 2021). This action primarily impairs the patient's autonomy and has collateral consequences on informed decision-making and informed consent. Therefore, in the Anglo-Saxon culture, the role of the family is commonly seen as complementary, rather than decisive (Horn, 2015). Nonetheless, in Mediterranean countries, Eastern Europe and Asia, where familism has significant impact, the Western conception of autonomy does not seem to be appropriate (Pellegrino, 1992; Wong, 2020). Such conflicting views not only prompt further thinking about the proper response to a family's requests, but also about how Western bioethics can adapt to different cultures. This point is particularly pertinent to this project, in which China is essentially a familist country and Chinese healthcare professionals express various understanding of the role of the family (and, indeed, the meaning of 'ethical challenges').

B.7 Pain Relief and Symptom Management

The ethical challenges prevailing in the provision of pain relief and symptom management again derive from the need to balance harms and benefits (and thus honour the principles of beneficence and maleficence). In detail, symptom management lies at the heart of palliative care, although some of efforts to manage symptoms they can have potentially serious side effects. For example, one of the most frequently used painkillers – morphine – may cause pain, nausea, vomiting and respiratory depression (Randall and Downie, 2006; Macauley, 2018). In rare cases, morphine might even shorten patients' life (Dickenson *et al.*, 2010*a*). Some healthcare professionals suggest that the relief of pain or other critical symptoms can outweigh these side effects, as they can also bring psychological and spiritual comfort to the patient. Nevertheless, the possibility of these consequences risks violating the principle of nonmaleficence.

In addition to the side effects, the introduction of symptom management may also negatively impact the effectiveness of other treatments. Such problems have become increasingly significant since palliative care has gradually been integrated into the early stage of illness trajectories, at which point the patient is still receiving curative treatments (Woods, 2007*a*). While pain relief is a core element of palliative care, it perhaps should not be prioritised over any other treatments regardless of the influence on patients' wellbeing. As such, how to measure, compare and balance the potential harms and benefits brought by symptom relief can present ethical challenges.

B.8 Palliative Sedation

Palliative sedation refers to '*the use of sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness*' (de Graeff and Dean, 2007, 68). In practice, palliative sedation must be a last resort and ideally undertaken with the patient's informed consent (Macauley, 2018). The major difference between common symptom management and palliative sedation is that palliative sedation aims at diminishing a patient's consciousness as a means to alleviating distress. Therefore, in addition to the challenges presented by symptom management (e.g. hastening death and side effects), the introduction of palliative sedation will unavoidably weaken, if not terminate, patients' competency and thus ability autonomously to participate in decision-making.

A second ethical consideration relates to the influence of sedation on patients' quality of care. While patients are put to 'sleep', it seems hard to tell whether their quality of life is maintained, improved or actually worsened. In fact, for many patients and professional bodies, the lack of awareness is deemed as unacceptable since it diminishes the quality and meaning of the patient's life (Steinhauser *et al.*, 2000; Association *et al.*, 2001). Following such perspectives, the introduction of palliative sedation then does not seem to bring any visible benefits. Moreover, there are also suggestions that pain, or other types of suffering, might not be adequately addressed by palliative sedation. Yet, patients become incapable of expressing their distress after they have been sedated. An observational study suggests that the level of pain can increase even after the operation of palliative sedation (Gélinas *et al.*, 2011). This finding raises questions regarding the primary goal of palliative care. In general, the efficacy of palliative sedation seems to be built on the principles of beneficence and nonmaleficence. Since neither its benefits nor its harms are entirely clear, the ethical justification of palliative sedation remains a challenge.

B.9 Requests for Futile/Inappropriate/Nonbeneficial Treatments

In this section, the focus is on life-sustaining treatments. Life-sustaining treatments include (but are not limited to) antibiotics, mechanical ventilation, dialysis, advanced cardiac life support and medical administration of nutrition and hydration (Macauley, 2018; Kon, 2021). The primary aim of life-sustaining treatments, as its name shows, is to prolong patients' life expectancy. Both the provision of, and requests for, life-sustaining treatments commonly take place at the end of a patient's life.

Ethically, there continue to be debates about when such treatment should (not) be provided or continued. The term 'futile' (and 'futility') was first used to highlight the slim chance of meaningful survival that such treatments might sometimes present (American Thoracic Society, 1991). Yet the idea of 'meaningful survival' remains contested, due to conflicting interpretations. Sometimes, in the literature, a distinction is drawn between 'futile' and 'inappropriate' treatments (Youngner, 1988; Society of Critical Care Medicine, 1997). Futile treatments refer to those that do not provide physiological benefits or that are likely to fail to fulfil their physiological goals. Inappropriate treatments, in contrast, more obviously involve and invite values-based judgements, for example by healthcare professionals. Gradually, the terms 'inappropriate' (Kon, 2021) and 'nonbeneficial' (Macauley, 2018) have become more frequently used.

Nonetheless, a consensus still cannot be reached in terms of the classification of 'inappropriateness'. Healthcare professionals may refuse requests for life-sustaining treatment if they believe the potential benefits perceived by the patient or the family are overweighed by the likely harms (American Medical Association, 1999; Association *et al.*, 2001; World Medical Association, 2005; Canadian Medical Association, 2014). No doubt these professionals can form appropriate judgments regarding the clinical aspects of inappropriateness or futility. However, this is not merely a clinical judgment: it also involves a value-based judgement, which may come into conflict with a patient's autonomous choice or the opinion of their family. In palliative care, the patient's autonomy has been ranked top, and practitioners are required to satisfy the patient's and the family's wishes as much as possible (Macauley, 2018). Notwithstanding this, in such a case, professionals are expected to override certain requests in order to maintain or improve patients' quality of life. Ethical challenges can nevertheless arise if such commitments conflict with the views of the patient and/or their family, and the resulting conflicts can even trigger moral distress on the part of practitioners (Macauley, 2018; Kon, 2021).

B.10 Withholding and Withdrawing (Life-sustaining) Treatments

Challenges can also arise in relation to how best to characterise what is involved in withdrawing or withholding (life-sustaining) treatment. According to the General Medical Council (2002) and the American Medical Association (2016), there is little difference between withholding and withdrawing life-sustaining treatments. The essence of these two kinds of behaviours can both be summarised as 'omissions'. A justification resonating with this definition is that the removal of these life-sustaining treatments can leave the patient to die a *natural* death (Randall and Downie, 2006). This justification is aligned with the Christian heritage in palliative care, which favours the natural course of life over intentional interventions that shorten or end life (Woods, 2007*a*).

Notwithstanding this, the behaviour of withholding or withdrawing treatments is considered by some to be an active decision and behaviour (Macauley, 2018). In this vein, the nature of withholding and withdrawing life-sustaining treatment cannot be interpreted as passively 'letting go'. The fine line between an omission as 'letting die' and an action as 'killing' seems to be blurred, particularly when we consider withdrawing treatment. As a response, the doctrine of double effect may be applied to address the intention (to maximise or at least maintain the quality of life) instead of the outcome (possibly hastening death). Nonetheless, since the intention cannot be effectively monitored or verified, this question remains (Dickenson *et al.*, 2010*a*).

Ethical challenges regarding withholding and withdrawing life-sustaining treatment can occur when patients are incompetent. As previously noted, disagreement may arise among the healthcare professionals and different family members. The difficulty concerns how to balance the benefits and harms brought by these treatments and their influence on patients' quality of life as well as the quality of their death. Treatment withholding and withdrawal typically only becomes legally and ethically acceptable when this is judged appropriate by reference to the patient's quality of life (Dickenson *et al.*, 2010*a*; Macauley, 2018). Whether such judgments are sound ideally needs the patient's confirmation. However, if the patient is not capable of making autonomous choices, we likely lack their view about which decision may serve the patient's wellbeing. This point can be linked back to the discussion on DNACPR. Similar ethical challenges arise regarding the risk of violating a patient's wishes. In addition, debates about whether (or not) to remove life-sustaining treatment can also be impeded or complicated by the vague definition of 'quality of life', and by extension, the quality of death (Woods, 2007*a*; Dickenson *et al.*, 2010*a*). Without a convincing understanding or justification of such fundamental questions, the decision to stop or not provide life-prolonging treatments may be contested, particularly by those who uphold the sanctity of life.

Appendix C

PhD Research Proposal

C.1 Research questions

Aim: to explore the ethical challenges Chinese healthcare professionals face during their daily practice of palliative care (PC) and how these challenges are and should be addressed in relevant training.

Objectives:

1. To understand how ‘ethical challenges’ and similar terms (‘bioethics’, ‘ethical duty’, ‘moral virtue’, ‘human right’) are commonly understood by Chinese healthcare professionals;
2. To identify the ethical challenges Chinese healthcare professionals have encountered during their provision of PC;
3. To identify the training these professionals have received related to ethical challenges;
4. To explore the extent to which Chinese healthcare professionals feel they are prepared by existing training for encountering ethical challenges during the provision of PC; and if any changes can be made to increase their confidence and preparedness.

C.2 Why the idea is important

This project is deemed significant and necessary as firstly, the study of PC in China has been established quite recently, with limited data and experiences. Therefore, the data collected can increase the diversity and coverage of existing studies. Secondly, the project will explore the cultural transferability of bioethics. The applicant will elaborate if and how the western bioethical concepts, with predominant influence in practices and education, can be effectively applied in a distinctive culture.

This research has its theoretical root in a hypothesis:

- There is a mismatch between the ethical challenges Chinese healthcare professionals have met during their daily practices of PC and the ethical training they have received.

The focus will be on ethical issues encountered by care-providers during PC provision, particularly during the end-of-life period. How to make ethical end-of-life decisions has been highly sensitive and controversial due to the intrinsic conflicts embedded in the philosophy of PC. There are currently three pairs of conflictual concepts wedded to the development of PC: heterogenous values (Sandman, 2005) versus the singular definition of a good death (Saunders, 1996) in PC; the growth of individualism (Laurie, 2006) versus consensus-based medico-legal care model (Randall and Downie, 2006); and the attempt to imitate 'natural death' versus the intentional, purposive medical treatment (Woods, 2013). How such tensions are experienced and navigated in practice also seems to be obscure (Morley, Bradbury-Jones and Ives, 2019). Thus, the aim of this research is to explore such conceptual conflicts in real-life cases. The applicant expects to firstly verify the existence of these conflicts in up-to-date scenarios, and then acquire empirical knowledge about the nuanced factors involved. The research will help to ascertain whether or to what extent the different theories and concepts align with lived reality.

The applicant (who is Chinese) further narrows her focus to mainland China, given her interests in the transferability of bioethics between cultures. As a different culture from the West, China has long featured in debates about ethical universalism and relativism (Paul, 2001; Döring, 2003; Nie, 2011). For bioethics in the end-of-life period, many argue that the fundamental differences between Asian and Western cultures - Confucianism and familism - can lead to different understandings of bioethics and PC, and result in distinctive ethical challenges arising (Shi, 2011). Nevertheless, China has adopted several care models and training schemes from the West during its development of PC (Michio *et al.*, 1999) to compensate for inexperience and inadequate infrastructures (Pang *et al.*, 2011). It is therefore important to investigate whether the aforementioned conceptual contradictions of PC apply within Chinese society, how they affect the ethical challenges, and thus types of training and approaches to care that are provided in China, and what changes, if any, should be made.

Here the term 'ethical challenges' adopts the definition of '*traditional negative stress symptoms that occur due to situations that involve ethical dimensions and where the health care provider feels that she/he is not able to preserve all interests at stake*' (Kalvemark *et al.*, 2004,

p. 1082-3). The detailed challenges in practice tend to be multi-faceted, categorised as end-of-life decision-making issues, patient autonomy issues, justice issues, conflicts among parties, professional conduct, truth-telling and religious or cultural issues (DuVal *et al.*, 2004; Molewijk *et al.*, 2015).

In previous literature, the term ‘ethical challenges’ has been interchangeably used with ‘ethical dilemma’ (DuVal, *et al.*, 2004), ‘ethical distress’ (Corley, 2002; Zuzelo, 2007) and ‘moral distress’ (Gjerberg *et al.*, 2010). Such variation suggests that the difficulties experienced by healthcare professionals have not been consistently summarised under one particular concept. In addition, ethics, or particularly bioethics in this context, is believed to be culturally sensitive, whose interpretation can vary in different socio-cultural environments (Wang, 2010). This sensitivity implies that the corresponding challenges in this field can be distinctive to particular cultures. In this case, while the applicant will use Kalvemark *et al.*'s (2004) definition as a guideline, she will leave the investigation open and expect to derive inductive conclusions of what ‘ethical challenges’ mean in Chinese society from the data.

The project includes qualitative research in various institutions and settings, covering four major cities with established hospital PC teams –for example, Beijing, Guangzhou, Zhengzhou, Shenyang. Such institutional and geographical diversity will ensure that the research produces wide-ranging insights into practice in socio-economically advanced provinces. The focus is on professional participants, including medical professionals, as well as therapists, clinical psychologists, nutritionists, social workers and volunteers, which enriches the diversity of data and offers the possibility of exploring the influence and implications of interdisciplinary team working in PC provision.

C.3 Work leading up to this project

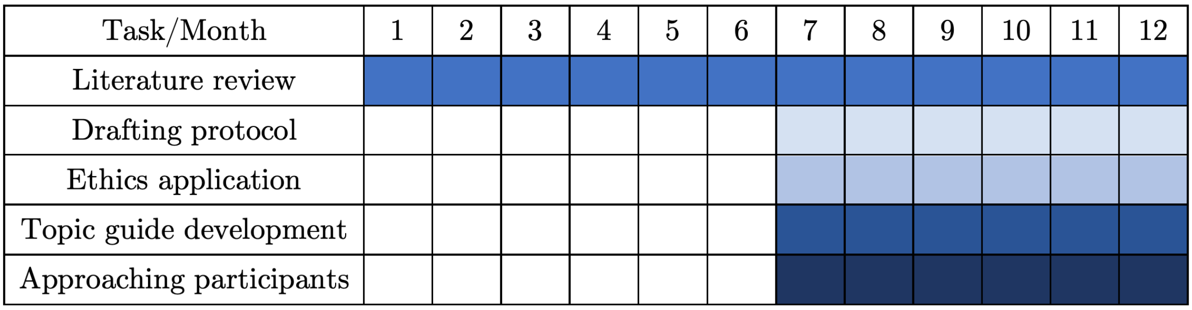
This work continues the theme of the applicant's Master's research (MSc-R) but significantly expands its theoretical and empirical scope. The MSc-R (completing September 2021) provides a preliminary exploration of “everyday” ethics in PC provision in China. Due to the COVID-19 pandemic, a small empirical element of the MSc-R was abandoned, and the remaining theoretical (desk-based) research element expanded. This PhD proposal builds on the preliminary work conducted in the MSc-R, taking advantage of the preparations for data collection (which received LREC approval), including networks established in China.

C.4 Research methodology

This is a three-year project, undertaken full-time by the applicant. As the research uses social science methods to investigate an ethical question, this project will adopt the Bristol “empirical bioethics" research framework. This framework identifies three key stages of empirical research: mapping existing literature and identified problems; framing and thus investigating practice through qualitative research; and, finally, shaping recommendations, by analysing and bringing together the literature and empirical findings, using an "empirical bioethics" methodology (Huxtable and Ives, 2019).

C.5 Timeline and milestones

C.5.1 Stage 1: Mapping the terrain (literature reviews)



Task/Month	1	2	3	4	5	6	7	8	9	10	11	12
Literature review	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Drafting protocol							🟦	🟦	🟦	🟦	🟦	🟦
Ethics application							🟦	🟦	🟦	🟦	🟦	🟦
Topic guide development							🟦	🟦	🟦	🟦	🟦	🟦
Approaching participants							🟦	🟦	🟦	🟦	🟦	🟦

Figure C.1: *Expected PhD Timeline of stage 1*

Stage 1 involves preparatory work, with milestones including the literature review and development of the empirical study e.g. the protocol, research ethics approval, and initial contact with potential participants.

C.5.1.1 Literature review

The applicant will start with an inclusive review, spending the first six months focusing solely on this work, and 12 months in total. The review will contribute background to the applicant's thesis. The purposes of this review are to map the existing issues within the fields of bioethics and PC in China and reveal the underexplored areas for further investigation. This critical interpretive review, which mainly aims at the identification and evaluation of existing key issues (McDougall, 2015), will capture empirical studies and theoretical contributions. Adapting from Dixon-Woods *et al.*'s critical interpretive synthesis (CIS) model, this review method is believed to suit the 'emergent and exploratory' research questions, which this research explores (2006, p. 3). Critical interpretive review also usefully captures a wide range of relevant literature, aiding in its comprehensiveness (McDougall (2015). The detailed process will follow the steps below, summarised by Birchley *et al.* (2020):

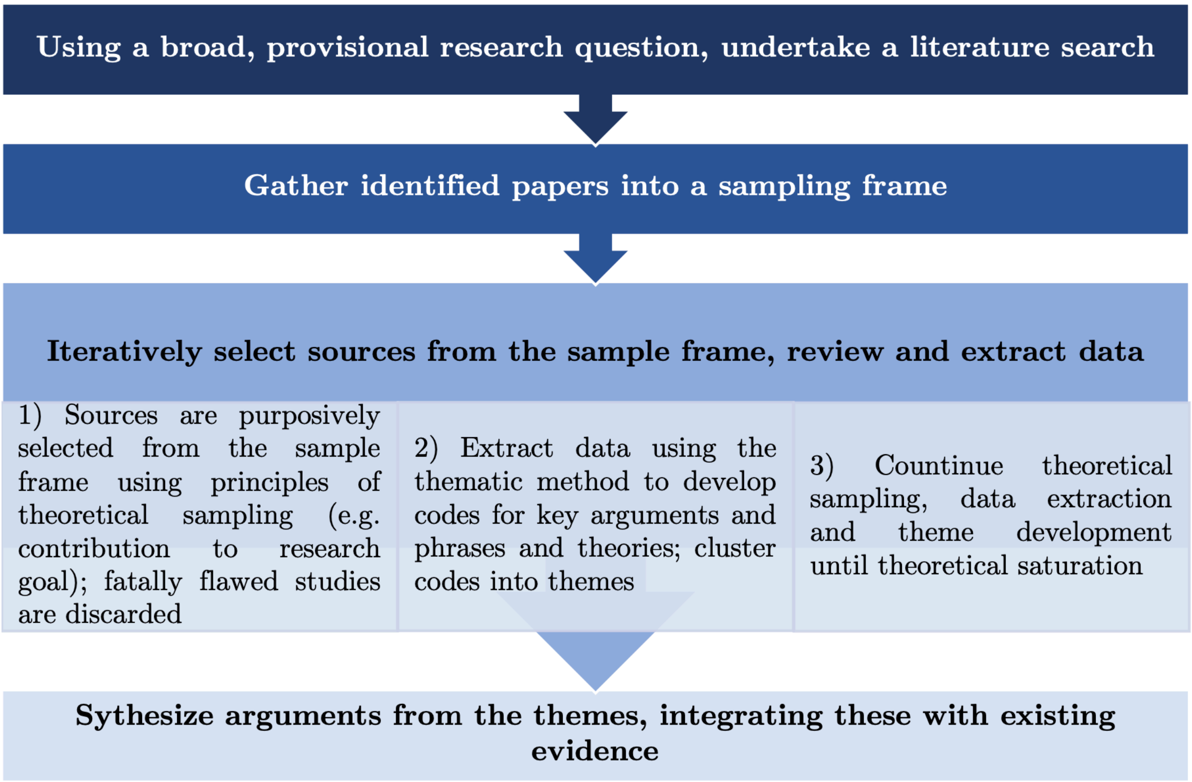
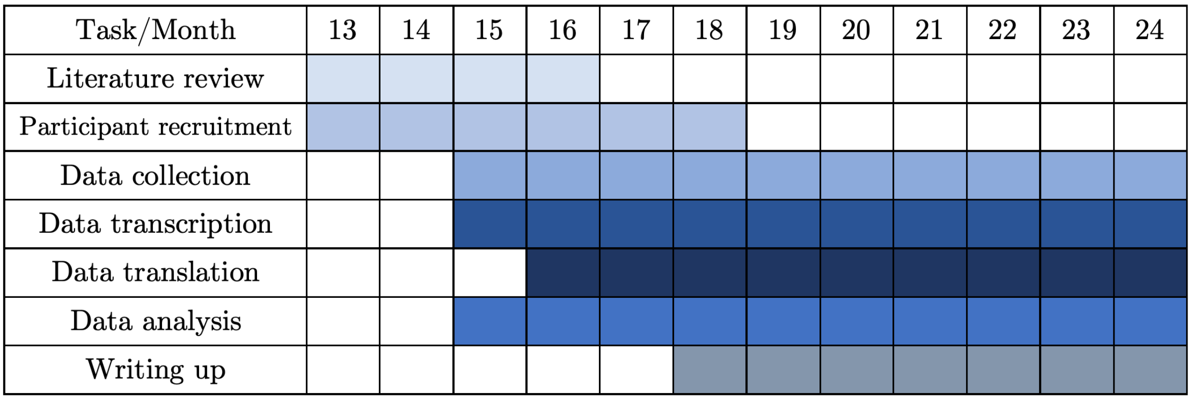


Figure C.2: *Model of Critical Interpretive Synthesis Development (Birchley et al., 2020, p. 80)*

C.5.1.2 Ethics approval(s)

The applicant anticipates producing the study materials and receiving institutional research ethics approval by month 12. The applicant will collect her data from settings based in China after acquiring ethics approval in corresponding institutions if the local institutional ethics committee(s) deem this necessary, while the project will be hosted and supervised by University of Bristol in the UK. Notwithstanding, according to the applicant's previous experience, research ethics approvals are complex to obtain as there is currently no collaborative ethics committee at either province or country level in China, and each institution has its own ethics committee and assessment procedure. As such, specific authorisation processes cannot be specified before the participants are identified. However, while the University of Bristol encourages ethical approval to be sought in the country where the research is to be conducted, in some cases ethics approval may be needed in the UK, and thus approval will be sought first from the University of Bristol faculty research ethics committee; please note that this was secured for the MSc-R and no further ethics approvals appeared to be required in Beijing, although COVID-19 prevented data collection at that time. Nevertheless, for the PhD, the applicant will seek and secure any necessary additional local approvals prior to her data collection process.

C.5.2 Stage 2: Framing (qualitative research)



Task/Month	13	14	15	16	17	18	19	20	21	22	23	24
Literature review	■	■	■	■								
Participant recruitment	■	■	■	■	■	■						
Data collection			■	■	■	■	■	■	■	■	■	■
Data transcription			■	■	■	■	■	■	■	■	■	■
Data translation				■	■	■	■	■	■	■	■	■
Data analysis			■	■	■	■	■	■	■	■	■	■
Writing up						■	■	■	■	■	■	■

Figure C.3: *Expected PhD Timeline of stage 2*

Informed by the findings from Stage 1, Stage 2 involves exploration of the “real world”, through qualitative data collection and analysis.

C.5.2.1 Population: size and inclusion criteria

40 interviews are intended, with numbers estimated using Malterud *et al.*’s (2016) model of information power. Participants will be sought from those practising in at least four major cities in different provinces in China. The sample size should help to capture diversity within and across these areas, given the novelty and breadth of the research question. Other qualitative empirical bioethics PhD studies have tended to interview approximately this number (e.g. those cited in Huxtable and Ives, 2019).

In terms of the selection process, the detailed inclusion criteria of suitable participants are listed below:

- Healthcare professionals (e.g. medical professionals, therapists, nutritionists, clinical psychologists, social workers, volunteers, etc.);
- Currently practicing or having previous experience working in PC (including, but not limited to, working as part of a specialist PC team/wards, if the host institution has such settings);
- Fluent Mandarin speaker;
- Willing and able to provide informed consent.

The focus here is on those in professional caring roles, rather than patients and families, given the likely sensitivities involved in exploring ethical challenges (the latter perspectives could usefully be explored in a follow-on study).

C.5.2.2 Source of participants and recruitment

All participants will be recruited by purposive and snowball sampling for their specific experiences of PC provision. The applicant will identify the qualifying institutes via the list created by a professional not-for-profit organisation based in Beijing, the Beijing Living Will Promotion Association (LWPA). After selecting suitable institutions, the applicant will contact the leading doctor of the PC team in the institution via her contact in LWPA. The leading doctor will be provided with materials about this project. With the leading doctor's permission, the applicant will be given access to the contact details of the rest of the team. Prospective participants will be contacted via phone call or text message. The leading doctor will also be invited to disseminate the materials and/or recommend any other suitable participants to the applicant.

LWPA is recognised as a leader of PC promotion in China. LWPA has long-term collaborations with several reputable hospitals and hospices in China and the UK, such as Peking Union Medical College Hospital, Shengjing Hospital of China Medical University in Shenyang, Ninth People's Hospital of Zhengzhou, Guangzhou Charitable Hospital and St Christopher's Hospice. This organisation provides voluntary companionship and emotional support for terminally ill patients. Occasionally, LWPA also offers training sessions for medical professionals who are interested in PC. LWPA has stable and reliable connections with PC settings and through them sufficient participants can be recruited.

C.5.2.3 Research instrument: interviews

Data will be collected through one-to-one interviews. Questions will be led by referring to a semi-structured topic guide of interview questions, developed in Stage 1. All interviews will be conducted in Mandarin to allow a nuanced and in-depth discussion of the cultural aspects in the ethical challenges that are encountered, as well as an understanding of how bioethical concepts are commonly translated, used and understood in China. The applicant will personally conduct the interviews, since she is a native Mandarin speaker.

The applicant plans to arrange interviews in the workplace but will be flexible and offer travel reimbursement if another location is more convenient for the participant.

As a culturally appropriate form of appreciation, all participants who take part in interviews will be given a small gift, consisting of university branded souvenirs. No cash payment will be involved.

C.5.2.4 Data analysis

Qualitative thematic analysis is considered the most appropriate method of data analysis for this study. As the purpose of this research is to explore (shared) ethical challenges and experiences, this approach allows space for rich details of values and feelings to emerge, while allowing the interviewer to remain in control of the overall rhythm and themes explored (Esterberg, 2002). Analysis will begin as soon as data is collected.

Notably, interviews in this research are designed to be conducted in a different language from the final thesis in which the results will first be presented. Therefore, the data analysis process of this project involves translation from Mandarin, the language used in interview, into English, the required language for final presentation. The detailed analysis procedure is shown as below:

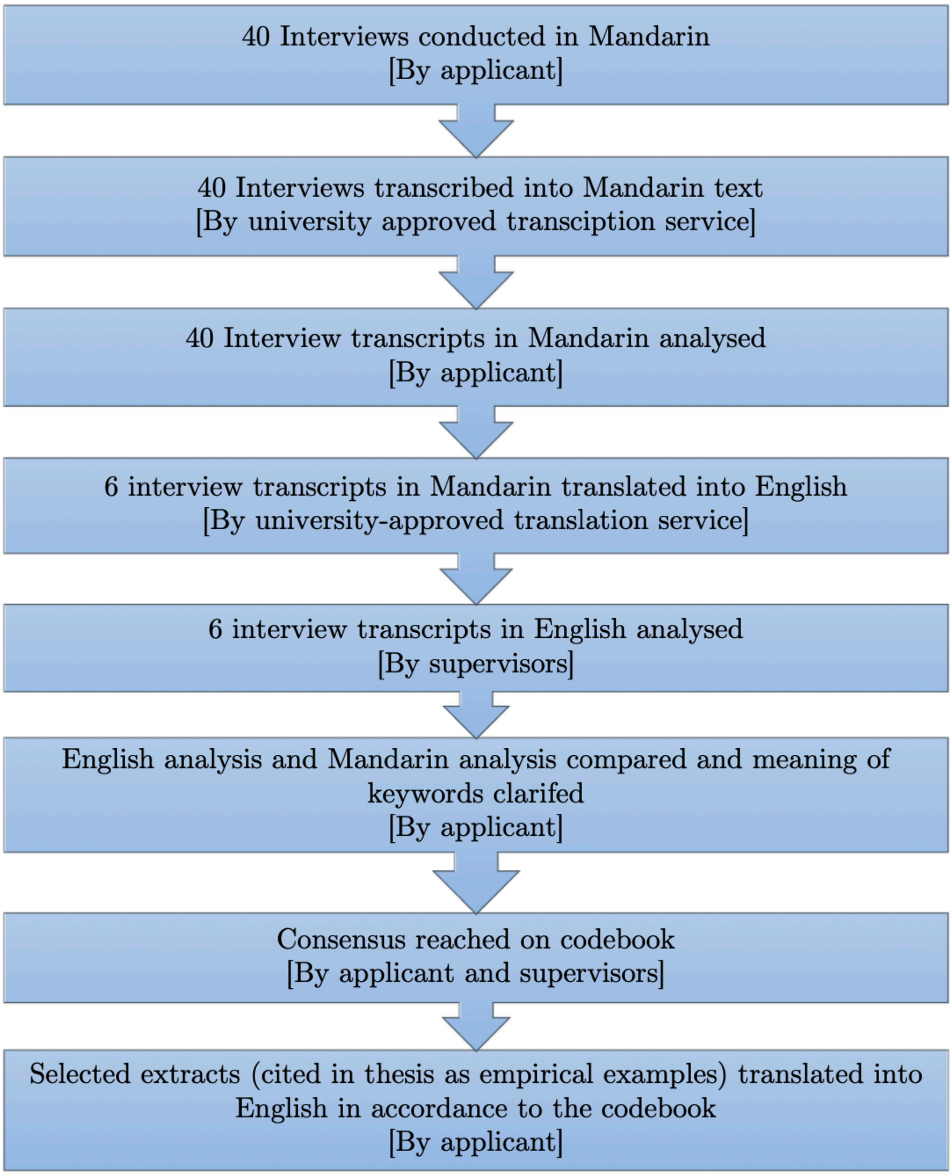
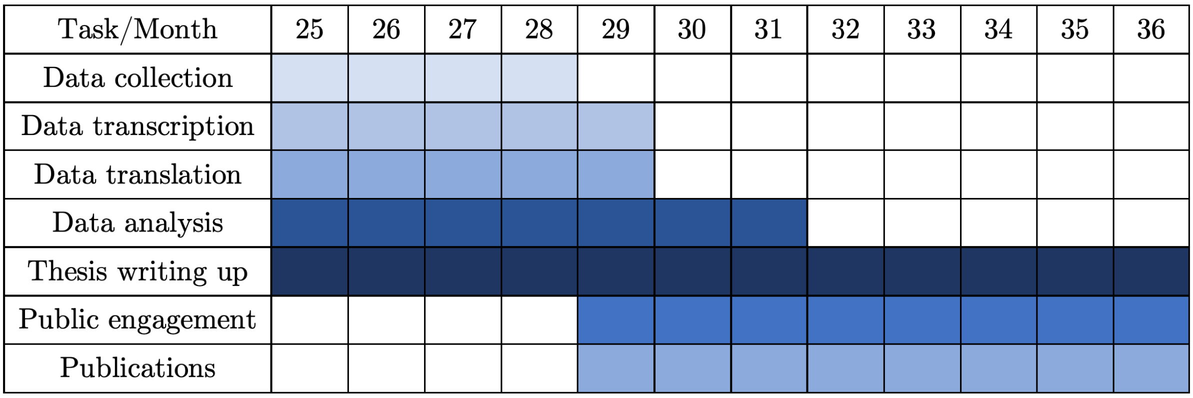


Figure C.4: *Data Analysis Process*

C.5.3 Stage 3: Shaping (making recommendations)



Task/Month	25	26	27	28	29	30	31	32	33	34	35	36
Data collection	■	■	■	■								
Data transcription	■	■	■	■	■							
Data translation	■	■	■	■	■							
Data analysis	■	■	■	■	■	■	■					
Thesis writing up	■	■	■	■	■	■	■	■	■	■	■	■
Public engagement					■	■	■	■	■	■	■	■
Publications					■	■	■	■	■	■	■	■

Figure C.5: *Expected PhD Timeline of stage 3*

In the final stage, the theoretical findings found in the framing stage and the empirical findings found in the mapping stage will be reconciled using an "empirical bioethics" methodology, specifically through the process of "reflexive balancing" (Ives, 2014). This is a process that involves the researcher iterating between their intuitions and the findings, resolving any conflicts by seeking the explanation with the greatest coherence within pre-determined boundary principles.

Other milestones in Stage 3 are finalising the thesis, publications/presentations and public engagement. The expected outcomes include: the applicant's PhD thesis; publications in relevant journals (e.g. Journal of Medical Ethics, Global Ethics, Chinese Medical Ethics and Chinese Medical Sciences Journal); brief report for non-academic audience in Mandarin and English, and posters, reports or presentations at conferences (e.g. International Association of Bioethics, Institute of Medical Ethics and Chinese Association for Humanistic and Palliative Care).

C.6 Relevance to scholarship, policy and practices

The project will provide new, original data regarding everyday ethics in PC in China, thus informing scholars in PC, bioethics and the social sciences. The findings will also inform policy and practice, by indicating how PC and training therein might be adjusted to better prepare professionals for practice in this field and specifically in China. The findings will enhance our existing knowledge about challenges in practice and how ethical challenges are framed and navigated and, complementing other international research into everyday ethics in PC, will enable cross-cultural comparison.

C.7 Bibliography

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