A systematic review and critical interpretive synthesis of public perceptions of palliative care

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Abstract

Introduction

Professional and public misperceptions about palliative care are common and may contribute to poor palliative care access in different settings globally. In this thesis, I aimed to better understand these public perceptions and the influences on them.

Methods

A systematic literature review and critical interpretive synthesis was conducted. Non-medical subject headings for palliative care and perceptions were used to search for relevant quantitative, qualitative, and mixed-methods studies in MEDLINE, EMBASE, PsycINFO, CINAHL and, Web of Science Social Science Citations Index Expanded and Conference Proceedings Citation Index from 1 Jan 2002 to 31 May 2020. Search results were screened against *a priori* inclusion criteria, data extracted, and quality appraised by two independent researchers. Data were analysed by narrative quantitative synthesis, qualitative thematic synthesis, and then combined in a critical interpretive synthesis.

Results

48/33985 studies from Europe, North America, Asia and Australasia were included (32 quantitative, 9 qualitative, 7 mixed methods), representing 32585 members of the public (aged 18-101 years; 54% women). Knowledge of palliative care was poor (especially for men, younger people, and ethnic minorities) with considerable variation in public perceptions. A perception consistent around the world is "palliative care *is* death". To some, this is euthanasia and giving up, to others it is comfort care allowing a natural death. Personal experience of palliative care improves understanding. In this context it is generally seen as good care offered by compassionate people – albeit still to be avoided until unavoidable.

Conclusion

Public understanding of palliative care is poor. Perceptions of palliative care are influenced by a triad of culture, socioeconomic position, and health literacy. To improve integration of a country's palliative care services and improve access to palliative care, an intervention to increase exposure to and education in palliative care that considers these factors is needed.

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Preface

This thesis comes after what has been a challenging time for both me personally and the world of healthcare in general. Despite these challenges, I started my academic clinical fellowship in palliative medicine (following a distinctly average but) successful interview at the Wolfson Palliative Care Research Centre, University of Hull. In this interview I stated I had dabbled in research throughout my varied career. This was challenged at the time and what I have come to realise is I had not previously ‘dabbled’ in research, rather I had been at the periphery looking in, wondering whether it was for me but never daring take the plunge, fearing both the unknown and that which did not come naturally. I feel this thesis and I hope future publication is evidence that I have now ‘dabbled’. I have grown, I have a better understanding of health services research, more importantly what I do not know and, that it is okay not to know. Despite the work being challenging, my aspirations and drive remain, and I hope the skills of self-awareness, discipline and intrigue persist for the long haul in my career.

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Declaration

I confirm that this work is original and that if any passage(s) or diagram(s) have been copied from academic papers, books, the internet or any other sources these are clearly identified by the use of quotation marks and the reference(s) is fully cited. I certify that, other than where indicated, this is my own work and does not breach the regulations of HYMS, the University of Hull or the University of York regarding plagiarism or academic conduct in examinations. I have read the HYMS Code of Practice on Academic Misconduct, and state that this piece of work is my own and does not contain any unacknowledged work from any other sources.

Chapter 1 Introduction

Access to palliative care is a stated human right (1). Palliative care is a mode of care that aims to reduce the symptom burden and improve the quality of life of patients with life limiting illness and their families. A common misperception of palliative care is that it is a form of healthcare exclusive to people in their last days or weeks of life (2, 3), whilst, in reality, it is applicable from diagnosis (4).

1.1 A brief history of palliative care

Prior to recent medical advances, the aim of medical treatment for the previous 2000 years was to ameliorate symptoms and relieve suffering, while the natural history of disease took its course to recovery or death (5). “Hopefully curing, helping without harming and keeping people comfortable”: this is in effect palliation (6) (p.206). The influence of advances in medical technologies in changing the focus of medicine from “caring” to “curing” has been highlighted (6). By the turn of the 20th century the search for the root causes and cures of illnesses became the focus of medicine, “with symptoms placed to one side and therapy directed at them denigrated” (5, 7) (p.430). Professional focus changed from holistic symptom focussed care to medical and surgical interventions to correct specific anatomical or physiological problems and save lives (6, 7). This led to escalating expectations among patients and clinicians, that cure was always possible with a corresponding neglect of the management of chronic diseases and care of the dying (6). A few physicians in the early 20th century identified this “deterioration” of practice (8) arguing that the relief of suffering by drugs, positioning and diet or by the simple act of presence should be fundamental to the training of all medical and nursing students (8). An anonymous author in the Journal of the American Medical Association, however, argued this lack of focus on cure was outside the mainstream, and that the obligations in care of the dying were “extra-medical” (9). Some felt that it was the focus on cure and the potential neglect of care that created a need for a revived specialty of palliative care (6).

The term hospice is often used synonymously with palliative care. Since the 11th century the concept of “hospice” referred to a place of hospitality for the sick and dying (as well as for travellers) (10, 11). The 18th and 19th centuries saw development of hospices run by religious orders, with a trend to care for patients with terminal diagnoses (12). In 1905 The Irish Sisters of Charity opened St Joseph's Hospice in London, it was here, in the 1950s that Cicely Saunders first worked as a doctor and researcher. At this time, these hospices provided nursing care for the terminally ill but only had minimal medical input.

The modern meaning of the word hospice came into use in the 1960s with Cicely Saunders founding St Christopher's Hospice in London. This is an institution committed to interdisciplinary education, research and excellence in clinical care (13) for patients irrespective of their religious faith or socioeconomic position. It was the scientifically based and patient-centred treatment, available in St Joseph's Hospice and later in St Christopher's that led to the development of a medical discipline (7). It was this new discipline, focussing on the relief of the physical, psychological, social, emotional and spiritual aspects of dying (14) that in 1974, Dr Balfour Mount described as "palliative care" (15). Although this term was disliked by Cicely Saunders (16), it was chosen ahead of "hospice care" due to the pejorative connotations associated with hospice in the French and Spanish speaking world, where hospice is a dysphemism for an institution housing destitute persons (17). While the term palliative care has gained acceptance around the world, over the years other terms have been used to describe the evolving concept (18).

1.2 Palliative care and end of life care definitions

As a concept, there is a view that neither palliative nor hospice care is understood by the public or healthcare professionals (19). This at least in part lies in the confusing plethora of terms used to describe an approach to care (18). "Terminal care," "total care," "end of life care," "care of the dying," "continuing care," "holistic care," "comfort care," "pain and symptom management" and more recently "supportive care" and "best supportive care" have all been used to describe this approach (18, 20-23). The focus of my thesis is how the general public understand and perceive what is meant by 'palliative care'. Prior to summarising the definitions of palliative care, it is best to consider some of the lexicon used to describe all, or facets, of palliative care.

End of life care is a term that has different meaning in different countries. In the UK, the NHS defines end of life care as care in the last months or years of life (24), in New Zealand it refers to the last days. Others define ‘end of life’ as a non-specific time period preceding a natural death from an illness or process that cannot be delayed by medical intervention (25) and interestingly, in the US, restriction of financing to those with a 6-month-or-less prognosis suggests end of life has a fixed, short time period (26). This term is often used synonymously with palliative care by service providers and governmental bodies which may lead to confusion (27). In providing this care, words associated with a finite time are used, such as, ‘pathway’ and ‘end’.

Terminal care is often used synonymously with end of life care, although historically used when a progressive disease or condition is the cause of a patient’s deterioration (26) and death is ‘not far off’ (28).

Care of the dying, a term often used by professionals, refers to care of patients who are ‘actively dying’. Actively dying has been defined as “The hours or days preceding imminent death during which time the patient’s physiologic functions wane” (29) (p.588).

In the context of palliative care, **hospice** was initially used to describe a building in which mostly dying persons received care but became a philosophy of improved care for dying persons (17). Most definitions of hospice describe it as “a philosophy, a system, a program or a facility” (18) (p.676). **Hospice care** can provide care for patients in inpatient units, day centres or outpatient settings (18). Hospice care is also associated with providing multi-disciplinary care for the wider community in which the hospices sit, caring for both patients and families up to and beyond death. Hospice care is closely linked with the entirety of palliative care, with one definition stating its purpose is to affirm life and death (30). It is a term that is most commonly used in the US where it refers to a specific, often home-based model of palliative care for those with a prognosis less than six months (17) often mutually exclusive with ongoing active medical care with many medical insurance companies. The term is often associated with fear and confusion (18).

While **palliative care** does involve all these facets of care, the focus is more than *just* care of the dying, it strives to provide care that improves the quality of life of patients and their families over the entire disease trajectory. In helping people live well until they die, different forms of palliative care exist.

Generalist palliative care is an approach to care provided to patients with serious disease in hospital or at home by specialist or generalist health care providers for whom palliative care is not their core responsibility and who are not trained in specialist palliative care. A palliative approach is focussed on the patient's wellbeing and symptom control over any disease modifying treatment. **Specialist palliative care** delivered by highly trained specialists in palliative care, encompasses hospice care (including inpatient hospice, day hospice, hospice at home) as well as specialist advice, support and care such as that provided by hospital palliative care and community palliative care teams. Specialist palliative care is available on the basis of need, not diagnosis for patients with complex physical or psychological symptoms that cannot be managed by their usual care team (24).

Supportive care is a relatively new term most frequently used in terms of cancer care. It is a broader concept than palliative care and in some centres it refers to the holistic care provided not just to those with a life-limiting illness but also to those living with the consequences of treatment of a serious but potentially curable condition, so called survivorship (18). It is defined by the National Institute for Health and Care Excellence (NICE) in the UK as an approach that, "helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease" (31).

In summary, there are differences and similarities among all these terms. All reflect an approach to care provided by an interdisciplinary team, focussing on quality of life; yet possibly with different scope (18). Hui *et al* suggest that chronologically "hospice care" sits at the end of someone's disease, with "supportive care" at the beginning, meaning, "palliative care" sits somewhere in between (18). They also note both hospice and palliative care are associated with a lot of stigma because of their association with death and dying but suggest that “supportive care” is gaining popularity as it is associated with less anxiety around mortality (18).

These multiple definitions complicate the issue of understanding. To simplify the scope of this thesis the focus was about the perception of “palliative care” – using this as an umbrella term, specifically including both generalist and specialist palliative care. I will discuss any findings in terms of perception of palliative care and only refer to the individual terms such as hospice or supportive care if that is how it is portrayed specifically in the literature to which I am making reference.

1.3 Exploring the definition of palliative care internationally

The word palliative comes from late Middle French, *palliatif* meaning that which relieves the symptoms of a disease or condition without dealing with the underlying condition. This in turn is an extension of the medieval Latin verb *palliare* “to cloak” (32). The Oxford English Dictionary defines palliative care as, “care for the terminally ill and their families, especially that provided by an organised health service” (32).

Cicely Saunders comments that the focus of palliative care has always been on living well until you die (7). Extended definitions of palliative care are provided by different countries as shown in table 1 and summarised in table 2. The commonalities in these definitions are that palliative care is for patients with serious conditions with the main aim to improve quality of life until death both for the patient and beyond death for the family. All but the Center to Advance Palliative Care (CAPC) (33) in the US, detail the specifics of managing the physical, psychological, emotional, social and spiritual needs of patients. The CAPC do mention “symptoms and stress” which may be all encompassing (33). All but New Zealand mention that palliative care involves the management of symptoms including but not limited to pain. The New Zealand definition uses the term ‘needs’ but neither mentions the word symptoms nor pain specifically (34). The Australians, Canadians and New Zealanders alongside the newer International Association of Hospice and Palliative Care (IAHPC) definition breakdown the psychosocial component further to include cultural obligations (34-37). The World Health Organisation (WHO), the European Association of Palliative Care (EAPC), CAPC, IAHPC and the Canadians detail the need for a team approach to care whereas it is not mentioned explicitly by the rest in their definitions (33, 36-39). Interestingly the normalisation of dying is only mentioned by the WHO, IAHPC, the UK and the EAPC definitions and conversely these same bodies mention that palliative care is about affirming life (37-40). The WHO, the IAHPC and the EAPC are clear on their definition that palliative care neither hastens nor postpones death but none of the other bodies are so explicit (37-39). The IAHPC is less explicit on the relief and prevention of suffering although palliative care is broadly defined as the care for patients with health-related suffering (37). The WHO comments that palliative care is applicable early in the course of an illness, in conjunction with therapies that are intended to prolong life (2), but the CAPC definition stands out as it is the only definition that explicitly comments palliative care can be provided <u>along with curative treatment</u> (33). More recently the consensus definition of palliative care provided by the IAHPC, whilst mentioning death, like the CAPC (although not explicitly stating), there is not a pre-requisite of having a terminal illness to receive palliative care (37). There remains a clear statement however, that palliative care is focussed on symptom relief and, that it neither hastens not postpones death but affirms life and aims to improve quality of life (37). The Indian Association of Palliative Care's (IAPC) definition is included for comparison as although healthcare is relatively under resourced in India, palliative care has been part of health care there since the 1980s. Only the IAPC definition refers to affordability of care (41).

There is significant overlap in these international definitions of palliative care which are useful when considering about what palliative care means to professionals, policy makers and the public, however the primary focus of this thesis will be with regard to the WHO definition and perception. Access to palliative care, as *per* this definition, is a stated human right with the United Nations Committee on Economic, Social and Cultural Rights, who comment that states are obliged "to respect the right to health and must not deny or limit equal access to preventive, curative, or palliative health services" (42) (p.21). It is my view that patients, carers, clinicians and policy makers do not fully understand palliative care and if they do not understand, the general public may also be oblivious to the purpose of both generalist and specialist palliative care, as defined by Dr Cicely Saunders is to facilitate "living until you die" (7). This lack of understanding is further emphasised by the evidence on public misperceptions and it these that I detail in the section after a reflection on the benefits of palliative care.

Table 1: International definitions of palliative care

Jurisdiction	Definition
The World Health Organisation (WHO)	“An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” Palliative care: • provides relief from pain and other distressing symptoms; • affirms life and regards dying as a normal process; • intends neither to hasten or postpone death; • integrates the psychological and spiritual aspects of patient care; • offers a support system to help patients live as actively as possible until death; • offers a support system to help the family cope during the patient’s illness and in their own bereavement; • uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; • will enhance quality of life, and may also positively influence the course of illness; • is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.” (38)
International Association for Hospice and Palliative Care (IAHPC)	“Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of lie. It aims to improve the quality of life of patients, their families and their caregivers. Palliative care: • Includes, prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence based. • Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care. • Is applicable throughout the course of an illness, according to the patient’s needs. • Is provided in conjunction with disease modifying therapies whenever needed. • May positively influence the course of illness. • Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process. • Provides support to the family and the caregivers during the patient’s illness, and in their own bereavement. • Is delivered recognizing and respecting the cultural values and beliefs of the patient and the family. • Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary). • Can be provided by professionals with basic palliative care training. • Requires specialist palliative care with a multiprofessional team for referral of complex cases.” (37)

Jurisdiction	Definition
National Institute for Health and Care Excellence (NICE) (UK)	"The active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. Palliative care aims to: • Affirm life and regard dying as a normal process. • Provide relief from pain and other distressing symptoms. • Integrate the psychological and spiritual aspects of patient care. • Offer a support system to help patients live as actively as possible until death. • Offer a support system to help the family cope during the patient's illness and in their own bereavement." (40)
The European Association for Palliative Care (EAPC)	"The active, total care of the patients whose disease is not responsive to curative treatment. Palliative care takes a holistic approach, addressing physical, psychosocial and spiritual care, including the treatment of pain and other symptoms. Palliative care is interdisciplinary in its approach and encompasses the care of the patient and their family. Palliative care should be available in any location: hospital, hospice and community. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death" (39)
The Center to Advance Palliative Care (CAPC), United States	"Palliative care, and the medical sub-specialty of palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment." (33)
Palliative Care Australia	"Palliative care is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness. Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social. Because palliative care is based on individual needs, the services offered will differ but may include: • Relief of pain and other symptoms e.g. vomiting, shortness of breath • Resources such as equipment needed to aid care at home • Assistance for families to come together to talk about sensitive issues • Links to other services such as home help and financial support • Support for people to meet cultural obligations • Support for emotional, social and spiritual concerns • Counselling and grief support • Referrals to respite care services Palliative care is a family-centred model of care, meaning that family and carers can receive practical and emotional support." (35)
Palliative Care in New Zealand	Palliative care is "care for people of all ages with a life-limiting illness which aims to: 1. optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs. 2. support the individual's family, whanau, and other caregivers where needed, through the illness and after death.

Jurisdiction	Definition
	Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life. It should be available wherever the person may be. It should be provided by all heath care professionals, supported where necessary, by specialist palliative care services. Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Maori, children and young people, immigrants, refugees, and those in isolated communities." (34)
Canadian Palliative Care	"Palliative care is a type of health care for patients and families facing life-limiting illness. Palliative care helps patients to achieve the best possible quality of life right up until the end of life. Palliative care is sometimes considered end-of-life care, with a main focus on comfort. However, it is increasingly recognized that a palliative approach, as part of health care is beneficial early on in serious and chronic illness. In Canada and around the world, quality palliative care: • focuses on the concerns of patients and their families; • pays close attention to physical symptoms such as pain, nausea, loss of appetite and confusion; • considers the emotional and spiritual concerns of patients and families; • ensures that care is respectful and supportive of patient dignity; • respects the social and cultural needs of patients and families; • uses a team approach that may include volunteers, social workers and spiritual leaders in addition to medical staff. Palliative care does not necessarily end when someone has died. Family members may need support as they grieve the loss of a loved one and try to manage numerous strains and stresses. Bereavement programs are often part of the comprehensive care offered as part of palliative care." (36)
Indian Association of Palliative Care (IAPC)	"Palliative care is the active total care applicable from the time of diagnosis, aimed at improving the quality of life of patients and their families facing serious life-limiting illness, through the prevention and relief of suffering from pain and other physical symptoms as well as psychological, social and spiritual distress through socially acceptable and affordable interventions." (41)

Table 2: The distribution of components of a palliative care definition

	WHO	UK	EAPC	IAHPC	CAPC	PCA	PCNZ	CVH	IAPC
Regard dying as normal	■	■	■	■					
Family support/bereavement	■	■	■	■	■	■	■	■	■
Holistic/total care		■	■	■					
Quality of life until death	■	■	■	■	■	■	■	■	■
Life threatening disease	■				■				
Life limiting illness	■	■	■			■	■	■	■
Prevent suffering	■								■
Relieve suffering	■								■
Individual needs based				■		■	■		
Care in any location			■	■			■		
Early identification/assessment (of symptoms)	■			■					
Active care		■	■	■					
Management of pain and other symptoms	■	■	■	■	■	■		■	■
Physical	■	■	■	■		■	■	■	■
Psychological	■	■	■	■		■	■	■	■
Social	■	■	■	■		■	■	■	■
Cultural				■		■	■	■	
Spiritual	■	■	■	■		■	■	■	■
Affirms life	■	■	■	■					
Neither hastens nor postpones death	■		■	■					
Live actively	■	■		■					
Team approach	■		■	■	■			■	
Applicable early in disease course	■			■				■	■

Abbreviations: WHO World Health Organisation; UK United Kingdom; EAPC European Association of Palliative Care; IAHPC International Association for Hospice and Palliative Care; CAPC Center to Advance Palliative Care; PCA Palliative Care Australia; PCNZ Palliative Care New Zealand (Ministry of Health); CVH Canadian Virtual Hospice; IAPC Indian Association of Palliative Care

1.4 The Benefits of a Palliative Approach

In many health systems, especially in high income countries, advances in medical technology has meant diseases that previously had a short prognosis have become chronic illnesses with a burden of symptoms and functional decline that worsen over years (43). In these health systems, a patient centred, holistic, palliative approach to patients with such diseases is beneficial to a patient's symptoms and quality of life (44). This approach alleviates suffering through focus on the physical, psychosocial, emotional, and spiritual well-being of patients and their families with specific evidence that this empowers patients and facilitates avoidance of the risks and costs associated with over treatment and hospitalisation (44). Access to palliative care more than four weeks before death reduces the cost of healthcare by a quarter and even accessing palliative care in the last seven days of life saves money (45).

In England and Wales 1% of the population die each year, approximately 500,000 people in 2014, of whom 75% had palliative needs (46). With a predicted 42% increase in the number of patients requiring palliative care by 2040 (46), in most healthcare systems, models of healthcare that integrate palliative care with other services will save money and more importantly, relieve suffering and improve the quality of life of patients and family with advanced disease (47, 48). Often in countries where palliative care is under developed however, there is a tendency towards more deaths from communicable disease, poorer nutrition and higher infant mortality rates (49). In these countries the life expectancy from diagnosis of a potentially terminal condition is relatively short, possibly reducing the benefit from adopting a palliative approach. As such, it has been hypothesised that as a nation's healthcare improves and deterioration from disease becomes more gradual there may be a "tipping point" where the benefits of an integrated palliative care service matches the relative need for life-prolonging therapies (49).

1.5 Misperception of palliative care

Despite the evidenced benefits to a palliative approach to care, there is considerable misperception as to the aims of palliative care (50). A fear of death and subsequent avoidance of discussion about what palliative care offers, may further the misperception of what palliative care is and can inhibit a palliative approach to care that would otherwise alleviate suffering of patients and families and improve quality of life.

1.5.1 Misperception of palliative care is a barrier to access

Despite the fact palliative care, as a stated human right, is an approach to care that both improves quality of life and saves the health service money, people do not access it or if they do, it is often only late in their disease (51).

Barriers to accessing palliative care services across the three WHO public health domains have been well documented and are summarised in table 3 (52).

Table 3: Barriers to accessing palliative care (52)

Domain	Barriers
Education	Lack of education/training
	The perception of palliative care as end of life care by healthcare providers and the public
Implementation	Inadequate size of palliative medicine-trained workforce
	Challenge of identifying patients appropriate for palliative care referral
	Need for culture change regarding palliative care across settings
Policy	Fragmented health care systems
	Need for greater funding for research
	Lack of adequate reimbursement for palliative care
	Regulatory barriers

Similarly, a 2014 review concluded that the most significant barrier to any model of palliative care is the widely held clinician perception that palliative care is end-of-life care (53). As such, the language we use is a potential barrier to the adoption of a palliative approach to care or early specialist palliative care referral from other medical specialties. Oncologists refer fewer patients to palliative care than may benefit, as they are concerned a referral would alarm patients and families (53) with some commentary suggesting that a name change to “supportive care” could reduce these fears and increase referrals to the service (52). It would be my concern that the misperception is likely to persist or recur. As the scope of care would be unchanged, it is not the name that is the problem, rather persistent misperception and the association of mortality with palliative care. Mount coined the term ‘palliative care’ to avoid the negative connotations associated with ‘hospice’, therefore any new name for palliative care may, in time, also carry negative connotations; “A Rose by any other name would smell as sweet” (11, 54). Tackling understanding and addressing misperceptions about palliative care has been identified as a possible way to facilitate a more frequent and earlier adoption of palliative care (55).

A scoping review published in November 2019 examining the knowledge, awareness and perception of palliative care in the general public over time (56) described 13 studies reiterating the understanding that public awareness and knowledge of palliative care was poor. The main perceptions of palliative care that persisted over time were that it was synonymous with terminal illness and end of life care.

1.6 Influences on public perception of palliative care

Acknowledging the potential impact of perception on access to palliative care, this section will consider some of the influences on public perception that exist.

1.6.1 Public policy

Access to modern generalist and specialist palliative care requires an understanding by both professionals and patients of what palliative care is, yet even among healthcare professionals an ambiguity regarding the concept of palliative care persists (57). To progress, palliative care requires public policy to engage with the integration of palliative care into health policy, education and training of health care professionals (58).

In the UK over the last decade there has been considerable government attention on "end of life" care, such as the Department of Health's End of Life Strategy 2008 (59) and the public health approach to "dying matters" (60). A recent review of UK healthcare policy not only identified the lack of priority put on palliative care but also identified that when it was considered, the focus was very much on "end of life" language (61). Out of 150 healthcare strategies identified, 78 mentioned end of life care, with the words "end-of" used 245 times. Similarly there were 180 uses of the word "death", "dying", or "die" and conversely "palliat*" was only mentioned 16 times in all 150 strategies (61). This focus on end of life care, while well-intentioned, may have furthered misperceptions by lay and professional alike that palliative care is *just* "care of the dying" leading to a fear of imminent death.

To try and counter this fear and improve the conversation, “dying matters” was set up by the National Council for Palliative Care (NCPC) in the UK to support the key messages coming from the UK’s 2008 End of Life Care strategy (62). The purpose being to raise public awareness of the importance of discussing death and dying, an attempt to change society and its attitudes from treating death as a taboo to making “living and dying well” the norm (63). Again, honourable intentions, but with a language that still focusses on the “end”, potentially furthering misperceptions of palliative care.

1.6.2 The media

The mass-media has a significant impact on the conceptualisation of palliative care (64) and in generating public opinion. Evidence suggests that although the media in general are key in delivering messages about palliative care, newspapers remain one of the main sources of information (65). Digital media is however, continually increasing its influence on the public, especially regarding health. Interestingly, evaluating public resources using internet searches and social media has shown that palliative care is generally portrayed positively (66). There has even been an acknowledgement that on social media, the taboo topic of death and dying was being more frequently accessed with a willingness and need to talk openly about it on the increase (67).

Getting a better understanding of the public view of palliative care and the influence of the media may be necessary to design promotional strategies aimed at palliative and end of life care resources (68). Examples of such resources include the previously mentioned dying matters in the UK and international examples include the United States “Get Palliative Care” website, sponsored by the Center to Advance Palliative Care. These do focus more on supporting living with a life-limiting illness.

1.6.3 Inequalities and inequities in palliative care

1.6.3.1 Inequalities in palliative care

Since 1992, it has been argued a common goal of both medicine and human rights, is the relief of the pain and suffering of patients with life limiting illness (1). Access to palliative care is fundamental to the right to health and is essential to health care (69). Yet, “throughout the world, there are wide disparities in the capacity, resources, and infrastructure devoted to the care of people with life-limiting illnesses” (70) (p.494). Access to palliative care mirrors absolute health and social deprivation; people in low-income and middle-income countries often die with little or no palliative care (71). In the recently published mapping of palliative care development in 198 countries, one-quarter (47 countries) had no palliative care activity, a further 13 countries were developing services (but none existed) and 87 only had limited palliative care development (e.g., fragmented services, palliative care not integrated into health care) (72). It may be that lower integration of palliative care services means the public in general have less exposure to this approach to care which may in turn affect their awareness and perception of it. An exploratory study by Clark *et al* in 2019 looking at an earlier version of the mapping of palliative care development, demonstrated that palliative care underdevelopment is highly consistent with broader national development challenges (49). Countries with no palliative care provision were associated with high levels of societal inequality, high mortality rates at younger ages from diseases with short prognosis from diagnosis and poor health system strength (49). These factors may also influence perception about palliative care. While acknowledging the need for palliative care is universal, the timing for policymakers to prioritise limited resources to further integrate palliative care services may need to follow a “tipping point” when health systems and countries develop to a point where the majority of deaths in a society are due to chronic illnesses (49) and it may be that not until this point greater awareness of palliative care becomes apparent in a population.

1.6.3.2 Inequities in palliative care

As well as differences between countries, within countries, inequities in access to palliative care and outcomes once receiving palliative care exist that are associated with socio-demographic and cultural factors. These disparities within countries are evident in poor and vulnerable people in high-income countries and many underserved groups (73):

- Older people receive disproportionately little palliative care (74).
- People from minority ethnic groups receive poorer quality end of life care (75).
- Lesbian, gay, bisexual and transgender people experience delays in accessing palliative care and report discrimination (76).

- Individuals from lower socio-economic groups experience barriers to access and worse outcomes in palliative care (77).
- The use of palliative services among patients with non-cancer diseases is low and the timing of referrals is typically late (78).

1.7 Summary and rationale of this thesis

While there are variations in the definitions of palliative care in the developed world, it can be deduced that overall the aim of palliative care is to facilitate “living until you die” by focussing on the physical, psychological, social (including cultural) and spiritual needs of patients with serious illness.

The misperception that palliative care is *only* care of the dying has led to an underutilisation of both a palliative approach to care and referral to specialist palliative care services. This is due, in part, to the death taboo with palliative care being associated with imminent death and death having become “sanitised, sequestered and removed from public gaze” (79) (p.45). The term palliative care itself was chosen to avoid negative connotations, but the ongoing close association with death has led to a persistence of negativity.

Perception of palliative care as care of the dying filters through the mass media and through government policy. While acknowledging this is an important part of palliative care, promoting care of the dying to the detriment of living may further promulgate a misperception of palliative care. It is also possible that as well as affecting the level of integration and availability of palliative care, the country where someone lives may also influence perception of palliative care from both a cultural perspective and due to different levels of exposure to this type of care. Perceptions of what palliative care is may affect access to an interdisciplinary holistic approach to care.

Despite primary research studies and a recent scoping review looking at the public perception of palliative care, to date, no published work has drawn together the existing primary research by a higher order synthesis or provided a more representative worldview of the public perception of palliative care. The plan for this Masters project, therefore, was to complete a full systematic review and mixed methods synthesis of the general public's perception of palliative care.

Agreeing with the scoping review published last year, the "the general public" represents a very heterogenous group of people from different countries with different levels of palliative care provision (56); looking at the whole, whilst useful, may hide discernible differences in palliative care perception in these different areas including the influence of the previously described "tipping point". As such I also hope to specifically ascertain whether there is an association between geographical location, level of palliative care development and the general public's perception of palliative care.

Dr Cicely Saunders wrote in 2001, "there remains a clamant need to address attitudes to end-of-life care among the professions, the public and the media" (7) (p.432). With evidence that early integration of palliative care improves patients quality of life (80) this is still not happening (51). Getting a true understanding of what the general public's perception of palliative care is may inform future research to:

- Analyse the origin of this perception.
- Inform an intervention to change perception.
- Improve access to and integration of palliative care services.

1.8 Aims

My aim is to provide an evidence-based understanding of the general public's perception of palliative care. This will add to the existing evidence from small studies and the recent scoping review (56) regarding the perception of palliative care and allow comparison with the definitions as put forward by the national bodies detailed previously.

Further to this primary objective, given the described issues of inequality and inequity in palliative care access, provision and outcomes, I also aim to understand the factors that influence public perception of palliative care. I will specifically enquire as to whether country and level of palliative care development is related to perception and, look further to see if the public perception of palliative care has changed over time. Finally, I will try to ascertain whether the public perception of palliative care impacts access.

1.9 Research questions

1. What is the general public's perception of adult palliative care?
2. What influences the general public's perception of palliative care?
    - 2a. Does this perception relate to country or level of palliative care development?
    - 2b. Is there any evidence to suggest perception has changed over time?
3. Is there evidence that this perception of palliative care impacts access to palliative care?

Chapter 2 Methodology and Methods

2.1 Overview

From the previous chapter we learned that misperceptions of palliative care may be a barrier to access. To better understand this barrier, we need an evidence-based knowledge of the public perception of palliative care. To further the work done by Patel (56), this Masters project looked not only to gain an understanding of the perception of palliative care but also to identify what influences this perception and whether any discernible differences in palliative care perceptions exist in different countries, whether that relates to the different levels of palliative care development in these countries or even simply to the different terms used for this type of care. This chapter will discuss both the methodological approach to the questions asked and the methods used.

2.2 Methodology

2.2.1. Philosophical approach: Research paradigm

A paradigm, defined by Kuhn in 1962 as a philosophical way of thinking (81) is “a basic belief system representing a *worldview* that defines, for its holder, the nature of the ‘world’, the individual’s place in it, and the range of possible relations to that world and its parts” (82) (p.107). A selection of paradigms exist (such as positivism, post-positivism, critical theory) and the beliefs that make up each paradigm can be summarised by the assumptions regarding ontology, epistemology and axiology (82).

I took an interpretivist approach to exploring the public perception of palliative care. This approach, and the desire to understand individuals and their interpretation of the world, led to my choice of answering the research question by systematically finding, exploring and synthesising data from both quantitative and qualitative primary research (83) with the intention of shedding light on the human behaviour and beliefs around the perception of palliative care (84). This interpretivist paradigm is interdependent on my position on ontology and epistemology as described below.

2.2.2 Ontology

Ontology is the philosophical study of the nature of existence or reality (84, 85). Underpinning a interpretivist paradigm is an ontological perspective that there is no single truth, rather knowledge is dependent on the mind and, as such, there are multiple socially constructed realities (84, 86). That is, whilst there is a world that is ‘out there’, our understandings of it are socially constructed in an individual’s mind through meaning-making processes (87). In the context of this work, therefore, I resist the assumption that a singular, ‘objective’, and fixed definition of palliative care exists. Rather, I understand that the public’s perceptions of palliative care are multiple and subjective, and are likely to change over time, place, and context.

2.2.3 Epistemology

Epistemology is study of knowledge, the exploration of how reality is known (85), the process of thinking (88), the relationship between the researcher and what is known (84). My epistemological belief is that realities can be understood through many lenses that reflect both deductive and inductive evidence (85, 89). Whilst this allows any described perceptions of palliative care to remain grounded in the data, it also acknowledges both my own preconceived ideas regarding the public’s perception of palliative care and my understanding of the pre-existing frame of knowledge in the WHO and international definitions of palliative care, fitting my abductive reasoning (90).

2.2.4 Axiology

Axiology is the role of values in research (85). The intention of my research is to benefit people (84). As per my interpretivist approach, I endeavoured to maintain a balanced axiology, acknowledging the outcome of the research reflected my values, and I tried to present a balanced report of the findings.

2.2.5 Research design

All research questions were addressed by systematic review with data brought together by modified critical interpretive synthesis (CIS) of the relevant qualitative and non-experimental quantitative literature (91). CIS is a “method of reviewing, developed from meta-ethnography, which integrates systematic review methodology with a qualitative tradition of enquiry" (91) (p.201). CIS has a similar approach to meta-ethnography, in that rather than testing a specific hypothesis, it sets out to identify an intellectual interest that qualitative research might inform (92) and allows this interest be refined during the review process. Such an interpretive synthesis sits within my interpretivist approach as it involves both interpretation and induction (93).

Within the CIS, qualitative and quantitative data were analysed separately. For qualitative data, I used Thomas and Harden's thematic synthesis (94) and, for quantitative data, a narrative synthesis (95, 96). These findings were then synthesised as a CIS to answer the research questions.

The purpose of reviewing non-experimental quantitative and qualitative studies was to attempt to gain an understanding of the public perceptions that is both credible and greater than the sum of its parts. Quantitative research provides a broad-brush view of perceptions normally based on pre-defined frameworks. These data inform an understanding that can then be explored through qualitative findings which yield an in-depth and rich understanding of the public perceptions of palliative care in all of its complexity and nuance (89).

Qualitative research is often deemed specific to the context, time and participants involved in the primary research and controversy exists as to whether it is legitimate and feasible to bring together findings of research studies from different methods (97). It has been argued that bringing findings together may destroy the integrity of individual studies (98) and potentially any generalisability. Noblit and Hare, however, argue that through induction and interpretation these reviews subsume concepts from original studies into a higher-order theoretical structure (92, 99). The whole stage of my analysis culminating in the CIS, while grounded in the data, is conceptual in process and output, with any product being theory rather than aggregations of data (99).

2.2.6 Theoretical frameworks

For this research I have used a number of theoretical frameworks to inform my work. Firstly, the WHO definition of palliative care (38) fits with my interpretation of what palliative care is, or should be, and I have used this as a theoretical framework as a starting point by which to compare the general public's perception of palliative care.

Culturally congruent care is care that incorporates an individual patient's beliefs and is related to the patient's perception of care (100). It is this concept I have used as my second theoretical framework. Acknowledging that culture influences human behaviour (including perceptions of palliative care), an understanding of this may help address health inequalities and inequities in diverse populations introduced in section 1.6.3 (101). Culture in healthcare has been defined as "a shared ecologic framework that is internalized and acts as a refracted lens through which group members 'see' reality and, in which both the individual and collective group experiences the world" (101) (p.242). Culture cannot be separated from other characteristics such as ethnicity, gender age or sexual orientation (102) but equally none of these are synonymous with the other (103). An individual belongs to multiple cultures rather than a single one (102). Culture can be shared, yet it is also what is unique about an individual and shapes how an individual's worldview is constructed, including the concepts of health, wellness, and illness (104). Healthcare providers not being aware of the cultural needs of patients can impact a patient's experience and understanding of healthcare services (including palliative care) (104).

Moving beyond an awareness of culture, so called cultural competence, Madeleine Leininger suggested culturally congruent care is care that incorporates an individual patient's beliefs and, crucially, is related to the patient's perception of any care received (100). DeWilde argues culturally congruent and culturally competent care are inextricably linked and that cultural distress occurs if the perception of the care offered does not match the perception of the care received (104). This itself may influence the perception of palliative care within different cultures. This cultural distress model (104) was useful for this study and allowed for consideration of how people perceive palliative care both as individuals and as members of a collective group. In turn, this allowed for an enquiry into whether the perception of the care by those who would potentially receive care in the future differs from the perceptions of those offering care.

2.2.7 Reflexivity

Finlay defined reflexivity as a: “thoughtful, conscious self-awareness. Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself. It involves a shift in our understanding of data collection from something objective that is accomplished through detached scrutiny of ‘what I know and how I know it’ to recognizing how we actively construct our knowledge” (105) (p.532).

I acknowledged that all my interpretations of data from quantitative and qualitative studies were affected by the research process and my own beliefs, values, gender, class, and physical ability. I am a doctor with significant primary care experience, now training in palliative medicine. I am white British, middle-class and from the North of England. I have an assumption derived from my clinical practice that palliative care is poorly understood by professionals and the public alike. The definitions of palliative care with which I am already most familiar are those of Western countries. My interpretation of these definitions alongside my experience in both primary care and palliative care is what forms my understanding of what palliative care is (or should be). My findings were inevitably co-constructed, whilst allowing the public’s perception of palliative care to be generated from the data, I acknowledged that both my own values and my understanding of the definitions of palliative care influenced my interpretation.

I have strived to engage with obvious, conscious, or systematic bias by reflecting as much as possible during the collection, interpretation and presentation of the data. Having access to the researchers of different disciplinary (sociology) and cultural (less affluent, first in family to gain higher education) backgrounds supporting independent review as part of the methods have helped me reflect on my own biases. I endeavoured to be as reflexive as possible throughout data collection and analysis by keeping a reflexive journal that documented the ways in which my own background and biases impacted my interpretations of data.

2.2.8 Research ethics

This was a systematic review of publicly accessible literature and did not require institutional ethics board approval. Acknowledging the potential impact of systematic reviews on policy, practice and public perception, consideration was given to representation of stakeholders (researchers, the public, the specialty). I have endeavoured to maintain an ethical approach to the research through informed subjectivity and reflexivity, purposefully informed selective inclusivity and transparency in methodology and methods (106). All data for this evidence synthesis were anonymised and stored on a password secured network. Only the research team had access to the data. As part of my quality appraisal, I checked ethical approval for all included studies.

2.3 Methods

Having discussed the methodological approach underpinning my research, in this section I will present the methods I employed, including what was done, how it was done and the rationale behind the methods selected in this synthesis.

2.3.1 Protocol and registration

A protocol for this review was registered with the international prospective register of systematic reviews (PROSPERO registration number CRD42018085745) and is available at: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=85745

2.3.2 Eligibility criteria

Inclusion criteria:

Types of study: Any qualitative, non-experimental quantitative (or experimental where data pre-intervention could be extracted), or mixed methods primary research where data of interest could be extracted, including secondary analysis studies.

Participants: The adult general public (16 years old and over)

Exposure: Palliative care

Outcomes: Awareness, perceptions, knowledge of and attitudes towards palliative care

Exclusion criteria

Types of study: Experimental studies (where pre-intervention data could not be extracted separately), systematic reviews, dissertations, case reports and opinion pieces.

Participants: The general public under 16 years old and patients, carers and healthcare professionals and people working in the remit of palliative care (including but not limited to volunteers) of any age.

Experimental studies were excluded because this was not an effectiveness review and so as not to conflate the general public's perception with those who had received an intervention aimed at changing familiarity or perception. This was not a review of reviews and systematic reviews were therefore excluded.

The participants of interest in this thesis were the general public (over 16), so studies with mixed populations were only included where data on the general public could be extracted.

Adult palliative care was chosen as the phenomenon of interest as this included generalist and specialist palliative care but excluded studies that discussed only facets of palliative care such as perceptions of symptom management or advance care planning. Care was taken with studies detailing hospice, hospice care and palliative care due to the potential differences and similarities between the meanings of these words. I included studies where the phenomena of interest appeared to be palliative care broadly consistent with the WHO definition of palliative care (107). Paediatric palliative care is a separate entity from adult palliative care in terms of diseases, disease trajectories, service delivery models, as well as having different funding and governance structures. Studies enquiring about palliative care for those less than 16 years or studies looking at all age ranges where data for those over 16 years could not be extracted separately were excluded.

2.3.3 Electronic searching

The following electronic databases were searched from the 1st January 2002 to 31st December 2017 and subsequently updated on 31st December 2019 and 31st May 2020:

- MEDLINE (OVID)
- EMBASE (OVID)
- PsycINFO (EBSCOHost)
- CINAHL (EBSCOHost)
- Web of Science Social Science Citation Index Expanded (Clarivate Analytics)
- Web of Science Conference Proceedings Citation Index (Clarivate Analytics)

These databases were chosen as they had the greatest potential to yield both relevant qualitative and quantitative studies. The start date of 2002 was chosen to coincide with the publication of the WHO definition of palliative care (107).

2.3.4 Search strategy

The search strategy was developed using MEDLINE following scoping searches, advice from the University of Hull Library Skills Team and the Thesis Advisory Panel. The search strategy was translated into the appropriate format for all other databases (see appendix 1 for search strategies).

The purpose of defining and systematically applying *a priori* search strategies and study inclusion criteria was an attempt to minimise selection bias (108). Following advice from the University of Hull library skills team, search limitations were set by searching non-Medical Subject Headings just in keywords, title or abstract (.kw, .ti, .ab). This was to ensure more relevant studies were identified compared with searching anywhere. A date restricted pilot search comparing the database output with these limits with terms searched without limits did not yield any differences in finding key studies. The criteria used in the search aimed to identify all studies on the public perception of palliative care as an entity/approach to care. There was no search filter for, “the general public,” as the initial plan had been to review the perception of the general public, patients, healthcare professionals and carers. It was only after screening all titles and abstracts that the decision to limit this project to just the public was made due to the vastness of data and time allowed for the work. There were no restrictions with regard to language and, as recommended in the work by Mays (2005), there was no study design filter in the search strategy given the plan to include a range of study designs (109).

Searching other resources

The reference sections of relevant review articles and of the included studies were also scanned to identify additional eligible studies. A pragmatic decision was made not to check the grey literature or perform further searches on Google or Google Scholar search engines. I acknowledged this may introduce a publication bias (108, 110) and reflect on this and other biases in the strengths and limitations section (section 4.4).

2.3.5 Screening and study selection

The titles and abstracts of studies were reviewed against the pre-specified eligibility criteria. Full text papers were retrieved electronically via the University library, the British Library or contact with authors. The retrieved full text papers were then independently considered against the inclusion criteria. Where there was a lack of clarity from reviewing the title and abstract, full articles were retrieved and considered against the same criteria.

The initial plan had been that a second reviewer would review all titles and abstracts but due to the high number of citations (n=33,985) yielded from the search, this was modified to a second reviewer reviewing a randomised 10% (randomised by exporting all citations to Microsoft Excel, assigning a random number to each article, sorting in ascending order and selecting the first 10%). This enabled double screening within resources available, whilst maintaining scientific rigour (95). Inter-assessor reliability was not formally assessed using a Kappa statistic rather, agreements were made by constant iterative discussion. Any disagreements were discussed and resolved by consensus after referring to the protocol; or when necessary a third reviewer. Had there been unresolved disagreements a further 10% of studies would have been double screened until consistency had been achieved. Given this is not an effectiveness review where it is highly important to identify all the relevant trials, the risk of missing papers is unlikely to materially influence the findings.

Excluded studies were recorded in a table, together with the reason(s) for exclusion. Multiple reports from the same study were collated, but authors did not need to be contacted for clarification. In situations where a single survey was published in more than one paper, these were only included where unique data were presented. The studies were not anonymised before assessment. The process of selection was reported according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

2.3.6 Data management

All titles and abstracts of studies were initially uploaded to EndNote X8 and subsequently managed with the Rayyan review management web application (111). For qualitative data, complete papers were uploaded into NVivo 12 software package (112). Microsoft Excel (113) and Word (114) were used to collate the quantitative data and to record all other study details for all research designs.

2.3.7 Data extraction

For all studies, data were extracted alongside study characteristics from all the included studies using a specifically designed data collection form (see appendix 2). A second reviewer independently extracted data from a randomised 10% of these studies (randomised by the same method as for screening). The data recorded included study design, aim, location, participants including demographics, sample size, methodology and key findings. The two reviewers compared results. Disagreements were resolved by discussion or by referral to a third reviewer if necessary. Where data were reported in serial or duplicate publications, the primary data set was only used once. The extraction form was piloted on the first three papers, and adjustments made with the consensus of all reviewers.

Consistent with Thomas and Harden’s methods for thematic synthesis, qualitative data were extracted from all text labelled as findings or results in each included paper (94).

2.3.8 Quality appraisal

The rigour of research for studies in this review were considered using the quality appraisal tools detailed below reflecting on Lincoln and Guba’s evaluative criteria (115):

Credibility – trustworthiness of the findings

Transferability – what is the applicability of findings in other contexts

Dependability – demonstrating the findings are consistent and could be repeated if in similar circumstances

Confirmability – demonstrating the findings are born of the data and researcher bias, motivation, or interest is minimised.

2.3.8.1 Quantitative approach

The PROSPERO protocol stated the Newcastle Ottawa scale would be used, but following piloting on 10 papers, this was changed to the Appraisal tool for cross-sectional studies (AXIS) (appendix 3) (116). AXIS is a validated, 20 question assessment tool designed specifically for cross-sectional studies. Questions include one regarding objectives, ten regarding methods, five about the results, two questions about the authors discussion, and one question each about conflicts of interest, and ethical approval. Quality appraisal was not used to decide whether to include or exclude studies, rather it was reflexively used to assess the weight of the individual studies when considering the data as a whole. Quality appraisal was completed by a second researcher on a randomised 10% of the included studies and results compared. Disagreements were resolved by discussion or by referral to a third reviewer if necessary.

2.3.8.2 Qualitative approach

Debate as to whether quality can be assessed in qualitative research persists (94) with some arguing measures used to appraise this type of research can falsely reassure a researcher as to what stands for quality (117). Some scholars have argued that structured appraisal is no better than an unprompted judgement based on opinion (118). Even when appraisal is done, whether it should be used as a judgment to include or exclude studies into reviews also remains contentious (109). Yet, there remains a demand for rigour and a desire to avoid qualitative work being judged by quantitative standards (119). The NHS Centre for Reviews and Dissemination (CRD) favours *a priori* structure quality assessment and, as such, the quality of included studies were assessed but not used to decide whether to include or exclude studies. The weight given to study findings was considered considering the outcome of quality appraisal. The Critical Appraisal Skills Programme (CASP) qualitative studies checklist (120) (appendix 3) was used to appraise the quality of all qualitative research, as I am most familiar with this tool, it is useful for the novice, is readily available and there is evidence available as to the advantages and disadvantages (121, 122). A second researcher appraised a randomised 20% of included studies and agreement checked.

2.3.9 Data analysis

As described in section 2.2.2, analysis was completed with a narrative synthesis of quantitative data first, followed by a thematic synthesis of qualitative data and ultimately a critical interpretive synthesis of both.

2.3.9.1 Quantitative narrative synthesis

Descriptive statistics were used to present the quantitative data in tables. Modifying the approach described in the Centre for Reviews and Dissemination's guidance for undertaking reviews in health care (123) the steps involved in the narrative synthesis are described in table 4.

Table 4: Applying a narrative synthesis framework (123)

Stage		Steps
1	Developing a preliminary synthesis	Tabulation Translating data via thematic analysis Looking at groupings and clusters
2	Exploring relationships within and between studies	Idea webbing/conceptual mapping Visual representation of relationship
3	Assessing the robustness of the synthesis	Reflecting critically on the synthesis process
4	Final synthesis	Conclusions and recommendations

This narrative synthesis of quantitative data was chosen as the populations and outcomes in the included studies were not sufficiently similar to facilitate a meta-analysis (96). Nonetheless, bringing together all the data narratively provided a better understanding of the whole evidence based story (96).

2.3.9.2 Qualitative thematic synthesis

Qualitative data from included studies were analysed using a modified Thomas and Harden thematic synthesis (summarised in table 5). Similar to thematic analysis, the purpose of thematic synthesis is to summarise recurrent findings under higher order thematic headings (94). This method involves identifying key concepts from studies and integrating them into one another (94); that is taking concepts and explanations of concepts from one study and recognising the same in another study. Pulling corroborating concepts together and, crucially, going beyond the content of the original studies, is what makes this a synthesis rather than just a review of the literature (94).

Table 5: Thematic synthesis framework modified from Thomas and Harden, 2008 (94).

Stage		Description
1	Familiarisation	Reading and re-reading included full texts
2	Coding	Data coded according to review questions Each line of text was coded collaboratively by two researchers for meaning and content and, codes created inductively. As each study was coded, the bank of codes were added to and translation from one study to another occurred by using the same codes when appropriate. All coded text was examined to check consistency of interpretation and to see whether additional levels of coding were needed
3	Generation of descriptive themes	Similarities and differences between the codes were identified to start grouping into hierarchical tree structure. New codes were created to capture the meaning of initial codes resulting in a tree structure with several layers with overarching descriptive themes.
4	Generation of analytical themes	Conceptualisation of the research questions analysing the meanings of the descriptive themes.

In this review, this method facilitated remaining grounded in the data, identifying themes from the data itself yet, also allowed interrogation of the data considering pre-conceived concepts such as the WHO definition of palliative care in fitting with the notion of abductive reasoning (i.e., analysing through a combined process of induction and deduction) (99, 107). Using a recognised method provides credibility to the processes involved and ensured any product was more than the sum of parts (94). The aim with the data was to reach conceptual saturation to allow a confidence in my overall conclusions.

2.3.9.3 Modified critical interpretive synthesis

Following the separate syntheses of quantitative and qualitative data, further analysis occurred in the form of a critical interpretive synthesis (CIS). The first steps in CIS (getting started, deciding what is relevant, understanding the paper in relation to itself and, translating the studies into one another) in this thesis are subsumed by the previous separate stages in analysis. Table 6 is a summary of the subsequent stages.

Table 6: Critical Interpretive Synthesis Framework modified from Flemming, 2009 (91)

Stage		Description
1	Determining how the studies are related	Relationships between the qualitative and quantitative studies were determined
2	Synthesising translations	Through examining previous analyses, concepts from the qualitative analysis were explored to determine whether they encompassed accounts in the quantitative analysis (Reciprocal Translation Analysis (RTA)). Through RTA, synthetic constructs were developed. These constructs remained grounded in the evidence found in the primary papers but represented an interpretation of the whole body of evidence.
3	Expressing the synthesis	Evidence from across studies was integrated into a comprehensible theoretical framework. This framework represented the network of synthetic constructs and explained the relationships between them (93) incorporating higher order constructs

CIS “draws on traditional systematic review methodology whilst incorporating a qualitative tradition of enquiry” (91) (p.202). Acknowledging that single method analyses may not fully elicit the complexity in a review of the public’s perception of palliative care, combining a diverse body of qualitative and quantitative work into a single synthesis by this recognised methodology enabled me to generate new theory which is greater than a sum of its parts (93), providing further confidence in my conclusions, including whether the influences on public perception of palliative care include time, country of study and level of palliative care development.

Chapter 3 Results

3.1 Study selection

Database searching identified 33,985 potentially relevant papers. A further 22 papers were identified through reviewing the reference lists of included papers. The identification, screening, eligibility and inclusion process for included studies is summarised according to PRISMA guidelines in the figure 1 below (124).

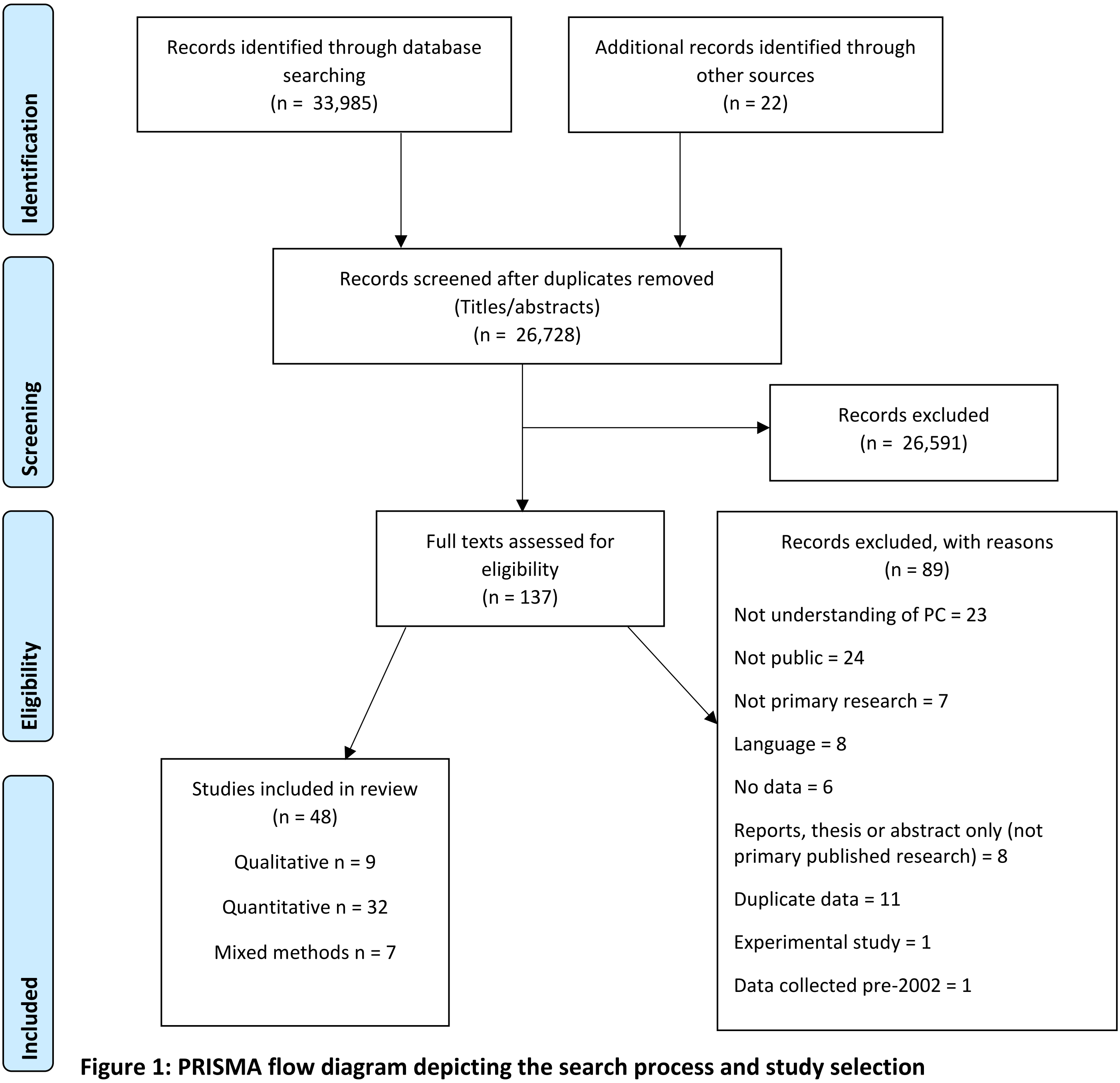


Figure 1: PRISMA flow diagram depicting the search process and study selection

3.2 Study characteristics

Forty-eight studies were included with a total sample size of 36021 detailing 32585 individual participants (due to multiple publication). The sample sizes of 32 quantitative, nine qualitative and seven mixed method studies were 28480, 419 and 7122 respectively, with sample sizes of individual studies ranging from 57 to 3194 participants for the quantitative and 13 to 169 for the qualitative studies.

Of the nine qualitative studies, six used focus groups (125-130), two semi-structured interviews (131, 132) and one cognitive interviews (133) to collect data. The 32 quantitative were all cross-sectional studies and the seven mixed methods studies were made up of six cross-sectional surveys with open questions (50, 134-138) and one focus group (139) which informed a cross-sectional survey. The qualitative and mixed method studies, were from the United States (50, 125, 126, 128-130, 132), Western Europe (127, 131, 133-135, 138), Canada (139), Australia (136) and Eastern Europe (Czechia) (137). The quantitative studies were more diverse; coming from the United States or Canada (140-156), Japan (157-159), Taiwan (160-162), South Korea (163, 164), India (165, 166), Australasia (167, 168), Bangladesh (169), Malaysia (170) and the United Kingdom (171). All were published between 2003 and 2020, with the qualitative papers published between 2006 and 2018. Study characteristics along with key findings are shown in the tables 7, 8 and 9. Extracted data tables are shown in appendix 5.

Table 7: Characteristics of included quantitative studies

First author, year, location	Key research question(s)	Study design	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
Karel 2003 USA	What is the knowledge, attitudes and practices relating to EOL issues (including hospice) among adults in Hawaii	CSS Convenience sampling, part of larger before and after study	N=388 Age all >18y F=79% M=21%	With regard to hospice: Awareness	• 83% responded had awareness of hospice • Age: 45-64y had more awareness of hospice than any other age group p<0.001 - test not reported • Race no significant difference	(148)
Claxton-Oldfield 2004 Canada	What is the understanding of the term palliative care in Atlantic Canada?	CSS Convenience sampling	Study 1 N=89 Age range 20-83y F=67% M=33% Study 2 N=81 Age range 18-82y F=74% M=26%	With regard to PC: Awareness If aware: Knowledge Attitude Source of awareness (study 2)	• 75.3% (67) aware of PC • No significant difference in PC awareness by age/gender • 48.4% of participants defined PC as care of terminally ill or dying, 18.8% care of the sick and 15.6% care in home • 64.5% of participants associated cancer with PC • 68.3% of participants viewed PC as received in hospital, Home 34.9%, Hospice 9.5% • 11.7% believed doctors provide PC • 92.3% of participants stated they would you use PC if family member terminally ill	(142)
Catt 2005 UK	What is the relationship between age and attitudes to and knowledge of hospices and specialist palliative care services.	CSS Random stratified sampling	N=256 Group 1 N=129 aged 55-74 Group 2 N=127 aged 75+ F=55% M=45%	With regard to hospice care: Knowledge Attitudes	• Older people more familiar with type of care offered by hospices • Attitudes to hospices similar in both age groups and unaffected by education, or fears of death • Majority of both groups believed a hospice is for all age groups, for care of the dying and hospice care is about pain and symptom control. • Half believed hospices depended entirely on voluntary funding and, majority aware not just for cancer Believe hospice care is not only for people with cancer	(171)
Dussen 2011 USA	What is the perception of and attitudes towards hospice care in community dwelling adults in Ohio?	CSS Cluster sampling	N=168 Age range 43-80+y F=44% M=56%	Regarding hospice: Awareness Attitudes Knowledge of funding Source of information	• Familiarity with hospice 86% • Older respondents more familiar with hospice vs young • No variation by race • 95% of participants viewed hospice care important but 32.1% viewed it as ‘‘giving up’’, 38.6% ‘‘about death’’ • Older respondents more likely to view hospice as giving up or only about death • Black respondents more likely to view as giving up • Funding of hospice an unknown	(144)
June 2012 USA	What are the attitudes and beliefs of sexually diverse middle-aged and older women regarding hospice	CSS Convenience quota sampling	N=145 Age 35-81y F=100%	With regards to hospice care: Attitudes Beliefs	• Both sexual orientations held positive views of hospice care but Lesbian women more so. • Older adult women held significantly more positive beliefs about hospice care than middle-aged women	(147)

First author, year, location	Key research question(s)	Study design	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
Manu 2012 USA	To assess older adults' familiarity with the terms ''hospice'' and ''palliative care"attitudes toward palliative principles whether experience with caring for a dying person was associated with more familiarity of the terms	CSS Convenience sampling	N=211 Mean age 78y all >18y F=63% M=37%	With regard to PC: awareness attitudes	• Familiar with term hospice 168 (93%) • Familiar with term PC 53 (30%) • 18% of participants believed hospice care means giving up on living, 82% that hospice can make patients feel better and 59% that hospice is offered when nothing more can be done • Respondents familiar with hospice care more likely to disagree ''receiving hospice care means patients are giving up on living'' (P=0.008). • No associations between prior experience with caring for a dying family member and familiarity with the terms hospice or PC	(149)
Igarashi* 2014 Japan	What are the general public's perceptions of palliative care units (PCU) and explore factors related to such perceptions.	CSS Part of larger OPTIM trial. Random stratified sampling	N=2990 Mean age 60 all >18y F=55% M=45%	Regards PCU: Perception Attitudes	• 24% of participants had sound knowledge of PCU • 76% of participants believed PCU relieve pain, 63% maintain dignity, 63% support the family 63% • A higher score for positive perceptions of PCU was associated with a female gender (P <0.001), younger age (P <0.001), sound knowledge of PCUs (P <0.001) • A higher score for negative perceptions of PCUs was associated with younger age (P <0.001), poor knowledge of PCUs (P <0.001).	(158)
Hirai* 2011 Japan	What is the public (healthy versus those with cancer experience): Awareness of palliative care services	CSS Part of larger OPTIM trial. Random stratified sampling	N=3190 Mean age 60 (SD 11) F=55% M=45%	Regarding PC: Awareness	• No awareness of PC 63.1% • Women and people with cancer-related experiences were more likely to be aware of PC (p<0.001). • Awareness of PC was significantly associated with knowing PC relieves pain and distress and is for patients close to death	(157)
Carrion** 2015 USA	What is the knowledge and attitudes regarding hospice in Hispanics and non-Hispanics	CSS Random stratified sampling	N= 123, 46% response rate Hispanic N=16 Mean age 45.3 (SD 19.7) F= 75% M=25% Non-Hispanic N=107 Mean age 48.1 (SD 17.1) F= 61.7% M= 38.3%	Regarding hospice and hospice care: Awareness Knowledge Attitudes	• Hispanics 9 (56%) of Hispanics had heard of hospice vs 97 (91%) of Non-Hispanics p<0.001 • Hispanics were familiar with hospice care p=0.05 • Overall knowledge as assessed by Hospice Knowledge Test (HKT) did not differ significantly between Hispanics and non-Hispanics • Hispanics were more likely to believe hospice was only for individuals over 65 years 93% vs 44% p=0.001 and less aware that hospice care helps care givers and 97% vs 67% p=0.008 • Hispanics were more likely to believe hospice services end when patient dies 89% vs 55% p=0.07	(141)
Cagle** 2016 USA	What is the hospice knowledge among geographically diverse adults and describe	CSS Random stratified sampling	N=123 Mean age 47.7 (all>18y) F= 63.4% M= 36.6%	Regarding hospice: Awareness Knowledge Attitudes (HPS-8 scale)	• 86% of participants heard of hospice • Younger and Hispanic less familiar (p=0.016 and p=0.038)	(140)

First author, year, location	Key research question(s)	Study design	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
	linkages between knowledge, attitudes and beliefs about hospice care and demographics?			Experiences Preferences	• 95% of those that heard of it reported favourable opinion and 90% reported if they were dying, they would want hospice services • 78% of HKT questions answered correctly • African American respondents who had heard of hospice had substantially lower than average levels of knowledge (no sig given) • Higher HKT score correlated with more positive attitudes (r=0.22, p=0.023) and with preference for hospice care (p=0.011) • More positive attitudes also correlated with preference for hospice (p=0.049) • Older people were less knowledgeable p=0.27 but have more favourable attitudes p=0.002	
Van Dussen** 2018 USA	What is the hospice attitude as measured by the HPS-8 in community dwelling adults? Do these attitudes correlate with other measured views of hospice?	CSS Random stratified sampling	N=123 Mean age 47.7 (All >18y) F= 63.4% M= 36.6% Hispanic 13% Non-Hispanic 87%	With regard to hospice: Attitude	• Attitude as measured by HPS-8 mean score 36.2 (SD 4.5; possible range = 8-40), indicating a moderate skew toward favourable attitudes. • No significant differences by age or gender • White respondents reported more favourable attitudes (Mean 37.2) than non-White (Mean 34.6); p = 0.003	(154)
Chandra 2016 India	What is the impact of a health awareness campaign in improving the awareness about palliative care	CSS Convenience sampling	N=145 Mean age NK, All >20 y F= 56.6% M= 43.4%	With regard to PC: Awareness	Awareness 0%	(166)
Hsu 2012 Taiwan	What is the knowledge and attitude toward hospice palliative care (HPC) among the elderly living in metropolitan Taiwan	CSS Sampling method not known	N=1332 Mean age 74.4 (all>18y) F= 55.8% M= 44.2%	With regard to HPC: Awareness Understanding of concept Attitude	• 56.5% of participants had awareness of HPC • 35.5% agreed they understood the concept • 7% of participants associated HPC with imminent death • 42.6% of participants associated HPC only with cancer (42% don't know) • Higher knowledge scores were associated with education: high school or above p<0.001 (independent sample t-test)	(160)
Sanjo 2008 Japan	What is the general population's awareness and perceptions of specialised palliative care service (SPC) in Japan?	CSS Random stratified sampling	N=2548 Mean age NK (all >18y) F= 53% M= 47%	With regard to specialist PC: Awareness Perceptions	• 37% of participants (self) reported knowledge of SPC • Female respondents more likely to be knowledgeable (standardised partial regression coefficient B=0.18, p<0.001) • 72% of participants perceived that SPC supports patients in living peacefully and 70% with dignity • 67% aware SPC provides care for families and 68% alleviates pain • 32% perceived that SPC provides no medical treatments and 28.5% that SPC isolates patients from community	(159)

First author, year, location	Key research question(s)	Study design	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
Pan 2015 USA	What is the self-reported familiarity and attitudes toward hospice among Asian and Hispanic groups	CSS Convenience sampling	N=604 Mean age 54.6y (all >18y) F=68% M=32% Chinese 16%, Korean 58% Hispanic 26%	With regards to hospice: Awareness	• 45% of Chinese participants, 56% Korean and 16% Hispanic reported having heard of hospice. All p<0.01 (Fisher's exact test) • Asian participants more likely to inform family about hospice	(151)
Schrader 2009 USA	What do people know about hospice?	CSS Random sampling	N=1042 Mean age 49.75, all >18y F=56% M=44% Caucasian 96%	With regard to hospice services: Awareness Attitude Understanding of financing	• 50% of participants had heard a lot about hospice 47% had heard little and 3% and never heard of hospice. • 65% of participants would want hospice care if they were dying • 25% of participants thought that medicare paid for hospice services, 68% weren't sure. Women more likely to be aware of hospice services p=0.015 (χ^2) • Awareness of hospice services significantly different according to age p=0.001; education p=0.001, marital status p=0.001 and religiousity p=0.012 (χ^2 comparisons).	(152)
Schrader 2009 USA	What is the understanding of attitudes, knowledge, and preferences about end-of-life (EOL) care among community-dwelling South Dakotans.	CSS Random stratified sampling	N=2533 Age range 18-95y F= 54% M= 46% Caucasian 96% American Indian 3% Other 1%	With regard to hospice: Self-reported knowledge of concept Source of knowledge	• 50% of participants reported knew a lot about hospice • 67% of participants would want hospice if they were dying • Women were had more self-reported knowledge (M=60% F=43%, p=0.001 (χ^2 comparisons). • Self-reported knowledge reduced with age p=0.001	(150)
Johnson*** 2009 USA	What are the racial differences in self-reported exposure to hospice information and how does this exposure impact beliefs about hospice care?	CSS Random stratified sampling	N= 200 Mean age 72.8 (All>65y) African American N= 105 F= 60% M= 40% White N=95 F= 56.8% M= 43.2%	With regard to hospice care: Awareness Source of awareness Beliefs Attitudes	• 19.1% of African American participants and 4.2% of white participants had never heard of hospice (χ^2 p=0.0004) • African American participants were more likely to view hospice care as no treatment (58.1% versus 86.3%, p<0.0001) or hospice care as not as good as treatment in the hospital	(146)
Johnson*** 2008 USA	Are differences between older African-American and white adults in attitudes toward hospice care explained by differences in cultural beliefs and values?	CSS Random stratified sampling	N=205 African American N=110 Mean age 73.4 (all >65y) F= 60.9% M= 39.1% White N=95 Mean age 72.5 F= 56.8% M= 43.2%	With regard to hospice care: Attitudes Beliefs	• African American participants mean score 26.2 on the hospice beliefs and attitudes scale (HBAS) (higher scores more favourable attitudes), with white participants scoring 29.4 p<0.001 (Wilcoxon) • Linear regression adjusting for demographics, self-reported health, preference for end of life, beliefs about dying and advance care planning, healthcare system distrust and spirituality scale meant no significant difference in HBAS between African American and white participants • Hospice may not be congruent with the cultural beliefs of some older African Americans	(145)

First author, year, location	**Key research question(s)**	**Study design**	**Participant details Size (N), Age (years), Sex (%), Ethnicity (%)**	**Relevant outcomes**	**Key findings**	**Ref**
Colon 2012 USA	Does acculturation impact Latino attitudes toward hospice?	CSS Convenience sampling	N=367 Mean age 35.6 (all>18y) F= 61.2% M= 38.8%	With regard to hospice: Awareness Knowledge Attitude	• 56% of participants had never heard the word hospice • Knowledge index scores consistently low • Hospice seen favourably as measured by 17 item attitude to hospice scale Median 61 (possible scores 17 to 85, higher more favourable) • No evidence that culture impacted attitudes • More income and years of education had a significant correlation with a positive attitude (r=0,3, p=0.000 and ANOVA F(4,341)= 3.664, p=0.002 respectively) • Awareness, not knowledge of hospice correlated with more preferable attitudes, p=0.001	(143)
MacLeod 2012 New Zealand	What are New Zealanders' views about palliative care and local hospice services.	CSS Convenience quota sampling	N=1011 Age range 18 to 70+ F= 52% M= 48% NZ European 85%, Maori 6%, Chinese 3%, Indian 2%, Other 9%	With regard to PC and hospice Source of knowledge Knowledge of services Perception	• 50% of participants perceived hospice as a place where people go to die • People >50 years old had more accurate perceptions of PC, were more aware that hospice is more than pain management, is for family and not only available in hospital • People >50 years old were more likely to view PC as helping people die and only for cancer patients • People <30 years old less knowledgeable • General understanding PC provides comfort to people with terminal illness, helps family members care for PC patients, cares for patients' emotional needs • Women more knowledgeable about hospice	(168)
Mahmudur Rahman 2017 Bangladesh	What are the perceptions about palliative care among young generations living in Dhaka city	CSS Random sampling	N=3152 Age range 20-28 F=45% M=55%	With regard to PC: Awareness Source of awareness	• 18.5% of participants described a clear concept of PC, 22% knew of the concept and 59.7% were unfamiliar with it	(169)
Park 2012 South Korea	What are the attitudes to hospice care in Korea? What is the relationship between individual characteristics and choice intention regarding hospice care?	CSS Convenience sampling	N=248 Mean age 39 (All >21y) F=60% M=40%	With regard to hospice care: Knowledge Attitudes	• Intention to use hospice services was 55% in women compared with 40% in men (p=0.028) • Those intending to use hospice had a better understanding of what hospice is (p=0.000) • Choice intender group had a more favourable attitude to hospice care	(163)
Mohamadali 2015 Malaysia	What is the awareness and perception of palliative care among students in Malaysia?	CSS Random sampling	N=62 Age range 18 to >60y F= 79% M= 21%	With regard to PC: Self-reported knowledge Source of knowledge Knowledge of services Perception	• 51.6% of participants reported no knowledge of PC, 30.6% some knowledge and 17.7% a lot of knowledge • 65% of participants did not know any details of services provided	(170)

First author, year, location	Key research question(s)	Study design	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
					• 79% of participants identified the purpose of PC is to give moral and emotional supports to the patients suffering with non-curable illness. • 58% agreed those who receive PC have a better quality of life • Costs associated with PC were not understood	
Sung 2019 Taiwan	What is the knowledge and attitude concerning palliative care in older residents in a long-term care institution?	CSS Convenience sampling	N=57 Mean age 79.6 F= 24.6% M= 75.4%	With regards to PC: Awareness Knowledge Attitude	• 93% of participants identified that had no understanding of PC • Knowledge of PC was poor on a bespoke scale (mean out of 21) 4.32 • Attitude to the benefit of PC was favourable	(162)
Huang 2019 Taiwan	What is the relationship between health literacy and hospice knowledge, attitude in community-dwelling elderly participants?	CSS Convenience quota sampling	N=990 Mean age 71.53 (SD 7.22) F= 49.8% M= 50.2%	With regards hospice care: Knowledge Attitude Choosing Hospice Correlations with health literacy (HL)	• Knowledge of hospice care 26.77 (out of 40, higher more knowledgeable) • There is a favourable attitude towards hospice • General HL positively and significantly predicted knowledge and attitude towards hospice care • Knowledge and attitude positively and significantly predicted the likelihood of choosing hospice care	(161)
Collins 2020 Australia	What are the community understandings of and attitudes to palliative care and what characteristics are associated with favourable attitudes?	CSS Convenience sampling	N=421 Mean age 51 F=75%, M=24%, non-binary 1%	With regard to PC: Exposure Self-reported knowledge Source of awareness Knowledge Attitudes	• 30% of participants said they knew what PC was and could explain it to others, 29% knew ‘a little’, 27% had heard the words but did not really know and 10% had never heard of it 10% • Median score on a 10-part questionnaire was 7 • Examples include 25% of participants thought to receive PC you must be in the last month of life, 20% thought people must be in hospital to receive PC • 77% and 69% of participants agreed PC focuses on improving a person’s quality of life and provides expert pain management for people with serious illness respectively • Attitudes to PC were favourable • Older age, previously undertaking a caregiving role, knowing someone who had received PC and more accurate knowledge of PC significantly predicted more favourable attitudes.	(167)
Selsky 2012 USA	What are the factors associated with Latino knowledge of and intention to use hospice for cancer care?	CSS Convenience sampling	N=331 Mean age 43 F=53% M=47%	With regard to hospice care: Awareness Knowledge Intent to use	• 29% of participants had heard of hospice. • Mean hospice knowledge score was 3.1/7. • Higher education level, being female and higher degrees of Latino cultural values and social acculturation were associated with higher knowledge scores. • Secrecy about death was inversely associated intention to use hospice (adjusted OR 0.81 (0.67-0.99)).	(153)

First author, year, location	**Key research question(s)**	**Study design**	**Participant details Size (N), Age (years), Sex (%), Ethnicity (%)**	**Relevant outcomes**	**Key findings**	**Ref**
Kozlov 2018 USA	What do laypersons know about palliative care as assessed by the Palliative Care Knowledge Scale (PaCKS)?	CSS Convenience sampling	N=301 Age range 18-98 F= 51.8% M= 48.2% Asian 4.7%, Black 9.3%, Hispanic/Latino 3%, White 80%, Multiracial 2.6%	With regard to PC: Knowledge	• Mean PaCKS score 5.25/13 (range 0-13, higher better). Breakdown by question available in appendix 5 • Significantly better PaCKS scores were associated with being female, older, having a higher education level, having heard of PC and knowing someone who used PC	(156)
Joseph 2009 India	What is the knowledge and attitude toward palliative care and it's contributing factors among people residing in urban and rural areas?	CSS Random stratified sampling	N=165 rural and 185 urban No other demographics	With regard to PC: Awareness Source of awareness Knowledge Attitudes	• 13.4% of participants had heard of PC • Living in Urban areas more likely to have heard of PC (20.5% vs 5.4% p<0.0001 (χ^2)) • 70%, 49%, 30% of participants aware that PC is for cancer, AIDS, cardiovascular ailments respectively • 85% of participants believed PC improved quality of life	(165)
Huo 2019 USA	What is the knowledge penetration of palliative care in a nationally representative sample of U.S. adults?	CSS Random stratified sampling from HINTS survey	N=3194 Age range 18 to 65+ F= 51.3% M= 48.7% Non-Hispanic white 60.8% Non-Hispanic black 10% Hispanic 14.8% Other 14.4%	With regard to PC: Knowledge Perception Source of knowledge	• 86.6% of participants had no or inadequate knowledge of PC • Better knowledge was associated with being older, a woman, non-Hispanic, employed and having higher levels of education, higher income, or a history of cancer • Higher odds of having knowledge of PC in respondents who were middle-aged or elder compared with the younger group • Lower odds of having knowledge of PC were observed in Hispanics • 92% of participants were aware PC helps pain and symptoms and 87% that it is to help family • 41.5% of participants thought of death when thinking of PC	(155)
Yim 2018 South Korea	What is the public perceptions and demands for palliative care in the Republic of Korea?	CSS Quota sampling	N= 1500 Age range 20 to >60 F= 49.2% M= 50.8%	With regard to PC: Awareness Source of information Perception Attitudes	• 55% of participants reported not knowing about PC 4% knew a lot • 76.5% of participants agreed that PC helps patients live in fullness for the rest of their lives and get comfortable deaths • 85.8% of participants saw PC as a necessity • 73.9% of participants stated they would use hospice • Education, living in urban areas, higher income and family history associated with better knowledge of PC	(164)

Abbreviations for quantitative studies: *, **, *** studies including the same participants; EOL end of life, EoLC end of life care, PC palliative care, PCU palliative care unit, HPC hospice palliative care, SPC specialist palliative care, CSS cross-sectional survey, OPTIM Outreach Palliative Care Trial of the Integrated Regional Model, HINTS Health Information National Trends Survey, N number, F female, M male, NK not known, HKT hospice knowledge test, HPS-8 hospice philosophy scale, HBAS hospice beliefs and attitudes scale, PaCKS palliative care knowledge scale, HL health literacy, OR odds ratio, ANOVA analysis of variance.

Table 8: Characteristics of included qualitative studies

First author, year, country	Relevant research aim(s)	Participant details. Size (N), Age (years), Sex (%), Ethnicity	Methods and methodology	Key findings	Ref
Taxis 2006 USA	To explore: 1. the perceptions of African American adult community members regarding the philosophy, services, support and accessibility of hospice programs? 2. the cultural values associated with end-of-life care and how do these interface with the philosophical stance of hospice programs?	N= 28 Age mean 64.5 (range 22-89) F=100% Ethnicity: African American	Methodology: Naturalistic inquiry (Lincoln and Guba, 1985) (115) Data collection: Focus groups (semi-structured) Recruitment: Purposive sampling in churches	• A pervasive lack of information about hospice, produces numerous assumptions about hospice services • Cultural and institutional barriers • Assumptions that the care would be inadequate • People would die lonely, painful deaths • Hospice inaccessible to African Americans due to cost • Mistrust and misconceptions permeated the data.	(125)
Kwak 2007 USA	To examine social and cultural factors influencing views of Korean-American older adults and caregivers on advance care planning and hospice care	N= 20 Age (mean) 68 (all >60y) F=20%, M=80% N= 16 (non-professional caregivers) Age (mean) 40 (range 18-59) F=69% M=31% Ethnicity all Korean-American	Methodology: Modified grounded theory (Strauss and Corbin, 1990) (172) Data collection: Focus group (semi-structured) Recruitment: Purposive sampling via churches and Korean neighbourhood newspapers	• Cultural and structural barriers to and hospice use • A lack of knowledge about hospice • Filial piety supports and rejects hospice • The traditional norm of home death and importance of physician communication influenced preferences for hospice	(126)
Seymour 2007 UK	To seek views of older Chinese and non-Chinese adults living in the UK on end of life care	Chinese N= 92 Age range 50 to over 85 F= 72% M=28% Non-Chinese N= 77 Age range 50 to over 85 F= 68% M= 32% Ethnicity: White British, White Irish, Black Caribbean, Black British	Methodology: 1. Focus groups: thematic analysis 2. Interviews: Framework analysis (based on themes from focus groups) Data collection: Focus groups and interviews Recruitment: Snowballing sampling	• Non-chinese elders perceived hospices in idealised terms of the 'good death'. • Chinese elders perceived places of 'inauspicious' care in which opportunities for achieving an appropriate or good death were limited • These preferences seemed to related to often cultural concerns about the demands on the family	(127)
Daveson 2011 England and Germany	To identify English and German understandings of EoLC within the context of an EoLC survey	England N= 15 Age (median) 61 (range 17-81) F= 53% M=47% Ethnicity: British 10, European 2, Turkish 1, Indian 1, Chinese 1 Germany N= 15 Age (median) 45 (range 19-81) F= 67% M= 33% Ethnicity: German 13, Turkish 2	Methodology: 1. Modified grounded theory 2. Meta-ethnography synthesis Noblit and Hare (173) Data collection: Cognitive interviewing Recruitment: Purposive sampling within convenience sampling frame and further snowball sampling.	• Expectations of a high standard of EoLC involving autonomy, choice, and context • Evolving decision making amid anticipated change • Thoughts about living and existing • Worldviews shaping EoLC in real and hypothetical scenarios	(133)

Enguidanos 2013 USA	To explore older Chinese Americans' knowledge, understanding, and perceptions of hospice care.	N= 34 Age: All >18y F= 65% M= 35% Ethnicity: Chinese 91%, Other 6%, missing 3%	Methodology: Grounded theory (174) Data collection: Focus groups Recruitment: Purposive sampling from Chinese social service agency.	• A lack of knowledge • Death timing (waiting for death in a hospice so as to relieve burden) • Burden (financial, emotional, physical toward family or government) • Peaceful death (relief of suffering)	(128)
McIfatrick 2014 UK	To explore public perceptions of palliative care and identify strategies to raise awareness.	N= 50 Age all >18y F= 74% M= 26%	Methodology: Thematic content analysis using Miles and Hubermans' framework. (175) Data collection: Interviews (semi-structured) Recruitment: Convenience sampling:	• Most participants had a general knowledge of PC, largely influenced by their own personal experience. • Palliative care was identified as: caring for people who were dying and maintaining comfort in the last days. • Expectations of PC included holistic support, symptom management, good communication and carer support.	(131)
Pullis 2011 USA	To examine the perceptions of hospice care among African Americans	N= 41 Age (mean) 58y (range 21-85y) F= 76% M= 24% Female 76% Ethnicity: African American	Methodology: Thematic analysis Data collection: Focus group (semi-structured) Recruitment: Purposive sampling	• The perception of hospice care was generally positive • Being African American did not influence the care they would want at the end of life	(129)
Boucher 2018 USA	To understand study participants' knowledge of PC and acceptability of a new community-based PC model	N= 18 Age all >24y F= 44% M= 56% Ethnicity: White 89%, Black of African American 5.5%, Mixed ethnicity 5.5%	Methodology: Descriptive content analysis (176) Data collection: Focus group Recruitment: Convenience sampling via community postings	• Gaps in knowledge related to knowing the services available in palliative care, how palliative care is paid for and how palliative care affects the patient's relationship with existing providers. • Participants perceived more attention to individualised care and a broader application of palliative care.	(130)
Tasseff 2018 USA	To explore the palliative care perceptions of rural dwelling adults	N= 13 Age (mean) 65.3 F= 46% M= 54%	Methodology: Thematic analysis following grounded theory approach (Braun and Clarke (177)) Data collection: Semi-structured interview Recruitment: Purposive sampling eg through newspaper adverts	• Unfamiliarity with the term • Experience is a strong teacher.	(132)

Abbreviations for qualitative studies: EOLC end of life care, PC palliative care, N number, F female, M male, NK not known

Table 9: Characteristics of included mixed methods studies

First author, year, location	Key research question(s)	Study design	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
Benini 2011 Italy	What is the awareness, understanding and attitudes of Italians regarding palliative care?	CSS Random stratified sampling Content analysis of one open question	N=1897 Age range 18-74y F= 51.2% M= 48.8%	With regard to PC: Awareness Understanding Attitudes	• 60% of participants had heard of PC but only 7% described a precise idea • Better awareness was associated with being (χ^2 p<0.001) a woman, middle-aged (age 45-54y), someone with higher income or education • Open question - the prevalent identification of PC was with "the treatment of pain and improved of quality of life" • Perceptions of PC assigned to 3 categories: care that does not cure, care for terminal patients and care for patients that will not recover	(134)
McIlfatrick 2013 UK	What are the public views towards palliative care and what are strategies to improve awareness?	CSS Convenience sampling Content analysis of responses to open questions (Miles Huberman framework)	N=600 All >18y Modal age group 60-69 F= 69% M= 31% Ethnicity White 92%	With regard to PC: Awareness Knowledge	• 83% of participants had heard of PC but 75% described no or low understanding of it • Higher levels of knowledge associated with being a woman (Mann-Whitney 2 tailed p=0.01) or in an older age group (Nonpar. Correlation, Spearman's rho p=0.005) • Comfort, pain relief and dignity were seen as aims of PC • 76.8% of participants believed PC could be offered in a hospice or home and only 58.2% in hospital • Having experience in the past (χ2, p < 0.001) was associated with higher knowledge • Knowledge of PC themes included pain relief for those with terminal illness at the end of life, cancer and older people.	(135)
O'Connor 2019 Australia	What are community attitudes toward palliative care? What are the determinants?	CSS Convenience sampling Content analysis of responses to open questions	N=180 Mean age=41.3 (all >18y) F= 65% M= 35%	With regard PC: Attitude Beliefs Emotions Knowledge	• 75.6% and 62.1% of participants reported positive beliefs and emotions regarding PC respectively • Participants scored a mean of 13 (out of 16) on a questionnaire regarding knowledge of PC, for example: • 93.3% aware PC includes psychological, emotional and spiritual care • 82.8% aware also provides family support • 28.5% were unaware/unsure if euthanasia was part of PC • 29.5% thought or were unsure that specialist PC was only available in hospital • Younger participants had less favourable attitudes toward PC (r=0.297, P <0.001). • Age and place of birth significantly accounted for 11.2% of the variability in attitude scores, ΔR2=0.112, F(2, 177)=11.12, P <0.001.	(136)

First author, year, location	Key research question(s)	Study design	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
					• Themes for belief about PC: supports family, more resources needed, essential, care for the dying • Themes for emotions: Sad, comfortable/relief, happy/good, angry/frustrated	
Voseckova 2016 Czechia	What is the general public knowledge and attitudes of hospice care?	CSS Sampling and analysis methods unknown	N=85 Demographics Not known (adult general public)	With regard to hospice and PC: Awareness Attitudes	• 61% of participants reported awareness of hospice care and 20% of PC • 47% agreed that hospice care is important for citizens of the Czech Republic • 31% or participants would use hospice care themselves and 25% would use hospice care for relatives	(137)
Shalev 2018 USA	What is the palliative and hospice care awareness, misperceptions, and receptivity among community-dwelling adults?	CSS Random sampling Framework analysis of responses to open questions	N=800 Mean age 47 (all >18y) F= 49% M= 51% Ethnicity: White 60.4% Black 16.6% Hispanic 5.1% Asian 4.6% Mixed/Other 13.3%	With regard to hospice and PC: Associations Perceptions Receptivity (attitude)	• 60% of participants associated hospice care with end of life care, whereas 13.4% and 3.3% associated with comfort and symptom management, respectively (themes) • 9% saw PC as applicable at any course of an illness and <1% saw hospice or PC as affirming life • 74% of participants associated PC with end of life care and six participants viewed hospice care as euthanasia • 62.9% responded likely or very likely to recommend PC • Lower receptivity to PC associated with male ($p<0.001$); lower income ($p=0.043$) and awareness ($p=0.038$)	(50)
Westerlund 2018 Sweden	What is the Swedish general public (age 18 to 66) awareness of palliative care and understandings about existing EoL care?	CSS Random stratified sampling Thematic analysis of responses to open questions	N= 2020 Mean age 44.7 (all >18y) F= 50% M= 50%	With regard to PC: Awareness Source of awareness Knowledge	• 59% of participants reported they were somewhat, fairly or very aware of PC • Being female (χ^2 ($p<0.05$)), older (Mann-Whitney U ($p<0.05$)) and having a university level education associated with higher awareness • Knowledge of aims (by theme) included 60% of participants saw the aims of PC as care before death and pain relief, 50.4% saw aims of PC as a peaceful death. 40% viewed family support and quality of life as part of PC	(138)
Roulston 2017 Canada	Do public health awareness campaigns effectively improve the awareness and quality of palliative care?	CSS Focus groups informed survey. Further methods unknown	N=1540 Mean age NK	With regards to PC: Awareness Understanding	• 16% of participants reported being very aware of PC, 43% somewhat and 14% not at all • 10% of participants reported being very aware of residential hospice care, 39% somewhat, 15% not at all	(139)

Abbreviations for mixed method studies: PC palliative care, N number, F female, M male, NK not known, CSS cross sectional study

Participants within included studies

All participants were adults (18 years old or over). All but two studies described some age data such as age range or bands, but a mean age could not be calculated due to missing data. After removing participants counted in duplicate publications of the same survey, in studies where sex was reported (45/48), 16,511/30,191 (54%) were women.

Twenty-five out of the 48 studies reported ethnicity data (n=13,026), with the focus of some studies being differences in perceptions between ethnic groups. Ethnic groups included Hispanic American, Asian (Korean, Chinese, Malay), Black British, African American, Native American and Indian. Other groups from specific papers included Maori, Pacific Islander or Hawaiian. There were also heterogenous groups termed ‘other’.

Characteristics including marital status and religion were variably reported, the details of which can be seen in appendix 5. Interestingly, socio-economic status was only formally reported in three studies, but surrogates of income, employment and education were reported in 13, 15 and 27 of the published papers respectively.

Design of included studies

All quantitative study was cross-sectional survey. Sampling methods included random sampling plus or minus stratification e.g. for ethnicity, convenience plus or minus quota systems, cluster sampling, or quota sampling alone (see tables 7 and 9 for details).

All qualitative sampling was purposive; one augmented by snowball sampling. Seven studies detailed a sampling frame for their recruitment. Four described a grounded theory approach (126, 128, 132, 133) and one of these studies further synthesised findings by meta-ethnographic synthesis (133). McIlfatrick used thematic content analysis (131) and Boucher a descriptive content analysis (130). The remainder were not specific about methods beyond stating thematic analysis.

One of seven mixed method studies involved ‘traditional’ qualitative methods (focus groups) and the output of these informed a quantitative cross-sectional survey (139). The Westerlund Swedish cross-sectional survey (138) translated the non-validated bespoke

Northern Irish survey by McIlfatrick (135). All remaining studies utilised bespoke cross-sectional surveys with open questions. Five papers referred to specific methods of analysis, all but one of these was content analysis (131, 134, 136, 138), with the remainder employing framework analysis (50).

Measurement tools used for quantitative data collection in included studies

Only one validated palliative care knowledge assessment tool, the Palliative Care Knowledge Scale (PaCKS) (178) was used and this was only used once (156). Other validated instruments were used but these were not specifically for assessing perceptions of palliative care rather to assess attitudes in general, health related quality of life and, health literacy. Twenty-six studies used bespoke measurement instruments, ten were derived by consensus between experts and two were unknown (one referred to “standardised scales” (162)). Despite lacking validation, there was some consistency in the questions being asked. Two studies based their measurement tool on the Life's End Institute: Missoula Demonstration Project (150, 152, 179), four used modified versions of the Hospice Philosophy Scale (albeit three of these studies involved the same participants) (140, 141, 144, 154). Several papers merely commented that their instrument was based on similar tools used in pre-published studies, although these were not consistently referenced.

Reported outcomes of interest within included studies

Seventeen papers stated the phenomenon of interest was “palliative care”, eight “hospice”, six “hospice care”, four “palliative care and hospice” and, one paper looked at “hospice and hospice care”, one at “palliative care units”, one at “specialised palliative care” and one at “hospice services”. For each study, outcomes were classified as awareness, source of awareness, knowledge and understanding, attitudes, choice intention and perception.

3.3 Quality Appraisal

3.3.1 Quantitative quality appraisal

Details of the quality appraisal by paper can be seen in appendix 4. Table 10 below demonstrates an overview of the quality by pooling studies by AXIS criteria. Scores (out of 20) ranged from three (Voseckova, 2016 (137)) to 20 (Catt, 2005 (171)). The mean and median quality scores were 14 and 15, respectively. In summary, the choice of cross-sectional study to estimate prevalence of a behaviour in a population (in this case perceptions of palliative care) was suitable for most studies (33 out of 39 studies) (180). All included quantitative and mixed methods papers described clear aims and objectives. Methods were variably described; for example, sample size was rarely justified (only done by means of a power calculation in seven studies), and similarly categorising and describing non-responders was rarely described. Despite the majority of measurement tools being non-validated and bespoke, many referred to modification from previous publication.

Table 10: Synthesised results of AXIS quality appraisal for cross-sectional studies (n=39)

Question		Answer	Studies (n)
Introduction	1. Were the aims/objectives of the study clear?	Yes*	39
		No	0
Methods	2. Was the study design appropriate for the stated aim(s)?	Yes*	33
		No	6
		Don't know	0
	3. Was the sample size justified?	Yes*	5
		No	33
		Don't know	1
	4. Was the target/reference population clearly defined? (Is it clear who the research was about?)	Yes*	35
		No	4
		Don't know	0
	5. Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?	Yes*	26
		No	9
		Don't know	4
	6. Was the selection process likely to select subjects/ participants that were representative of the target/reference population under investigation?	Yes*	18
		No	15
		Don't know	6
	7. Were measures undertaken to address and categorise non-responders?	Yes*	7
		No	27
		Don't know	5
	8. Were the risk factor and outcome variables measured appropriate to the aims of the study?	Yes*	36
		No	0
		Don't know	3
	9. Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?	Yes*	25
		No	12
		Don't know	2
	10. Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)	Yes*	33
		No	6
		Don't know	0
	11. Were the methods (including statistical methods) sufficiently described to enable them to be repeated?	Yes*	34
		No	5
		Don't know	0

Question		Answer	Studies (n)
Results	12. Were the basic data adequately described?	Yes*	36
		No	3
		Don't know	0
	13. Does the response rate raise concerns about non-response bias?	Yes	11
		No*	6
		Don't know	22
	14. If appropriate, was information about non-responders described?	Yes*	10
		No	27
		Don't know	2
	15. Were the results internally consistent?	Yes*	39
		No	0
		Don't know	0
	16. Were the results presented for all the analyses described in the methods?	Yes*	35
		No	1
		Don't know	3
Discussion	17. Were the authors' discussions and conclusions justified by the results?	Yes*	33
		No	4
		Don't know	2
	18. Were the limitations of the study discussed?	Yes*	31
		No	8
		Don't know	0
Other	19. Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?	Yes	1
		No*	33
		Don't know	5
	20. Was ethical approval or consent of participants attained?	Yes*	29
		No	4
		Don't know	6

*answer implying better quality

3.3.2 Qualitative quality appraisal

The design of the included studies is detailed in the previous section. The included qualitative studies were of moderate to good quality. All demonstrated significant use of quotes to confirm researcher conclusions and positionality was documented consistently. The quality of the qualitative sections of the mixed methods studies was generally low with findings often quantified using descriptive statistics. Table 11, below, summarises the quality appraisal by the CASP tool. Sections one to nine of the tool can be answered “yes, no, or can’t tell.” Section ten asks the value of the research. Overall, the quality of all the quantitative, qualitative, and mixed methods studies was mixed and it is therefore important that the findings are interpreted in that context.

Table 11: Results of CASP quality appraisal for qualitative studies (including mixed methods)

	CASP questions										
First author, year	1	2	3	4	5	6	7	8	9	10	Reference
Benini, 2011*	🟩	🟩	🟥	🟥	🟩	🟥	🟩	🟥	🟩	🟥	(134)
McIlfatrick, 2013*	🟩	🟩	🟨	🟥	🟥	🟥	🟩	🟥	🟩	🟩	(135)
Voseckova, 2016*	🟩	🟩	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	(137)
Roulston, 2017*	🟥	🟩	🟩	🟨	🟨	🟥	🟥	🟥	🟥	🟨	(139)
Shalev, 2018*	🟩	🟩	🟩	🟩	🟨	🟥	🟥	🟥	🟥	🟨	(50)
Westerlund, 2018*	🟩	🟩	🟩	🟩	🟥	🟨	🟩	🟥	🟥	🟨	(138)
O'Connor, 2019*	🟩	🟩	🟥	🟥	🟥	🟥	🟩	🟥	🟩	🟨	(136)
Taxis, 2006	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟥	🟩	(125)
Kwak, 2007	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟩	(126)
Seymour, 2007	🟥	🟩	🟩	🟩	🟩	🟥	🟩	🟥	🟨	🟩	(127)
Daveson, 2011	🟩	🟩	🟩	🟩	🟨	🟩	🟨	🟩	🟨	🟩	(133)
Pullis, 2011	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟥	🟥	🟥	(129)
Enguidanos, 2013	🟩	🟩	🟩	🟩	🟩	🟥	🟥	🟥	🟥	🟩	(128)
McIlfatrick, 2014	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟥	🟩	(131)
Boucher, 2018	🟩	🟩	🟥	🟥	🟩	🟩	🟥	🟩	🟩	🟩	(130)
Tasseff, 2018	🟩	🟩	🟥	🟩	🟩	🟥	🟩	🟩	🟩	🟩	(132)

Key to CASP questions:

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

*mixed methods study

Answers (questions 1-9):

🟥 No
🟨 Don't know
🟩 Yes

Answers (question 10):

🟥 Poor value
🟨 Average value
🟩 Very valuable

3.4 Narrative synthesis of quantitative findings

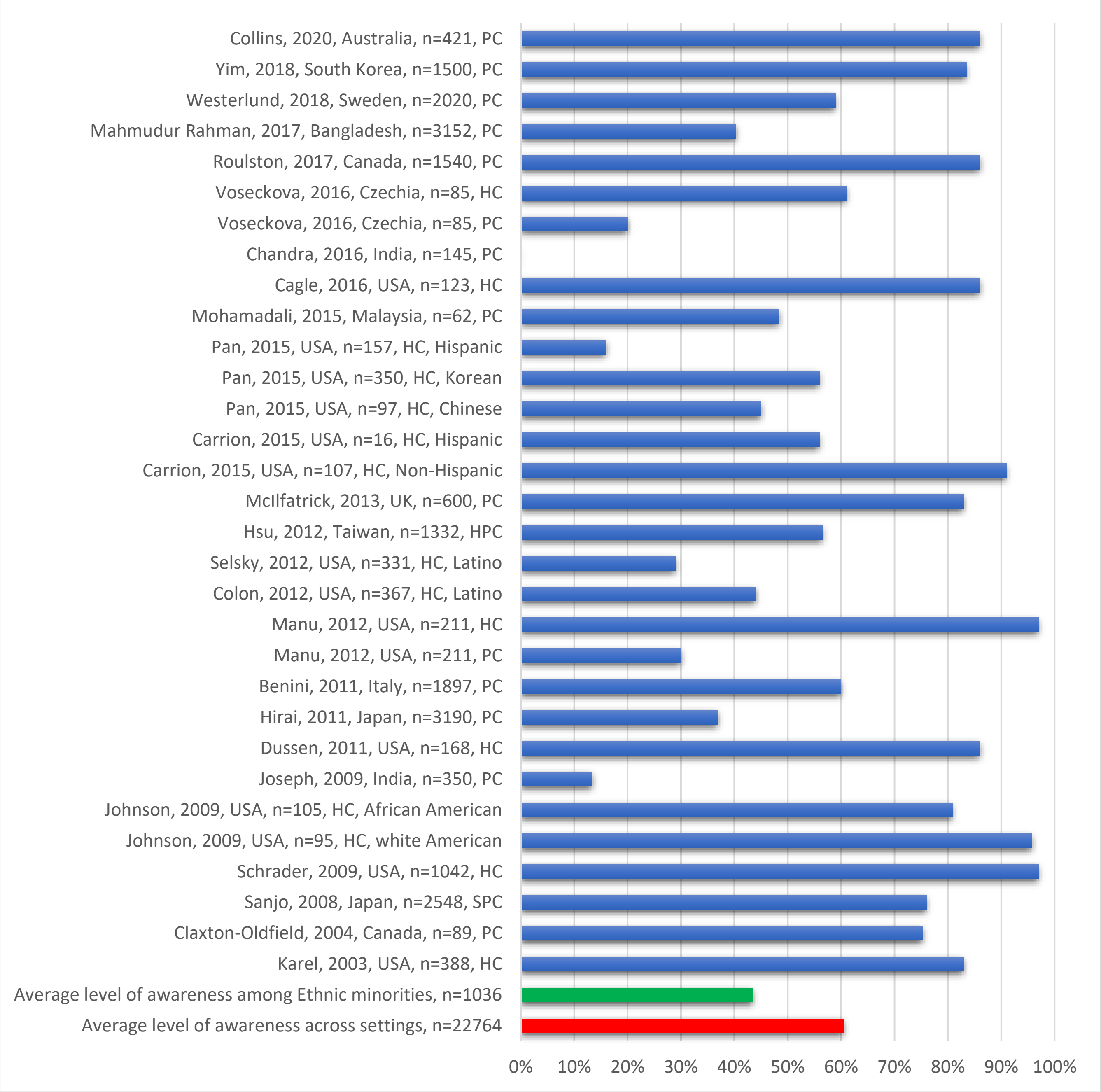
Outcomes in the studies included the public's awareness, knowledge and perceptions of, and attitude toward palliative or hospice care. It is in the context of these outcomes that I will present the results of this narrative synthesis in exploring the first two of my research questions (what are public perceptions of palliative care and what influences these perceptions?).

3.4.1 Awareness

Twenty-four of the included studies reported levels awareness of palliative care or hospice care (shown in figure 2 in chronological order). Overall, a mean average of just over half (60% participants) were aware of hospice/palliative care (range 0% to 97%). Awareness varied by country (two studies from India reporting the lowest (0% and 13.4% of participants) (165, 166) and the five studies with the highest (> 80% of participants), were all from North America (139, 140, 149, 152), with two of these being surveys of over 1000 participants (139, 152)). Overall, 73% of participants had an awareness of hospice care (all US) compared with 55% of participants reporting an awareness of palliative care (all settings; in the only US study enquiring specifically about awareness of 'palliative care' only 30% of 211 participants reported an awareness (149)).

As can be seen in figure 2 awareness also varied within nations, these differences were consistently associated with differing ethnic groups. For example, African Americans had over twice the odds of reporting that they had never heard of hospice or had only heard a little about hospice compared with white Americans (odds ratio 2.24 (95% confidence interval 1.17 – 4.27)) (146) and Hispanic and Latino Americans consistently reported the lowest awareness, with a mean of 34% of 851 participants across four studies (141, 143, 151, 153). From the data available on ethnic minorities (Hispanic, Latino, Korean, Chinese and, African American) only 44% of 1403 participants had heard of palliative or hospice care. Being a woman, being older, having a higher level of education and previous experience of palliative/hospice care or serious illness were significantly and positively associated with awareness of palliative care in most of the data (134, 138, 140, 142, 144, 152, 157). Affluence influenced level of awareness (in India, living in (more affluent) urban areas, people were more likely to have heard of palliative care (20.5% vs 5.4% $p<0.0001$ (χ^2)) (165)

and in Italy higher income related to better awareness (134)). Participants in studies from middle-income countries had lower levels of awareness of palliative or hospice care (Bangladesh and India (165, 166, 169)) compared with higher-income countries.



Key: HC = Hospice care; PC = Palliative care; HPC = Hospice palliative care; SPC = Specialist palliative care
When ethnicity not stated data are unselected ethnicity

Figure 2: Awareness of palliative care and hospice care across settings (percentage of study participants that had heard of palliative and/or hospice care)

3.4.2 Knowledge and perceptions

The understanding of the public knowledge and perceptions of palliative and hospice care as provided by this narrative synthesis is best understood through the subheadings: 1) what is palliative care? 2) who is palliative care for? 3) who provides palliative care and where can it be accessed? 4) funding and cost of palliative care; 5) overall knowledge of palliative care and 6) self-rated knowledge.

What is palliative care?

In the context of variable but moderately high reported levels of awareness of palliative care, overall knowledge of what palliative care entailed was low and perceptions of palliative care were varied and at times contradictory, although better awareness was associated with better knowledge (156). Despite confusion between hospice and palliative care, as demonstrated in the summary tables (table 7-9), both terms were commonly associated with care in the last days or weeks of life. For example, 73% New Zealanders identified palliative care as aiming to provide a peaceful death (171). So pervasive was the view that palliative care is associated with "death", fewer than 1% of participants saw palliative care as affirming life in one US study (50), and Dussen *et al.* found that 38.6% of participants saw hospice care as *only* about death (144). Euthanasia was frequently linked to palliative care with 28.5% of participants in an Australian study (136) viewing palliative care *as* euthanasia. "Giving-up" on living and an association with no further medical treatments were also common perceptions of palliative care, especially in older participants and ethnic minority groups (59% of participants in one US study believed hospice care was only offered when nothing more could be done (149)). One example, in an American study, the majority of "Latino" participants reported they would not choose hospice because that would mean that they were not fighting for their life (143). Interestingly in the US, where palliative care can be received alongside curative treatments, 7% of respondents in one study believed they had to 'give up their other doctors' (with 49% answering don't know) (156) and 16% expressed a belief that palliative care encouraged people to stop treatments aimed at curing their illness (156).

Despite the association with death and "giving-up", there was evidence from a small number studies to suggest palliative care supports patients in "living" (135, 159). Seventyseven percent of participants in an Australian study compared with 38.3% in a study from Sweden saw palliative care as improving quality of life (138, 167)). Further international variation to this perception showed in India, where overall awareness of palliative care was low, 85% of participants who were aware of palliative care, associated palliative care with improving quality of life (165).

Relating palliative care to comfort (at the end of life) was presented in several studies, for example, McIlfatrick in the UK identified that 82% of 600 participants agreed one of the aims of palliative care was comfort (135), interestingly this finding was again lower in Sweden (34.3%) (138). In one study in the US only 13.4% of the public saw hospice care as providing comfort and, palliative care 21.9% (50). Underlining variability in perceptions between and within nations, a focus of palliative care on pain and symptom management was generally well known, yet still not consistent, with only 42.9% of participants in the Swedish study (138) and only 26.4% in a US study (50) being aware of this focus.

A perception that palliative care included emotional and psychological support at the end of life further varied by region (79% of participants in a Malaysian study (170) and 93.3% in Australia (136) but only 38% in a US study (156)).

Who is palliative care for?

Palliative care was predominantly seen as for people with cancer. Although not directly comparable given the disease focus of palliative care is likely to be different in different areas, this was consistent across middle-income regions (78% of participants in Bangladesh (169) and 70% in India (165)). In India, however, there appeared to be a growing understanding that palliative care was broader than just cancer, with 30%, 32% and 48% identifying cardiovascular disease, respiratory disease and AIDS as diseases requiring palliative care, respectively (165). Some studies from higher income countries found more people were aware of the scope of palliative care (82% of people viewed hospice care as not only for cancer (UK) (171) and only 5% of participants viewed palliative care as specifically for cancer (US) (156)). An interesting conundrum in the data, a considerable proportion of the population studied did not associated palliative care with cancer, for example, in Canada a study identified that only 64.5% of 170 participants saw palliative care associated with cancer (142).

Despite palliative care being associated with the end of life, there were also data suggesting palliative care could be received alongside other treatments. For example, an Australian study viewed palliative care as a possibility alongside potentially curative treatments (59% of participants) (167) and 62.3% in a US study said the same about hospice (140). Conversely, in another US study of 800 participants, only 8.8% of respondents believed palliative care (not hospice care) was applicable at any course of an illness (50).

There was a paucity of evidence in these data regarding when palliative care stopped, but what was available again suggested confusion. Out of 123 participants in one US study, 57.5% believed palliative care stopped when a patient died (140), yet in the same paper, 87.7% acknowledged bereavement support was part of palliative care (140). Bereavement services were not seen as part of palliative care in another study in the US (<1%) (50). Ethnicity, specifically in the US, appeared to influence the view whether care stopped at death, for example, 89% of Hispanics participants believed hospice services end when a patient dies compared with 55% of non-Hispanic participants ($p=0.07$) (141).

Despite acknowledgement by some that palliative care extended beyond the patient to care for family and caregivers, conflicting perceptions were apparent. Factors associated with this perception were again country of study and ethnicity. For example, 97% of non-Hispanic Americans but only 67% of Hispanic Americans believed hospice care helped caregivers (141) and despite an Australian study reporting that 82.8% of participants saw palliative care extending beyond the patient (136), in Sweden, only 6.2% of participants identified support for caregivers as part of palliative care (138).

Who provides palliative care and where can it be accessed?

Despite some variability, many regions saw palliative care and hospice care as an approach offered by nursing staff rather than a multi-disciplinary team (142, 167). In the US a study only 5 out of 664 participants viewed hospice care and 3 out of 216 palliative as delivered by an interdisciplinary team (50). Countering this view, in another US study ($n=123$) 97.2% of people agreed that a hospice care team included physicians, nurses, social workers, and chaplains (140).

There was a sense that the public viewed palliative care as available in hospital, with 68.3% of participants agreeing with this in a Canadian study and an Australian study going further, stating 20% of participants perceived that to receive palliative care a patient *must* be in hospital (142, 167). Conversely, there was evidence from the US that only 5% of 301 participants thought people needed to be in hospital to receive palliative care (although 49% answered “don’t know”) (156); 18.9% of participants in another US study believed that individuals receiving hospice care cannot be taken to hospital at all (140). Awareness that palliative care is available at home was less prevalent, with studies commonly describing around 30% of participants being aware of this (138, 142) and interestingly, in one US study, 9.4% of participants believed hospice care is not provided at home at all (140).

Funding and cost of palliative care

Funding structures and costs of palliative care were mostly unknowns. In American studies where insurance mostly covers palliative and hospice care, public awareness of this was low (144, 152). In the UK there was a view that hospices depend entirely on voluntary contributions (43.4% of participants) (171). Across both high-income and middle-income countries there was a perception that palliative and hospice care was expensive (31.3% (US) (144), 61% (Japan) (159)) with some studies (US and Malaysia) reporting the public viewed that a lack of money would prevent use of hospice services (143, 170).

Overall knowledge

A number of studies assessed overall knowledge. While not directly comparable, the mean scores were converted into percentages and are shown in figure 3. Scores varied again between and within regions, commonly overall knowledge scores were low (range 20.6% (Taiwan) (162) to 78% (US) (140). The only study using a validated palliative care knowledge scale (PaCKS) reported a mean knowledge score of 5.25 out of 13, (range 0-13) (156).

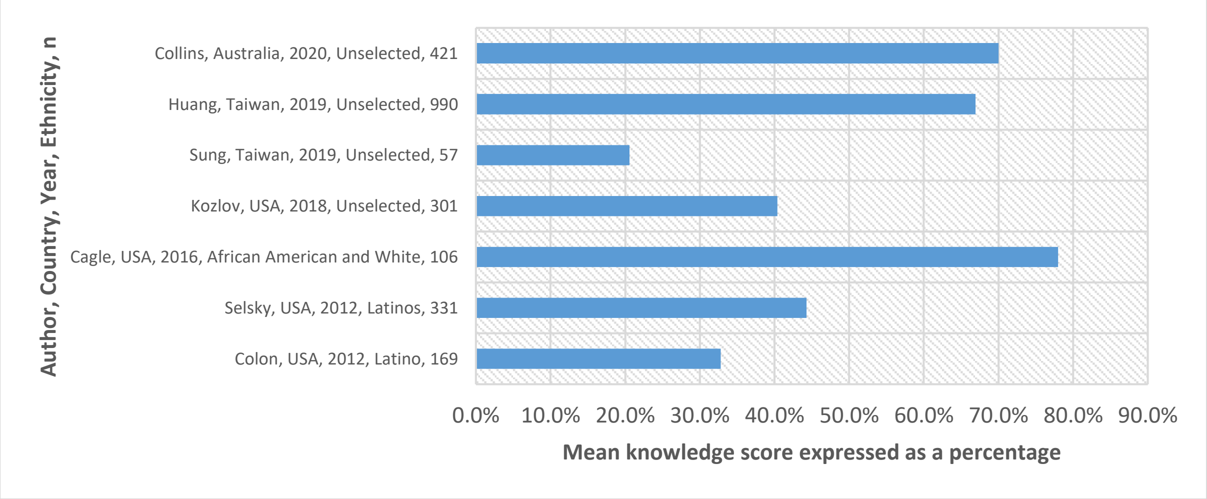


Figure 3: Reported overall knowledge about palliative care

Despite older age groups associating palliative care with death, they were consistently found to have higher knowledge scores (135, 156, 168). Being part of an ethnic minority group, male, or unemployed, or having a lower level of education was associated with a lower level of knowledge of palliative care. Further to the association with being part of an ethnic minority group, interestingly, one American study showed that social acculturation among Latino participants was associated with more hospice knowledge (153). Having health insurance, greater health literacy or having experience of cancer or palliative care were associated with higher knowledge of palliative care.

Self-rated knowledge

In the context of moderately high awareness of palliative care but low overall assessed knowledge, self-rated knowledge in these studies was low and again varied across studies and region (from 7% in Taiwan to 59% in Australia) (see table 12). From the data, being male and being older were significantly associated with higher self-rated knowledge. One study referring to self-rated knowledge about hospice, identified that 60% of male participants self-reported “knowing a lot” about hospice compared with 43% of females (p=0.001) (152). This finding is despite the fact, when knowledge was actually assessed, women were consistently found to have significantly higher levels of knowledge regarding palliative and hospice care (135, 153, 155, 156, 159, 168).

Summary

In summary, palliative care is mostly an unknown to the general public and many perceptions exist that are not aligned with professional definitions. The national setting in which the studies were conducted appears to demonstrate differences in awareness and perceptions of palliative care both across and within nations. Differing views were shown to frequently be associated with ethnic group, sex, education and income. Death appeared synonymous with palliative care for most, more frequently among older and ethnic minority participants, yet there was some awareness that a focus on pain, symptom management, dignity and emotional wellbeing of a patient at the end of their life was part of palliative care. Access to palliative care was seen as difficult to minority and vulnerable groups, in part due to poor understanding of the funding structure, a perception that it was expensive and, due to confusion around what settings palliative care could be provided.

3.4.3 Attitudes

Most studies found that public attitudes towards palliative care were favourable. Free text beliefs reported by participants in an Australian study were identified as positive 75.6% of the time, yet this leaves a significant proportion of beliefs as negative or uncertain (136). A further example includes a US study that showed favourable attitudes as measured by the Hospice Philosophy Scale (HPS-8). These findings were mostly similar across regions.

Being a woman (163), having a higher awareness (140, 143) and a more accurate knowledge of palliative care (140, 158, 161, 167) were associated with more favourable attitudes towards palliative care . Ethnicity was reported as a significant factor influencing attitudes towards palliative care, for example, in one study white American respondents scored higher on the HPS-8 scale, representing more favourable attitudes than non-white respondents ($p=0.003$) (154). Education, occupation, age, and individual income were not consistently reported to impact the public attitude toward palliative care.

An interesting concept regularly presented in the data was ‘choice intention’. In the context of the described knowledge, personal preference for hospice or palliative care at a time of need was high. For example, Schrader (2009) identified that 65% of participants would want hospice support if they were dying (152) with similar levels seen in South Korea (164) and

Australia (167). This preference was less prevalent in Czechia where 47% of participants agreed that hospice care was important for their citizens but only 31% reported they would use hospice care themselves and 25% for relatives (137). Both lower palliative care awareness (50) and knowledge negatively and significantly predicted the likelihood of participants choosing hospice care (161). Interestingly, an Australian study also showed that secrecy about death was significantly inversely associated with intention to use hospice care (167). Perhaps unsurprisingly, intention to use hospice care was associated with more favourable attitudes towards hospice care compared with those not intending to use hospice care (p=0.000) (163). Further negative associations with choice intention included being from a minority ethnic group and being male.

3.4.4 Influence of location, level of integration and time on perceptions of palliative care

Table 12 summarises, where available, data on reported awareness, self-rated knowledge and my overall subjective view as to whether the level of public understanding of palliative care in each study is in line with the international definitions of palliative care. The studies are in the table in chronological order to give a sense as to whether time has had any impact on these outcomes. To help identify any associations, age, level of palliative care development, location and population subgroups are also included. Public awareness of hospice and palliative care in these data shows irregular variation between countries but appears to be consistently lower in regions with lower levels of palliative care integration (which are also the middle-income countries). The association of self-rated knowledge and level of understanding is variable and does not appear to correlate with location of study or level of palliative care integration. There does not appear to be any pattern to suggest awareness of palliative care or self-rated knowledge has changed with time. While unable to link any causality, the public understanding of palliative care appears to have ‘improved’ over time with the subjective judgement as to whether findings of individual papers more accurately reflect the international definitions of palliative care improving from 2016 onwards. There is some caution with this observation given both the subjectivity of this rating, the heterogenous nature of the research designs, and participants and the nuanced differences in palliative care services in different regions.

Table 12: Awareness, self-rated knowledge and level of understanding of palliative/hospice care

First author, year, country	N	*integration	Subgroups	Mean age unless stated	Awareness	Self-rated knowledge	**Level of understanding
Karel, 2003, USA	388	4b	Unselected	NK >18y	83%	▨	▨
Claxton-Oldfield, 2004, Canada	170	4b	Unselected	49y	75.30%	▨	🟧
Catt, 2005, UK	256	4b	Unselected	Over 54y	▨	▨	🟧
Sanjo, 2008, Japan	2548	4b	Unselected	NK >18y	76.30%	38.30%	🟧
Johnson*1, 2008, USA	205	4b	African American and White	AA 73.4y, W 72.5y	88%	▨	▨
Joseph, 2009, India	350	3a	Urban and rural	NK, adult	13.40%	▨	🟧
Johnson*1, 2009, USA	200	4b	African American and White	72.8y	▨	▨	▨
Schrader, 2009, USA	1042	4b	96% Caucasian. 3% American Indian	49.8y	97%	▨	▨
Schrader, 2009, USA	2533	4b	96% Caucasian. 3% American Indian	49.8y	97%	▨	▨
Benini, 2011, Italy	1897	4b	Unselected	NK (18y-74y)	83%	23%	▨
Hirai*2, 2011, Japan	3190	4b	Unselected	60y	46.90%	▨	🟧
Dussen, 2011, USA	168	4b	African American, White and Hispanic	NK (43y-80+y)	86%	▨	▨
MacLeod, 2012, New Zealand	1011	4b	Unselected	NK (18y-70y)	▨	▨	🟧
Park, 2012, South Korea	248	4b	Unselected	NK (all >21y)	▨	▨	▨
Hsu, 2012, Taiwan	1332	4b	Unselected	74.4y	56.50%	35.50%	🟥
June, 2012, USA	145	4b	Lesbian and heterosexual women	Older 65y Younger 50y	▨	▨	▨
Colon, 2012 USA	367	4b	All Latino	35.6y	44%	▨	🟥
Selsky, 2012, USA	331	4b	All Latino	43y	29%	▨	🟧
Manu, 2013, USA	211	4b	Unselected	78y	30%	▨	🟥
McIlfatrick, 2013, UK	600	4b	Unselected	Modal age group 60-69y	83%	20.30%	🟧
Igarashi*2, 2014, Japan	2990	4b	Unselected	60y	▨	24%	🟧
Pan, 2015, USA	4	4b	Asian and Hispanic	54.6y	44%	▨	▨
Carrion*3, 2015, USA	123	4b	Hispanic and Non-Hispanic	47.7y	86%	▨	🟧
Mohamadali, 2015, Malaysia	62	3a	Unselected	NK (18y - >60y)	▨	48.30%	🟧
Cagle*3, 2016, USA	123	4b	Hispanic and Non-Hispanic	47.7y	86%	▨	🟩
Voseckova, 2016, Czechia	85	4a	Unselected	NK, adult	20%	▨	🟥
Chandra, 2016, India	145	3a	Unselected	NK all >20y	0%	▨	▨
Mahmudur, 2017, Bangladesh	3152	3a	Unselected	NK (20y – 28y)	40.30%	▨	🟧
Roulston, 2017, Canada	1540	4b	Unselected	NK, adult	86%	▨	🟩
Westerlund, 2018, Sweden	2020	4b	Unselected	44.7y	59%	▨	🟥
Shalev, 2018, USA	800	4b	Unselected	47y	▨	▨	🟥
Yim, 2018, South Korea	1500	4b	Unselected	NK (20y - >60y)	83.50%	39.50%	🟧
Kozlov, 2018, USA	301	4b	Unselected	NK (18y-98y)	▨	▨	🟧
Van Dussen*3, 2018, USA	123	4b	Hispanic and Non-Hispanic	47.7y	▨	▨	▨
Huang, 2019, Taiwan	990	4b	Unselected	71.5y	▨	▨	🟩
Sung, 2019, Taiwan	57	4b	Unselected	79.6y	▨	7%	🟥
O'Connor, 2019, Australia	180	4b	Unselected	41.3y	▨	▨	🟩
Huo, 2019, USA	3194	4b	Unselected	NK (18y - 65+y)	▨	13.40%	▨
Collins, 2020, Australia	421	4b	Unselected	51y	90%	59%	🟩

Key to table 12: Abbreviations: NK not known; N number of participants *1, *2 and *3 studies with same participants

No data ▨

*Level of palliative care integration

3a	isolated palliative care provision
4a	Palliative care services at a preliminary stage of integration
4b	Palliative care services at an advanced stage of integration

**Level of understanding of palliative care, subjective measurement as to how in line the findings of each paper are with the WHO definition of palliative care

🟩 Good 🟧 Moderate 🟥 Poor

Source of information

Some of the included studies detailed participant reported source of information regarding hospice and palliative care (summarised in figure 4). Within the limitations of looking at data from different studies using different measurement tools, the representation of palliative care in the media (TV, radio, print and internet) was the most frequently reported source of information and likely influences public perceptions (57.3% of 12,461 participants). Interestingly, of the 7,135 participants who reported the media as their source of knowledge, only 34.7% of these specifically reported the internet as a source of information despite this being where more promotional material is appearing. Despite palliative care developing from religious beginnings, religious organisations were not a frequently reported source of information.

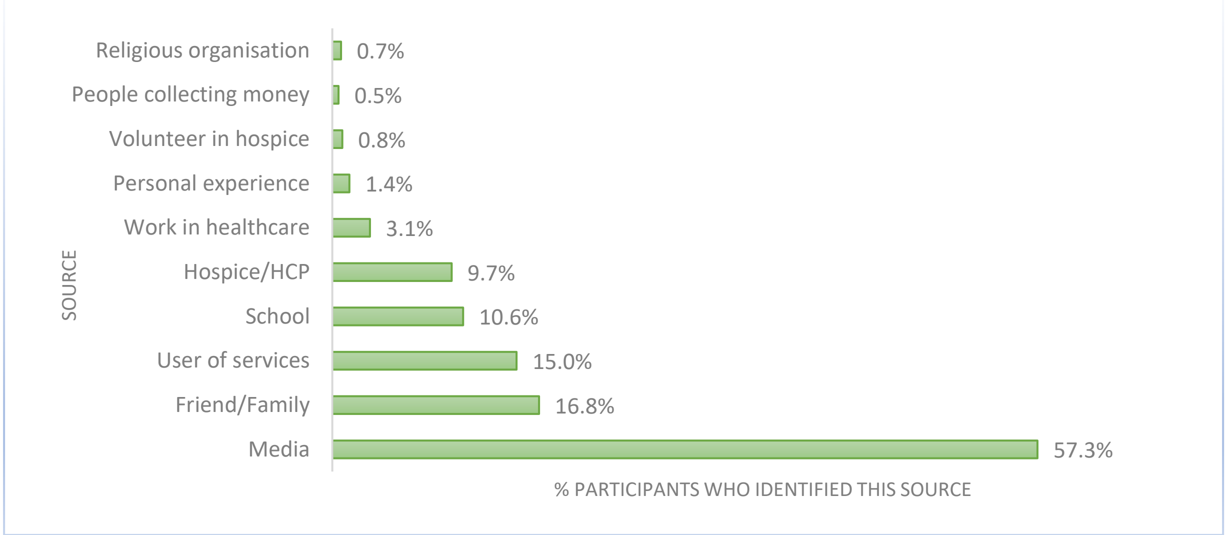


Figure 4: Source of information on palliative care n=12461

3.4.6 Summary of quantitative findings

Overall, the key findings from the narrative synthesis are that in the context of favourable attitudes towards palliative care and moderate awareness, the general public has a poor understanding of palliative care and "misperceptions" are common. Palliative care is frequently associated with death and "giving-up" and, mainly about dying from cancer. Influences on the public perceptions of palliative care consistently appear to be ethnicity, sex, and age. Identification of these influences leads to a need for a deeper understanding which will be explored in the qualitative synthesis.

3.5 Thematic synthesis of qualitative findings

This thematic synthesis builds on the findings described in the quantitative narrative synthesis to start to explain perceptions and the influences on them. The method of synthesis as described in section 2.3.9.2 yielded a total of 124 codes from 241 items of evidence extracted from 16 papers. From further analysis, four analytic themes and 10 sub-themes were generated from the data: (1) the ethos of palliative care; (2); who palliative care is for; (3) structure and provision of palliative care and; (4) cultural congruency. An overview of themes, sub-themes and categories with exemplar quotes can be seen in table 13. A summary of which codes contributed to each theme and a framework matrix of all extracted findings data is included in appendices six and seven.

The following section will detail how these analytic themes are understood both individually through their subthemes and how they are interrelated. Briefly, as an analytic theme, the understanding of the ethos of palliative care characterises the general public's understanding and perceptions of palliative and hospice care as an approach to care. The perceptions of who palliative care is for, focuses on types and stage of disease. The structure and provision theme includes perceptions of models of care, finances, and access. Finally, the theme of cultural congruency furthers the concept introduced by the quantitative findings that perceptions are influenced by demographics and culture.

Table 13: Overview of themes and subthemes from thematic synthesis

Analytic theme	Subtheme	Categories	Example quotes
The ethos of palliative care	Palliative care and hospice care are unknowns	Awareness and understanding	*"At one end of the spectrum, respondents had no former knowledge, they only learned about palliative care when invited to participate in this study." [Researcher, McIlfatrick, 2014 (131)]* *"Uncertainty regarding how, where, and who will provide the care was felt." [Researcher, Daveson, 2011 (133)]*
		Relationship between hospice and palliative care	*"It [palliative care] really looks, to me, like the hospice model. It's just being taken outside the hospice." [Participant, Boucher, 2018 (130)]*
	Characteristics of palliative care	Compassionate care	*"I feel ... that people really do care during this sad time of loss" [Researcher, O'Connor, 2019 (136)]* *"focusing on respect for and dignity of patient and family." [Researcher, Westerlund, 2018 (138)]*
		Patient centred care	*Autonomy and choice were perceived as possible and desired. ... to support you and help you cope." [Participant, Daveson, 2011 (133)]*
		Family	*"I believe ... it [palliative care] supports families at such a challenging time." [Participant, O'Connor, 2019 (136)]*
		Comfort care	*"care provides pain relief, guarantees a dignified end of life". [Researcher, Voseckova, 2016 (137)]*
	Palliative care is only about death	Palliative care is equated to death	*The most common responses were coded as referring to the timing of care (end of life or care of persons with a fatal or incurable illness)" [Researcher, Westerlund, 2018 (138)]* *Long-standing 'stigma' attributed to cancer was generally reinforced with people preferring not to publicly discuss their illness. Assumptions or myths were commonly associated between cancer, palliative care and death: Well I think that a lot of people automatically assume palliative care, you are going to be dead in a few days." [Researcher, participant, McIlfatrick, 2014 (131)]*
		Palliative care is about quality of death	*"My definition is probably going to have to be about end-of-life…letting a patient die as comfortably as possible. – 'To make it so they are not in pain; making them comfortable until they die". [Participant, Tasseff, 2018 (132)]*
Who palliative care is for	Disease		*"Although participants were not asked to specify conditions, many associated palliative care with cancer and care of older people." [Researcher, McIlfatrick, 2013 (135)]* *"Most respondents assumed that palliative care focuses on cancer." [Researcher, McIlfatrick, 2014 (131)]*
			"hospice care is care about long-term ill patients or about elder people who don't have family or relatives and are not able to look after themselves." [Researcher, Voseckova, 2016]
			"…some awareness of the recent inclusion of other life-limiting illnesses (motor neurone disease, multiple sclerosis, Parkinson's disease, dementia and heart or renal failure)." [Researcher, McIlfatrick, 2014]
	Disease trajectory		*"perception of palliative care varied and included sentences like: care that does not have a curative effect, care for patients who will not recover." [Researcher, Benini, 2011 (134)]*
			"palliative care is more of an ongoing. It's not preparing for an end, but it's just an ongoing process." [Participant, Boucher, 2018 (130)]
Structure and provision of	Access		*"Perceptions that hospice played a key role in the delivery of palliative care led to the general public assuming that treatment choices were limited to urban populations that are proximate to a hospice." [Researcher, McIlfatrick, 2013 (135)]*

Analytic theme	Subtheme	Categories	Example quotes
palliative care	Models of care		*"There was acknowledgement that people needing palliative care services have an incurable illness impacting their life expectancy and that care is best delivered by trained specialists." [Researcher, McIlfatrick, 2014 (131)]* *"When respondents were asked where they thought palliative care takes place, most suggested hospital, hospice, nursing home or home: I assume home, hospital and hospice … but it is more at home, but I don't know why that is, maybe that is a common misconception … but I think the term palliative care would make me think about the home environment." [Participant, McIlfatrick, 2014 (131)]*
	Financial issues		*"I didn't know what palliative care was and hospice and how to deal with the cost and different things." [Participant, Boucher, 2018 (130)]*
Cultural congruency	Awareness and understanding		*"I think that in the African American community as a whole there are definitely conceptions about what hospice is and what hospice does, but we really don't know."* *[Participant, Taxis, 2006 (125)]* *"Isn't the hospice a program provided by the government like a nursing home program?" [African American participant, Kwak, 2007 (126)].* *"Misconceptions about hospice included assumptions that the care would be inadequate, people would die lonely, painful deaths." [Researcher, Taxis, 2006 (125)]*
	Cultural division	Mistrust in hospice staff	*"The participants overwhelmingly expressed a desire for greater respect from healthcare providers … participants agreed that they would have misgivings about a white healthcare practitioner suggesting hospice." [Researcher, Taxis, 2006 (125)]*
		Palliative care is inaccessible	*"It is so much easier as an African American student [nursing] to care for an African American patient. It's just that—it's when they print off those brochures, and there's not a black person [emphasis added] on the brochure. That tells me, "This is not the place for me." [Group agreement—"Right—that says it"]." [Participant, Taxis, 2006 (125)]* *"Many participants also voiced the opinion that African Americans need more education regarding hospice care and EOLC care: "We don't like to talk about death or to prepare for it." "Will you educate us on hospice?" Why don't hospitals tell us about hospice?" [Researcher and participant, Pullis, 2011 (129)]*
	Lack of cultural sensitivity	Filial piety	*"In the African American community, you didn't throw away your old folks, you keep them at home until they died—regardless." [African American participant, Taxis, 2006 (125)]* *"Entering a hospice would also demonstrate that one had become a 'burden' to one's family and that there was no other option for care at the end of life. To this extent, hospice care was not seen as a positive 'choice' that one might make for care at the end of life. Instead it seemed to contradict important notions about family care and support during death." [Researcher, Seymour, 2007 (127)]*
		Language	*"You know sometime we pretend that we understand and we don't … if they would … ask, "Do you know what I am saying?" If they would just use words we understand and make really clear explanations—that would help." [Participant, Taxis, 2006 (125)]*
		Spirituality	*"concern about the adequacy of care and the respect for African American traditions and values at the end of life." [Researcher, Taxis, 2006 (125)]*

3.5.1 Analytic theme 1: The ethos of palliative care

The ethos of palliative care can be understood through three interconnected subthemes; 1) palliative care and hospice care are unknowns; 2) the characteristics of palliative care and 3) palliative care is only about death.

Subtheme 1: Palliative care and hospice care are unknowns

Public perceptions of palliative and hospice care are unknowns is best understood through two interrelated categories, 1) awareness and understanding and 2) the relationship between hospice and palliative care.

From the included qualitative papers (not presented in any mixed methods papers) that palliative care appeared to be an unrecognised, unknown phenomenon to many:

> *"The term palliative care was not known by any respondents." [Researcher, Seymour, 2007 (127)]*

> *"Palliative care? Never heard of it" [Participant, Tasseff, 2018 (132)]*

Even when there was some awareness of the term, participants often presented perceptions not fitting with any of the international definitions of palliative care, with uncertainty regarding who it was for and how it was provided (see later themes):

> *"Many questions regarding the kind of patient in hospice care were voiced: 'Can you be in hospice if you are alert?' 'Is it long term?' The issue of financial access was mingled with discussion." [Researcher and participant, Pullis, 2011 (129)]*

It was also acknowledged that palliative care is something the public do not become aware of until it is needed:

> *"… people do not know about palliative care services and…such knowledge is acquired when 'you are in the situation of needing care' or in a caring role." [Researcher and participant, McIlfatrick, 2014 (131)]*

The relationship between palliative care and hospice care is complex. The approach to care provided under ‘palliative care’ or ‘hospice care’ is deemed by most professionals to be of the same nature, yet differences, including models of care and funding can exist. The public did not appear to understand how palliative and hospice care relate to each other. For some, palliative care was viewed as synonymous with hospice care, with an appreciation that the same approach to care was delivered in multiple settings:

> *“It [palliative care] really looks, to me, like the hospice model. It’s just being taken outside the hospice.” [Participant, Boucher, 2018 (130)]*

Others perceived hospice to be a key part in the delivery of palliative care (as opposed to it operating as a separate entity). Though many respondents made distinctions, and/or postulated the similarities and differences between palliative and hospice care, the overall message from the data suggested that the public were uncertain how the two were related. There were examples, generally from the USA, where participants were familiar with one term but not the other:

> *“Despite the ambivalence surrounding palliative care, all 13 rural dwelling adults stated they were familiar with hospice care and provided an accurate definition.” [Researcher, Tasseff, 2018 (132)]*

Subtheme 2: The characteristics of palliative care

This subtheme is further understood through four categories; 1) compassionate care; 2) patient-centred care; 3) comfort care; and 4) palliative care for the family.

The category of compassionate care mostly captures the high esteem in which palliative care is held by the public. Palliative care itself and the people working within it are seen as caring, offering holistic care and providing dignity for patients and carers/family:

> *“See I haven’t any first-hand experience of [hospice] but I would think there are people there who you know [and] comfort you, you know if someone is in there you’ve got proper caring people who try to put your mind at ease.” [Participant, Seymour, 2007 (127)]*

A common perception of palliative care was that it was safe, sensitive, compassionate, individualised care with human connection:

> *"…focus on palliative care as characterized by compassion, empathy and human connection." [Researcher, Westerlund, 2018 (138)]*
>
> *It [palliative care] takes in your wishes a lot more as to what you want other than what people are deciding for you." [Participant, Boucher, 2018 (130)]*

Further evidence overlapping both compassionate care and the focus on patient-centred care was palliative care seen as 'maintaining dignity':

> *"I believe ... palliative care enables a person to live out their last days with dignity." [Participant, O'Connor, 2019 (136)]*

Across all papers, although generally associated with end of life, there was a perception that palliative care was about improving comfort through alleviating suffering and providing symptom control:

> *"Er, my opinion is if I was ill like that, personally, I would like to be in a hospice, er, for the simple reason that the comfort is there, you cannot always get comfortable at home, where in a hospice they spend all of their time making you comfortable and. . . . once they are comfortable, they are at peace and that is what they need I think, to me that is the reason, that is the reason of a hospice, that's what it is there for... In another focus group in the study of white elders, two men debated the meaning of hospice, making it clear that for them it was associated with familiarity, comfort and care…" [Participant, Seymour, 2007 (127)]*
>
> *"the prevalent identification of palliative care was with 'the treatment of pain and improved of quality of life'." [Researcher and participant, Benini, 2011 (134)]*

Furthermore, there was an identification that palliative care achieved this through skilful, interdisciplinary, holistic care:

> *"Skilful physical, personal, emotional, social, spiritual, and medical care was expected. Good medical care, secondly good human companionship ... safety in the care ... medical, human-psychological care." [Researcher, Daveson, 2011 (133)]*

Although these data describe palliative care including aspects of emotional, social and spiritual care, in many studies, these 'extra-medical' aspects of palliative care were not mentioned, with some commenting that palliative care was viewed as lacking in spiritual support:

> *"None of the participants including those who were familiar with hospice, were knowledgeable regarding the spiritual support offered in hospice care."*
> *[Researcher, Pullis, 2011 (129)]*

From this synthesis of qualitative data, the general public perceived palliative care as care that reaches beyond the individual and provides care and support for the family at the end of life:

> *"I believe ... it [palliative care] supports families at such a challenging time."*
> *[Participant, O'Connor, 2019 (136)]*

The data demonstrated that some of the public viewed palliative care as a means to give families time with their loved ones through extending good symptom control to allow access during dying. (131).

> *"Some benefits of open communication are illustrated in the following: 'My wife had very progressive ovarian cancer and was told that she only had days to live … the palliative care team come and seen me the next day and told me … It was an absolute God send … We had six or seven days where we were able to talk things over, between ourselves … so those were very precious days to me.' This illustrates the importance of people being aware of the preciousness of time and facilitating open communication so that patients can 'tie up their life and issues'." [Researcher and participant, McIlfatrick, 2014 (131)]*

In summary, palliative care is perceived as a compassionate, holistic, multi-disciplinary, person-centred approach that aims to help patients (and their families) at the end of life, through a focus on dignity and comfort. This focus on comfort at the end of life links to an overwhelming perception from the included studies that palliative care is only about death.

Subtheme 3: Palliative care is only about death

The theme that palliative care is only about death is understood through the categories; 1) palliative care is equated to death and, 2) palliative care is about quality of death.

Palliative care was synonymous with death in most participants' perceptions. Furthermore, language associated with mortality and a finite time, such as 'end of life', 'end of journey', 'terminal illness' and, 'fatal' was seen in all texts. Often this focus on death and terminality was associated with inevitability or imminence:

> *"One common example of this was the lack of discussion of palliative care at diagnosis or when treatment starts. Respondents noted that palliative care was introduced at the end of the patients' journey." [Researcher, McIlfatrick, 2013 (135)]*

> *"most of the white elders expressed underlying concerns about what was perceived as the obvious relationship of hospices with death. This was especially prominent among those respondents living in the more deprived areas of Sheffield. For example, Eddie, a man who had witnessed the painful death of his father from cancer, said the following: 'It's a place to stop permanent, it's like St [local hospice] . . . So if you, well, you see, once people start saying, 'We're going to put you in this hospice', then they know they're going to die, don't they? So I think you'd want to spend your last few months with your family, wouldn't you?'" [Researcher and participant, Seymour, 2007 (127)]*

When reflecting on palliative care as synonymous with death, the topic of euthanasia was often brought up. Some respondents viewed euthanasia as part of palliative care with some even referring to hospice as euthanasia or 'mercy killing' (128).

> *"Palliative care and euthanasia (euthanasia is part of palliative care)." [Researcher, O'Connor, 2019 (136)]*

Yet others saw palliative care as an alternative to euthanasia, suggesting that 'better palliative care' would diminish the argument for euthanasia.

> *"I believe ... that confusion and misunderstanding are fuelling the push for euthanasia. Better palliative care would diminish the argument for taking control of one's death especially in those with no serious illness other than 'old age'" [Participant, O'Connor, 2019 (136)]*

A further take on palliative care being associated with death was interlinked with the view that palliative care is giving up. This suggests that a move to hospice care is equivalent to no further care and people are left to die painful and lonely deaths.

> *"When they put them in another setting [other than a hospital], like in a hospice that they will be alone. In a hospital, at least they have to come in and poke you to see if you are still alive. I think that people may think that in hospice or nursing homes no one is going to check on you...they put them in the bed and close the door." [Participant, Taxis, 2006 (125)]*

Whether it be seeing palliative care as death, as imminent or inevitable death, being closely linked to euthanasia or being merely being left to a painful and lonely death, it is clear there is a public perception that palliative care is synonymous with death. There was, however, considerable evidence that palliative care was perceived as a quality death:

> *"it (palliative care) is an essential service in helping to promote a "good death" for terminal patients." [Researcher, O'Connor, 2019 (136)]*

There was also a perception that palliative care was about symptom relief (see quality of life section) at the end of life with the aim of achieving a peaceful and comfortable death.

> *"What do the public expect for patients? Although there was recognition that 'it is not always possible to relieve pain 100%' and that 'sometimes we want our loved ones to live forever', findings revealed the importance of ensuring that patients are comfortable, suffering is alleviated and dignity is promoted in the last days of life: It's looking after people*

> *who are dying and making their death as easy and comfortable as possible." [Researcher, McIlfatrick, 2014 (131)]*

Countering the view that palliative care is euthanasia, in this category of palliative care being about quality of death, data shows palliative care allows a natural death and neither hastens nor postpones death (107).

> *"Maintaining quality of life and letting life end naturally was important. Artificially prolonging life was, at times, rejected. ... To keep artificially alive, that is not for me." [Participant, Daveson, 2011 (133)]*

Acknowledging that palliative care is about living until you die, the latter part of this death subtheme; palliative care is about quality of death, demonstrates positive interconnectivity with 'quality of life', in that part of the perception aligning palliative care with death focuses on the quality and comfort of death.

Analytic theme 2: Who is palliative care for?

The perception of who palliative care was for largely related to subthemes, 1) the types of disease and 2) disease trajectories.

Subtheme 1: Types of disease

Palliative care was commonly perceived as a type of care that was exclusive to people diagnosed with advanced cancer and older people:

> *"Although participants were not asked to specify conditions, many associated palliative care with cancer and care of older people." [Researcher, McIlfatrick, 2013 (135)]*

That said, some were aware that the scope of palliative care was equally for people with non-cancer and chronic conditions:

> *"Most respondents assumed that palliative care focuses on cancer with some awareness of the recent inclusion of other life-limiting illnesses (motor neurone disease, multiple sclerosis,*

> *Parkinson's disease, dementia and heart or renal failure." [Researcher, McIlfatrick, 2014 (131)]*

Subtheme 2: Disease trajectory

There was conflict in the public perception between those who viewed palliative care as a type of healthcare that was solely for people who had incurable illnesses and were at the end-stage of their disease/life, and those who saw palliative care as an ongoing process, applicable early in the disease:

> *"The most common responses were coded as referring to the timing of care (end of life or care of persons with a fatal or incurable illness)." [Researcher, Westerlund, 2018 (138)]*

> *"palliative care is more of an ongoing. It's not preparing for an end, but it's just an ongoing process." [Participant, Boucher, 2018 (130)]*

Analytic theme 3: Structures and provision of palliative care

The perceptions of the structures and provision of palliative care is further understood through its subthemes of 1) access to palliative care; 2) financial issues and 3) models of palliative care.

Subtheme 1: Access to palliative care

Access to palliative care services appeared high up in the public's agenda with a perception that palliative care services were not readily available to all. Consistent with the confusion between the terms hospice and palliative care, in the UK there was a perception that to benefit from palliative care services you must live close to a hospice, with those in urban areas therefore being served better:

> *"Perceptions that hospice played a key role in the delivery of palliative care led to the general public assuming that treatment choices were limited to urban populations that are proximate to a hospice." [Researcher, McIlfatrick, 2013 (135)]*

Fear and sadness was expressed that there is insufficient care for all:

> *"I feel ... sad that not everyone who needs it receives it." [Participant, O'Connor, 2019 (136)]*

Subtheme 2: Models of care

The perceptions of models of palliative care were that care could be facilitated in a hospice, hospital or at home, with a preponderant view that palliative care was care in the home environment:

> *"When respondents were asked where they thought palliative care takes place, most suggested hospital, hospice, nursing home or home: 'I assume home, hospital and hospice … but it is more at home, but I don't know why that is, maybe that is a common misconception … but I think the term palliative care would make me think about the home environment.'" [Researcher and participant, McIlfatrick, 2014 (131)]*

This perception aligned with the public view that dying at home should be the norm:

> *"I believe ... that dying at home should be the norm, not dying in a clinical environment." [Participant, O'Connor, 2014 (136)]*

While acknowledging that palliative care was provided at home or hospital, more apparent was the view that palliative care was a model of care only offered in nursing homes or that hospices were synonymous with nursing homes:

> *"The participants assumed that hospice care was delivered in a nursing home, where care would be inadequate and the patient would be isolated." [Taxis, 2006 (125)]*

Subtheme 3: Financial issues

There was variability in how the public view palliative care funding. Building on the understanding of the public perceptions of both access and models of care, this subtheme provides some insight into these perceptions. For example, in the US, the view that palliative care is provided in a nursing home is associated with a perception that such care is publicly or insurance funded and that in itself had negative connotations:

> *"We still have this negative connotation with the word, "nursing home." ...How can we be sure that it's not going to be that horrible nursing home? Because if Medicare is paying for it, we don't know if it is really a good hospice and this is a bad one. You may hear, oh. Medicare pays for it—it must he that kind of care, and you don't want to put your loved one in THAT kind of care." [Taxis, 2006 (125)]*

There was also an apparent concern that the funding of palliative care can impact an individual's wishes at the end of life and leave carers without support. This perception was informed by a view that funding of services was either too *ad hoc* or insufficient to meet the needs of a population. Some stressed that this type of care should be funded by government:

> *"Although budgetary constraints on Trusts and charities delivering specialist palliative care were acknowledged, they result in some not being offered a home death and families being left with very little support. An integrated health service and less reliance on family were recommended: 'I think there is an obligation on the state and an essential part of the health service and that palliative care should be as much part of the health service as any other part as it is too important and too relevant to just depend on the man in the street.'" [Researcher and participant, McIlfatrick, 2014 (131)]*

In the US, costs and funding of palliative care were not understood, for example, it was not known whether funding was different between what they saw as hospice and palliative care:

> *"I didn't know what palliative care was and hospice and how to deal with the cost and different things." [Participant, Boucher, 2018 (130)]*

With some even viewing palliative care with suspicion, seeing it as a way to redirect costs from the government to families:

> *"Although some were protective of government resources, others felt hospice was the government's way of shifting costs and burden to the family. According to a Cantonese man, 'This kind of hospice care [at home] is just a way that the government throws the ball back to the family'." [Researcher and participant, Enguidanos, 2013 (128)]*

In summary, perceptions differed as to the accessibility of palliative care, how it is provided and the implications of financing, perhaps aligning with the unknowns around palliative care in general.

Analytic theme 4: Cultural congruency

Perceptions were influenced by the backgrounds of the participants. Cultural congruency is best understood through the interconnected subthemes: 1); awareness and understanding of palliative care 2) cultural division and 3) the lack of cultural sensitivity.

Subtheme 1: Awareness and understanding of palliative care

Culture is both individual and shared; influenced by membership to specific social groups. Association between perceptions and these social groups may not suggest causality, but the effect of culture is implied. For example, here we see that palliative care is misunderstood by Cantonese and Mandarin speaking participants in the US, with a possible interpretation that it is the culture of participants that influence perceptions:

> *"The vast majority of participants in the Cantonese- and Mandarin-speaking focus groups were unfamiliar with hospice, and after the facilitator provided a description of hospice, some mistakenly thought hospice was the same as mercy killing." [Researcher, Enguidanos, 2013 (128)]*

Palliative care is frequently an unknown with some suggestion in this synthesis that this is more the case for people from ethnic minorities. For example, compared with non-ethnic minority groups, Chinese elders in the UK and African Americans and Hispanic Americans expressed unfamiliarity with the term hospice:

> *"Among the Chinese elders, only one person said that they had heard of a Macmillan nurse, and only one quarter of the interview respondents said that they had heard of the term 'hospice'." [Researcher, Seymour, 2007 (127)]*

> *"I think that in the African American community as a whole there are definitely conceptions about what hospice is and what hospice does, but we really don't know." [Participant, Taxis, 2006 (125)]*

Other views could be considered misperceptions including associating hospice with nursing homes.

> *"Isn't the hospice a program provided by the government like a nursing home program?" [African American participant, Kwak, 2007 (126)].*

Or seeing hospice as only about death, or giving up:

> *"But I think the Chinese would find it difficult to accept this; as when you are in there, they are people who are about to die . . . Entering a hospice means you're proclaiming to the world . . . I am not going to come out of it." [Seymour, 2007 (127)]*

> *"Several group members believed that the high percentage of African Americans who chose aggressive hospitalized care at the end of life, instead of hospice, did so because hospice was equated with death and 'giving up'." [Taxis, 2006 (125)]*

Subtheme 2: Cultural division

It was apparent in the literature that people from African American backgrounds in the US, exhibited mistrust in palliative care and those that worked within it.

> *"If you [directed to white facilitator] came in and suggested hospice, some of us would say, "Oh, you're trying to get her out of here—you're trying to get rid of her" [Group agreement—"yes, that's right"]. It's the trust factor. And although you are probably very compassionate and very clinically astute, you don't have our history and you don't know the words that we need to hear." [African American participant, Taxis, 2006 (125)]*

Similarly, palliative care was also seen as inaccessible by African Americans. Lack of cultural representation and lack diversity in the palliative care workforce reinforced these perceptions:

> *"Because the perception among the participants was that hospice services are predominantly staffed and used by whites, there was concern about the adequacy of care and the respect for African American traditions and values at the end of life." [Researcher, Taxis, 2006 (125)]*

This lack of cultural representation went beyond perceptions of the direct patient facing service with a perception of a lack of outreach to different cultures. This was seen by some as having an impact on access to a palliative approach to care:

> *"I don't know if it is the hospice organization's sole responsibility or if they have been ineffective communicating that to us. But for whatever reason, it's just not being disseminated [The group nods, and agrees]." [Taxis, 2006 (125)]*

Subtheme 3: Lack of cultural sensitivity

Many of the factors discussed can be viewed as a lack of cultural congruence, this disharmony in values could affect the perceptions of care and cause both discomfort and a difficulty in developing any human connection, so called cultural distress. Further cultural differences that may cause distress are; 1) filial piety, 2) language culture and 3) spirituality.

Representatives from different ethnic minority groups (UK Chinese, Korean American, and African American) saw, that through a moral obligation and respect, looking after relatives through disease was their responsibility. This obligation, or filial piety, was not one that could be avoided, and palliative care was seen at odd to this usual cultural practice:

> *"The underlying reason for this wide range of preferences expressed by older adults and caregivers was filial piety, the moral obligation of an adult child to respect and obey one's parents and provide support for them in old age. Older adults and caregivers who preferred curative treatment options believed that adult children would choose curative treatment, because children would perceive such a decision as the morally right thing to do for their parents. They perceived giving up curative treatment, which is required by the Medicare hospice benefit, as not fulfilling the moral duty as an adult child to do everything to prolong life." [Researcher, Kwak, 2007 (126)]*

Language was also a factor that influenced different ethnic groups' perceptions of palliative care. Using terms of respect were very important to some and influenced opinions whether the care on offer was aligned with their views. Equally choice of language could perpetuate misunderstandings and there was a view that this was not accounted for by professionals working in palliative care.

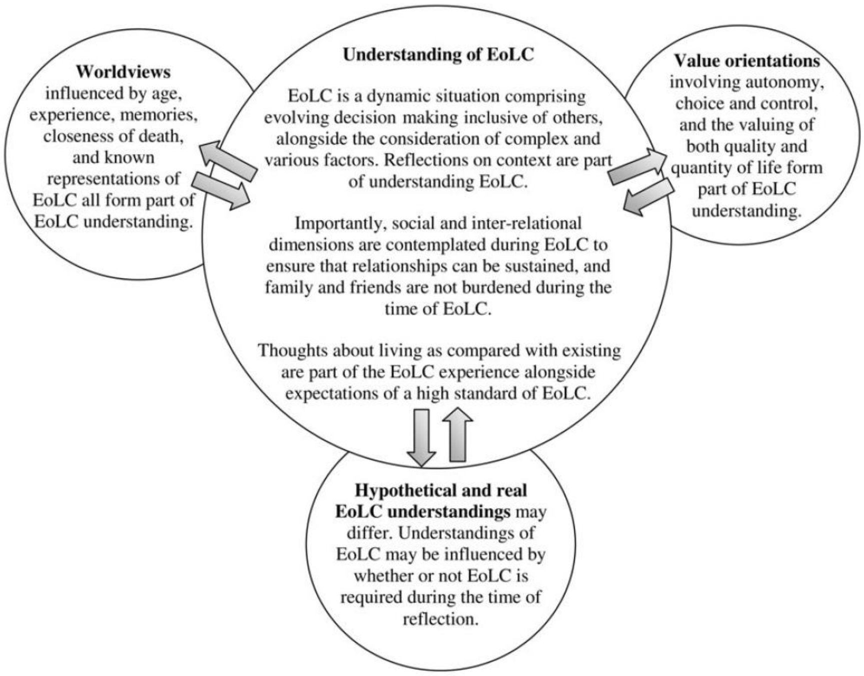
> *"Calling us by our last name—you know it is so universal to have the Mr. or Mrs. before a person's name. That's important to us." [Participant, Taxis, 2006 (125)]*

> *"You know sometime we pretend that we understand and we don't. So if they would repeat things and ask, "Do you know what I am saying?" If they would just use words we understand and make really clear explanations—that would help." [Participant, Taxis, 2006 (125)]*

There was a view that spirituality, meaning, and traditions of individual cultures were not accounted for by palliative care and a suggestion this may impact access due to the importance placed on being cared for by people who embrace shared traditions. It was felt that palliative care was not a form of care that was appropriate for all.

> *"You know, church—that's the kind of hymns we want to hear and preaching we want to hear, and you aren't going to get it at a white facility." [Taxis, 2006 (125)]*

In summary, the frequently negative and erroneous perceptions of palliative care are common throughout the public, with evidence to suggest even more so among minority groups. Culture can directly affect the care received by an individual and, cultural distress influences perceptions of care. In Daveson's model (133), the understanding of (what they term as) end of life care is both individual and dynamic, influenced by experience, worldviews and values these are in part affected by culture.



[Daveson, 2011 (133)]

3.5.5 Summary of qualitative findings

Table 14: Key findings from thematic synthesis

The ethos of palliative care

Awareness and understanding

- Confusion exists as to what hospice, hospice care, palliative care and end of life care mean and how they are related
- Palliative care is seen by many as an unrecognised, unknown phenomenon (until you need it).

Characteristics of palliative care

- Palliative care is a holistic, patient-centred, approach to care at the end of life
- Palliative care maintains dignity and provides comfort and relief of suffering through managing pain and other symptoms.

Palliative care is about death

- Palliative care is associated with the very end of life and imminent and inevitable death
- To some it is synonymous with euthanasia and is seen as giving up.
- For many palliative care is too difficult to consider due to fear of mortality, yet to fewer it is reassuring as it is known to provide a peaceful and comfortable death

Key findings: Who is palliative care for?

- Palliative care is seen as mainly for people with cancer although there is some burgeoning awareness of care for non-cancer, albeit end-stage disease only

Key findings: Structures and provision of palliative care

- Access to palliative care is not universal and is influenced by proximity to hospice and hence urbanisation
- Funding of palliative care is an unknown and palliative care is seen as not having the resources it needs
- Palliative care is seen as shifting the responsibility for care to families
- There is a perception that palliative care is available in hospital, hospice, or home but this is by no means universal and some see palliative care as institutionalised care

Key findings: Cultural congruency

- Palliative care is well known to minority groups
- Structural barriers to palliative care are perceived, such as no outreach to minority groups
- Palliative care does not account for shared traditions and values of minority groups

In summary, this thematic synthesis builds on the findings of the quantitative narrative synthesis giving a deeper understanding on my first two research questions: 1) what are the public perceptions of palliative care and 2) what influences the public perceptions of palliative care. There is a perception that palliative care is care provided by compassionate people focussing on symptom control to alleviate the suffering of those with incurable disease at the end of their life. However, it seems that these perceptions trigger fear and avoidance because palliative care is often equated with death and dying. To demonstrate a fully conceptualised understanding of the public's perception of palliative care the following section seeks to synthesise the qualitative and quantitative findings by means of a critical interpretive synthesis.

Table 15: Critical interpretive synthesis: The general public's perceptions of palliative care

Research question	Relevant findings from quantitative studies	Relevant findings from qualitative studies	Synthesised findings
The general public's perceptions of palliative care	♦Despite variations, awareness of hospice and palliative care was moderate across nations. ♦Self-rated knowledge and measured knowledge was poor. ♦Confusion between hospice and palliative care was present. ♦Attitudes towards hospice and palliative care were commonly favourable. ♦The majority view palliative care as offered by nurses only ♦The majority view palliative care as available in hospital, lower awareness that palliative or hospice care available at home. ♦Some believe hospice care precludes people from hospital care. ♦Palliative and hospice care are about death: – Dying with dignity – Last month of life – Often viewed as euthanasia – Seen as giving up on life. ♦Palliative and hospice care are associated with comfort care and symptom control, in the last weeks or months of life, predominantly for people with cancer. ♦Family and carer support variably understood ♦Palliative care stops at death. ♦Palliative care funding is not understood but it is seen as expensive and not funded publicly or by private insurance	♦Palliative care and hospice care and the relationship between the two are poorly understood. ♦Individuals become aware of palliative and hospice care only when it is needed ♦Palliative and hospice care are only associated with death: – Imminent, inevitable death – Euthanasia – A natural and peaceful death ♦Palliative care is patient-centred care for older people, predominantly with advanced cancer (and their family). ♦Palliative and hospice care teams are a caring, compassionate highly skilled team who focus on relief of suffering at the end of life. ♦Uncertainty where palliative and hospice care fit in disease trajectories (some seeing it for end-stage terminal disease, others from diagnosis) ♦Variability in the understanding of where palliative and hospice care can be accessed, viewed as care in a nursing home or 'institutionalised care'. ♦Access to palliative and hospice care services not universal – Proximity to hospice and living in urban areas seen as better access ♦Financing not understood with concerns that the cost of palliative and hospice care may impact on quality of care at the end of life. ♦Seen to shift costs of care to carers/family	♦Palliative and hospice care as terms and as an approach to care are unknowns to many of the general public ♦The time many people become aware of palliative care is when it is needed and it is avoided until that point ♦Confusion persists regarding hospice and palliative care. ♦The need for palliative care is seen as universal, but it is not available as such. ♦Palliative care is perceived as patient-centred and holistic, provided by compassionate people, yet it is unwanted because: – The public see palliative care as "death", whether that be imminent death, euthanasia, giving up on life or comfort in death, it means they are dying – Palliative care is seen as care for older people with advanced cancer – Palliative care is only seen as available in healthcare institutions rather than home – There are concerns about funding
Influences on public perceptions of palliative care	♦ Lower awareness and knowledge were associated with: – Ethnic minorities – Being a man – Being younger – Lower income households and countries – Lower educational attainment ♦ Higher awareness was associated with previous experience of palliative care and serious illness. ♦ Better knowledge was associated with more favourable attitudes ♦ Being older and an ethnic minority were associated with viewing palliative and hospice care as giving up and death. ♦ The media is the most reported source of information ♦ Country of study affects understanding where palliative/hospice care can be received. ♦ Overall understanding may have improved over time although the association with death persists.	♦ Palliative and hospice care perceived differently by ethnic minorities – Reported as unknowns – Perceived as only about death or giving-up – Mistrust in hospice staff reported ♦ Cultural congruence – Views that palliative care lacked sensitivity to the cultural values of minority groups and a lack of diversity in those providing services and lack of outreach to the same groups culminated in cultural distress influencing the perception of palliative care	♦Being younger, male, from an ethnic minority and lower income, education and health literacy are associated with lower awareness of palliative care and perceptions less consistent with international definitions ♦Being older or from an ethnic minority groups increases the view that palliative care is death ♦Higher exposure to palliative care (experience and integration in health systems) equates to more awareness, which then equates to more knowledge ♦More favourable attitudes are associated with perceptions of palliative care consistent with international definitions ♦The passage of time may be bringing public perceptions of palliative care more consistent with international definitions. ♦Cultural incongruence leads to a perception of palliative care most associated with death and least in line with international definitions
The effect of perceptions on access to palliative care	♦ Factors associated with poor health literacy likely create structural barriers to accessing palliative care ♦ Death taboo likely creates barrier to access	♦ Cultural disharmony and mistrust reduce access ♦ Perception of expense reduces access ♦ Association with death, older people and cancer may effect access	♦ Perception that palliative care is death defers access ♦ Cultural distress and poor health literacy influence access
Summary	Awareness of palliative care is variable with palliative and hospice care often confused and poorly understood. Palliative care is associated with death. Location of study, ethnicity, age and gender commonly affect perceptions.	Participants expressed poor understanding of palliative care, often viewed it as solely about death. Who palliative care was for and where it was delivered were mostly unknowns. Participants reported significant cultural distress, leading to views that palliative care is less available to minority cultures.	Knowledge of palliative care is poor (especially for men, younger people, and ethnic minorities) with considerable variation in public perceptions. A perception consistent around the world is "palliative care *is* death". To some, this is euthanasia and giving up, to others it is comfort care allowing a natural death. Experience of palliative care improves understanding. In this context it is generally seen as good care offered by compassionate people – albeit still to be avoided until unavoidable.

3.6 Critical interpretive synthesis

The general public's understanding of palliative care was inconsistent with the accepted international definitions. The findings from the qualitative and quantitative syntheses are summarised by research question in the critical interpretative synthesis table, table 15.

3.6.1 The general public's perceptions of palliative care?

In the context of over half of the public being aware of palliative care, self-rated knowledge and, assessed knowledge and understanding is poor. Acknowledging that in some locations palliative and hospice care are synonymous, and yet elsewhere they refer to different models of care, it is clear from this synthesis that the terms are often confused and poorly understood by the public. Exploring the public understanding to the level of specific perceptions reveals a "SCEW'd" view with regards to factors relating to the **S**tructure and provision of palliative care and, a **C**ulturally dependent view of the **E**thos of palliative care and **W**ho palliative care is for (see figure 5).

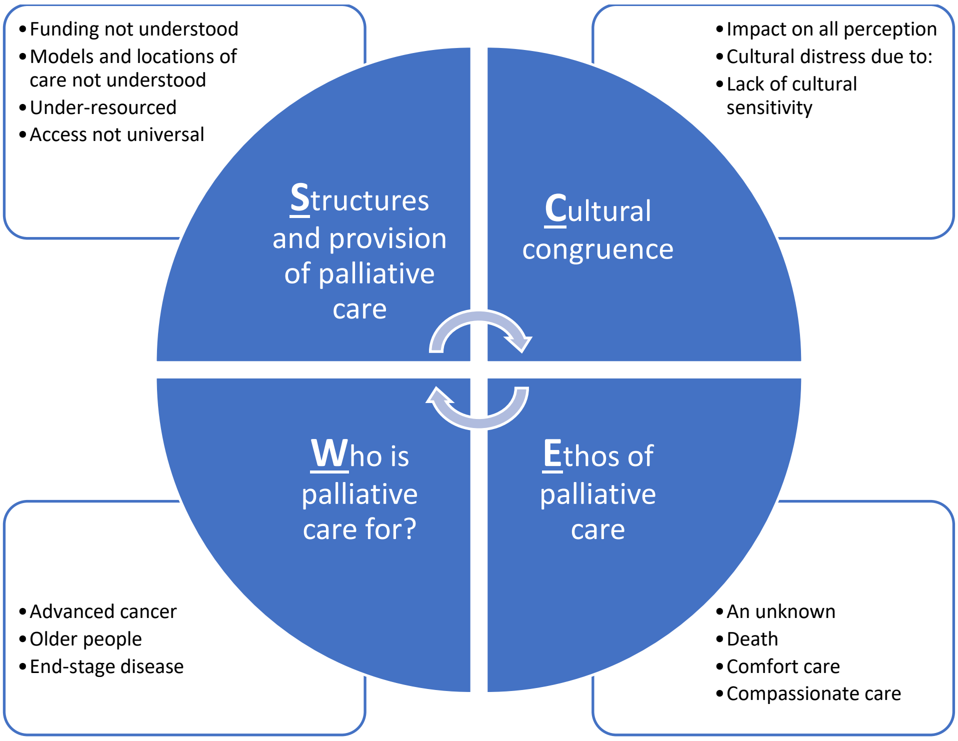


Figure 5: A SCEW'd view of palliative care

Synthesised findings confirm an ongoing association between palliative care and death. Considerable focus in the public's mind is on palliative care only being for when death is imminent. The public fear of mortality and the sanitisation of death is recreated in a fear of palliative care and something that is avoided until it becomes unavoidable. Yet, there is a perception that palliative care is holistic, patient-centred, compassionate care for patient and family, focussing on comfort through physical symptom control, albeit with a lower awareness of psychological and social support. These two possibly conflicting views can be considered as one: accepting palliative care means to accept and acknowledge as fact that a person is dying. Once accessed, perceptions are positive, but still relate primarily to the quality of death (a peaceful and comfortable death, neither hastened, nor postponed) rather than aiming also to improve living until death.

Another common perception is that palliative care is for older people with advanced cancer with only an emerging perception that palliative care can be accessed by people with other illnesses. Even so, the perception remains that palliative care is only for end-stage disease and older people. Such perceptions likely limit access to appropriate care for people who may benefit from palliative care, but are unaware of its availability.

The public, mostly in the US, also describe conflicting views as to where and how palliative care can be received, with palliative care at home being less well known than in hospital. Funding structures are poorly understood and are met with some concern. One perception in the US being that funding structure may lead to a service that is not universal or the expense associated with palliative care may mean quality of care at the end of life cannot be achieved. Moreover there is a concern that palliative care services are a way to shift the burden of healthcare funding to families.

These perceptions are interrelated; the perception that palliative care is for advanced cancer or end-stage disease reinforces both the association with death and the need for good symptom control. Even in the US, where palliative care can be received in hospital alongside curative therapies, it is still associated with end of life care. The perception of palliative care being predominantly in hospital or institutionalised care, may further the view that death is sequestered away from public view, exacerbating fear of the unknown.

3.6.2 What influences the general public’s perceptions of palliative care?

Awareness, understanding and perceptions of palliative care are influenced by age, gender, ethnicity, country of study, education, health literacy and income. Reflecting on DeWilde’s theoretical framework of cultural distress, any of these factors can influence both an individual’s culture and the collective culture of groups with similar characteristics. Through these cultural lenses the shared realities which influence how individuals perceive palliative care can be understood. Cultural congruency is core to the public’s perceptions of palliative care. This synthesis demonstrates that palliative care is perceived less favourably and less well understood by ethnic minority groups and younger people. Yet, the association of palliative care with death is stronger among older members of the public and, ethnic minority groups. The synthesis even suggests that being a member of a minority group led to perceptions that palliative care is prejudicial, not accessible, and not in line with traditions and values of that group. This has been interpreted as palliative care not being an approach to care that is suitable for some people. Thus, rather than supporting a culturally appropriate way to receive care, the perception is that palliative care subsumes the family role by taking the required responsibility of caring for people away from those that want, and are expected, to do it. Equally, a poor understanding of the view of different cultures on death further antagonises the relationship between individuals, their families, and palliative care. Perceptions of palliative care within countries varied; the most obvious example of this being the US. The majority of US studies looked specifically at hospice care but those that did look at palliative care consistently showed relatively low levels of awareness and poor knowledge, still associating palliative care with death. It is not clear whether it is a characteristic of the participants that influences this, or the terms being used to describe similar approaches to care.

Beyond the positive association between levels of palliative care integration in health systems and public awareness, the specific research question as to whether the public perceptions of palliative care relates to the level of integration is not possible to answer from these data. All but one of the qualitative papers were from countries with high levels of integration and comparisons beyond those shown in the quantitative narrative synthesis were not possible. Yet, exposure to palliative care does increase awareness and knowledge and although integration does not guarantee exposure, this may follow. Perceptions of palliative and hospice care did vary between countries but generally there was no clear pattern to this variation. As for the influence of time on perceptions, there was some quantitative evidence that this is improving but this was not confirmed by CIS and overall, the described misperceptions persist.

3.6.3 The effect of public perceptions on access to palliative care

While evidence in this synthesis did not discretely answer the question whether the public's perceptions of palliative care impacts access it certainly suggests that it does, with negative perceptions and a lack of knowledge/awareness likely limiting access. Perception that palliative care is death and therefore avoided until necessary likely defers access to palliative care. Similarly, the factors that increase this association such as lower socioeconomic position and, cultural distress (resulting from cultural incongruence) are known to create structural barriers to accessing health care.

3.7 Summary of results

In summary, this critical interpretive synthesis of the general public's perceptions of palliative care suggests palliative care is often an unknown and is mostly associated with cancer and the very end of life. Younger people, men and ethnic minorities have the least accurate perceptions. Most people appear to learn about palliative care either through first-hand experience, or through the media. Perceptions appear to improve following exposure to palliative care, suggesting high levels of acceptability. Yet, it remains that many of the public see palliative care as "death", meaning it is avoided until it is unavoidable, delaying access to an approach to care that can improve quality of life and, relieve suffering for patient and family.

Given the ongoing associations between palliative care and death (leading to negative perceptions), portrayals of palliative care by the media may warrant attention.

Chapter 4 Discussion

4.1 Discussion of findings

This is the first study to systematically review and synthesise to a higher order framework, public perceptions of palliative care. My findings indicate that over half of those studied were aware of palliative or hospice care, with it generally seen as care provided by a compassionate workforce. Only a proportion of the public perceive palliative care as a holistic, patient-centred approach and for the public as a whole, the detail and context of what palliative care provides is an unknown. These findings complement and extend recently published scoping reviews (56, 181) that describe a public view that palliative care is only for the end of life. My synthesis demonstrates that the predominant public perception is that palliative care is not just related to the end of life but, that palliative care *is* "death" and therefore to be avoided until unavoidable. This, combined with modern society's unease with mortality and, with death being sequestered from view (60), makes it unsurprising that palliative care is poorly understood as it too is hidden from view until it can be blocked from sight no longer.

Although no direct link was found between public perceptions of palliative care and access, low levels of knowledge about palliative care, including the awareness of how, when and who can access it, are illustrations of poor health literacy. Although a number of health literacy definitions exist, Berkman's more recent one describes many of the issues found in this review: "the degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions" (182) (p.16). Health literacy and factors affecting it influence perceptions fostering the observed wish to "avoid", thereby acting as a barrier to timely access to palliative care. The consequence of such factors is likely to be that many people who would benefit from palliative care, do not receive it.

4.1.1 The general public’s perceptions of palliative care

The relationship between palliative and hospice care

In the context of over half of the public being aware of palliative care globally and a greater number aware of hospice care in the US, it is apparent that public perceptions commonly conflict with the international definitions. Palliative and hospice care are frequently unknowns and the relationship between them poorly understood. These country relevant terms have different meanings in different settings. In the US, the term palliative care was initially rejected, and care for those with terminal illness was termed hospice care (to honour the founder or the modern hospice movement, Cicely Saunders). In the US, this model of care is generally only offered in the last 6 months of life, most frequently in someone’s home (although can be in a healthcare institution). Specific funding structures for hospice care exist, for example Medicare insurance, where in return for payment, “hospice” is expected to provide <u>all</u> services which the patient and family need. This can mean giving up some disease and symptom modifying treatments (183). A separate specialty of palliative care has subsequently developed in the US, with a similar focus to hospice care but with differences in definition, including that it is care based on the needs of a patient, not the prognosis and that it can be provided <u>along with curative treatment</u> (33). While the term palliative care was adopted by most of the rest of the world as an inclusive term for care of those with terminal illness, hospice is also still used, sometimes synonymously, or sometimes referring to a healthcare institution, a philosophy, or a different approach to care (18). The country specific use of these terms, the interchangeable use within some countries, along with the association of both palliative and hospice care with death, and lack of awareness of other key aspects of care they offer, has led to confusion and discomfort with both terms (53). A study at an international palliative care conference found *even* senior palliative care academics and clinicians expressed unease using palliative care as a term (184). This study shows the public share this confusion and unease.

There have been calls to wholly change the name of palliative care to supportive care, with some evidence demonstrating that this may put referrers and patients at ease (185). This term has grown in use in the oncology setting in both the UK and the US, with one randomised trial suggesting it was associated with better patient understanding and more favourable impressions (186). Others argue it is not the terminology that is the concern, rather, a more nuanced issue involving working relationships between specialities and to what level people are informed that influences comfort and understanding with the specialty (11). If discretely introduced to a “the palliative care team”, this exposure in time would likely increase awareness and understanding among the public as a whole. Furthermore, given the previous name changes, including the birth of palliative care itself (16), this synthesis suggests, that with the already existing confusion between terms, a further name change is unlikely to help understanding or access to a palliative approach to care. With a name change, the scope of care is likely to be unchanged or if it is, it may describe a similar but separate model of care, not for terminal illness, but for all serious illnesses. This would risk further hiding those with terminal illness from view, promoting the fear of death and promulgating misperceptions of care at the end of life. Until the concept of palliative care is better understood by the public, misperceptions will persist irrespective of names used (11, 187).

Who palliative care is for

Despite these results suggesting that the public view palliative care as a form of care exclusive to older people or those with advanced cancer, unlike most other medical specialties, palliative care does not have a focus on a single disease, bodily organ or life stage (188). The focus on quality of life from diagnosis to death, ahead of the more traditional medical approaches of other specialties, could create a challenge to understanding for those who work in healthcare and the public alike. It may be “easier” to view palliative care as only for a single population such as older people with cancer or, *just* for death. It is likely this view also relates to the historical development of palliative care as a cancer intervention delivered close to the end of life. A failure to tackle this understanding likely exacerbates inequitable access to palliative care for those with non-cancer diseases (78).

Interestingly, despite the public seeing palliative care as for older people, evidence suggests older people have less access to generalist palliative care, later referral to specialist palliative care and poorer control of symptoms (51, 74). This reduced access and poorer outcomes mirrors non-palliative care specialist clinicians reluctance to adopt a generalist palliative care approach, perhaps again due to perceptions that palliative care is just for cancer or just for people who are dying which, in non-cancer diseases in the elderly, tends not to be diagnosed until close to death (189). Some have suggested ageism exists in relation to equitable access to palliative care (189).

Structures and provision of palliative care

Most of the public expressed an intent to use palliative or hospice care in the future should they need it but, perceived it to be inaccessible and not universally available. There is a global view that palliative care should be accessible to all with advocates arguing service implementation is feasible in all settings (49). Yet, in 2017, it remained that in 47 countries (24%) there was no palliative care activity and, only 41 countries (26%) had *any* integration of palliative care within their health system (72). The public perception that palliative care is not universal, in part, relates to country specific concerns about cost, location it can be accessed as well as level of integration of palliative care in the country’s health system.

This study found considerable differences in the public perceptions of where palliative care can be accessed. Some understood palliative and hospice care to be available in a hospice institution but less so at home. Levels of knowledge about hospice access was low and thought to be available only to those living physically near a hospice and, as such, living in urban areas. Availability of palliative care in hospital was variably known, with some (mainly US studies) viewing palliative care as only available in hospital with a further view that once receiving hospice care, admissions to hospital were precluded, which as previously discussed can be the case in US healthcare funding models.

The public generally perceived palliative care and hospice care as an approach offered by nursing staff rather than a multi-disciplinary team (142, 167), mirroring views of non-palliative specialist doctors who have described palliative care as “not very medical”, and “largely nursing based care for people who are terminal” (190) (p.495).

One of the challenges clinicians, policy makers, and managers have in integrating palliative care into health systems is the sheer scale of need, due to a widening remit of disease and needs increasing in a variety of settings including acute care, residential care and primary care (191). Not all situations require specialist palliative care, and a palliative approach to care provided by generalists has been suggested to improve access to palliative care for all, especially older people with non-malignant disease (192). The Global Atlas of Palliative Care suggests an “essential package” of care (a defined minimum package of generalist palliative care services) can facilitate this palliative approach cost effectively in all parts of the world (193). My study suggests that while misunderstood, the public perception of palliative care is that it is a specialist medical approach, rather than this more generalist approach to care. Integration of palliative care services to the level of this “essential package” and further training of generalists to adopt a palliative approach may firstly improve clinicians understanding of palliative care and, provide downstream exposure to palliative care for the public, thereby increasing knowledge and awareness.

Characteristics of palliative care

Higher awareness of palliative care is, unsurprisingly, associated with a better understanding which is, in turn, associated with more favourable attitudes towards palliative care. In these circumstances, there are perceptions that palliative care provides comfort at the end of life. Comfort care was mostly interpreted as pain and symptom management with less acknowledgement of psychological and social support. The purpose of comfort care was viewed as an approach to facilitate a comfortable death rather than one to promote living as well as possible. There is commentary suggesting that palliative care as comfort care is viewed mutually exclusive to disease modifying treatments, emphasised in the US when former First Lady Barbara Bush died in 2018; her family declared she would no longer seek medical treatment but rather focus on comfort care (194), perhaps further adding to the view that palliative care is “death”.

Reflecting on the international definitions of palliative care (table 1) the elements least described by this synthesis are spiritual care, that palliative care affirms life, neither hastens nor postpones death, helps people live actively, is care in any location and, is applicable early in the disease course. While acknowledging the quality of life components of palliative care are vital and generally missing from public perception, it is also important to recognise that the definitions and practice of palliative care **do** involve care for people with terminal illness, including care at the end of life. This lack of awareness among the public regarding the life affirming nature of palliative care should not be considered at the expense of better understanding their perceptions of how palliative care and death are related.

Palliative care as synonymous with death

The overarching public perception in this synthesis is that palliative care <u>is</u> “death”. This finding complements findings in scoping reviews by Patel and Lyons, 2019 and Grant, Back and Dettmar in 2020, who described the public perception of palliative care as synonymous with terminal illness and end of life care (56, 181).

One reason palliative care is poorly understood may be the known societal death taboo. Prior to the first half of the 20th century, death was commonly at home and mourning shared by a community. Gradually, death moved from home to hospital, with an avoidance of discussion about death even by healthcare professionals (195). Medicine was a panacea and death a failure. It was argued that this medicalisation of death lead to an inability to see death as part of life, a view that death must be fought off at all costs, a devaluing of rituals surrounding death and a rejection of intervention even at the very end of life seen as an aberration (196). The medicalisation of death and focus on cure at the expense of care is what led the birth of the separate medical specialty of palliative care (6). Yet in this study, the public associate palliative care only with death. While a minority acknowledge “better” palliative care would diminish the argument for euthanasia, this perception was noted in the context of confusion and misunderstanding around palliative care and death. For most, palliative care was seen as death, associated with “giving-up”, isolated from public view, and in itself euthanasia; this appears to have caused a palliative care taboo.

Some argue that the death taboo has lessened with time, evidenced by an increase in death and dying research, an increased representation of death in the media, and a glut of organisations promoting normalisation of death such as the UK’s dying matters and the international death cafes (197). Others suggest it may still be taboo in some quarters (195) with a UK survey of over 30,000 members of the public finding 29% of participants were uncomfortable talking about death (198).

This synthesis suggests even if the death taboo has lessened, palliative care has fallen behind and remains a taboo. This may be because while the death taboo has been tackled by removing some of the "medicalisation", some have argued that as palliative care has developed, a "creeping medicalisation" of the specialty has occurred, with focus on the physiology of physical symptoms associated with dying becoming the primary concern for some that work in the specialty (188). This may mean palliative care has retained some of the taboo associated with death even when death itself has started to shed it.

In summary, despite a reasonable level of awareness and overall favourable attitudes towards palliative care, there is a need to firstly, improve public understanding that palliative care is about helping people to "live" with disease and, secondly, reframe the negative perceptions regarding care of the dying to one focussed on a natural and quality death.

4.1.2 Influences on the public perceptions of palliative care

Favourable attitudes towards and awareness of palliative care are associated with perceptions more consistent with the international definitions of palliative care. The factors that influenced public perceptions of palliative care are described below.

Demographics and health literacy

Similar to findings by Patel (2019) (56), being younger, being a man and having a lower level of education are associated with both lower awareness and, perceptions of palliative care less consistent with international definitions. In addition, being a member of an ethnic minority group and lower income were also associated with lower awareness and knowledge. Complementing their finding that experience with a close friend or relative needing palliative care increased awareness and knowledge of palliative care, I further found that any experience with serious illness was associated with a better awareness.

There is evidence from my study that general health literacy ("the degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions" (182) (p.16)) positively and significantly predicts both the public's knowledge and attitude towards hospice (161). In

Europe and the US, 47% and 36% of adults have basic or below basic health literacy, respectively (199, 200). Interestingly, health literacy is dependent on socioeconomic indicators (200); more specifically, the characteristics described above (young, male, lower education, lower income) have been shown to correlate with poor health literacy (201, 202). It can be extrapolated therefore, that health literacy influences the public's perception of palliative care. Furthermore, acknowledging that people with a lower socioeconomic position have reduced odds of accessing specialist palliative care and, increased odds of dying in hospital versus home and receiving acute care in the last three months of life (203), these structural factors likely influence awareness and understanding of palliative care.

Country and level of palliative care integration

Perceptions of palliative care and hospice care varied by country of study, although the perception associating palliative care with death was universal. Palliative care being associated with a peaceful, comfortable death was more consistent in Western European countries. The association of palliative and hospice care with isolated deaths, painful deaths, or euthanasia mainly came from the US. Sweden was an interesting outlier in Europe where awareness of palliative care was consistently lower than other European nations. Despite the facets of palliative care such as pain and symptom management, care for family, and psychosocial care, being variably recognised in most countries, in Sweden these were also consistently less well known than in their European counterparts. This may be explained by the fact that palliative care only became its own medical subspecialty in Sweden in 2015 (138) which may mean the public has had a reduced exposure to the concept, potentially with fewer people championing the specialty.

The Swedish study comments on the influence of language on public perception of palliative care, suggesting that the term “palliative” is an unknown and if a “more Swedish” word was used then awareness and understanding would likely be better (138). In the US, terminology similarly has influenced perception. As discussed, there is confusion between the terms, but here hospice care is better known than palliative care, possibly reflecting the history of the terms. The confusion between terms appears to influence the public perceptions of where palliative and hospice care are available. In addition, perceptions of palliative care in the US may be related to exposure being less explicit, with experience likely only in hospital settings. Hospitals are bewildering places with patients seeing many different types of professionals from many different teams. If a palliative healthcare team is not introduced or if a patient does not recall who they are, it is likely they will remain unaware of palliative care, which in turn permeates into public perceptions.

Forty-four of the included 48 studies in this synthesis were from high-income countries. The four studies from middle-income countries had lower level of palliative care integration in their health systems (72). Awareness of palliative care was low in all four studies and perceptions were generally inconsistent with international definitions of palliative care. Regarding the perceptions of who palliative care is for, while the countries with higher levels of palliative care integration had a better awareness that this was more than “just” cancer (72, 135, 156), one of the Indian studies also showed a burgeoning awareness that palliative care was for more than cancer. Interestingly, this study was from Kerala, a part of the country with significantly greater integration of palliative care in the healthcare system (204). It is difficult to be certain whether lower levels of integration of palliative care and/or not being a higher income-country are associated with perceptions of palliative care from this study (as there was so much variability and unknowns globally), but there seems to be an association with awareness; higher income-countries have a greater awareness of palliative and hospice care.

The passage of time

The timescale of this review covers an interesting period of development of palliative care. In the UK, there has been media interest where palliative care and dying in healthcare settings have been associated with euthanasia. Examples include the Neuberger report into the Liverpool Care Pathway (205) and more recently the inquiry into deaths at Gosport War Memorial Hospital (206). Across the world there has also been a steady spread of legalisation of physician assisted dying during the time period of the review.

I found no convincing evidence that awareness of palliative care has changed over time but there was some indication that perceptions of palliative care have become more closely aligned to international definitions more recently. It is difficult to point as to why this may have happened or even if it is significant, yet it fits with there being more exposure to death and dying, perhaps with the aforementioned reduction in the death taboo and public campaigns to promote palliative care such as getpalliativecare.org, in North America (207).

Cultural factors

One of the major influences on the public perception of palliative care is both individual and shared culture. Cultural competence in healthcare refers to how a healthcare provider recognises their own culture in order to better understand the culture of a patient (104). Culturally congruent care is related to an individual's perception of care received and whether that care incorporates an individual's beliefs (100). A healthcare provider may assume they are offering culturally competent care, but this may not be perceived by the patient, leading to an incongruence. Despite an acknowledgement that people working in palliative care are compassionate and patient-centred, and therefore hopefully culturally competent, it is clear from this synthesis that minority groups see palliative care as culturally incongruent. Cultural distress is described as a "negative response rooted in a cultural conflict in which a patient lacks control over the environment and the practices taking place in the patient-provider encounter" (104) (p.336). This distress can result from illness, the power imbalance between patient and provider, and/or a sense of "otherness". Othering is a process by which anyone can experience discrimination due to visible differences from the majority (208). This othering can also influence an individual's perception of self in relation to the rest of society (209). In my synthesis, palliative care was perceived as not aligned to the cultural needs and values of minorities along with a view that there is a lack of minority representation in workforce and outreach. This likely increased a feeling of otherness and cultural distress. In turn this distress is likely a barrier to both the understanding of palliative care and access to a culturally harmonious approach to palliative care.

Migrants tend to have poor health literacy and, due to understandable structural barriers, difficulty understanding and accessing palliative care (210). Interestingly acculturation improved understanding of palliative care, likely related to a reduction in cultural distress because they as individuals had a better understanding of local culture (143). This perhaps suggests an opportunity for professionals in palliative care to adopt a more culturally congruent approach, which may then similarly yield better understanding among the public and reduce some of the structural barriers to access.

Source of information

The media has potential to influence public perception, as it is the most frequently reported source of information. One example where this may be having an effect includes North America, where the Center to Advance Palliative Care developed a website (getpalliativecare.org) (207) promoting palliative care through education.

In summary, the passage of time, culture, health literacy and country have influence public perception of palliative care. Further work is needed to fully appreciate the processes by which these occur.

4.1.3 The effect of perceptions on access to palliative care

Despite growing calls for both a generalist palliative care approach and early needs-based referral to specialist palliative care services irrespective of diagnosis, this still happens late in disease trajectories or not at all (51, 211). This synthesis suggests that increased exposure to palliative care increases awareness, this in turn leads to more accurate perceptions of palliative care, which subsequently is associated with better access (52).

A socioeconomic divide exists in healthcare and a low socioeconomic position (along with the associated factors of being an ethnic minority, a man, having low income and/or low education) is a barrier to accessing palliative care (77, 203). A strong association between a low socioeconomic position, having poor health status, and poor levels of health literacy has been described (202). Low health literacy increases the challenges of understanding and navigating a health care system (212), likely leading to structural barriers in accessing palliative care (213). Structural barriers to palliative care include the confusion about where palliative care can be accessed, concerns and confusion about costs and, the confusion around the relationship between hospice care and palliative care. Addressing health literacy related barriers may help reduce disparities in access (201).

The perception of palliative care being only for advanced cancer and older people is shared by professionals and public alike. Professionals are less likely to adopt a generalist palliative care approach or refer to specialist palliative care services, especially those with non-malignant disease and given both the public perception of palliative care and the aforementioned health literacy, this is unlikely to be challenged.

It can be extrapolated that a perceived fear of death and perhaps a separate fear of palliative care affects willingness to accept referral to palliative care, thereby reducing access (52). Cultural mistrust and cultural incongruence increase this fear and distress which likely reinforces this barrier. Specifically, evidence suggests that migrants and ethnic minorities in developed countries experience barriers to accessing healthcare and have worse health outcomes than other populations (214, 215). The process of othering described above can create barriers to care because those who experience otherness feel unwelcome and are less inclined to seek care (216, 217). These structural barriers again likely reflect complex interaction between health literacy, cultural distress and perceptions of palliative care.

In countries with lower levels of palliative care integration, there is a suggestion that a lack of awareness about palliative care and a perception that it is only “preparation for death” is because of the limited availability of services and a lack of coordinated approach (218). This may be one of the factors affecting access to palliative care. Interestingly though, there is non-peer reviewed evidence that in some lower-income countries, poorer members of society have more access to palliative care. This suggestion stems from “financial inequality, whereby those with the resources will seek cure at all costs” (219) (p.201). This is further referenced in journalistic pieces, “low-income families, when they have access to free palliative support from government hospitals or non-profits, seem to have a better quality of life in their last days. The well-off, however, who pursue aggressive treatments which prolong their lives marginally end up dying in intensive care units, alone and away from families” (220).

4.2 Implications for clinical practice and policy

4.2.1 What does this mean for healthcare users?

It has been estimated that the number of people who will die with serious health-related suffering globally, and could benefit from palliative care, could nearly double to 48 million by 2060, with the majority of these people being in low-income and middle-income countries (221). The public perceptions of palliative care as described in this synthesis are a barrier to accessing this approach to care. Without the integration of palliative care services and an understanding and acceptance of palliative care by the public, underuse of such services to relieve suffering and affirm life will continue (194). Furthermore, acknowledging that health literacy is a global concern, and there is an as yet undefined relationship between health literacy, cultural distress and perceptions of palliative care, unless this is tackled, those in marginalised groups such as ethnic minorities and those from lower socio-economic positions, will continue to experience structural barriers to understanding and accessing palliative care. Given exposure increases awareness, education needs to engage with demystifying palliative care through exposure, starting with healthcare professionals introducing the concept explicitly at an earlier stage to all patients.

4.2.2 What does this mean for healthcare providers?

Published literature suggests that non-palliative care healthcare providers share the public's confusion between palliative and hospice care and view that palliative care is only for patients who are dying (190, 222, 223). A lack of clinician palliative care health literacy likely means a lack of advocacy for palliative care and is therefore a barrier to access.

It could be argued that the creeping medicalisation of palliative care, while potentially beneficial to the clinician from the point of view of understanding symptoms and disease, has detracted from the original purpose of palliative care. The view in the early 20th century that focus on cure and subsequent neglect of management of chronic diseases and care of the dying (8) lead to the need for the new specialty of palliative care (6) yet, the focus now seems to have returned to disease and physiology. Given this medicalisation potentially adds to the palliative care taboo, a return to the broader purpose of palliative care may be needed to improve public understanding of its value and change perceptions. To achieve this, the relief of suffering not only by drugs but also by positioning, diet, or the simple act of presence again needs to be fundamental to all healthcare trainees (8).

Cultural competence training is not adequate in most clinical educational programmes (214). Healthcare providers not being aware of the cultural needs of patients can influence experience and understanding of healthcare services (including palliative care) (104). This potentially exacerbates structural barriers to care relating to cultural distress and health literacy. According to Suarez-Balcazar, as cited by Sorensen *et al* (214) (p.6), all healthcare professionals need to, "be capable of promoting (a) the capacity to adopt a multicultural mission that embraces equality and diversity as values; (b) services and organisational processes that are adapted to the needs of multicultural collective groups; (c) horizontal and reciprocal relationships by including users in the decision-making processes; (d) the capacity to engage in new roles, (e) pluralistic leadership capable of equally representing the needs and views of all constituents and (f) quality and systems change rather than pursuing a quick fix approach, i.e., seeking to maintain services and practices that support multicultural populations". Given the effect of culture on the public's perceptions of palliative care, engaging with strategies to better train clinicians in these aspects of multicultural care need to be embedded into training curricula. This would aid in removal of some structural barriers the public have to both understanding and accessing palliative care.

4.2.3 What does this mean for policy makers and public health?

Public attitudes can help shape public policy and influence the political will that determines future service provision (224). It is important that policy makers are aware that the public attitudes towards palliative care are favourable to ensure opportunities to develop palliative care are not missed.

As people live longer and health systems around the world improve, more people are living with and dying of serious chronic conditions rather than acute illness (225). Many of these people have palliative care needs and a palliative approach not only has the potential to improve patients' lives but also save health systems money through reducing admissions and avoiding unnecessary interventions in the last months of life. The World Hospice Palliative Care Alliance Global Atlas of Palliative Care published earlier this year states, "the need for palliative care has never been greater and is increasing at a rapid pace," (193) (p. 12). Furthermore, access to palliative care is a "health, equity, and human rights imperative" (71) (p.1397). Yet, in public health agenda, the focus on prevention and cure means quality of life offered by palliative care has often been neglected (226). As people in more countries are dying from chronic disease, these countries are approaching or are at the "tipping point" where there is a need for policy makers to prioritise limited resources to further integrate palliative care into their health system (49). The Global Atlas of Palliative Care public health model for palliative care development, identifies education involving both the media and public advocacy as a key component to improving integration (193). This synthesis shows that not only is education needed to improve integration but also as part of it; without an understanding of palliative care, barriers to access will persist irrespective of integration.

Exposure to palliative care improves understanding of it, yet even in countries with high levels of integration of palliative care, most people have little exposure to it. Exposure to illness and mortality are mostly "social experiences, shaped by culture, geography, beliefs, communities and relationships" (227) (p.5). Therefore, to improve understanding and to meet remaining challenges with accessibility, palliative care needs to engage with the community (228). Abel and colleagues (2018) describe a public health model of palliative care involving four components working in partnership: specialist palliative care, generalist palliative care, compassionate communities and civic institutions (such as civic partnerships with schools, workplaces or churches) (229). Through this partnership with communities, greater exposure to and culturally consistent advocacy for palliative care would likely facilitate public perceptions of palliative care more consistent with the international definitions and remove barriers to access.

Furthermore, to ensure equitable access to palliative care, a systematic, targeted and personalised approach is needed to overcome the influence of low socioeconomic position, having poor health status and poor levels of health literacy on perceptions of and access to palliative care (202). A health promotion approach to changing public perceptions of palliative care could follow the "health literacy as an outcome of health promotion" model proposed by Nutbeam (2000) (230). This should include improving knowledge through health education, for example, through involving the media; developing social action to promote culturally appropriate palliative care to marginalised groups and improving public policy through advocacy and political lobbying (230).

Through this systematic approach to promoting palliative care, specific educational interventions are likely needed. These interventions must acknowledge the perception that palliative care is often seen as death and look to re-orientate this perception to one about palliative care allowing a natural and normal death. Furthermore, any intervention needs to address and promote the aspects of palliative care that focus on living. Examples of some educational tools that exist include those on getpalliativecare.org in the US or Hospice UK in the UK, and while death and palliative care is portrayed favourably on electronic media, it is clear from this review that the major source and potential influence on public perceptions of palliative care is print and televisual media. Given the aforementioned exposure to mortality in social experiences, a further public health approach to education could be one employing popular entertainment media.

Without integration of a culturally congruent health promotion approach to the development of palliative care services and improving the cultural competence training of healthcare professionals it is likely that many people who could benefit from palliative care will not receive it.

4.3 Implications for future research

Any intervention in the context of these issues should look to:

1) Increase public exposure to palliative care through the media
2) Reframe palliative care as an approach to affirm a culturally aligned natural death and,
3) Facilitate ways to promote the work palliative care does to affirm life.

4.4 Studies published since this review

Since the electronic searches were completed further studies have been published. These include a study from Hangzhou China which showed awareness of hospice care among community residents was 50% and intention to use hospice positively correlated with understanding (231). A further study from Portugal again showed knowledge of palliative care among the public is poor, and that women and older participants had a higher knowledge of palliative care (232).

4.5 Strengths and limitations

I conducted a synthesis of both quantitative and qualitative data which allowed a breadth and depth of understanding of the findings that either alone would not have provided. I have used robust methods, followed recognised guidelines and appraised all included studies.

Palliative care was chosen as a generic term as the exposure of interest, as an umbrella term to include generalist and specialist hospice and palliative care. This may be a limitation, although mitigated by pre-determined eligibility criteria in line with any of the international definitions of palliative care. Although most studies were from high income countries, marked heterogeneity existed between studies in terms of the participants and tools used to assess awareness and perceptions, potentially making comparisons difficult. Much less representation from lower and middle-income countries (although not completely excluded) may affect global generalisability.

Evidence provided by this CIS is only as good as the primary research (see quality appraisal section 2.3.8) and any conclusions should be taken in that context. The quantitative data were from cross-sectional surveys which have well-recognised potential biases: non-response (when participants who complete surveys differ from those that do not (180)), selection (when participants systematically differ from the population of interest due sampling methods), volunteer (when volunteers differ from the population of interest), and ascertainment (for example, when respondents under-report information) (233). My mixed methods approach allowed the qualitative data to redress at least some of these survey restrictions by providing more in-depth data. The qualitative studies were generally of high quality. One potential limitation was the quality assessment of the mixed methods studies; the qualitative and quantitative components were appraised separately, rather than with a validated mixed methods appraisal tool, such as the mixed methods appraisal tool (MMAT) (234). Although the assessment tools I used were not validated for mixed methods, which may lead to an under or overestimation of study quality; the qualitative and quantitative data were presented separately in the included papers and appraising them as such was appropriate. As is often seen in health services research the quality, especially of the qualitative component, of these mixed methods studies was poor (235). Justification for mixed methods was inconsistently reported and qualitative methods were either of low sophistication or not described in sufficient detail and reflexivity rarely commented on. Integration of qualitative and quantitative data did not happen, and presentation of the data tended to follow a quantitative approach, including presenting qualitative themes with counts rather than exemplar quotes suggesting little conceptualisation had gone into the analysis. Inferences from the qualitative and quantitative components of the studies, however, were on the whole appropriate.

Bias in research is defined as conscious or unconscious systematic error but this is dependent on acceptance of objective truth. Through my interpretivist paradigm I view knowledge as dependent on the mind and as such the public's perceptions of palliative care are multiple and subjective. My epistemological position transforms the concept of bias from one concerning validity and truth to one concerning credibility, transferability, dependability and confirmability (115). However, it remains that a reflection on bias is needed to provide accountability for my research process and output (236), without this, my conclusions could be seen as merely my biased point of view (237). The systematic approach to methods and abductive approach to CIS counters this, facilitating both a systematic method and an output that remains grounded in the data but also acknowledges the influence of my own preconceived ideas of palliative care. Rather than defining this as a confirmation bias (238), my approach, extensive reflexivity and balanced axiology is a strength, reducing bias and yielding a higher order conceptualised framework of the public perceptions of palliative care (93).

Through the systematic process described in section 2.3 I have also reduced the likelihood of selection biases such as ascertainment, citation and, inclusion/exclusion bias (238). Reporting bias is minimised by the adoption of a pre-defined protocol including the methods of data extraction and analysis (239). The time limits set for my search may introduce a bias due to exclusion of earlier studies, however, it is my view that in a rapidly developing area of clinical care, obtaining an understanding of perceptions since the publication of the WHO definition of palliative care (107) is most relevant to what palliative care is today, and as detailed this covers an interesting timeline in palliative care, where in the UK there was considerable press regarding the Neuberger report and the Liverpool Care Pathway (which was viewed by many as passive euthanasia) and the legalisation of medical assistance in dying across many nations.

A conference proceedings database was included in the electronic searches to identify unpublished work, but unlike clinical trials there are no registries to identify studies for this type of mixed methods research and along with not searching the grey literature, this increases the risk of publication bias. Language bias is a possibility as although including studies from the whole world and not limiting searches by language, papers not fully published in English were excluded. This potentially explains the relatively few papers from low- and moderate-income countries where the primary language is often not English.

The conclusions from this research should be interpreted with due consideration given to these limitations.

4.6 Dissemination

Results of this study will be disseminated through presentation at specialist conferences and publication in a peer reviewed academic journal. Any publication will adhere to the PRISMA criteria for reporting systematic reviews (124).

4.7 Conclusions

This is the first study to systematically review and synthesise to a higher order framework, public perceptions of palliative care internationally. In the context of moderate awareness, palliative care is poorly understood. The predominant public perception is that palliative care *is* "death" and therefore hidden from view with what appears to be a conscious decision by the public and professionals alike to avoid it until it is unavoidable. Reduced exposure to palliative care and factors associated with a low socioeconomic position and the related poor health literacy influence perceptions of palliative care negatively, worsening access for those in marginalised groups.

I propose an, as yet undefined complex relationship between health literacy, cultural distress and perceptions of palliative care which, through structural barriers, influence access to palliative care. The consequence of not tackling public perceptions of palliative care, even with further global development of palliative care services, is likely to be that many people, especially those from marginalised groups, will not access palliative care and therefore continue to endure unnecessary suffering associated with severe illness.

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Appendix 1: Search strategies

Medline (OVID)

1. exp Palliative Care/
2. exp Terminal Care/
3. Terminally Ill/
4. palliat*.ti,ab,kw.
5. (terminal* adj1 (care or ill* or diseas*)). ti,ab,kw.
6. (terminal-stage* or terminal stage* or dying or (close to death)). ti,ab,kw.
7. (end of life). ti,ab,kw.
8. hospice*. ti,ab,kw.
9. ((end-stage* or end stage*) adj1 (disease* or illness* or care)). ti,ab,kw.
10. or/1-9
11. perception*.ti,ab,kw
12. attitude*.ti,ab,kw
13. understanding.ti,ab,kw
14. or/11-13
15. 10 and 14

Embase (OVID)

1. Exp palliative therapy/
2. Exp terminal care/
3. Exp terminal disease/
4. Exp hospice/
5. Exp hospice care/
6. Exp hospice patient/
7. Exp hospice nursing/
8. palliat*.ti,ab,kw.
9. (terminal* adj1 (care or ill* or diseas*)).ti,ab,kw.
10. (terminal-stage* or terminal stage* or dying or (close to death)).ti,ab,kw.
11. (end of life).ti,ab,kw.
12. hospice*.ti,ab,kw.
13. ((end-stage* or end stage*) adj1 (disease* or illness* or care)). ti,ab,kw.
14. or/1-13
15. perception*.ti.
16. attitude*.ti.
17. understanding.ti.
18. or/15-17
19. 14 and 18

CINAHL (EBSCOHost)

(TI (perception* or attitude* or understanding) OR AB (perception* or attitude* or understanding)) AND ((palliat* or terminal* or "end of life" or "close to death" or hospice or "end stage*" or "end-stage*") N1 (care or ill* or disease*))

PsycINFO (EBSCOHost)

1. Perception* .ti,ab
2. Attitude* .ti,ab
3. Understanding .ti,ab

4. ((palliat* or terminal* or “end of life” or “close to death” or “end-stage*” or “end-stage*”)adj1(disease* or ill* or care)).mp
5. 1 or 2 or 3
6. 4 and 5

Web of Science (Social Science Citation Index and Conference Proceedings Citation Index) search strategy (Clarivate Analytics)

(palliat* or terminal* or "end of life" or "close to death" or hospice or "end stage*" or "end-stage*") NEAR/1 (care or ill* or disease*)
AND
perception* or attitude* or understanding (limited to TOPIC)

Appendix 2: Data extraction template

Study ID:

Name of review author completing this form

Date form completed

Name of review author checking the data extracted to this form

Notes

Citation	
Eligibility:	
Is the study 2002 onwards?	Yes / No
Is the population being studied patients?	Yes / No
Are the study participants >= 16 years?	Yes / No
Is palliative care the phenomenon of interest	Yes / No
Do not proceed if the answer to any of the above is no, or if not participant of interest	
Author contact details	
Further information required?	Yes / No

Characteristics:	
Research question	
Study design	
Study location (country / setting)	
Recruitment context and sampling	
Data collection methods	
Data analysis methods	
Researcher (background, demographics, funding, conflicts of interest etc)	

Participant characteristics (age, sex, ethnicity, socioeconomic position, income, employment, education, religion	
Notes	

Qualitative findings:	
Themes (integrated discoveries/judgements) Understanding Perception Attitudes Influences Notes	

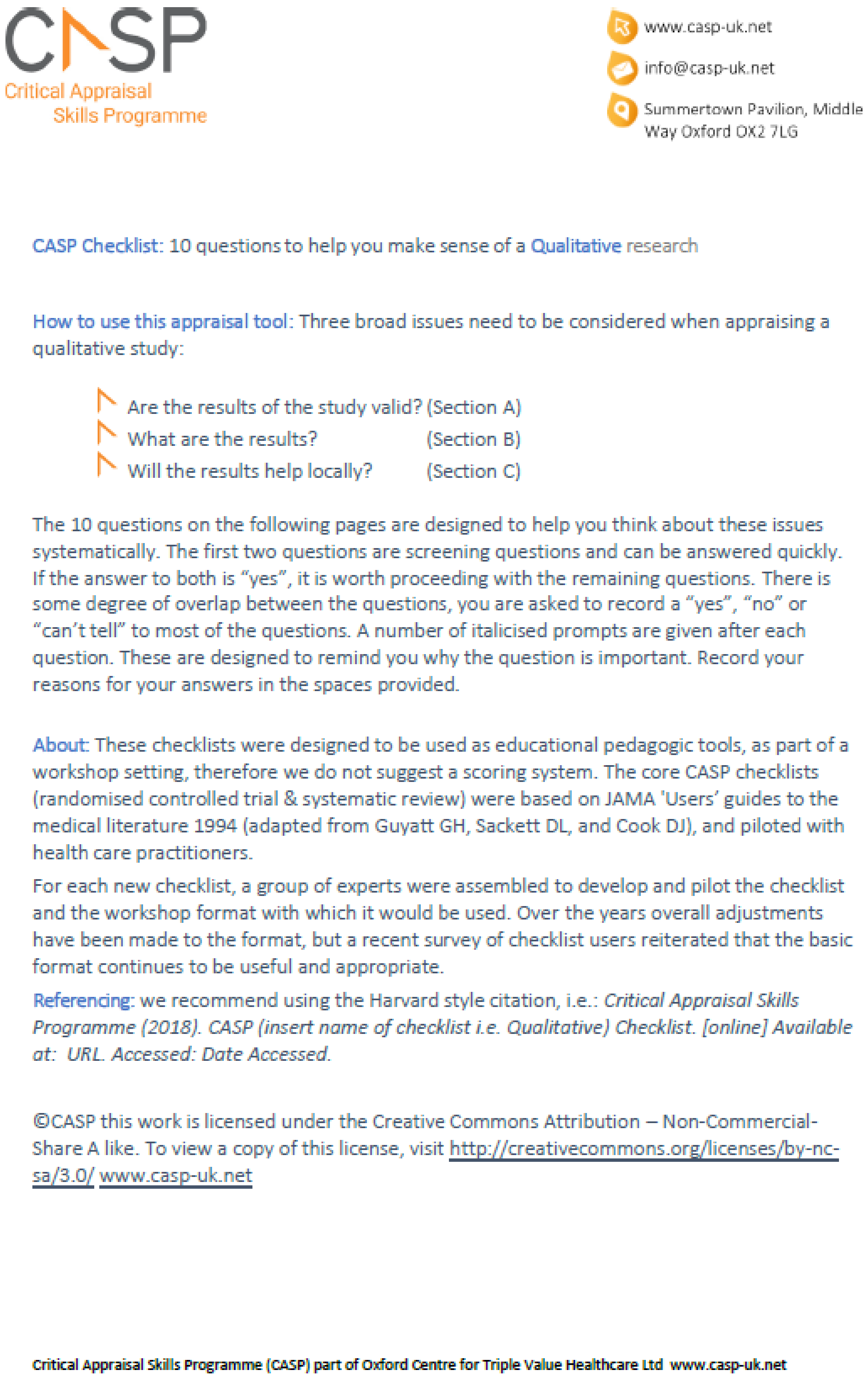
Quantitative findings:	
Non-interventional quantitative data	
Author recommendations	
Generalisability	
Implications for policy	
Implications for practice	

Appendix 3: Quality Appraisal Tools

Appraisal of Cross-sectional studies (AXIS) (Quantitative)

	Question	*Yes*	*No*	*Don't know/comment*
Introduction				
1	Were the aims/objectives of the study clear?			
Methods				
2	Was the study design appropriate for the stated aim(s)?			
3	Was the sample size justified?			
4	Was the target/reference population clearly defined? (Is it clear who the research was about?)			
5	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?			
6	Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?			
7	Were measures undertaken to address and categorise non-responders?			
8	Were the risk factor and outcome variables measured appropriate to the aims of the study?			
9	Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?			
10	Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)			
11	Were the methods (including statistical methods) sufficiently described to enable them to be repeated?			
Results				
12	Were the basic data adequately described?			
13	Does the response rate raise concerns about non-response bias?			
14	If appropriate, was information about non-responders described?			
15	Were the results internally consistent?			
16	Were the results presented for all the analyses described in the methods?			
Discussion				
17	Were the authors' discussions and conclusions justified by the results?			
18	Were the limitations of the study discussed?			
Other				
19	Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?			
20	Was ethical approval or consent of participants attained?			

Critical Appraisal Skills Programme Qualitative Checklist



CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle
Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

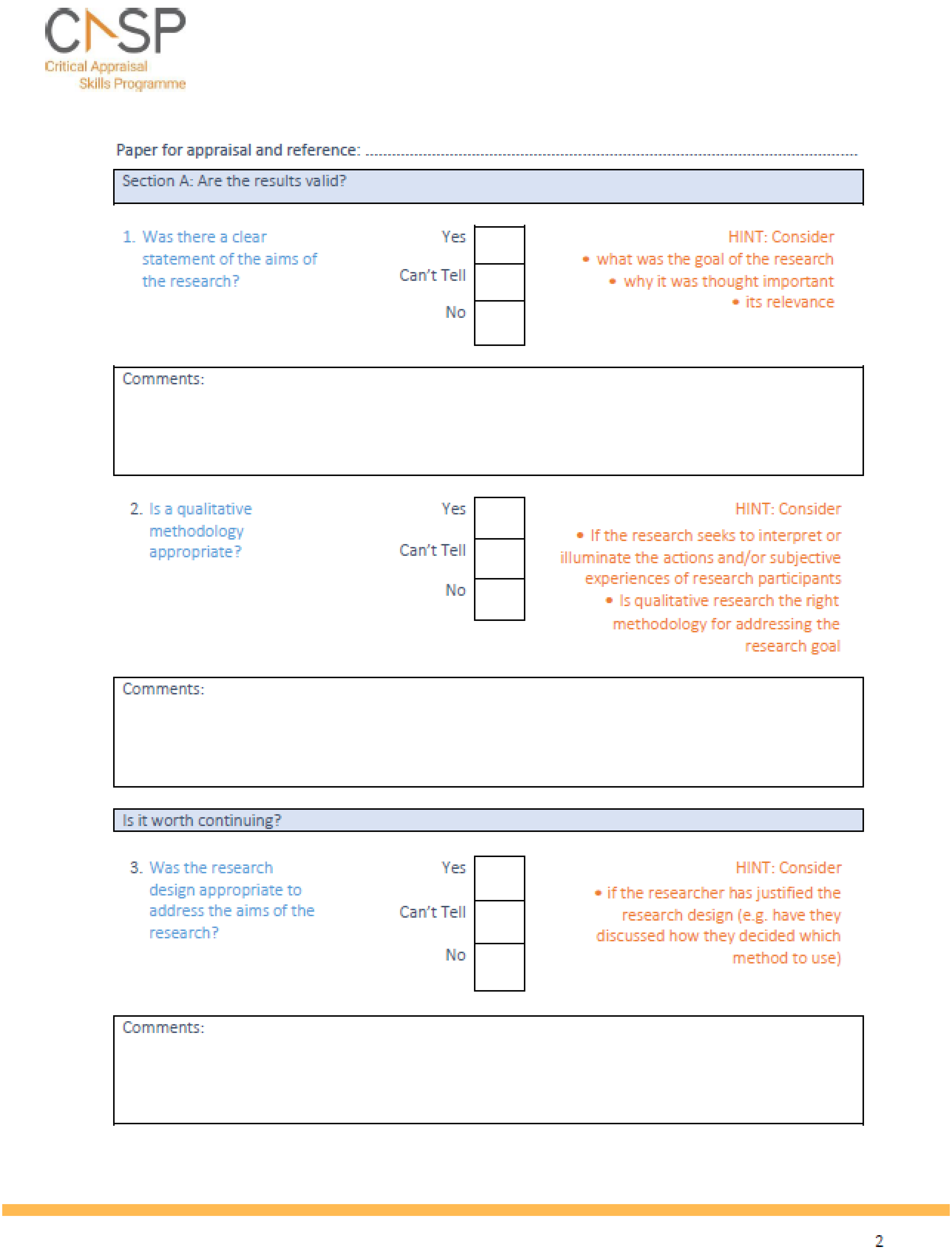
- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*



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Critical Appraisal
Skills Programme

Paper for appraisal and reference: ....

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

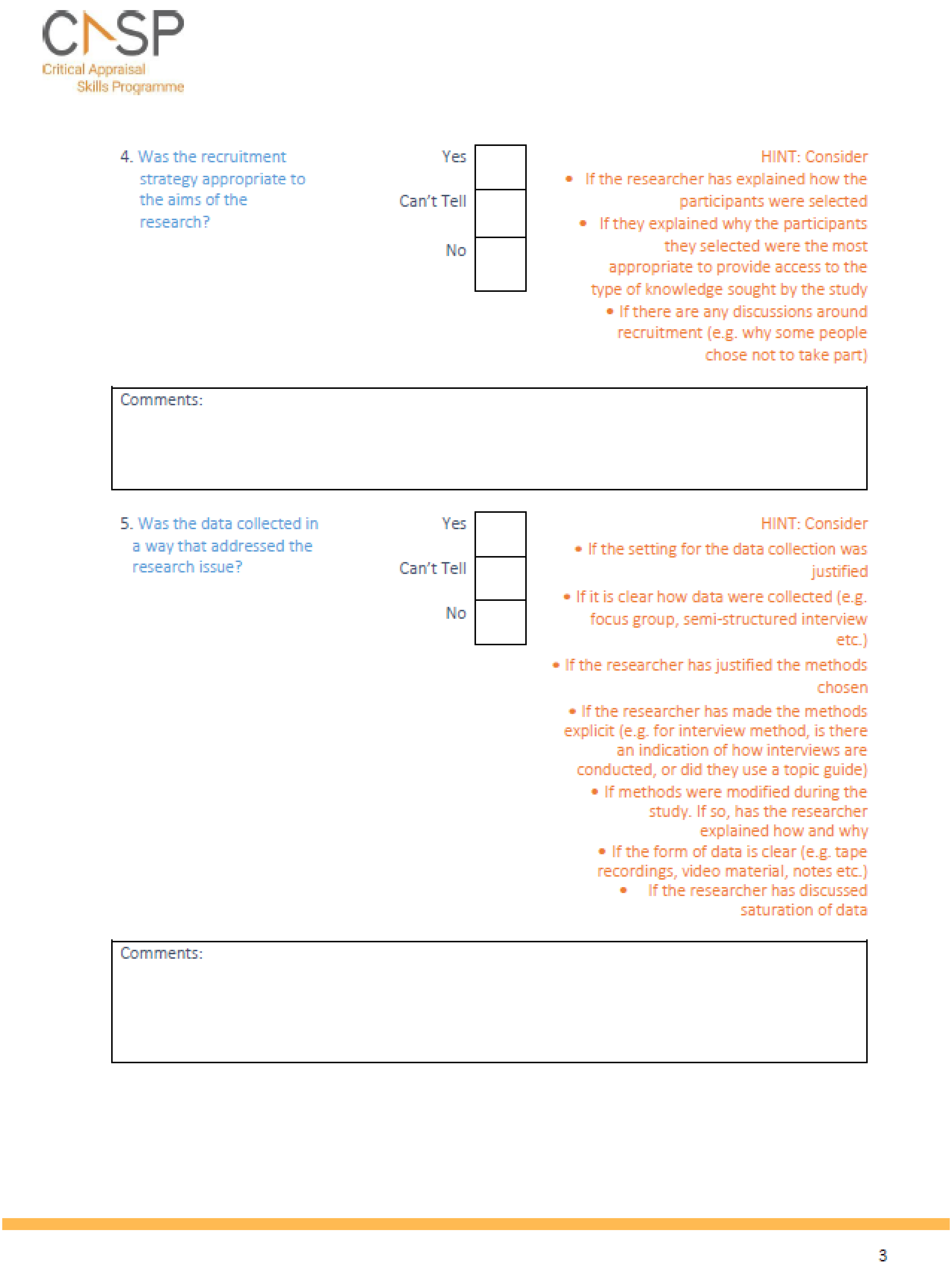
3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

2



CASP
Critical Appraisal
Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

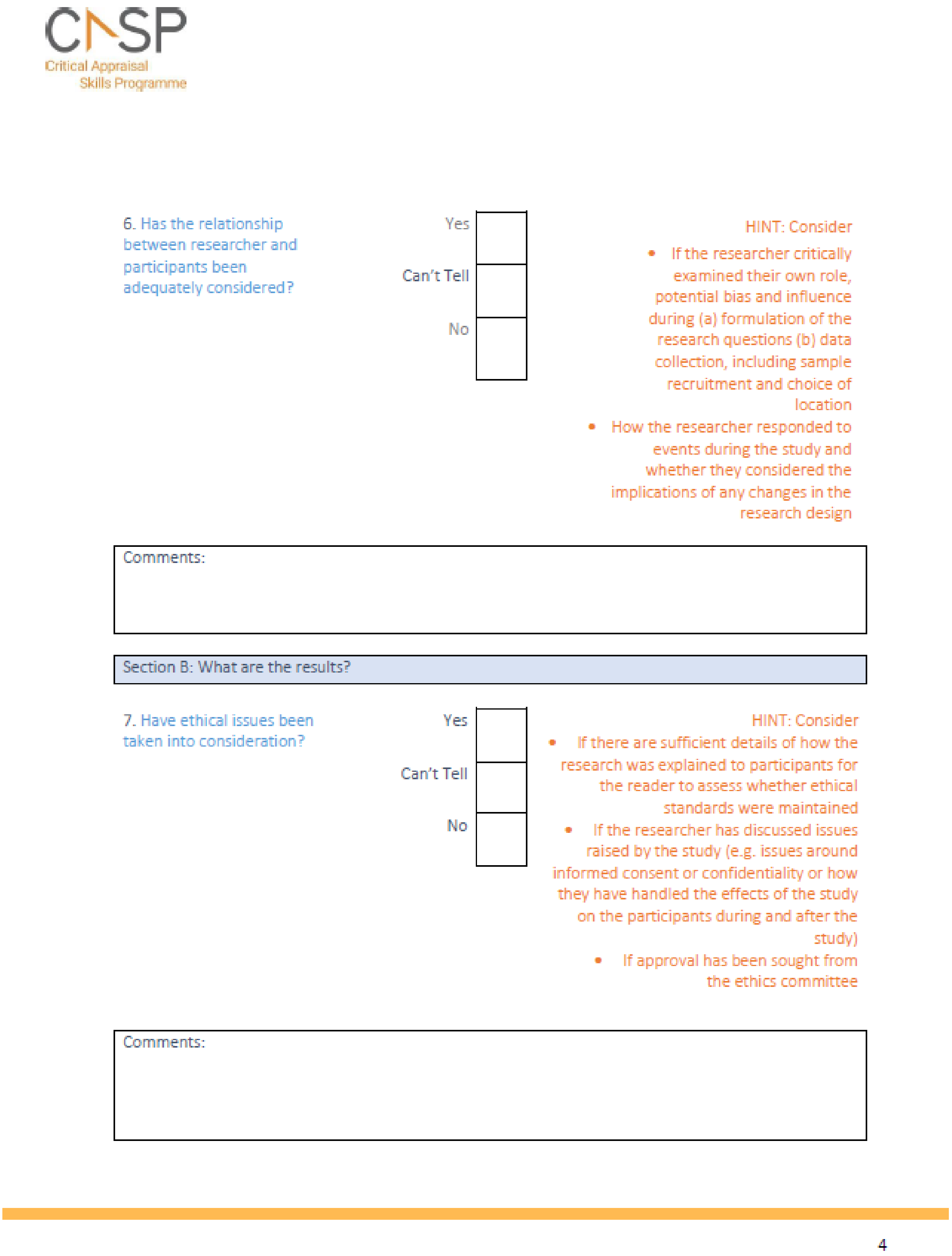
Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:



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6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

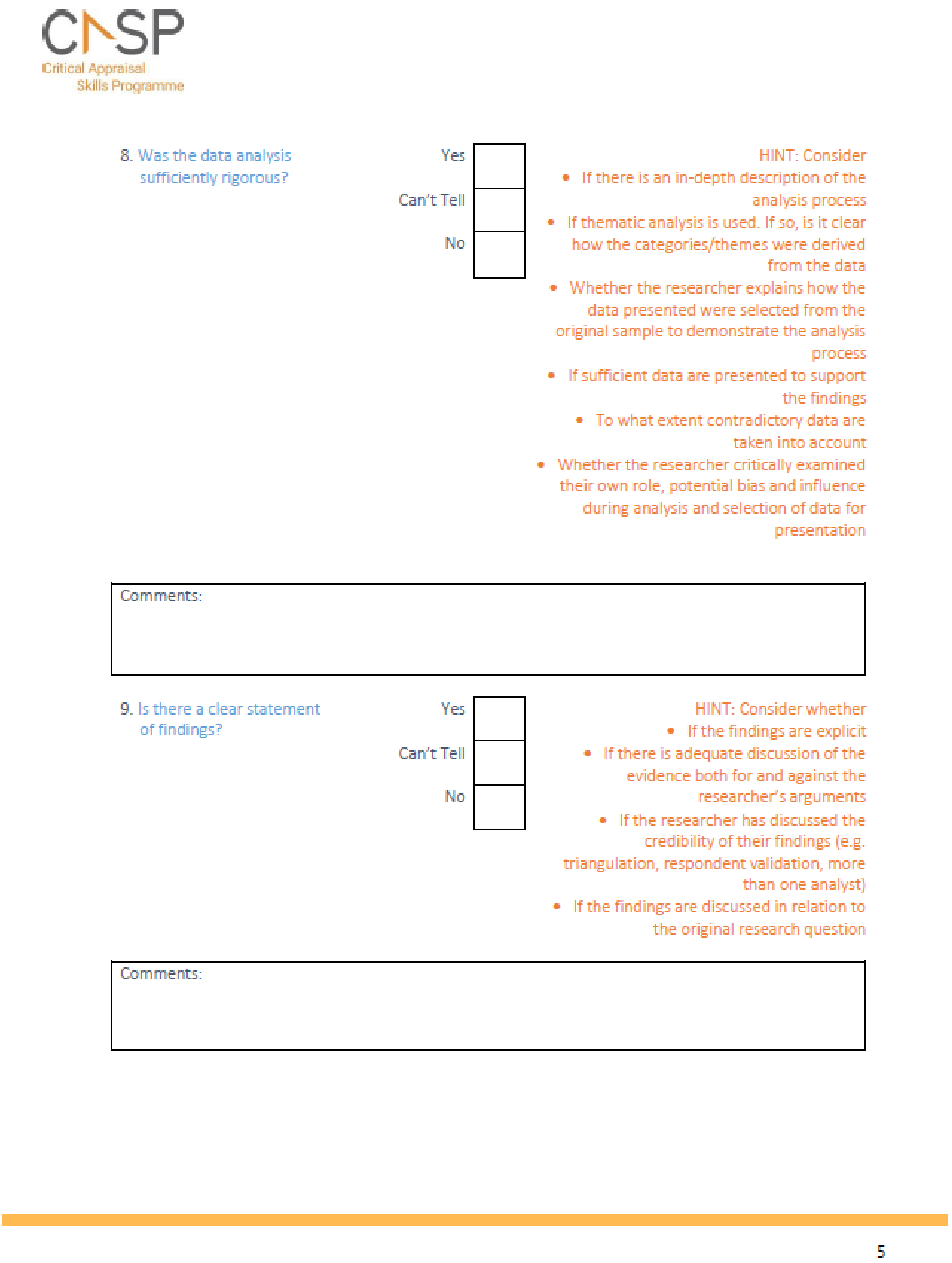
Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:



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Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

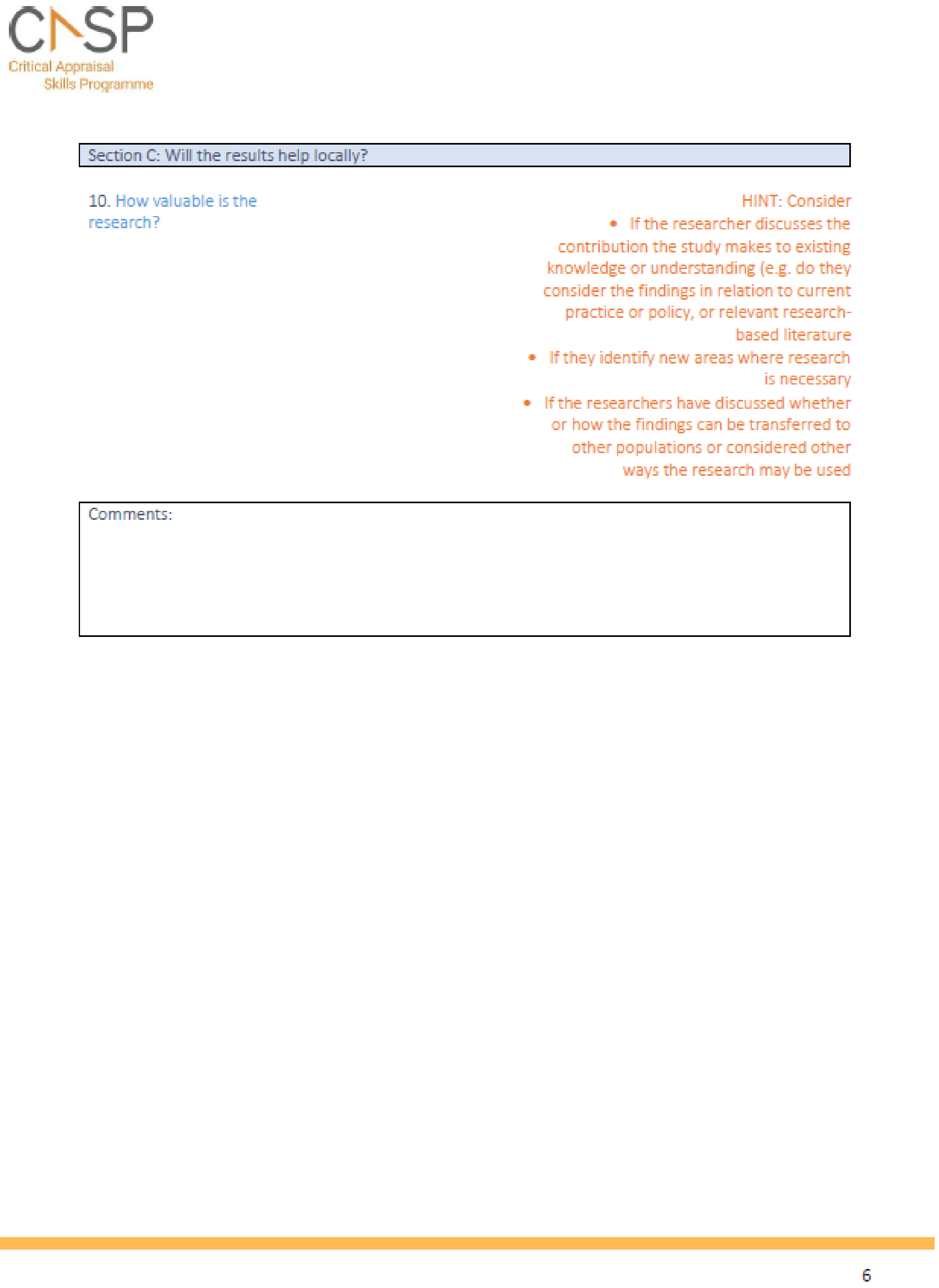
9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

5



Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

6

Appendix 4 Quality appraisal for all included quantitative and mixed method studies by study using AXIS tool

First author, year	Introduction	Methods	Results	Discussion	Other	Total score (out of 20)	Reference
Schrader, 2009	🟩	🟩🟩🟩🟩🟩 🟩🟩🟩🟥🟥	🟩🟩🟥 🟥🟥	🟩🟥	🟩🟩	14	(152)
Karel, 2003	🟩	🟩🟥🟥🟥🟥 🟥🟥🟥🟥🟥	🟩🟩🟥 🟥🟥	🟩🟥	🟩🟥	6	(148)
Claxton-Oldfield, 2004	🟩	🟩🟩🟩🟥🟥 🟥🟥🟥🟥🟥	🟩🟩🟩 🟥🟥	🟩🟥	🟥🟥	8	(142)
Catt, 2005	🟩	🟩🟩🟩🟩🟩 🟩🟩🟩🟩🟩	🟩🟩🟩 🟩🟩	🟩🟩	🟩🟩	20	(171)
Dussen, 2011	🟩	🟩🟩🟩🟩🟩 🟩🟩🟥🟥🟥	🟩🟩🟩 🟩🟥	🟩🟩	🟩🟩	16	(144)

First author, year	Introduction	Methods	Results	Discussion	Other	Total score (out of 20)	Reference
June, 2012	★	★★★★★ ★☆☆☆☆	★★★ ★☆	★★	★★	15	(147)
Manu, 2012	★	★★★★★ ★☆☆☆☆	★★★ ☆☆	★★	★★	14	(149)
Igarashi, 2014	★	★★★★★ ★★★☆☆	★★★ ☆☆	★★	★★	16	(158)
Carrion, 2015	★	★★★★★ ★★★☆☆	★★★ ☆☆	★★	★★	16	(141)
Cagle, 2016	★	★★★★★ ★☆☆☆☆	★★★ ☆☆	★★	★★	15	(140)

First author, year	Introduction	Methods	Results	Discussion	Other	Total score (out of 20)	Reference
Benini, 2011	★	★★★★★ ★★☆☆☆	★★★ ☆☆	★★	★☆	14	(134)
McIlfatrick, 2013	★	★★★★★ ★★★★☆	★★★ ☆☆	★★	★★	17	(135)
O'Connor, 2019	★	★★★★★ ★★★☆☆	★★★ ☆☆	★★	★★	16	(136)
Chandra, 2016	★	★★★★★ ★☆☆☆☆	★★★ ☆☆	★☆	★★	13	(166)
Hsu, 2012	★	★★★★★ ★☆☆☆☆	★★★ ☆☆	★★	★☆	13	(160)

First author, year	Introduction	Methods	Results	Discussion	Other	Total score (out of 20)	Reference
Sanjo, 2008	★	★★★★★ ★★★☆☆	★★★ ★★	★★	☆☆	16	(159)
Pan, 2015	★	★★★★★ ★★☆☆☆	★★★ ☆☆	★★	★★	15	(151)
Schrader, 2009	★	★★★★★ ★★★☆☆	★★★ ★☆	★★	★★	17	(150)
Johnson, 2009	★	★★★★★ ★★★☆☆	★★★ ★☆	★★	★★	17	(146)
Colon, 2012	★	★★★★★ ★☆☆☆☆	★★★ ☆☆	★★	★★	14	(143)

First author, year	Introduction	Methods	Results	Discussion	Other	Total score (out of 20)	Reference
MacLeod, 2012	🟩	🟩🟩🟩🟩🟩 🟩🟩🟥🟥🟥	🟩🟩🟩 🟥🟥	🟩🟥	🟩🟩	14	(168)
Mahmudur Rahman, 2017	🟩	🟩🟩🟩🟩🟥 🟥🟥🟥🟥🟥	🟩🟩🟩 🟥🟥	🟩🟥	🟩🟥	10	(169)
Park, 2012	🟩	🟩🟩🟩🟩🟩 🟩🟩🟥🟥🟥	🟩🟩🟩 🟥🟥	🟩🟥	🟩🟩	14	(163)
Mohamadali, 2015	🟩	🟩🟩🟩🟥🟥 🟥🟥🟥🟥🟥	🟩🟥🟥 🟥🟥	🟩🟩	🟥🟥	7	(170)
Voseckova, 2016	🟩	🟩🟥🟥🟥🟥 🟥🟥🟥🟥🟥	🟩🟥🟥 🟥🟥	🟥🟥	🟥🟥	3	(137)

First author, year	Introduction	Methods	Results	Discussion	Other	Total score (out of 20)	Reference
Shalev, 2018	🟩	🟩🟩🟩🟩🟩 🟩🟥🟥🟥🟥	🟩🟩🟩 🟥🟥	🟩🟩	🟩🟩	14	(50)
Sung, 2019	🟩	🟩🟩🟩🟩🟩 🟩🟥🟥🟥🟥	🟩🟩🟩 🟩🟩	🟩🟩	🟩🟥	15	(162)
Huang Hsiang-Yun, 2019	🟩	🟩🟩🟩🟩🟩 🟩🟩🟥🟥🟥	🟩🟩🟩 🟥🟥	🟩🟩	🟩🟩	15	(161)
Van Dussen, 2018	🟩	🟩🟩🟩🟩🟩 🟩🟩🟥🟥🟥	🟩🟩🟩 🟥🟥	🟩🟩	🟩🟩	15	(154)
Collins, 2020	🟩	🟩🟩🟩🟩🟩 🟩🟩🟩🟥🟥	🟩🟩🟩 🟩🟥	🟩🟩	🟩🟩	17	(167)

First author, year	Introduction	Methods	Results	Discussion	Other	Total score (out of 20)	Reference
Selsky 2012	🟩	🟩🟩🟩🟩🟩 🟩🟥🟥🟥🟥	🟩🟩🟩 🟩🟥	🟩🟩	🟩🟩	15	(153)
Westerlund, 2018	🟩	🟩🟩🟩🟩🟩 🟩🟩🟩🟥🟥	🟩🟩🟩 🟩🟥	🟩🟩	🟩🟩	17	(138)
Kozlov, 2018	🟩	🟩🟥🟩🟩🟩 🟩🟥🟩🟥🟥	🟩🟩🟩 🟥🟥	🟩🟩	🟩🟩	16	(156)
Joseph, 2009	🟩	🟩🟩🟩🟩🟥 🟥🟥🟥🟥🟥	🟩🟩🟩 🟥🟥	🟥🟥	🟩🟥	9	(165)
Johnson, 2008	🟩	🟩🟩🟩🟩🟩 🟩🟩🟩🟩🟥	🟩🟩🟩 🟩🟥	🟩🟩	🟩🟩	18	(145)

First author, year	Introduction	Methods	Results	Discussion	Other	Total score (out of 20)	Reference
Huo, 2019	🟩	🟩🟩🟩🟩🟩 🟩🟩🟩🟥🟥	🟩🟩🟩 🟩🟥	🟩🟩	🟩🟥	16	(155)
Roulston, 2017	🟩	🟩🟩🟩🟩🟩 🟥🟥🟥🟥🟥	🟩🟩🟩 🟥🟥	🟥🟥	🟩🟥	10	(139)
Hirai, 2011	🟩	🟩🟩🟩🟩🟩 🟩🟩🟥🟥🟥	🟩🟩🟩 🟥🟥	🟩🟩	🟩🟩	15	(157)
Yim, 2018	🟩	🟩🟩🟩🟩🟥 🟥🟥🟥🟥🟥	🟩🟩🟩 🟥🟥	🟩🟥	🟩🟩	11	(164)

Key: AXIS tool questions: Introduction, one question; Methods ten questions; Results five questions; Discussion two questions and; Other two questions

🟩 Answer implying quality criteria met

🟥 Answer imply quality criteria not met

Appendix 5: Data extraction tables

Quantitative studies

First author, year, location	**Key research question(s)**	**Study design and setting**	**Participant details Size (N), Age (years), Sex (%), Ethnicity (%)**	**Relevant outcomes**	**Key findings**	**Ref**
Schrader 2009 USA	1. What are Sioux Falls residents' attitudes about dying and EOL care? 2. **What do people know about hospice?**	CSS Random sampling of households in Sioux Falls, South Dakota	N=1042 from 5000 randomly chosen households Mean age 49.75 range 18-96 F=56% M=44% White 96%	With regard to hospice services: Awareness Attitude Understanding of financing	Have you heard of hospice services? 50% of participants had heard a lot about hospice 47% had heard little and 3% and never heard of hospice. 65% of participants would want hospice care if they were dying, 2% would not and 32% didn't know. 25% of participants thought that medicare paid for hospice services, 7% did not and 68% weren't sure. Women more likely to be aware of hospice services p=0.015 (χ^2) Awareness of hospice services significantly different according to age p=0.001; education p=0.001, marital status p=0.001 and religiousity p=0.012 (χ^2 comparisons).	(152)
Karel 2003 USA	**What is the knowledge, attitudes and practices relating to EOL issues (including hospice) among adults in Hawaii**	CSS Part of larger before and after information dissemination project. Survey before participants given information leaflets.	N=388 Mean age NK Range 18 - 85+ F=79% M=21% Ethnicity Caucasian 19.5% Asian 54% Hawaiian/Pacific Islander 16%	With regard to hospice: Awareness	83% responded had awareness of hospice Comparisons: Age: <65y 217/243 (89%) were aware of hospice >65y 105/138 (76%) were aware of hospice age 45-64 had more awareness of hospice than any other age group p<0.001 - statistical test not reported Race no significant difference in knowledge of hospice	(148)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
		Convenience sampling through care giver support groups, volunteer organisations etc	Other 10% Missing 0.5%			
Claxton-Oldfield 2004 Canada 6	**What is the understanding of the term palliative care in Atlantic Canada?**	CSS Convenience sampling administered in grocery store, consecutive adult shoppers	Study 1 N=89 Mean age (SD)=49.3 (14.2) Range 20-83 F=67% M=33% Study 2 N=81 Mean age (SD)=29.5 (15.7) Range 18-82 F=74% M=26%	**Study 1** With regard to palliative care: Awareness If aware: Knowledge Attitude **Study 2** Following being given a definition of PC assessed: Awareness before being given definition If aware: Source of awareness – free text	**Study 1** 75.3% (67) aware of PC No significant difference in awareness of PC by age or gender. Of those aware: PC defined as: 48.4% care of terminally ill or dying 18.8% care of the sick 15.6% care in home Illnesses associated with PC: Cancer 64.5% Heart disease 12.9% Alzheimer's 11.3% HIV/AIDS 8.1% 5 did not answer Where do people receive PC: Hospital 68.3% Home 34.9% Specialised care home 12.7% Hospice 9.5% 4 did not answer Who provides PC: Nurses/extramural staff 56.7% The Victorian Order of Nurses 35% Family 20% Homecare providers/ homemakers 15% Doctors 11.7%	(142)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
					7 did not answer Would you use PC if family member terminally ill: 92.3% yes 2 did not answer **Study 2** 60.5% stated aware before reading definition	
Catt 2005 UK 7	What is the relationship between age and attitudes to and knowledge of: death cancer and **hospices and specialist palliative care services.**	CSS Random stratified sampling of people aged between 55 and 74 and 75 and over from ten London GP practices	N=256 Group 1 N=129 aged 55-74 Group 2 N=127 aged 75+ F=55% M=45%	With regard to hospice care: Knowledge Attitudes	Older people more familiar with type of care offered by hospices Attitudes to hospices similar in both age groups and unaffected by position in society, education, or fears of death **Aged 55-74** Believe a hospice is for care of the dying 82.9% Believe you do not have to be a Christian to receive hospice care 86% Believe hospice care is about pain and symptom control 88.4% Believe hospices care for all age groups 89.9% Believe hospices depend entirely on voluntary contributions 43.4% Believe hospice care is not only for people with cancer 82% **Aged 75+** Believe a hospice is for care of the dying 77.8% Believe you do not have to be a Christian to receive hospice care 84.8% Believe hospice care is about pain and symptom control 82.4% Believe hospices care for all age groups 91.2% Believe hospices depend entirely on voluntary contributions 52.8% Believe hospice care is not only for people with cancer 72%	(171)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
Dussen 2011 USA 16	**What is the perception of and attitudes towards hospice care in community dwelling adults in Ohio?**	CSS Cluster sampling People volunteered from or referred by 8 churches from 68 churches randomly selected from 450	N=168 Mean age NK Age range 43y – 80+y F=44% M=56% Ethnicity White 81.3% African American or Black 18.1% Hispanic 0.4%	Regarding hospice: Awareness Attitudes Knowledge of funding Source of information	Familiarity with hospice 86% Older respondents more familiar with hospice than younger (Mann-Whitney U = 623, p = 0.001) No variation by race for awareness about hospice services Attitudes 95% agreed hospice care important 32.1% agreed hospice care is seen as ‘‘giving up’’ 38.6% agreed hospice care is ‘‘only about death’’ 31.3% agreed hospice care is expensive Older respondents had more negative impressions of hospice than younger eg: Older respondents were more likely to see hospice as "giving up" (Spearman's rho = -0.17, p = 0.033) Younger respondents more likely to consider hospice a valuable service than older (Spearman's rho = -0.18, p=0.043) Older respondents more likely to view hospice as "only about death" than younger (Spearman's rho = -0.18, p=0.04) Black respondents more likely to view hospice as "giving up" (p=0.013 – test not indicated) Unaware insurance covers hospice care. Those who had received information from hospice were more likely to know that hospice services are covered by insurance (χ^2=5.079, df=1, P=0.024) Those with family members who had experience with hospice were less likely to perceive hospice as expensive	(144)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
June 2012 USA 17	What are the attitudes and beliefs among sexually diverse middle-aged and older adult women regarding: **hospice**	CSS Convenience quota sampling from 1) friends, family, 2) University Gerontology Participant Registry 3) University staff members and, 4) Pride centres newsletters and events.	N=145 Four groups: 1) Lesbian older women n=30; mean age 66 SD 5.5 Range 60-81 2) Heterosexual older women n=31; mean age 64.8 SD 4.6 range 60-77 3) Lesbian middle-aged women n=35; mean age 50 SD 7.3 range 35-59) 4) Heterosexual middle-aged women (n=49; mean age 50.5 SD 5.5 range 35-59) F=100% Ethnicity: Lesbian older = 90% white Heterosexual older = 87% white Lesbian middle-aged = 97% white Heterosexual middle-aged = 88% white	With regards to hospice care: Attitudes Beliefs	Both orientations held positive views of hospice care but Lesbian women more so. Older adult women held significantly more positive beliefs about hospice care than middle-aged women	(147)
Manu 2012 USA 18	To assess older adults' **familiarity with the terms ‘‘hospice’’ and ‘‘palliative care’’** **attitudes toward palliative principles**	CSS Convenience sampling from outpatient waiting room.	N=211 Mean age 78 SD 9 F=63% M=37% Ethnicity: Non-Hispanic white 72% African American 10%	With regard to palliative care: awareness attitudes	Familiar with term hospice 168 (93%) Familiar with term palliative care 53 (30%) Attitudes about hospice (% strongly agree or agree) Receiving hospice care means giving up on living 18% Hospice can make patients feel better 82% Hospice can make patients live longer 41%	(149)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
	whether experience with caring for a dying person was associated with more familiarity of the terms hospice and palliative care and attitudes consistent with current hospice and palliative principles.		Other 18% Household income: <$20000 22% >$20000 78% Currently employed 14% Education: High school or less 43% College/grad school 57%		Hospice is offered when nothing more can be done 59% Respondents who reported being familiar with the term palliative care were significantly more likely to disagree/strongly disagree that ‘‘morphine is offered when nothing more can be done’’ (P=0.00045) and ‘‘receiving hospice care means patients are giving up on living’’ (P=0.008). They strongly agreed/agreed with ‘‘hospice can make patients live longer’’ (P=0.051) but also that ‘‘hospice is offered when nothing more can be done’’ (P=0.031). In contrast, familiarity with the term hospice was not associated with significantly more correct attitudes. No associations between prior experience with caring for a dying family member (whether with or without hospice support) and familiarity with the terms hospice and palliative care or with attitudes more in favour of palliative care concepts	
Igarashi 2014 Japan 19	What are the general public’s perceptions of opioids and **palliative care** units (PCUs) and explore factors related to such perceptions.	CSS Part of larger OPTIM trial. Random stratified sampling of 8000 residents in 4 regions of Japan	N=2990 (from 3984 returned questionnaires) Mean age 60 (SD 11) F=55% M=45%	Regards PCUs: Perception Attitudes	Most of the general population had positive perceptions of PCUs Knowledge of PCUs was significantly associated with both higher positive and lower negative perceptions of these care units 699 (24%) had sound knowledge of PCUs Following show % agreement PCUs relieve pain 76% (unsure 20%) PCUs maintain dignity 63% (unsure 31%) PCUs support the family 63% (unsure 32%)	(158)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
					PCUs provide autonomy 46% (unsure 43%) PCUs provide no medical treatment 21% (unsure 45%) PCUs are difficult to be admitted to 61% (unsure 32%) PCUs are a place to wait to die 43% (unsure 38%) PCUs are only available for hospital-treated patients 29% (30%) PCUs cost is expensive 64% (unsure 27%) A higher score for positive perceptions of PCUs was associated with a female gender (P < .001), younger age (P < .001), sound knowledge of PCUs (P < .001) A higher score for negative perceptions of PCUs was associated with younger age (P < .001), poor knowledge of PCUs (P < .001). Having cancer related experiences not	
Hirai 2011 Japan 132	**1) With regard to palliative care, what is the public (healthy versus those with cancer experience): awareness knowledge of availability readiness for palliative care services** 2) What is the perceived reliability of information resources?	CSS Part of larger OPTIM trial. Random stratified sampling of 8000 residents in 4 regions of Japan	N=3190 (from 3984 returned questionnaires Mean age 60 (SD 11) F=55% M=45%	Regarding palliative care: Awareness Knowledge of availability	No awareness of palliative care 63.1% Using palliative care services 0.5% Those who knew about palliative care yet did not know about service availability 18.6% Women and people with cancer-related experiences were more likely to be aware of palliative care (p<0.001). Awareness of palliative care was significantly associated with knowing: Palliative care relieves pain and distress Palliative care is for patients close to death, Cancer-related experiences were not.	(157)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
Carrion 2015 USA 20	**1) What is the knowledge and attitudes regarding hospice** in Hispanics and non-Hispanics 2) What are their beliefs about pain and pain medication	CSS Random stratified sampling of participants in the contiguous USA, oversampling Hispanics and African Americans	N= 123, 46% response rate Hispanic N=16 Mean age 45.3 (SD 19.7) F= 75% M=25% Income 0-$39999 57.1% $40000-$79999 35.7% $80000+ 7.1% Employment Unemployed 37.6% Non-Hispanic N=107 Mean age 48.1 (SD 17.1) F= 61.7% M= 38.3% Income 0-$39999 43.9% $40000-$79999 20.4% $80000+ 35.7% Employment Unemployed 18.7%	Regarding hospice and hospice care: Awareness Knowledge Attitudes	Heard of the term hospice Hispanics 9 (56%) Non-Hispanics 97 (91%) p<0.001 Hispanics less familiar with hospice care than non-Hispanics (p=0.05) Knowledge of hospice Differences in scores on hospice knowledge test (HKT) (only given to those who had heard of hospice) did not differ significantly between Hispanics and non-hispanics Four questions on HKT yielded significant differences Hispanics were: more likely to believe hospice was only for individuals over 65 years 93% vs 44% p=0.001 less aware that hospice care helps care givers and family members as well as dying individual 97% vs 67% p=0.008 less aware that while receiving hospice care individuals cannot received curative treatment 0% vs 41% p=0.02 more likely to believe hospice services end when patient dies 89% vs 55% p=0.07 No significant difference in attitudes towards hospice care	(141)
Cagle 2016 USA 21	**What is the hospice knowledge among geographically diverse adults and describe linkages between knowledge, attitudes and beliefs about**	CSS Random stratified sampling of participants in the contiguous USA, oversampling	N=123 46% response rate Mean age 47.7 (SD 17.4) F= 63.4% M= 36.6% Ethnicity	Regarding hospice: Awareness Knowledge Attitudes Experiences Preferences	**Awareness** Heard of hospice 106 (86%) Younger and Hispanic less familiar (p=0.016 and p=0.038) Of those that had heard of it:	(140)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
	hospice care and demographics?	Hispanics and African Americans	Hispanic 13% Non-Hispanic 87% Race White 61% Black 23.6% Other 15.4% Income Less than $19999 29.3% $20000-$59999 28.4% $60000-$99999 21.6% Over $100000 20.7% Unemployed 21.2%		95% reported favourable opinion and 90% reported if they were dying, they would want hospice services **Knowledge of hospice test** Knowledge of hospice n=106 78% questions answered correctly Subset of African American respondents who had heard of hospice had substantially lower than average levels of knowledge about it. Higher knowledge of hospice correlated with more positive attitudes as measured by HPS-8 (r=0.22, p=0.023) and with preference for hospice care (p=0.011) More positive attitudes also correlated with preference for hospice (p=0.049) Older people were less knowledgeable p=0.27 but have more favourable attitudes p=0.002 Accurate statements (% agreed with statement): Hospice services are typically paid for by health insurance. 67% Hospice care can be provided in a nursing home 69.8% People who live alone can receive hospice services. 78.3% A primary goal of hospice is to treat emotional needs of the dying individual and their family. 78.3%	

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
					Hospice provides medications, treatments, medical equipment and supplies that are related to a patient's primary illness. 81.1% Hospice provides grief support to families. 87.7% Hospice staff are available by phone any time, day, or night. 91.5% Hospice care focuses on managing an individual's pain and other symptoms. 91.5% Hospice care helps caregivers and family members as well as the dying individual. 94.3% The hospice care team includes physicians, nurses, social workers, and chaplains. 97.2% False statements (% incorrectly agreed with statement): Can receive curative treatments at same time 62.3% Hospice services end when patient dies 57.5% Hospice must stop services if an individual lives longer than six months 28.3% Individuals receiving hospice care cannot be taken to the hospital for treatment. 18.9% Hospice care is only appropriate for people who have a few days to live. 15.1% A person with Alzheimer's disease cannot have hospice services. 15.1% While in hospice, spouses, partners, or children of the dying individual are not allowed to directly participate in his or her care. 13.2% Only individuals over age 65 are eligible for hospice services. 11.3% Hospice care cannot be provided at home. 9.4% Hospice care is available only to individuals with cancer 6.6% Hospice care helps the dying individual by speeding up the dying process. 5.7%	

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
Van Dussen 2018 USA 88	**What is the hospice attitude as measured by the HPS-8 in community dwelling adults?** **Do these attitudes correlate with other measured views of hospice?**	CSS Random stratified sampling of participants in the contiguous USA, oversampling Hispanics and African Americans	N=123 46% response rate Mean age 47.7 (SD 17.4) F= 63.4% M= 36.6% Ethnicity Hispanic 13% Non-Hispanic 87% Race White 61% Black 23.6% Other 15.4% Income Less than $19999 29.3% $20000-$59999 28.4% $60000-$99999 21.6% Over $100000 20.7% Unemployed 21.2%	With regard to hospice: Attitude	Attitude as measured by HPS-8 mean score 36.2 (SD 4.5; possible range = 8-40) with a skew of −1.8 and kurtosis of 3.3, indicating a moderate skew toward favourable attitudes. No significant differences by age or gender White respondents reported more favourable attitudes (Mean 37.2 (SD 3.5)) than non-White respondents (Mean 34.6 (SD 5.3)); p = .003.	(154)
Chandra 2016 India 33	What is the impact of a health awareness campaign in improving the awareness about palliative care	CSS Convenience sampling from randomly selected houses in selected village	N=145 Mean age not known, but all >20 y F= 56.6% M= 43.4%	With regard to palliative care: Awareness	Awareness 0%	(166)
Hsu 2012 Taiwan 34	**What is the knowledge and attitude toward hospice palliative care (HPC) among the elderly**	CSS States purposive sampling (but not clear) of over 65s	N=1332 Mean age 74.4 (SD 5.6) F= 55.8% M= 44.2%	With regard to palliative care: Awareness Understanding Attitude	Aware of HPC No 42.6% Yes 56.5% Understanding role of HPC	(160)

First author, year, location	**Key research question(s)**	**Study design and setting**	**Participant details Size (N), Age (years), Sex (%), Ethnicity (%)**	**Relevant outcomes**	**Key findings**	**Ref**
	living in metropolitan Taiwan	from a health centre in Taipei City	Education below high school 53%		Yes 35.5% No 62.8% Did not answer 1.7% HPC means (20.2% did not answer): Do not resuscitate 27.9% The physician will provide the most suitable treatment to alleviate discomfort 58.5% Patient about to die 7.1% The physician does not want to perform further treatment 3% HPC is a service specifically for cancer patients (2.4% did not answer) Yes 42.6% No 13% Don't know 42% **Factors affecting better knowledge score (independent sample t-test):** Education: high school or above p<0.001	
Sanjo 2008 Japan 40	**What is the general population's awareness and perceptions of specialised palliative care service in Japan** compared with bereaved families who received specialised inpatient palliative care?	CSS Random stratified sampling of general population	N=2548 Mean age NK (all >18y) F= 53% M= 47%	With regard to specialist palliative care: Awareness Perceptions	Awareness of Specialist palliative care % No knowledge 24% Some knowledge 38% Moderate knowledge 34% Considerable knowledge 4.3% Female respondents more likely to be knowledgeable (standardised partial regression coefficient B=0.18, p<0.001) Nil else significantly associated Perceptions of palliative care (% of respondents that agree/somewhat agree) Supports patients in living peacefully 72% Supports patients in living with dignity 70%	(159)

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					Provides care for families 67% Provides compassionate care 67% Alleviates pain 68% Expensive 61% Provides no medical treatments 32% Isolates patients from the community 28.5% A place where people only wait to die 31% Shortens the patient's life 8.1%	
Pan 2015 USA 42	**What is the self-reported familiarity and attitudes toward (1) hospice (2) interest in using hospice** and (3) receiving further information about hospice among Asian and Hispanic groups in Queens, NY	CSS Convenience sampling of Asian (Chinese and Korean) and Hispanic residents in Queens, New York	N=604 Chinese N=99 Mean age 55.2 F= 80% M= 20% Korean N=349 Mean age 58.5 F= 61% M= 39% Hispanic N= 156 Mean age 45.5 F= 77% M= 23%	With regards to hospice: Awareness	Chinese vs. Korean - Chinese vs. Spanish - Korean vs. Spanish (Controlling for Age and Gender) Ever heard of hospice? Chinese 45% Korean 56% Hispanic 16% All ethnicity comparisons (Fisher's exact test) p<0.01	(151)
Schrader 2009 USA 46	What is the understanding of attitudes, advance planning, knowledge, and preferences about end-of-life (EOL) care among community-dwelling South Dakotans.	CSS Random stratified sampling of 10204 South Dakotan households with disproportionate sampling of American Indian households	N=2533 Mean age NK Median age 54 (range 18-95) F= 54% M= 46% Caucasian 96% American Indian 3% Other 1% Employment Nonworkers/retired 33%	With regard to hospice: Knowledge Source of knowledge	If dying, want hospice support 67% Amount known about hospice: A lot 50% A little 47% Nothing 3% Know Medicare pays for hospice 24% Significant and relevant comparisons regarding knowledge about hospice (bivariate analysis): % that know nothing or a little about hospice Gender: p=0.001	(150)

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			Education <high school 4% Bachelor's of higher 35%		M= 60% F= 43% Age: p=0.001 18-39y 60% 40-59y 50% 60-95 47%	
Johnson 2009 USA 47	**What are the racial differences in self-reported exposure to hospice information and how does this exposure impact beliefs about hospice care?**	CSS Random stratified sampling of people 65 and over from two primary care practice lists stratified for race (African American or white)	N= 200 Mean age 72.8 African American N= 105 F= 60% M= 40% Education <high school 41% White N=95 F= 56.8% M= 43.2% Education <high school 10.5%	With regard to hospice care: Awareness Source of awareness Beliefs Attitudes	**Awareness** Never heard of hospice (χ^2 p=0.0004) African Americans 19.1% Whites 4 4.2%) Heard a little about hospice AA 35 (33.3%) White 23 (24.2%) Heard a lot about hospice African Americans 50 (47.6%) Whites 68 (71.6%) African Americans had a two times higher odds of reporting that they had never heard of hospice or only heard a little about hospice versus heard a lot about hospice compared with whites (odds ratio [OR]=2.24 [1.17, 4.27] (logistic regression)) **Relationship between ethnicity and awareness and beliefs (χ^2)** African Americans were less likely than whites to agree that they would want hospice care in the future (75.2% versus 89.5%, p=0.01) A smaller proportion of African Americans disagreed that: They would not be able to afford hospice (37.1% versus 53.7%, p=0.02) They would not need hospice in lieu of family care (46.7% versus 65.3%, p=0.01)	(146)

First author, year, location	**Key research question(s)**	**Study design and setting**	**Participant details Size (N), Age (years), Sex (%), Ethnicity (%)**	**Relevant outcomes**	**Key findings**	**Ref**
					Hospice care means you get no treatment (58.1% versus 86.3%, p<0.0001) Hospice care is not as good as treatment in the hospital (50.5% versus 79.0%, p<0.0001) Hospice causes people to die before their time (72.4% versus 89.5%, p=0.002). **Relationship between awareness and beliefs and attitudes (Spearman correlations)** Greater exposure to hospice information was associated with more favourable beliefs about hospice care as measured by the total score on the Hospice Belief and Attitude Scale (parameter estimate 1.34, standard error 0.44, p=0.002	
Johnson 2008 USA 118	Are differences between older African-American and white adults in the use of advance directives and **attitudes toward hospice care** explained by differences in cultural beliefs and values?	CSS Random stratified sampling of people 65 and over from two primary care practice lists stratified for race (African American or white)	N=205 African American N=110 Mean age 73.4 F= 60.9% M= 39.1% Income <$30000 75.5% Education <high school 41.8% White N=95 Mean age 72.5 F= 56.8% M= 43.2% Income <$30000 42.2% Education <high school 10.5%	With regard to hospice care: Attitudes Beliefs	Hospice beliefs and attitudes scale (range 8 to 40) higher scores more favourable attitudes toward hospice care AA mean 26.2 (SD 4) (range 16-38) White 29.4 (SD 4.3) (range 18-39) p<0.001 (Wilcoxon test) Linear regression to determine whether race was a predictor of hospice beliefs and attitudes scale, mean difference in scores between whites and AAs, adjusting for: demographics and self-reported health 2.06 (p=0.001) preference for end of life scale 1.68 (p=0.008) beliefs about dying and advance care planning scale 1.51 (p=0.02) Healthcare system distrust scale 1.37 (p=0.03) Spirituality scale 1.34 (p=0.03) All independent variables 0.38 (p=0.53)	(145)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
Colon 2012 USA 50	Does acculturation impact attitudes toward hospice?	CSS Convenience sampling of Latino's attending a cultural event	N=367 (after 43 excluded) Mean age 35.6 (SD 13.4) F= 61.2% M= 38.8% Median income $25340 Unemployed 8% Education <12 years 24.3% 12 years 39.8% 14 years 14.6% 17 year 8.2%	With regard to hospice: Awareness Knowledge Attitude	Never heard the word hospice 56% Hospice care is only provided in a nursing home 15.2% (47% said don't know) Knowledge index (score 0-4 high scores better) Comparison between ethnic groups by ANOVA - no significant differences between different Latino groups (range 1.07 – 1.59) Attitudes toward hospice Place and type of care if incurable illness Home with hospice services 53.7% Hospice but not in own home 11.1% No hospice service use 3.5% Would want hospital 24 7% Not sure/other 24.6% 17 item attitude to hospice scale (each item marked 1 to 5, 5 being seen more preferably) Median 61 Mean 61.81 (SD 9.81) Study does breakdown by ethnicity but no significant difference Selected attitude scores - Mean score (SD) Hospice care helps families. 4.25 (0.83) If I were dying I would prefer to be at home with a caregiver and hospice support. 4.12 (1.07) If I were dying I would prefer to be cared for only by family members. 2.77 (1.23) I would want hospice services whether or not I had family to care for me. 3.97 (0.99) I would prefer to die in the hospital. 3.60 (1.30) I would not choose hospice because that would mean that I am not fighting for my life. 3.36 (1.20)	(143)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
					Lack of money would prevent my use of hospice services. 2.95 (1.24) If I were dying, I would want hospice to help my family take care of me. 4.00 (1.05) No evidence that lower acculturation have more negative attitudes (Pearson product-moment correlation coefficient) No evidence being bicultural meant more positive attitudes (t-test (p=0.291)) More years of education had a significant correlation with a positive attitude (r=0,3, p=0.000) Increasing income correlated with positive attitudes toward hospice care (ANOVA F(4,341)= 3.664, p=0.002) Awareness of hospice associated with more preferable attitudes (t-test, p=0.001) Knowledge as measured by 4 point scale no significant relationship with attitudes	
MacLeod 2012 New Zealand 55	What are New Zealanders' views about palliative care and local hospice services.	CSS Convenience quota sampling via a sampling matrix of New Zealand population	N=1011 Mean age NK, range 18 to 70+ F= 52% M= 48% NZ European 85% Maori 6% Chinese 3% Indian 2% Other 9%	With regard to palliative care and hospice Source of knowledge Knowledge of services Perception	Hospice is a place where people go to die p<0.05 Agree 50% Hospice staff help coordinate care between different health and support services Agree 63% People >50 years old had greater confidence that hospice staff coordinate care (71% cf 62% p<0.05) More likely to strongly disagree with: staff only help patients manage their pain (19% cf 13% p<0.05)	(168)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
					Hospices only provide help for patients, not family members/carers (20% cf 16% p<0.05) Hospice service are only available in hospitals (27% cf 20% p<0.05) People <30 years old least likely to be accurate in responses to above statements Understanding of palliative care: Palliative care staff provide comfort to people with terminal illness 85% agree, 3% don't know Palliative care is an essential part of medical care services 82% agree, 16% don't know Palliative care staff help family members care for palliative care patients 74% agree, 16% don't know Palliative care is designed to help people die with dignity 73% agree, 21% don't know Palliative care staff care for patients' emotional needs 71% agree, 26% don't know Palliative care staff care for patients' psychological needs 59% agree, 37% don't know People >50 years old had more accurate perceptions of palliative care as evidenced by higher strongly agree scores for the following statements (all p<0.05): • Palliative care is an essential part of medical care services (51% cf. 41% average for all respondents) • Palliative care staff provide comfort to people with terminal illness (43% cf. 31% average for all respondents) • Palliative care is designed to help people die with dignity (50% cf. 34% average for all respondents) • Palliative care staff care for patients’ emotional needs (27% cf. 20% average for all respondents)	

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
					• Palliative care staff care for patients' psychological needs (17% cf. 11% average for all respondents) Opinions about PC People >50 years old were more likely to know: • Palliative care staff care for patients' social needs (15% cf. 10% average for all respondents). and were more likely to disagree or strongly disagree with three inaccurate statements: • Palliative care staff care for patients' physical needs only (74% cf. 64% average for all respondents). • Palliative care staff help people die when they want to (e.g. physician assisted suicide – 66% cf. 59% average for all respondents). • Palliative care services are for cancer patients only (76% cf. 68% average for all respondents). Females were revealed as more informed about hospice: • Females were more likely to strongly disagree that hospices only provide help for patients, not family members/carers and that hospice services are only available in hospitals (21% and 23% respectively cf. 10% and 17% for males). • Females were also more likely to strongly agree that hospice staff help coordinate care between different health and support services (12% cf. 6% for males). There was also a clear gender difference in perceptions of palliative care with females more likely than males to agree or disagree with all statements depending on their accuracy.	

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Mahmudur Rahman 2017 Bangladesh 63	What are the fundamental perceptions about palliative care among young generations living in Dhaka city, Bangladesh	CSS Random sampling of adult students from Dhaka City colleges, Universities and recent graduates	N=3152 Mean age NK, range 20-28 F= 45% M=55% Education: College students 15.3% University students 77.1% Graduates 7.6%	With regard to palliative care: Awareness Source of awareness	Knew of the concept of palliative care 40.3%* Unfamiliar 59.7% *only 46% of these had clear concept Source of knowledge Internet 62% Books 14% Health professionals 8% Mass media 12% Other 4% Palliative care is only for cancer patients 78%	(169)
Park 2012 South Korea 72	What are the attitudes as related to hospice care in Korea? What is the relationship between individual characteristics and choice intention regarding hospice care?	CSS Convenience sampling of Seoul and Gyeonggi adult (>21y) residents	N=248 Mean age 39 (SD 12.5) F= 60% M= 40% Not in employment 18.5% Education: Below middle school 4% High school 37% Above college 59%	With regard to hospice care: Knowledge Attitudes	Intention to use hospice services Women 55%, men 40% (p=0.028) Those intending to use hospice had a better understanding of what hospice is (p=0.000) Choice intender group had a higher attitude to hospice care score than the non intender group 7.93 cf. 7.46 p=0.000 Choice intender group had higher hospice beliefs and outcome evaluation scores than non intenders p<0.000	(163)
Mohamadali 2015 Malaysia 75	What is the awareness and perception of palliative care among students in Malaysia?	CSS Random sampling from 30000 adult doctorate students	N=62 Mean age NK (range 18 to >60) F= 79% M= 21%	With regard to palliative care: Awareness Source of awareness Knowledge of services Perception	Self-reported knowledge of palliative care: No knowledge 51.6% Some or enough knowledge 30.6% Very knowledgeable of PC 17.7% Knowledge of services provided (n=51) (home care, day care, bereavement support and training and education services).	(170)

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					65% of participants did not know any details of services provided Relevant questions about perception (% strongly agree or agree): The purpose of palliative care is to give moral and emotional supports to the patients suffering with non-curable illness. 79% PC is only available for those who can pay the services offered by the centre 30.7% Those who receive PC generally have a better quality of life. 58% Services offered by Palliative care centre/hospice are free of charge. 22.6%	
Sung 2019 Taiwan 84	What are the effects of an advance care planning (ACP) program on **knowledge and attitudes concerning palliative care**, and decisions regarding DNR orders in the older residents in a long-term care institution?	CSS before and after intervention (only before data extracted) Convenience sampling from long-term care institution in Taiwan	N=57 Mean age 79.6 F= 24.6% M= 75.4% Widowed 35.1% Education: None 40.4% Elementary 38.6% Junior High 10.5% Senior school 8.8% Postgraduate 1.7%	With regards to palliative care: Awareness Knowledge Attitude	Self-rated understanding of palliative care Not at all 93% Partial 5.3% Full 1.7% Knowledge of PC (mean out of 21) - experimental 4.28 (SD 0.54); control 4.32 (SD 0.5) Attitude to benefits of PC (mean out of 60) - experimental 39.58 (6.15); control 39.18 (6.15)	(162)
Huang 2019 Taiwan 86	**What is the relationship between health literacy and hospice knowledge, attitude** and decision making in community-	CSS Convenience quota sampling by population density of over 65	N=990 Mean age 71.53 (SD 7.22) F= 49.8% M= 50.2%	With regards hospice care: Knowledge Attitude Choosing Hospice	Total general health literacy (GHL) score 37.10 (SD 10.17) Knowledge of hospice care 26.77 (SD 4.13) (out of 40, higher more knowledgeable)	(161)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
	dwelling elderly participants?	population in three Taiwanese cities	Income: None 29.8% =<US$8000 24.6% US$8001-US$16000 32.7% >US$16000 12.8% Employment White collar 31.9% Blue collar 11.4% Agriculture 13.1% Other 43.5% Education: None 27.2% Elementary school 21.1% Junior high school 10.4% Senior high school 21% College/University 15.8% Graduate or above 4.5%	Correlations with health literacy (HL)	Attitude towards hospice care 19.88 (SD 3.27) (out of 25, higher more positive attitude) 60.7% had sufficient or excellent knowledge of hospice care 77.3% had weakly positive or positive attitude towards hospice care Correlations (all partial leasts square) General HL positively and significantly predicted knowledge of hospice care (β = 0.73, p < 0.001) attitude towards hospice care (β = 0.06, p = 0.038) Knowledge of hospice care and attitude towards hospice care positively and significantly predicted the likelihood of participants choosing hospice care (β = 0.77, p < 0.001; and β = 0.70, p < 0.001 respectively). Knowledge of hospice care was associated with attitude towards hospice care and choosing hospice care regardless of education level and income.	
Collins 2020 Australia 106	**What are the community understandings of and attitudes to palliative care and what characteristics are associated with favourable attitudes?**	CSS Convenience sampling of Australian adults (over 18)	N=421 Mean age 51 (SD 15.1) F= 75%, M= 24%, non-binary 1% Employment: Full time 41% Student 40% Retired8% Part time/casual 7%	With regard to palliative care: Exposure Awareness Source of awareness Knowledge Attitudes	**Awareness of PC** Knew what PC was and could explain it to others 30% Knew 'a little' 29% Had heard the words but did not really know what it was 27% Had never even heard of it 10% **Understanding PC (10 part questionnaire)** 12% achieved 10/10 correct Median was 7 (IQR 5-9) - suggesting over 50% had at least three misperceptions	(167)

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			Home or caring duties 2% Volunteer 2% Education: Postgraduate 27% Undergraduate 30% TAFE or apprenticeship 11% High school certificate/year 12 27% Year 10 2% Unknown 3%		Example statements with percentage of participants agreeing with each statement (red false statements, green true): People must be in the hospital to receive palliative care 20% Palliative care is a type of care provided to people only in the last month of their life 25% Palliative care is a type of nursing care, provided exclusively by nurses 33% Palliative care focuses on improving a person's quality of life 77% Palliative care provides expert pain management for people with serious illness 69% Palliative care can help manage a person's symptoms, such as nausea or breathlessness 63% Palliative care provides support for a person's family 63% Palliative care can be provided alongside other curative medical treatments 59% **Attitudes** (0-10 scale assessing likelihood would choose palliative care, higher score more positive) Mean score 7.9 +/- 2.1 Multiple regression: Four of the predictors remained significant predicting a more favourable attitude to palliative care: older age (β = 0.01) previously undertaking a caregiving role (β = 0.58) knowing someone who had received palliative care (β = 0.57) more accurate knowledge of palliative care (β = 0.22)	

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Selsky 2012 USA 111	**What are the factors associated with Latino knowledge** of and intention to use **hospice for cancer care?**	CSS Convenience sampling of recently immigrated (<10y) Latinos (>21y) from a safety net health clinic	N=331 Mean age 43 (SD 14) F= 53% M= 47% Education =< high school 81% > high school 19%	With regard to hospice care: Awareness Knowledge Intent to use	**Hospice awareness** Had heard of hospice care 29% **Mean hospice knowledge score** 3.1 (+/- 2.5) (out of 7) **Associations with more hospice knowledge:** Higher education Higher degrees of Latino cultural values Social acculturation was associated (but language acculturation was not) **Intent to use hospice** (hypothetical situation provided): Should use hospice 35% Should continue treatment 38% Leave the country 12% Associations with greater knowledge (adjusted odds (95% CI)): Being female 1.84 (1.02-3.34) Being a high school graduate 2.72 (1.29-5.74) Familism (Latino value) 1.03 (1.01-1.04) Being a member of community social organisations 2.99 (1.72-5.22) Associations with intention to use the hospice Being high school graduate 2.55 (1.32-4.93) Social acculturation was associated with hospice intent 1.19 (1.06-1.34) Secrecy about death was inversely associated 0.81 (0.67-0.99)	(153)
Kozlov 2018 USA	**What do laypersons know about palliative care as assessed by the**	CSS	N=301 Mean age NK, range 18-98	With regard to palliative care: Knowledge	Scored out of 13, higher meaning better knowledge, mean PaCKS score 5.25 (SD +/- 4.77, range 0-13) (median 5, mode 0)	(156)

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113	**Palliative Care Knowledge Scale (PaCKS)?**	Convenience sampling of community dwelling adults invited via Amazon's Mechanical Turk website	F= 51.8% M= 48.2% Ethnicity Asian 4.7% Black 9.3% Hispanic/Latino 3.3% White 80.1% Multiracial 2.6% Widowed 3.7% Income: $0-$19 999 19.6% $20 000-$39 999 32.6% $40 000-$59 999 21.9% $60 000-$79 999 12.6% $80 000-$99 999 4.3% $100 000+ 9.0% Education: Some high school 0.5% High school graduate 14% Some college 28% Associates degree 13.7% Bachelor's degree 34.3% Graduate's degree 9.3% Missing 0.2%		Percentage of people agreeing with statements (green true, red false): Palliative care is a team-based approach to care. 42% A goal of palliative care is to help people better understand their treatment options. 34% A goal of palliative care is to improve a person's ability to participate in daily activities. 39% Palliative care helps the whole family cope with a serious illness. 46% A goal of palliative care is to address any psychological issues brought up by serious illness. 38% Stress from serious illness can be addressed by palliative care. 44% Palliative care can help people manage the side effects of their medical treatments. 46% When people receive palliative care, they must give up their other doctors. 7% (don't know 49%) Palliative care is exclusively for people who are in the last 6 months of life. 18% (don't know 57%) Palliative care is specifically for people with cancer. 5% (don't know 48%) People must be in the hospital to receive palliative care. 5% (don't know 49%) Palliative care is designed specifically for older adults. 9% (don't know 50%) Palliative care encourages people to stop treatments aimed at curing their illness. 16% (don't know 50%) Significantly better PaCKS scores were associated with: Being female (t(298)= 3.37, P<.001) (t Test)	

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					Higher education (r=0.18, P=0.002) (Pearson correlations) Being older ($F_{5,\,295}$ = 7.15, P < .01) (ANOVA) Having heard of palliative care (t(297)=15.91, P<.001) (t Test) Knowing someone who used palliative care scored (t(116)=3.03, P=0.003.) (t Test)	
Joseph 2009 India 117	What is the knowledge and attitude toward palliative care and it's contributing factors among people residing in urban and rural areas?	CSS Random stratified sampling of most senior member of randomly selected households in rural and urban Kerala	N=165 rural and 185 urban No other demographics	With regard to palliative care: Awareness Source of awareness Knowledge Attitudes	Awareness: Heard of palliative care 13.4% Living in Urban areas more likely to have heard of palliative care (20.5% vs 5.4% p<0.0001 (χ^2)) Knowledge of diseases requiring palliative care Cancer 70.2% AIDS 48.9% Cardiovascular ailments 29.8% Respiratory ailments 31.9% Perceived benefits of PC (no significant difference) Prolongs the period of survival 8.5% Improves the quality of life 85.1% Both 6.4%	(165)
Huo 2019 USA 119	What is the knowledge penetration of palliative care in a nationally representative sample of U.S. adults?	CSS Random stratified sampling of American adults who completed the HINTS 5 cycle 2 survey who answered question about knowledge of palliative care	N=3194 Mean age NK, range 18 to 65+ F= 51.3% M= 48.7% Ethnicity Non-Hispanic white 60.8% Non-Hispanic black 10% Hispanic 14.8% Other 14.4% Income	With regard to palliative care: Knowledge Perception Source of knowledge	No knowledge of PC 65.7% Inadequate knowledge 20.9% Adequate knowledge 13.4% Associations with better knowledge (χ^2 p<0.001 unless stated otherwise): Being older p=0.001 Being female Being non-Hispanic (84.5% of Hispanic respondents had no knowledge of palliative care) college education or higher being married high household income being employed p=0.004	(155)

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			<$20,000 15.8% $20,000 - <$35,000 10.7% $35,000 - <$50,000 12.2% $50,000 - <$75,000 16.8% $75,000 or more 36.3% Unknown 8.2% Employment: Employed 57.7% Not 42.3% Education: Less than high school 8.4% High school graduate 21.6% Some college 40.6% College or higher 29.4%		having health insurance having a personal or family history of any cancer (p=0.026 and 0.016 respectively) Logistic regression: Higher odds of having knowledge of palliative care were observed in: Respondents who were middle-aged or elder compared with the younger group: 50-64 years: odds ratio [OR], 1.58; 95% CIs, 1.15-2.19, P=0.006 65 years or older: OR, 1.70, 95% CI, 1.30-2.22, P < 0.001) Being female OR 2.19 95% CI, 1.67-2.88, P < 0.001) Having education higher than high school compared with some college: OR, 4.40, 95% CI, 1.63-11.87, P=0.004 college or higher: OR, 8.88, 95% CI, 3.42-2308, P < 0.001 Being married compared with being single OR, 1.54, 95% CI, 1.03-2.30, P=0.036 Lower odds of having knowledge of palliative care were observed in Hispanics (OR, 0.53; 95% CI, 0.30-0.95, P=0.033) 86.8% strongly or somewhat agreed that a goal of PC was to help friends and family cope with a patient's illness 89.7% strongly or somewhat agreed that a goal of PC is to offer social and emotional support 92.1% strongly or somewhat agreed that a goal of PC is to manage pain and other physical symptoms 55.1% strongly or somewhat agreed that a goal of PC is to give patients more time at the end of life	

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					14.1% strongly or somewhat agreed that accepting palliative care means giving up 81.3% strongly or somewhat agreed that it is a doctor's obligation to inform all patients with cancer about the option of palliative care 13.3% strongly or somewhat agreed that if you accept palliative care, you must stop other treatments 30.9% strongly or somewhat agreed that palliative care is the same as hospice care 41.5% strongly or somewhat agreed that when I think of palliative care, I automatically think of death	
Yim 2018 South Korea 133	What is the public perceptions and demands for PC in the Republic of Korea?	CSS Quota sampling according to sex, age and region from larger survey in Republic of Korea	N= 1500 Mean age NK range 20 to >60 F= 49.2% M= 50.8% Income <3,000 36.1% 3,000 to ≤5,000 35.3% ≥5,000 28.7% Education ≤Middle school 5.8% High school 20.7% University 67.3% Graduate school 6.3%	With regard to palliative care: Awareness Source of information Perception Attitudes	Self-assessed knowledge on palliative care I know very well about it. 4.4% I know a little about it. 35.1% I have heard about it, but I don't know about it. 44% I have no idea about it. 16.5% Information Sources Television/newspaper 47.8% Internet 20.0% Family/friend 16.2% Health care provider 4.6% Religious organization 4.0% Promotional material 3.2% Book 3.0% School lesson 0.5% Movies/TV drama/documentary 0.4% I can't remember 0.2% Perception of PC Helping the patients live in fullness for the rest of their lives and get comfortable deaths 76.5%	(164)

First author, year, location	Key research question(s)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%)	Relevant outcomes	Key findings	Ref
					Prolonging the lives of terminally ill patients 6.1% Efforts to overcome human death 4.9% Passive euthanasia 3.5% All applicable 0.1% No idea 9% Attitudes Necessity for Palliative Care Absolutely necessary 25% Necessary 60.8% Unnecessary 4.0% Not necessary at all 1.2% No idea 9.0% Intentions to use the services of palliative care I will definitely use it 15.5% I will use it 58.4% I will not use it 5.7% I will never use it 1.7% I don’t know 18.7% knowledge about palliative care higher in people who lived in large cities, who graduated from the university or graduate school, who had monthly incomes of over 5 million, had any religions, who perceived their health as healthy, who had a private insurance, or who had family history. Significance unclear	

Abbreviations for quantitative studies: *, **, *** studies including the same participants; EOL end of life, EoLC end of life care, PC palliative care, PCU palliative care unit, HPC hospice palliative care, SPC specialist palliative care, CSS cross-sectional survey, OPTIM Outreach Palliative Care Trial of the Integrated Regional Model, HINTS Health Information National Trends Survey, N number, F female, M male, NK not known, HKT hospice knowledge test, HPS-8 hospice philosophy scale, HBAS hospice beliefs and attitudes scale, PaCKS palliative care knowledge scale, HL health literacy, OR odds ratio, ANOVA analysis of variance.

Mixed methods studies

First author, year, location	Research question(s) (relevant to research question in bold)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%), Widowed (%), SE status (%), Income (%), Employment status (%), Education (%)	Relevant outcomes	Results	Ref
Benini 2011 Italy 23	**What is the awareness, understanding and attitudes of Italians regarding palliative care?**	CSS Random stratified sampling of Italian population after demographic stratification Content analysis of one open question	N=1897 Mean age not known, range 18-74y F= 51.2% M= 48.8% Years in education: Basic (5-8y) 50.1% Intermediate (13y) 37.2% Academic (17-19y) 12.7%	With regard to palliative care: Awareness Understanding Attitudes	Awareness and perception of Palliative Care (PC) among the Italian population is inadequate; Heard of palliative care 60% Precise idea of palliative care 7% Adequate idea 16% Better awareness was associated with being (χ^2 $p<0.001$): a woman middle-aged (age 45-54y 23.2% reported awareness) someone with a higher income or a higher level of education Open question - the prevalent identification of PC was with "the treatment of pain and improved of quality of life".	(134)
McIlfatrick 2013 UK 24	**What are the public views towards palliative care and what are strategies to improve awareness?**	CSS Convenience sampling from patient and client council for Northern Ireland Content analysis of open questions (Miles Huberman framework)	N=600 Mean age not known Modal age group 60-69 F= 69% M= 31% Ethnicity White 92%	With regard to palliative care: Awareness Knowledge	Heard of palliative care 83% Regarding palliative care: No understanding of concept 19% Low understanding of concept 56% Quite a bit of knowledge 16% Very knowledgeable 4.3% Missing/NA 4.7% Higher levels of knowledge associated with: Women (Mann-Whitney 2 tailed $p=0.01$)	(135)

First author, year, location	Research question(s) (relevant to research question in bold)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%), Widowed (%), SE status (%), Income (%), Employment status (%), Education (%)	Relevant outcomes	Results	Ref
					Older age groups (Nonpar. Correlation, Spearman's rho p=0.005) Aims of palliative care Comfort 82% Pain relief 81.3% Dignity 76.3% Beliefs where palliative care could be offered: Hospice and home 76.8% Hospital 58.2% Associations with a higher knowledge: Having direct (n = 14) or vicarious (n = 405) experience in the past (χ2, p < 0.001)	
O'Connor 2019 Australia 25	**What are community attitudes toward palliative care?** **What are the determinants?**	CSS Convenience sampling of Australian adults Content analysis of responses to open questions about beliefs and emotions regarding PC	N=180 Mean age=41.3 (SDS 19.4) F= 65% M= 35% Employment: Full-time employed 29.4% Part-time employed 11.7% Casual employed 4.4% Student 27.2% Retired 17.2% Full time parent 2.8% Unemployed 1.1% Other 6.1% Education:	With regard palliative care: Attitude Beliefs Emotions Knowledge	768 beliefs reported (qualitative) Negative 21% Neutral 3.4% Positive 75.6% 641 emotions reported (qualitative) Negative 31.8% Neutral 4.5% Positive 62.1% Knowledge mean score 13.21 (SD 2.4) out of 16 Eg. 94.4% identified control of pain and other symptoms as an important part of palliative care 93.3% aware palliative care includes psychological, emotional and spiritual care 82.8% aware also provides family support	(136)

First author, year, location	Research question(s) (relevant to research question in bold)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%), Widowed (%), SE status (%), Income (%), Employment status (%), Education (%)	Relevant outcomes	Results	Ref
			Did not complete school to year 12 7.2% Completed school to year 12 22.8% Technical and Further Education or trade education 16.7% Undergraduate university degree 33.9% Postgraduate university degree 19.4%		56.1% aware PC does not prolong or shorten life 28.5% were unaware or unsure whether euthanasia was part of PC 29.5% thought or were unsure that specialist PC was only available in hospital Younger participants had less favourable attitudes toward palliative care (r=0.297, P < .001). People who were born outside of Australia had more favourable attitudes toward palliative care than Australian-born people (r=0.191, P < .05). Age and place of birth significantly accounted for 11.2% of the variability in attitude scores, R2=0.112, F(2, 177)=11.12, P < .001. Beliefs, emotions, and knowledge accounted for an additional 14.3% of variance in attitude, ΔR2=0.143, ΔF(3, 174)=11.095, P < .001.	
Voseckova 2016 Czechia 78	**What is the general public** and professional public **knowledge and attitudes of hospice care?**	CSS Unknown sampling method of participants from non-healthcare University setting Not clear how responses to open questions analysed	N=168 (general public =85) Demographics NK	With regard to hospice and palliative care: Awareness Attitudes	Awareness of hospice care 61% Awareness of palliative care 20% 47% agreed that hospice care is important for citizens of the Czech Republic 31% would use hospice care themselves 25% would use hospice care for relatives	(137)
Shalev 2018	What is the palliative and hospice care	CSS	N=800 (out of 2875 attempted calls)	With regard to hospice and palliative care:	Associations with Hospice Care (n=664) end-of-life care 399 (60%)	(50)

First author, year, location	**Research question(s) (relevant to research question in bold)**	**Study design and setting**	**Participant details Size (N), Age (years), Sex (%), Ethnicity (%), Widowed (%), SE status (%), Income (%), Employment status (%), Education (%)**	**Relevant outcomes**	**Results**	**Ref**
USA 80	awareness, misperceptions, and receptivity among community-dwelling adults?	Random sampling of (telephone numbers) adults in New York State Framework analysis of responses to open questions (based on WHO and the National Hospice and Palliative Care Organization definitions of PC)	Mean age 47 (SD 17) F= 49% M= 51% Ethnicity: White 60.4% Black 16.6% Hispanic 5.1% Asian 4.6% Mixed/Other 13.3% Widowed 5.4% Education: High school or lower 31.5% Technical school 2.5% College 47.1% Postgrad school 18.6%	Associations Perceptions Receptivity (attitude)	Comfort care 89 (13.4%) Care to both patients and families 35 (13.4%) Symptom management 22 (3.3%) Assists with goals of care 5 (<1%) Delivered by an interdisciplinary team 5 Bereavement services 5 affirms life and regards dying as a normal process 1 Associations with Palliative Care (n=216) Symptom management 57 (26.4%) A type of comfort care 47 (21.9%) Applicable at any course of an illness 19 (8.8%) Delivered by an interdisciplinary team 3 Bereavement services 2 Affirms life 2 Misperceptions: 248 (37%) expressed misperception of HC Of other 6 were HC is euthanasia 115 (53.2%) expressed misperception of PC PC is end of life care 85 (73.9%) Only for the elderly 8 (7%) Receptivity 503 (62.9%) responded likely or very likely to recommend PC to a loved one Lower receptivity to PC associated with male ($p<0.001$); conservative social ideology ($p=0.004$), lower household income ($p=0.043$) and lower palliative care awareness ($p=0.038$)	

First author, year, location	**Research question(s) (relevant to research question in bold)**	**Study design and setting**	**Participant details Size (N), Age (years), Sex (%), Ethnicity (%), Widowed (%), SE status (%), Income (%), Employment status (%), Education (%)**	**Relevant outcomes**	**Results**	**Ref**
Westerlund 2018 Sweden 112	What is the Swedish general public (age 18 to 66) awareness of palliative care and understandings about existing EoL care? What in the Swedish general public's view are the barriers to greater familiarity with and strategies to improve access to palliative care?	CSS Random stratified sampling of adults from a nationally representative panel in Sweden Thematic analysis of responses to open questions	N= 2020 Mean age 44.7 F= 50% M= 50% Education Primary school 8% Secondary school 51% University/tertiary education 35% Other qualification 3% Missing 3%	With regard to palliative care: Awareness Source of awareness Knowledge	Awareness Somewhat, fairly or very 59% None 41% Associations with better awareness ($p<0.05$): Being female (χ^2) Being older (Mann-Whitney U) Having a university level education You work in palliative care 5.3% Have personally received palliative care 0.6% Understanding of aims of palliative care: End-of-life care 61.7% Pain relief 60.7% Dignity 53.8% A peaceful death 50.4% Relieve physical symptoms 42.9% Family support 39.8% Quality of life 38.3% Emotional support 35.7% Well-being/comfort 34.3% Ease family burden 31.5% In-home support 24.8% Don't know 24.4% Reduce stress 23.0% Respite care 17.1% Counselling 15.5% Aged care 9.3% Improving health in general 6.3% Care for caregiver 6.2% Other 0.3%	(138)

First author, year, location	Research question(s) (relevant to research question in bold)	Study design and setting	Participant details Size (N), Age (years), Sex (%), Ethnicity (%), Widowed (%), SE status (%), Income (%), Employment status (%), Education (%)	Relevant outcomes	Results	Ref
Roulston 2017 Canada 124	Do public health awareness campaigns effectively improve the awareness and quality of palliative care?	CSS Adult participants identified through IPSOS survey. Sampling strategy unknown Qualitative methods unknown	N=1540 Mean age NK	With regards to palliative care: Awareness Understanding	Awareness of PC Palliative care very aware 16% somewhat aware 43% not very aware 28% not at all aware 14% Residential hospice care Very aware 10% Somewhat aware 39% Not very aware 36% Not at all aware 15%	(139)

Abbreviations for mixed method studies: PC palliative care, N number, F female, M male, NK not known, CSS cross sectional study

Qualitative studies

First author, year, country	Aim	Participant details Size (N), Age (years), Sex (%), Ethnicity	Methods and methodology	Results	Ref
Taxis 2006 USA	To explore: 1. the perceptions of African American adult community members regarding the philosophy, services, support and accessibility of hospice programs? 2. the cultural values associated with end-of-life care and how do these interface with the philosophical stance of hospice programs? 3. the interface of these values with the philosophical stance of hospice programs	N= 28 Age (mean) 64.5 (range 22-89) Sex: Female 100% Ethnicity: African American	Methodology: Naturalistic inquiry (Lincoln and Guba, 1985) (115) Data collection: Focus groups (semi-structured) Recruitment: Purposive sampling in churches	- a pervasive lack of information about hospice, producing numerous assumptions about hospice services - cultural and institutional barriers - assumptions that the care would be Inadequate - people would die lonely, painful deaths - hospice was inaccessible to African Americans because of cost. Themes of mistrust and misconceptions permeated the data.	(125)
Kwak 2007 USA	To examine social and cultural factors influencing views of Korean-American older adults and caregivers on advance care planning and hospice care	Older adults N= 20 Age (mean) 68 (SD 5.2) Sex: Male 80% Female 20% Ethnicity: Korean American N= 16 Age (mean) 40 (SD 6.7, range 18-59)	Methodology: Modified grounded theory (Strauss and Corbin, 1990) (172) Data collection: Focus group (semi-structured) Recruitment: Purposive sampling via churches and Korean neighbourhood newspapers	- diverse attitudes among Korean Americans toward end-of-life care - cultural and structural barriers to advance care planning and hospice use. - Older adults and caregivers expressed a lack of knowledge about (advance care planning and) hospice - Family make the final decision about the end of-life care, while acknowledging the challenge of initiating communications about treatment preferences. - Filial piety supports both curative and palliative treatment.	(126)

First author, year, country	Aim	Participant details Size (N), Age (years), Sex (%), Ethnicity	Methods and methodology	Results	Ref
		Ethnicity: American Korean		- The traditional norm of home death and importance of physician communication influenced preferences for hospice (and advance care planning respectively).	
Seymour 2007 UK	To seek views of older white, and Chinese adults living in the UK on end of life care	Chinese N= 92 Age self-defined as older, all >50 up to over 85 Sex: Male 28% Female 72% Ethnicity: British Chinese, Hong Kong Chinese, Mainland Chinese, Taiwan Chinese, Malaysian Chinese, Singapore Chinese, Vietnamese Chinese White N= 77 Age: self-defined as older, two participants <55y, rest up to >85y Male 32% Female 68% Ethnicity: White British, White Irish, Black Caribbean, Black British	Methodology: 1. Focus groups: thematic analysis 2. Framework analysis (based on themes from focus groups) Data collection: 1. Focus groups 2. Interviews with vignettes to prompt Recruitment: Purposive and snowballing sampling: White: interviews via local voluntary groups, focus groups GP surgeries asked to draw participants from list Chinese: interviews and focus groups via interaction with Chinese community	- White elders perceived hospices in idealised terms of the 'good death'. - Chinese elders perceived places of 'inauspicious' care in which opportunities for achieving an appropriate or good death were limited (preferring medicalised environment of hospital). Both groups these different preferences seemed to be related to shared concerns about the demands on the family that may flow from having to manage pain, suffering and the dying body within the domestic space. These concerns, which appeared to be based on largely practical considerations among the white elders, were expressed by Chinese elders as beliefs about 'contamination' of the domestic home (and, by implication, of the family) by the dying and dead body.	(127)
Daveson 2011 England and Germany	To 1. identify English and German understandings of EoLC within the context of an EoLC survey, and	England N= 15 Age (median) 61 (range 17-81)	Methodology: 1. Modified grounded theory 2. Synthesised through a lines-of-argument meta-ethnography (Noblit and Hare) (173)	English and German commonalities included: 1. the importance of social and relational dimensions (Social relationships are sustained during the time of care) 2. dynamic decision making comprising uncertainty	(133)

First author, year, country	**Aim**	**Participant details** **Size (N), Age (years), Sex (%), Ethnicity**	**Methods and methodology**	**Results**	**Ref**
	2. synthesise these understandings to aid interpretation of results from a cross-national survey (PRISMA EOLC survey)	Sex: Male 47% Female 53% Ethnicity: British 10, European 2, Turkish 1, Indian 1, Chinese 1 Germany N= 15 Age (median) 45 (range 19-81) Sex: Male 33% Female 67% Ethnicity: German 13, Turkish 2	Data collection: Cognitive interviewing (done to inform survey but analysed separately to inform aims) Recruitment: Purposive sampling within convenience sampling frame. Lay individuals known to researchers invited with further snowball sampling.	3. a valuing of life's quality and quantity 4. expectations for holistic care involving autonomy, choice, and timely information from trusted professionals. Differences involved 1. attention to practical matters, and thoughts about prolongation of life, preferred place of death, and the role of media and context. Synthesis resulted in four concepts: 1. expectations of a high standard of EoLC involving autonomy, choice, and context 2. evolving decision making amid anticipated change 3. thoughts about living and existing 4. worldviews shaping EoLC preferences in real and hypothetical scenarios	
Enguidanos 2013 USA	To explore older Chinese Americans' knowledge, understanding, and perceptions of hospice care.	N= 34 Age: <65 26% 66-74 47% >=75 24% Missing 3% Sex: Male 35% Female 65% Ethnicity: Chinese 91%, Other 6%, missing 3%	Methodology: Grounded theory analysis (174) Data collection: Focus groups Recruitment: Purposive sampling from Chinese social service agency.	1. A lack of knowledge 2. Death timing (waiting for death in a hospice so as to relieve burden) 3. Burden (financial, emotional, physical toward family or government) 4. Peaceful death (relief of suffering) 5. Quality of care (and its influence on perception of best care location).	(128)
McIfatrick 2014 UK	To explore public perceptions of palliative care and identify strategies to raise awareness.	N= 50 Age all >18y Sex: Male 26% Female 74%	Methodology: Thematic content analysis using Miles and Hubermans' framework. (175)	Most participants had a general knowledge of palliative care, largely influenced by their own personal experience. Palliative care was identified as:	(131)

First author, year, country	**Aim**	**Participant details** **Size (N), Age (years), Sex (%), Ethnicity**	**Methods and methodology**	**Results**	**Ref**
		Ethnicity: no details	Data collection: Interviews (semi-structured) Recruitment: Convenience sampling: Members of an independent membership scheme's database who had previously taken part in a quantitative phase of the study.	1. caring for people who were dying 2. maintaining comfort in the last days of life. Expectations of services included: 1. holistic support 2. symptom management 3. good communication 4. practical support to enable choice 5. carer support. Key aspects for promoting palliative care included: 1. the development of understanding 2. use of the term itself 3. targeted educational strategies.	
Pullis 2011 USA	To examine the perceptions of hospice care among African Americans	N= 41 Age (mean) 58y (range 21-85y) Sex: Male 24% Female 76% Ethnicity: African American	Methodology: Thematic analysis Data collection: Focus group (semi-structured) Recruitment: Purposeful sampling at three African American churches	The perception of hospice care was generally positive Being African American did not influence the care they would want at the end of life	(129)
Boucher 2018 USA	To understand study participants' knowledge of PC and acceptability of a new community-based PC model	N= 18 Age all >24y Sex: Male 56% Female 44% Ethnicity: White 89%, Black of African American 5.5%, Mixed ethnicity 5.5% NB Hispanic/Latino 1 of 18	Methodology: Descriptive content analysis (176) Data collection: Focus group Recruitment: Convenience sampling via community postings	Gaps in knowledge related to: 1. knowing the services available in palliative care 2. how palliative care is paid for 3. how palliative care affects the patient's relationship with existing providers. Participants perceived more attention to individualised care and a broader application of palliative care.	(130)
Tasseff 2018	To explore the palliative care perceptions of rural	N= 13 (just public)	Methodology:	1. ~~Palliative care is comfort for the dying or end-of-life care;~~	(132)

First author, year, country	Aim	Participant details Size (N), Age (years), Sex (%), Ethnicity	Methods and methodology	Results	Ref
USA	dwelling ~~(providers, nurses, and)~~ adults ~~(and, to explore the relationship between the knowledge and perceptions of palliative care held by rural providers and nurses, using a convergent parallel design.)~~	Age (mean) 65.3 (SD 7.4) Sex: Male 54% Female 46% Ethnicity: no details	Thematic analysis following grounded theory approach (Braun and Clarke, 2008 (177) Data collection: Semi-structured interview Recruitment: Purposive sampling through newspaper adverts, word of mouth, posters om community and rural message boards	2. Unfamiliarity with the term ~~3. Uncertainties about the differences between palliative care and hospice;~~ ~~4. Conflicts between theory and practice;~~ ~~5. Timing is everything;~~ 6. Experience is a strong teacher.	

Abbreviations for qualitative studies: EOLC end of life care, PC palliative care, N number, F female, M male, NK not known

Appendix 6: Summary of qualitative codes generated

Analytic theme: Understanding of the ethos of palliative care

Subtheme	Categories	Subcategories	Original coding
Palliative care and hospice care are unknowns	Relationship between hospice and palliative care		Differences between palliative care and hospice care unknown
			Hospice is key to delivering palliative care
			Palliative care is different from hospice care
			Palliative care is equated with hospice
			Palliative care is hospice care outside the hospice
	Awareness and understanding of palliative care		Palliative care is an unknown
			Palliative care not understood
Characteristics of palliative care	Compassionate care		Hospice associated with caring staff
			Hospice care idealised, transform death from a bad experience to a good one
			Hospices are special places and help anybody who's ill
			Hospices are wonderful
			Palliative care is a lifesaver
			Palliative care is compassionate human connection
	Patient centred care		EOLC provides individualised care
			Palliative care is focussed on individual wishes
			Palliative care provides autonomy and choice
	Family	For wider family	Hospice care provides support for patients and families
			Hospice is associated with sad surroundings
			Palliative care provides an opportunity to say goodbye
			Palliative care supports family
			Palliative care supports family communication
		Family loss	Palliative care is associated with loved ones feeling helpless
	Comfort care	Comfort	Hospice care is about comfort care
			Hospices make you comfortable
			Hospices provide a familial standard care
			Palliative care is about making you comfortable
			Palliative care is comfort care
			Palliative care reduces suffering
		Pain and symptom control	Palliative care focuses on symptom control
			Palliative care provides symptom and pain management
			EOLC is painless
			Hospice care relieves pain and suffering
			Palliative care is about pain relief
			Palliative care is pain relief at the end of life
		Promoting life	Palliative care allows people to live life to the fullest
			Palliative care can improve the final phase of life
			Palliative care involves the prolongation of life
			Palliative care is about quality of life
		Skilful holistic care	Palliative care involves skilful physical, personal, emotional, social, spiritual and medical care
		Social support	EOLC compensates for loss of autonomy and independence
			Hospice care is for people without family that can't look after themselves
			Purpose of hospice to help bathe and eat

Subtheme	Categories	Subcategories	Original coding
			Social care
		Spiritual wellbeing	Hospice care meets social and religious needs
			Not a spiritual place
			Not known that palliative care provides spiritual support
Palliative care is only about death	Palliative care is about quality of death	Allowing a natural death	Palliative care is letting someone die
		Appropriate care	Palliative care is appropriate care for the dying
		Comfortable death	Palliative care is comfort for the dying
		Dying in peace	Hospice is associated with dying in peace
		Good death	Hospice perceived as hope for good death
			Palliative care is an essential service to promote a good death
			Transforms death to a good experience
	Palliative care is equated to death	Euthanasia	Euthanasia is not part of palliative care
			Euthanasia is part of palliative care
			Hospice care is euthanasia
			Hospice is mercy killing
			Palliative care diminishes the argument for euthanasia
		Fatalism	Death denying
		Imminent death	Palliative care is equated to end of life
			Palliative care is linked with imminent death
			Palliative care only introduced at the end of someone's journey
		Inevitable death	Hospice is associated with definite death
			Inevitable
		Painful lonely death	Hospice is a lonely place where left to die
			Painful death

Analytic theme: Perceptions of who palliative care is for

Subtheme	Categories	Subcategories	Original coding
Disease	Advanced cancer		Palliative care is associated with cancer
			Palliative care is end of life care for advanced cancer
			Palliative care is for older people
	Chronic illness		Palliative care is for chronic illness
	Non-cancer		Palliative care includes non-cancer life-limiting illnesses
Disease trajectory	Non-curative		Hospice care is in lieu of curative care
			Palliative care is for patients who will not recover
			Palliative care is for terminal patients
			Palliative care is not curative
			Palliative care is treatment when treatments to completely change the situation are no longer available
			Palliative care services are for people with incurable disease
	Ongoing process		Palliative care is an ongoing process (not just the end)

Analytic theme: Structure and provision of palliative care

Subtheme	Categories	Subcategories	Original coding
Access	Not always available	Access limited by geography or proximity to a hospice	Palliative care limited to urban populations
		Concerns that not available when needed	Palliative care not always available
			Perception that not everyone who needs PC receives it
			Not everyone who needs it receives it

	Needs to be universal		Palliative care needs to be universal
Provision	Budgetary issues	Misunderstanding of funding	Costly to individuals
			Funding for palliative care uncertain
			Hospice care is associated with increased burden for family
		Underfunding	Palliative care (at home) not always available due to budgetary constraints
			Palliative care is under resourced
			Palliative care is essential
Structure	Models of care	Institutionalised care	Care in a nursing home
			Hospice care is a smaller hospital with well-paid supervision
			Hospice is an institution
		Location of care	Palliative care is provided in hospital, hospice or home
			Palliative care promotes dying at home
		Specialist team approach	EOLC is a team approach to help patients and families with the dying process
			Palliative care is delivered by trained specialists

Analytic theme: Cultural congruency

Subtheme	**Categories**	**Subcategories**	**Original coding**
Awareness and understanding	Understanding impacts care		EOLC is impacted by values, understanding of hypotheticals and worldviews
	Palliative care is an unknown entity to ethnic minorities		African Americans lack awareness of what hospice care is
			Chinese elders less aware of palliative care
	Palliative care is misunderstood		Different perceptions amongst different ethnic groups
			Giving up
Cultural division	Mistrust in hospice staff		Hospice staff lack of cultural awareness
			Hospice staff show lack of respect
			Mistrust
	Palliative care is inaccessible (racial prejudice)	Concerns about care	White facility
		No cultural representation	Feeling uncomfortable due to lack of diversity in workforce
			Hospices not inclusive (of African American community)
			Staffed by people of different cultures
			Struggle to connect with hospice staff due to lack of diversity
		No outreach	Doesn't reach out to other groups
			Lack of information produces assumptions
		Not offered	Don't access care due to lack of information provided
			Not offered or available to BAME
Lack of cultural sensitivity	Filial piety		Hospice barrier to usual cultural practice
			Hospice care not in line with cultural moral values
			Hospice is contrary to important notions about family care at EOL
	Language		Lack of communication skills
	Spirituality		Not in keeping with culture

Appendix 7: Qualitative framework matrices

Analytic theme: The ethos of palliative care

Subtheme: Relationship between palliative care and hospice care	
McIlfatrick, 2013	*Perceptions that hospice played a key role in the delivery of palliative care led to the general public assuming that treatment choices were limited to urban populations that are proximate to a hospice* *Palliative care was equated with hospice and end of life care, caring mainly for older patients or those suffering from cancers.*
Boucher, 2018	*It [palliative care] really looks, to me, like the hospice model. It's just being taken outside the hospice.d(FG 2a)*
Tasseff, 2018	*Uncertainties about the differences between palliative care and hospice* *Despite the ambivalence surrounding palliative care, all 13 rural dwelling adults stated they were familiar with hospice care and provided an accurate definition, as did the 12 rural providers and nurses.*

Subtheme	Awareness and understanding of palliative care
Seymour, 2007	*The term palliative care was not known by any respondents*
Daveson, 2011	*Uncertainty regarding how, where, and who will provide the care was felt*
Enguidanos, 2013	*The vast majority of participants in the Cantonese- and Mandarin-speaking focus groups were unfamiliar with hospice* *The majority of focus group participants lacked knowledge of hospice.* *most participants lacked knowledge of the hospice program and specific details including eligibility, insurance coverage, and care provision.* *Most lacked knowledge about hospice*
McIlfatrick, 2014	*At one end of the spectrum, respondents had no former knowledge, they only learned about palliative care when invited to participate in this study:* *Well, I honestly didn't know what it was until I read that it was to do with dying. I hadn't got a clue … I've honestly never heard of it. (ID50)* *It was suggested that people do not know about palliative care services and that such knowledge is acquired when 'you are in the situation of needing care' (ID2, former hospital patient) or in a caring role: What I would say is it would probably be important for people who maybe had a relative, a very close relative maybe nearing the end of time. (ID49)* *Although some had heard of 'palliative care', they did not understand it, compared to others with first-hand experiences of being diagnosed with cancer or caring for relatives*
Pullis, 2011	*When asked if they would consider using hospice services, most participants indicated that they would. Some were not sure, however, as they did not know much about hospice services or how to access hospice. Many questions regarding the kind of patient in hospice care were voiced: "Can you be in hospice if you are alert?" "Is it long term?" The issue of financial access was mingled with discussion. Questions such as "Is hospice covered under most insurance?" illustrated this concern.*
Boucher, 2018	*I didn't know what palliative care was and hospice and how to deal with the cost and different things.d(FG 1a)*

Subtheme	Awareness and understanding of palliative care
Tasseff, 2018	*Palliative care? Never heard of it* *The majority of interviewed rural dwelling respondents were adults who are uncertain what palliative care may be and what it entails. As many as seven rural dwelling adults reported they were unfamiliar with the term palliative care.* *"Pail-ee-uh-tiv? The care I would like? I really don't know. [Laughs]" – RD05 "I'm not exactly sure of the definition – it is one of a circle of cares that you can receive when you are sick or injured… Curative? I would hope so, but I really don't know." – RD02*

Subtheme: Characteristics of palliative care part 1				
Categories	**Compassionate care**	**Patient centred care**	**Provides dignity**	**Family**
O'Connor 2019	*I feel ... that people really do care during this sad time of loss* *I feel ... at peace knowing that we have these services available in the event a family member requires hospitalization*		*I believe ... palliative care enables a person to live out their last days with dignity*	*I feel ... sorry for the family who have to visit the patient in sad surroundings if in a hospice* *I feel ... glad that when it is well managed, families have time to say goodbye* *PC provides support for family* *I believe .. . it [palliative care] supports families at such a challenging time* *I feel ... helpless to see my loved one pass away without being able to help*
Voseckova, 2016				*General public perceive positive outlook at hospice care within the meaning that hospice care "helps dying ones in the greatest possible comfort and finish one's days in dignity", "facilitates families caring for family members", "pain relief" etc. General public responded in a similar way, they see benefit mainly in "possibility to family relief and also patient's relief in difficult life situation", "facilitates farewell to loved one", "provides farewell with a loved one and accompanies during dying", "patient's family's and also bereaved persons' support"*
Westerlund, 2018	*focus on PC as characterized by compassion, empathy and human connection*		*focusing on respect for and dignity of patient and family*	
Seymour, 2007	*See I haven't any first-hand experience of [hospice] but I would think there are people there who you know [and] comfort you, you know if someone is in there you've got proper caring people who try to put your mind at ease. I'm quite happy with that Gordon: it's got a very good name, it's got a very*			

Subtheme: Characteristics of palliative care part 1				
Categories	**Compassionate care**	**Patient centred care**	**Provides dignity**	**Family**
	good name for that hasn't it? (Focus group 3, part 1, men aged 65–74) *(palliative care) was often referred to by them in highly idealised terms. These invoked what were perceived to be the essential elements of hospice care for the dying: 'wonderful' or 'special' staff; the ability to transform death from the expected bad experience to a good one, and the provision of care, comfort and 'ease'* *Sally, a 90-year-old woman living near the local hospice where she had visited a number of friends who had died there, said: . . . And a hospice would . . . I think the hospices must help people. That . . . I mean I've only been up to St [local hospice], I've never been in another one, but it's such a wonderful atmosphere and it, there's no, there must be, it's so quiet and so beautiful up there, it must be a great help to anybody who's ill. And I think that must help a lot. And they must have special nurses in these places, have they? (Interview 34, Woman aged over 85).* *my own husband and lots of friends I know have been in [hospice] and they are absolutely wonderful there should be more hospices like that*			
Daveson, 2011		*It was hoped that safe, sensitive, and individualized care provided in a human environment would form part of EoLC* *Autonomy and choice were perceived as possible and desired. ... support you and help you cope with it .. . not ... too much treatment that you wouldn't be able ... to make choices and things like that ... High-quality care should be provided especially as people are dying and not able to be cured. What would be best for me. If I was in that situation? Where you feel confident that everything is being done that can be done.*		

Subtheme: Characteristics of palliative care part 1				
Categories	**Compassionate care**	**Patient centred care**	**Provides dignity**	**Family**
McIlfatrick, 2014			*What do the public expect for patients? Although there was recognition that 'it is not always possible to relieve pain 100%' and that 'sometimes we want our loved ones to live forever' findings revealed the importance of ensuring that patients are comfortable, suffering is alleviated and dignity is promoted in the last days of life: It's looking after people who are dying and making their death as easy and comfortable as possible. (ID7)*	*Some benefits of open communication are illustrated in the following: My wife had very progressive ovarian cancer and was told that she only had days to live … the palliative care team come and seen me the next day and told me … It was an absolute God send … We had six or seven days where we were able to talk things over, between ourselves … so those were very precious days to me. (ID6) This illustrates the importance of people being aware of the preciousness of time and facilitating open communication so that patients can 'tie up their life and issues' (ID34).*
Pullis, 2011	*Several of the participants had experienced hospice care in the illness and death of close family members and recounted their positive experiences. One participant whose mother had hospice care related her respect for hospice nurses, "I was in denial at first... they were there in the middle of the night if I needed them. They gave me a new understanding of death." Another member stated, "Hospice care is a good thing, a really good thing." Many participants stated they would consider hospice care at the end of life.*			
Boucher, 2018		*It [palliative care] takes in your wishes a lot more as to what you want other than what people are deciding for you.d(FG 1a)*		
Tasseff, 2018	*RD03, "I had a sister- 20 years ago- who we had hospice care for…she had ovarian cancer. It was a lifesaver, a very positive experience."*			

Subtheme: Characteristics of palliative care Part 2						
Category: Comfort care						
Subcategories	**Comfort and suffering**	**Physical symptom control**	**Promoting life**	**Skilful holistic care**	**Social support**	**Spiritual wellbeing**
Benini, 2011		*the prevalent identification of PC was with "the treatment of*	*care that can improve the final phase of life*			

Subtheme: Characteristics of palliative care Part 2						
Category: Comfort care						
Subcategories	**Comfort and suffering**	**Physical symptom control**	**Promoting life**	**Skilful holistic care**	**Social support**	**Spiritual wellbeing**
		pain and improved of quality of life”.	*the prevalent identification of PC was with “the treatment of pain and improved of quality of life”.*			
McIlfatrick, 2013		*The majority defined palliative care as pain relief for people with terminal illness at the end of life with the aim of achieving a peaceful death*				
O'Connor, 2019		*PC provides symptom and pain management* *I feel ... comforted because the patient’s pain and distress are managed* *PC provides symptom and pain management* *I believe ... that excellent palliative care should ease the way to a peaceful and pain free death for the patient*	*I believe ... that it is a very good thing to offer as everyone should be entitled to live life to the fullest*			
Voseckova, 2016	*General public perceive positive outlook at hospice care within the meaning that hospice care "helps dying ones in the greatest possible comfort and finish one's days in dignity"" "possibility to family relief and also patient's relief in difficult life situation"*	*(hospice care) "facilitates families caring for family members", "pain relief" etc. "hospice care provides pain relief, guarantees a dignified end of life".*			*The responses were formulated as: "hospice care is care about long-term ill patients or about elder people who don't have family or relatives and are not able to look after themselves"* *General public perceive positive outlook at hospice care…"facilitates families caring for family members" "to die in dignity without being lonely…"*	*"helps dying ones in the greatest possible comfort and finish one's days in dignity", "facilitates, "patient's family's and also bereaved persons' support", "to die in dignity without being lonely, with necessary diligence", "ensuring a clergyman and social needs".*
Westerlund, 2018	*reduction of suffering and quality of life (n = 340)*	*focus on symptom control*	*Only a handful of respondents indicated that PC involved the prolongation of life or delay in disease progression (n = 9) or mentioned euthanasia in some form (n = 6) in their responses.*			

Subtheme: Characteristics of palliative care Part 2						
Category: Comfort care						
Subcategories	**Comfort and suffering**	**Physical symptom control**	**Promoting life**	**Skilful holistic care**	**Social support**	**Spiritual wellbeing**
			reduction of suffering and quality of life (n = 340)			
Taxis, 2006						*When you're dying—[Group says, "That's important"]—it is of the utmost importance. To feel the spirit and if you can't feel it—who wants to be in that sort of a place? [Group agrees] I don't want to die in a place where the spirit isn't there*
Kwak, 2007	*Conversely, caregivers who supported hospice care in lieu of curative treatment endorsed hospice, because they expected that their parents would want comfort care and wanted to respect their wishes as part of their moral duty. I think that, if my parent were terminally ill, I would prefer the comfort care, which would be hospice. I want my parent to feel comfortable, rather than too much pain trying some kind of medical experiment on him.*				*I think that it is home health program which provides help with basic activities like bathing and eating.*	
Seymour, 2007	*Er, my opinion is if I was ill like that, personally, I would like to be in a hospice, er, for the simple reason that the comfort is there, you cannot always get comfortable at home, where in a hospice they spend all of their time*					

Subtheme: Characteristics of palliative care Part 2						
Category: Comfort care						
Subcategories	**Comfort and suffering**	**Physical symptom control**	**Promoting life**	**Skilful holistic care**	**Social support**	**Spiritual wellbeing**
	making you comfortable and. . . . once they are comfortable, they are at peace and that is what they need I think, to me that is the reason, that is the reason of a hospice, that's what it is there for (Focus group 1, woman aged 75–84). *In another focus group in the study of white elders, two men debated the meaning of hospice, making it clear that for them it was associated with familiarity, comfort and care* *Among some of the white female respondents, hospices were especially preferred because of their perceived ability to provide a 'familial' standard of care: a standard that they perceived was becoming hard to achieve with the rapid demographic and social changes they had experienced. For example, in one focus group a woman who had lived in a small rural community in her youth recalled the management of illness and death in her childhood and contrasted this with the present:* *Catherine: Oh yes, not many people died away from home and they were laid out and everything at home, they were, I never laid one out*					

Subtheme: Characteristics of palliative care Part 2						
Category: Comfort care						
Subcategories	**Comfort and suffering**	**Physical symptom control**	**Promoting life**	**Skilful holistic care**	**Social support**	**Spiritual wellbeing**
	mind you (laughter) They didn't give me that job, but er no and they need somewhere where they can finish their days in quiet and comfort and loving care 24 hours a day not just when somebody has got time to go and look at them, and that's what they get in [hospice] my own husband and lots of friends I know have been in [hospice] and they are absolutely wonderful there should be more hospices like that, and er, like I say, before not a lot of wives did full-time work so you were more or less expected to look after the family . . . 1 mean if we have [to look] after any one like that I don't think our age would er be upset by it, because we are used to it – but I don't think our young people are really used to it . . . yes; we lived with the dead as well as the living. But now no, er, life's too busy and so there needs to be proper care for the elderly (Focus group 2, women aged 75–84).					
Daveson, 2011		*A high standard of EoLC, delivered in relation to the proximity and anticipation of death, in a contextually relevant manner was expected. .. . an environment where professionals are helping .. . in*	*Effort to enable enjoyment, pleasantries, respect and dignity, and to be symptom-free were important.*	*Skilful physical, personal, emotional, social, spiritual, and medical care was expected. Good medical care, secondly good human companionship ... .safety in the care .. .*	*Attention to independence, autonomy, and practical matters during EoLC. During EoLC, declining health alongside a loss of physical*	

Subtheme: Characteristics of palliative care Part 2						
Category: Comfort care						
Subcategories	**Comfort and suffering**	**Physical symptom control**	**Promoting life**	**Skilful holistic care**	**Social support**	**Spiritual wellbeing**
		the dying process ... helping my partner, children .. . in a way that people wouldn't be able to do individually and in an environment which is truthfully painless and fits that situation.		*medical, human-psychological care.*	*independence and autonomy would occur over a period of many years. EoLC could be going on for years. It is the point in time where it really becomes difficult to participate autonomously in life. Through attention to practical day-to-day matters it is possible to compensate, to a degree, for loss of independence. Attention to and compensation of this loss was important. Who will care for me? How seriously ill will I get? Who will look after my body? That would be very important for me. And then naturally, as I want to die at home, who deals with the household? Who will look after the food, the washing, my children? That would be in my head the first place.*	
Enguidanos, 2013	*For many, hospice was viewed as a mechanism to relieve pain and suffering and as an opportunity for comfort and support, and therefore, most participants viewed it positively: "I think, no one would be unwilling to receive it [hospice care]. Everyone would love to have*	*For many, hospice was viewed as a mechanism to relieve pain and suffering and as an opportunity for comfort and support, and therefore, most participants viewed it positively: "I think, no one would be unwilling to receive it [hospice care]. Everyone would love to have someone to be*				

Subtheme: Characteristics of palliative care Part 2

Category: Comfort care

Subcategories	**Comfort and suffering**	**Physical symptom control**	**Promoting life**	**Skilful holistic care**	**Social support**	**Spiritual wellbeing**
	someone to be concerned about us, and when we are in pain, we will be given pain killers, I don't see why people do not want hospice care" (Mandarin man, before learning hospice care was provided primarily in the home).	*concerned about us, and when we are in pain, we will be given pain killers, I don't see why people do not want hospice care" (Mandarin man, before learning hospice care was provided primarily in the home).*				
McIlfatrick, 2014	*One respondent (ID10) emphasised the importance of 'helping someone to be comfortable', which was based on memories of her sibling 'screaming in agony in hospital … as she never saw a palliative care nurse'. Others shared positive experiences of specialist palliative care at home or hospice.* *and give reassurance that palliative care services are there for the 'necessity and comfort of patients and their families' (ID15).*					
Pullis, 2011						*Generally, although the participants reported having a positive perception of hospice, they were not informed of the services offered by hospice. None of the participants including those who were familiar with hospice, were knowledgeable regarding the spiritual*

Subtheme: Characteristics of palliative care Part 2						
Category: Comfort care						
Subcategories	**Comfort and suffering**	**Physical symptom control**	**Promoting life**	**Skilful holistic care**	**Social support**	**Spiritual wellbeing**
						support offered in hospice care.
Tasseff, 2018	*Rural dwelling adults also shared memories of family members who received hospice care at home, describing palliative care as hospice care. "I would define it [palliative care] as treatment during a stage of life when there aren't any avenues for complete change to the situation, and you are making that person comfortable for as long as possible – until another factor takes over and they pass away." – RD03*					

Subtheme: Palliative care is only about death		
Categories	**Palliative care is about quality of death**	**Palliative care is equated to death**
McIlfatrick, 2013	*The majority defined palliative care as pain relief for people with terminal illness at the end of life with the aim of achieving a peaceful death*	*Palliative care was equated with hospice and end of life care, caring mainly for older patients or those suffering from cancers.* *One common example of this was the lack of discussion of palliative care at diagnosis or when treatment starts. Respondents noted that palliative care was introduced at the end of the patients' journey* *The majority defined palliative care as pain relief for people with terminal illness at the end of life with the aim of achieving a peaceful death*
O'Connor, 2019	*PC provides appropriate care for the dying* *I believe .. . that palliative care ensures appropriate care is provided to the dying* *I believe ... that excellent palliative care should ease the way to a peaceful and pain free death for the patient* *I feel ... thankful that my loved ones ended their days in such a peaceful and cared for environment* *it is an essential service in helping to promote a "good death" for terminal patients*	*PC and euthanasia (euthanasia is part of PC and not part of PC)* *I believe .. . that confusion and misunderstanding are fuelling the push for euthanasia. Better palliative care would diminish the argument for taking control of one's death especially in those with no serious illness other than "old age"*
Voseckova, 2016		*In open questions respondents in both groups showed knowledge of this issue, regardless to the fact, if they ever met with this situation in family or in immediate neighbourhood. The responses were formulated as: "hospice care is care about long-term ill patients or about elder people who don't have family or relatives and are not able to look after themselves", "hospice care is*

Subtheme: Palliative care is only about death		
Categories	**Palliative care is about quality of death**	**Palliative care is equated to death**
		provided to dying persons, incurably sick persons who are in their last stage of life", "hospice care provides pain relief, guarantees a dignified end of life".
Shalev, 2018		*Of note, 6 of the misperceptions classified as other related hospice care to euthanasia (eg, an example of such a response is "It is euthanasia").*
Westerlund, 2018		*Only a handful of respondents indicated that PC involved the prolongation of life or delay in disease progression (n = 9) or mentioned euthanasia in some form (n = 6) in their responses.* *The most common responses were coded as referring to the timing of care (EoL or care of persons with a fatal or incurable illness)*
Taxis, 2006		*The participants believed that the avoidance of discussing or planning for one's death made the consideration of hospice service particularly problematic. They overwhelmingly described an avoidance of end-of-life planning or discussion and associated it with their culture. One participant summarized many of the comments* *Misconceptions about hospice included assumptions that the care would be inadequate, people would die lonely, painful deaths* *When they put them in another setting [other than a hospital], like in a hospice that they will be alone. In a hospital, at least they have to come in and poke you to see if you are still alive. I think that people may think that in hospice or nursing homes no one is going to check on you...they put them in the bed and close the door.* *Misconceptions about hospice included assumptions that the care would be inadequate, people would die lonely, painful deaths*
Seymour, 2007	*Thus hospice care seemed to be symbolic of the hope for the 'good death' among the white elders. These perceptions were especially notable among those who had had personal experience of hospice care* *Because hospice care was seen as clearly linked to inevitable death it was spoken about cautiously and warily by the white respondents but, at the same time, it was often referred to by them in highly idealised terms. These invoked what were perceived to be the essential elements of hospice care for the dying: 'wonderful' or 'special' staff; the ability to transform death from the expected bad experience to a good one, and the provision of care, comfort and 'ease'*	*As with the white respondents, those Chinese elders who had heard of hospice made a link with imminent death* *But I think the Chinese would find it difficult to accept this; as when you are in there, they are people who are about to die . . . Entering a hospice means you're proclaiming to the world . . . I am not going to come out of it (Interview 31, woman aged 58).* *they need somewhere where they can finish their days in quiet and comfort and loving care 24 hours a day not just when somebody has got time to go and look at them, and that's what they get in [hospice]* *It also seemed to contradict assumptions about the right way to die: carrying on with life and maintaining good spirits until the end, as one woman, who had lived in the UK for over 30 years but had very limited English, explained: I don't think the Chinese would prefer to go there. . . . they would not like the word 'death' . . . staring at it all the time . . . staring at it as they [try to] carry on with their life. Yes [otherwise] you might die without knowing or it is possible that you might just die; but if you were in a hospice, well you definitely would die; it seems that the word death would be thrown in your face all the time (Interview 22, woman aged 62).* *most of the white elders expressed underlying concerns about what was perceived as the obvious relationship of hospices with death. This was especially prominent among those respondents living in the more deprived areas of Sheffield. For example, Eddie, a man who had witnessed the painful death of his father from cancer, said the following: It's a place to stop permanent, it's like St [local hospice] . . . So if you, well, you see, once people start saying, 'We're going to put you in this hospice', then they know they're going to die, don't they? So I think you'd want to spend your*

Subtheme: Palliative care is only about death		
Categories	**Palliative care is about quality of death**	**Palliative care is equated to death**
		last few months with your family, wouldn't you? (Interview 5, Man aged 65–74) *Because hospice care was seen as clearly linked to inevitable death it was spoken about cautiously and warily by the white respondents* *Many spoke of "waiting for death," with this concept tied to wanting to reduce burden on others and quickly end their life once they receive a terminal diagnosis, as illustrated by a Cantonese woman, "Just put all the spare money on hospice care in an institution where we can wait for our death."*
Daveson, 2011	*Maintaining quality of life, and letting life end naturally was important. Artificially prolonging life was, at times, rejected. ... To keep artificially alive, that is not for me.*	*The context of EoLC influenced preferences ... palliative care ward means that you will die at any moment. That is bitter, but when you are so exhausted, I believe it [preferred place ofdeath] does not matter anymore. The main thing is that you are well cared for.*
Enguidanos, 2013	*For many, hospice was viewed as a mechanism to relieve pain and suffering and as an opportunity for comfort and support, and therefore, most participants viewed it positively: "I think, no one would be unwilling to receive it [hospice care]. Everyone would love to have someone to be concerned about us, and when we are in pain, we will be given pain killers, I don't see why people do not want hospice care" (Mandarin man, before learning hospice care was provided primarily in the home).* *The ability for individuals to die in peace was seen as a potentially positive feature of hospice care for some. According to a woman in the Mandarin-speaking group, "It [hospice] is a good thing, especially when you have no children. Like when you stop breathing or our heart stop beating, do not ask for resuscitation anymore. What's the point if you are already dying? We all need to die someday, why not let ourselves die peacefully?"*	*The vast majority of participants in the Cantonese- and Mandarin-speaking focus groups were unfamiliar with hospice, and after the facilitator provided a description of hospice (Table 1), some mistakenly thought hospice was the same as mercy killing.* *"Yes, it [hospice] is a service for the patient when there is no more treatment, but I not only want that, I even want mercy killing,"* *Misconception of hospice as form of "mercy killing"*
McIlfatrick, 2014	*What do the public expect for patients? Although there was recognition that 'it is not always possible to relieve pain 100%' and that 'sometimes we want our loved ones to live forever' (ID20, retired nurse), findings revealed the importance of ensuring that patients are comfortable, suffering is alleviated and dignity is promoted in the last days of life: It's looking after people who are dying and making their death as easy and comfortable as possible. (ID7)*	*What do the public expect for patients? Although there was recognition that 'it is not always possible to relieve pain 100%' and that 'sometimes we want our loved ones to live forever' (ID20, retired nurse), findings revealed the importance of ensuring that patients are comfortable, suffering is alleviated and dignity is promoted in the last days of life: It's looking after people who are dying and making their death as easy and comfortable as possible. (ID7)* *Long-standing 'stigma' attributed to cancer was generally reinforced with people preferring not to publicly discuss their illness. Assumptions or myths were commonly associated between cancer, palliative care and death: Well I think that a lot of people automatically assume palliative care, you are going to be dead in a few days*
Tasseff, 2018	*Six of the 13 rural dwelling adults who were interviewed view palliative care as keeping someone comfortable who was at the end-of-life. "My definition is probably going to have to be about end-of-life…letting a patient die as comfortably as possible." – RD04 "To make it so they are not in pain; making them comfortable until they die." – RD07* *Palliative care is comfort for the dying or end-of-life care* *Six of the 13 rural dwelling adults who were interviewed view palliative care as keeping someone comfortable who was at the end-of-life. "My definition is probably going to have to be about end-of-life…letting a patient die as comfortably as*	

Subtheme: Palliative care is only about death		
Categories	**Palliative care is about quality of death**	**Palliative care is equated to death**
	possible." – RD04 "To make it so they are not in pain; making them comfortable until they die." – RD07	

Analytic theme: Who is palliative care for?

Subtheme	**Disease**			**Disease trajectory**	
Categories	**Advanced cancer**	**Chronic illness**	**Non-cancer**	**Non-curative**	**Ongoing process**
Benini, 2011				*perception of PC varied and included sentences like: care that does not have a curative effect, care for patients who will not recover* *Answers could be assigned to 3 general categories: care that does not cure, care for terminal patients and care for patients that will not recover*	
McIlfatrick, 2013	*Although participants were not asked to specify conditions, many associated palliative care with cancer and care of older people.* *"It is making a person who has terminal cancer as comfortable and as pain-free as possible as end of life approaches"* *"Palliative care is a health unit which provides care and treatment for cancer patients"* *Palliative care was equated with hospice and end of life care, caring mainly for older patients or those suffering from cancer.*				
Voseckova, 2016		*At General public there were some answers such as "palliative care is care about persons with chronical illness*		*The responses were formulated as: "hospice care is care about long-term ill patients or about elder people who don't have family or relatives and are not able to look after themselves", "hospice care is provided to dying persons, incurably sick persons who are in their last stage of life"*	
Westerlund, 2018				*The most common responses were coded as referring to the timing of care (EoL or care of persons with a fatal or incurable illness, n = 1117 statements)*	

Subtheme	**Disease**			**Disease trajectory**	
Categories	**Advanced cancer**	**Chronic illness**	**Non-cancer**	**Non-curative**	**Ongoing process**
Kwak, 2007				*Conversely, caregivers who supported hospice care in lieu of curative treatment endorsed hospice, because they expected that their parents would want comfort care and wanted to respect their wishes as part of their moral duty. I think that, if my parent were terminally ill, I would prefer the comfort care, which would be hospice. I want my parent to feel comfortable, rather than too much pain trying some kind of medical experiment on him. (Caregiver)*	
Seymour, 2007	*white respondents were familiar with the role of GPs and Macmillan nurses in providing end-of-life care for people with advanced cancer, and almost everyone had heard of hospices*				
McIlfatrick, 2014	*Most respondents assumed that palliative care focuses on cancer with some awareness of the recent inclusion of other life-limiting illnesses (motor neurone disease, multiple sclerosis, Parkinson's disease, dementia and heart or renal failure): Palliative care used to focus on cancer but local hospices are now taking people with other life-limiting disease such as MND, which could be developed further to include heart or renal failure*		*Most respondents assumed that palliative care focuses on cancer with some awareness of the recent inclusion of other life-limiting illnesses (motor neurone disease, multiple sclerosis, Parkinson's disease, dementia and heart or renal failure): My interpretation of palliative care is […] I generally would have associated it with cancer but I'm now aware that it goes out into other illnesses as well. (ID44)* *Palliative care used to focus on cancer but local hospices are now taking people with other life-limiting disease such as MND, which could be developed further to include heart or renal failure.*	*There was acknowledgement that people needing palliative care services have an incurable illness impacting their life*	
Boucher, 2018					*palliative care is more of an ongoing. It's not preparing for an end, but it's just an ongoing process. d(FG 1a)*

Subtheme	**Disease**			**Disease trajectory**	
Categories	**Advanced cancer**	**Chronic illness**	**Non-cancer**	**Non-curative**	**Ongoing process**
Tasseff, 2018				*Rural dwelling adults also shared memories of family members who received hospice care at home, describing palliative care as hospice care. "I would define it [palliative care] as treatment during a stage of life when there aren't any avenues for complete change to the situation, and you are making that person comfortable for as long as possible – until another factor takes over and they pass away." – RD03*	

Analytic theme: Structure and provision of palliative care

Subtheme	**Access**		**Provision**			**Structure**		
Categories	**Not always available**		**Needs to be universal**	**Budgetary issues**		**Models of care**		
Subcategories	**Access limited by geography or proximity to a hospice**	**Concerns that not available when needed**		**Misunderstanding of funding**	**Underfunding**	**Institutionalised care**	**Location of care**	**Specialist team approach**
McIlfatrick, 2013	*Perceptions that hospice played a key role in the delivery of palliative care led to the general public assuming that treatment choices were limited to urban populations that are proximate to a hospice*							
O'Connor, 2019		*I feel ... fearful that they won't be around when I need them* *I feel ... sad that not everyone who needs it receives it*	*Need for universal access to palliative care* *Palliative care is essential* *I believe ... that it is a very good thing to offer as*		*I believe .. . there isn't enough palliative care resources to aid all who need it*		*PC promotes dying at home* *I believe .. . that dying at home should be the norm, not dying in a clinical environment*	

Subtheme	**Access**		**Provision**			**Structure**		
Categories	**Not always available**		**Needs to be universal**	**Budgetary issues**		**Models of care**		
Subcategories	**Access limited by geography or proximity to a hospice**	**Concerns that not available when needed**		**Misunderstanding of funding**	**Underfunding**	**Institutionalised care**	**Location of care**	**Specialist team approach**
			everyone should be entitled to live life to the fullest *I feel ... frustrated that there is not enough care available*					
Voseckova, 2016						*At general public there were also statements that showed certain ignorance of hospice cares area eg "hospice care is a smaller hospital with well paid supervision".*		
Taxis, 2006				*inaccessible to African Americans because of cost* *The institutional barriers included mistrust of the healthcare system and the predominantly white providers, lack of knowledge about the scope of services, accessibility, and the cost of hospice programs.*		*The participants assumed that hospice care was delivered in a nursing home, where care would be inadequate and the patient would be isolated.* *We still have this negative connotation with the word, "nursing home." ...How can we be sure that it's not going to be that horrible nursing home? Because if Medicare is paying for it, we don't*		

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						know if it is really a good hospice and this is a had one. You may hear, oh. Medicare pays for it—it must he THAT kind of care, and you don't want to put your loved one in THAT kind of care.		
Kwak, 2007						*Isn't the hospice a program provided by the government like a nursing home program? (Older adult)*		
Daveson, 2011								*A high standard of EoLC, delivered in relation to the proximity and anticipation of death, in a contextually relevant manner was expected. .. . an environment where professionals are helping .. . in the dying process ... helping my partner, children .. . in a way that people wouldn't be able to do individually and in an environment which is truthfully painless and fits that situation.*
Enguidanos, 2013				*Although some were protective of government resources, others felt hospice was the government's way*		*The few familiar with hospice mistakenly believed that hospice care is primarily provided in an*		

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				of shifting costs and burden to the family. According to a Cantonese man, "This kind of hospice care [at home] is just a way that the government throws the ball back to the family."		*institution, possibly because of their experiences with care systems in Hong Kong and other parts of Asia. According to a Cantonese woman, "I thought we were talking about what is happening in Hong Kong and China now—that hospice care happens in an institution."* *Across all focus groups, several stated they would prefer to have hospice care in a hospital or nursing facility or other institution rather than at home. As one Cantonese woman put it, "I think most of us here today are for the concept of hospice care as long as it takes place in an institution.*		
McIlfatrick, 2014					*Although budgetary constraints on Trusts and charities delivering specialist palliative care were acknowledged, they result in some not being offered a home*		*When respondents were asked where they thought palliative care takes place, most suggested hospital, hospice, nursing home or home: I*	*There was acknowledgement that people needing palliative care services have an incurable illness impacting their life expectancy and that*

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					death (ID49) and families being left with very little support (ID47). An integrated health service and less reliance on family were recommended: *I think there is an obligation on the state and an essential part of the health service and that palliative care should be as much part of the health service as any other part as it is too important and too relevant to just depend on the man in the street. (ID42)*		*assume home, hospital and hospice … but it is more at home, but I don't know why that is, maybe that is a common misconception … but I think the term palliative care would make me think about the home environment. (ID15)*	*care is best delivered by trained specialists.*
Boucher, 2018				*I didn't know what palliative care was and hospice and how to deal with the cost and different things. FG 1a*				

Analytic theme: Cultural congruency

Subtheme	**Awareness and understanding**			**Cultural division**		**Lack of cultural sensitivity**		
Categories	**Understanding impacts care**	**Palliative care is an unknown entity to ethnic minorities**	**Palliative care is misunderstood**	**Mistrust in hospice staff**	**Palliative care is inaccessible (racial prejudice)**	**Filial piety**	**Language**	**Spirituality**
Taxis, 2006		*lack of knowledge about the scope of services* *I think that in the*	*You know it's that whole fatalism thing in the hlack community—that's*	*The participants overwhelmingly expressed a desire for greater respect*	*The institutional barriers included mistrust of the healthcare system*	*The participants describe caring for a loved one at the end of life as a way to*	*You know sometime we pretend that we understand and we don't. So if they*	*You know, church—that's the kind of hymns we want to hear and preaching*

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		African American community as a whole there are definitely conceptions about what hospice is and what hospice does, hut we really don't know.	*just the way we are—we don't talk ahout wills, we don't talk ahout death, and we don't talk ahout hospice.*	*from healthcare providers, particularly at the end of life. When asked what would a healthcare provider do or say to show respect, they described several communication strategies, including speaking in terms that were understandable, eliciting questions, allowing time for dialog, and active listening.* *You know when they talk over you or if you are sitting right there and they don't include you in the conversation, well, it's just rude.* *They have absolutely no respect* *participants agreed that they would have misgivings about a white healthcare practitioner suggesting hospice.* *If you [directed to white facilitator] came in and suggested hospice, some of us would*	*and the predominantly white providers* *You know, church—that's the kind of hymns we want to hear and preaching we want to hear, and you aren't going to get it at a white facility* *Because the perception among the participants was that hospice services are predominantly staffed and used by whites, there was concern about the adequacy of care and the respect for African American traditions and values at the end of life* *participants agreed that they would have misgivings about a white healthcare practitioner suggesting hospice.* *It is so much easier as an African American student [nursing] to care for an African American patient. It's just that—it's*	*express respect and dignity for the individual.* *In the African American community, you didn't throw away your old folks, you keep them at home until they died—regardless.* *Now what y'all are bringing up about not wanting to put your parent away—that's not an old school kind of thing.* *I'm pretty young (22 years old) and when my mother gets to that time, I am NOT going to put her away. I know how great hospice is and that there are good nursing homes where I could put my mother—but even thinking about that—with our culture being so deep, I could not let her be part of that.*	*would repeat things and ask, "Do you know what I am saying?" If they would just use words we understand and make really clear explanations—that would help.* *Calling us by our last name—you know it is so universal to have the Mr. or Mrs. before a person's name. That's important to us.*	*we want to hear, and you aren't going to get it at a white facility* *It's important to be in a place were your traditions are embraced, not tolerated, embraced [Group agreement]—big difference!* *concern about the adequacy of care and the respect for African American traditions and values at the end of life*

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				say, "Oh, you're trying to get her out of here—you're trying to get rid of her" [Group agreement—"yes, that's right"]. It's the trust factor. And although you are probably very compassionate and very clinically astute, you don't have our history and you don't know the words that we need to hear.	*when they print off those brochures, and there's not a black person [emphasis added] on the brochure. That tells me, "This is not the place for me." [Group agreement—"Right—that says it"]* *Another member said, "My mother was in a hospice—she was the only person of color there."* *Another thing I think is obvious, at least from my experience (I'm a social worker) when I went into homes—African American homes, overwhelmingly I was immediately accepted. It was like—you look like me. You have my best interest at heart. And I think there is definitely a disparity in that there are not a lot of African American social workers out there and I think*			

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					that can contribute to this disconnect. Conversely, two health providers in the group (a nursing student and a social worker) expressed immediate rapport with patients and families who shared their ethnicity. *There was concern about adequacy of care and lack of information and outreach on the part of hospice.* *a pervasive lack of information about hospice, producing numerous assumptions about hospice services* *All of the participants agreed that there was a general lack of information about hospice in the African American community* *I don't know if it is the hospice organization's sole responsibility or if they have been ineffective communicating that to us. But for whatever reason,*			

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					it's just not being disseminated [The group nods, and agrees]. *Who is supposed to be explaining this [hospice information] to us? Do the hospitals explain this to all people? Hospice needs to put out the information. Why don't we know about hospice? Why isn't hospice spending more time marketing this to us?* *Although the group expressed concern that hospice may not be suggested to them as an alternative at the end of life, or perhaps hospice programs did not market to the African American community* *Finally, several members had questions about accessibility and thought that because hospice did not market to African Americans,*			

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					it must not be available to them. Some participants believed this deficit was due to the medical community not describing or offering it to African Americans and to the hospice not reaching out to the African American community. *perhaps hospice programs did not market to the African American community* *several members had questions about accessibility and thought that because hospice did not market to African Americans, it must not be available to them.*			
Kwak, 2007			*Isn't the hospice a program provided by the government like a nursing home program? (Older adult)*			*The underlying reason for this wide range of preferences expressed by older adults and caregivers was filial piety, the moral obligation of an adult child to respect and obey one's parents and*		

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						provide support for them in old age. Older adults and caregivers who preferred curative treatment options believed that adult children would choose curative treatment, because children would perceive such a decision as the morally right thing to do for their parents. They perceived giving up curative treatment, which is required by the Medicare hospice benefit, as not fulfilling the moral duty as an adult child to do everything to prolong life. *Although we would want hospice, children might think differently. They want to do everything to prolong our lives. (Older adult)* *I would do everything and pursue all curative treatment options for them (as opposed to*		

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						choosing hospice). That's what you should do for your parents as a child. (Caregiver)		
Seymour, 2007		*Thus hospice care seemed to be symbolic of the hope for the 'good death' among the white elders. These perceptions were especially notable among those who had had personal experience of hospice care, something that was markedly lacking among the Chinese sample.* *Among the Chinese elders, only one person said that they had heard of a Macmillan nurse, and only one quarter of the interview respondents (n = 12) said that they had heard of the term 'hospice'.*	*But I think the Chinese would find it difficult to accept this; as when you are in there, they are people who are about to die . . . Entering a hospice means you're proclaiming to the world . . . I am not going to come out of it (Interview 31, woman aged 58). Thus hospice care seemed to be symbolic of the hope for the 'good death' among the white elders. These perceptions were especially notable among those who had had personal experience of hospice care, something that was markedly lacking among the Chinese sample*			*Entering a hospice would also demonstrate that one had become a 'burden' to one's family and that there was no other option for care at the end of life. To this extent, hospice care was not seen as a positive 'choice' that one might make for care at the end of life. Instead it seemed to contradict important notions about family care and support during death. These were expressed clearly by Mrs Cho, a widow who lived near her adult children and who had strong views about the role of children in caring for their parents. She had cared for her own mother during a final illness many years earlier: Mrs Cho: [people]*		

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						would not have much opinion if they were ‘put’ there. Interviewer: Right, what did the family think? Those who visited. Mrs Cho: The family wouldn’t have much response; if you really cared, you would have taken the elder home to stay; well, it is because the children did not care so they ended up there. Interviewer: So they could not look after him and they would put him there? Mrs Cho: They could not look after him and that was why they dropped him at that sort of place. . . . if you could afford it of course you don’t want your parents to go to that sort of place, right? Unless you have no choice (Interview 29; Woman, aged 65).		
Daveson, 2011	*							

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Enguidanos, 2013		*The English-speaking group had the most familiarity with hospice, with 28.6% of participants indicating they knew someone on hospice, whereas 12.5% of Cantonese participants and none of the Mandarin participants reported knowing someone in hospice.*						
Pullis, 2011		*When asked if they would consider using hospice services, most participants indicated that they would. Some were not sure, however, as they did not know much about hospice services or how to access hospice. Many questions regarding the kind of patient in hospice care were voiced: "Can you be in hospice if you are alert?" "Is it long term?" The issue of financial access was mingled with discussion.*			*Many participants also voiced the opinion that African Americans need more education regarding hospice care and EOLC care: "We don't like to talk about death or to prepare for it." "Will you educate us on hospice?" Why don't hospitals tell us about hospice?"*			

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		Questions such as "Is hospice covered under most insurance?" illustrated this concern.						

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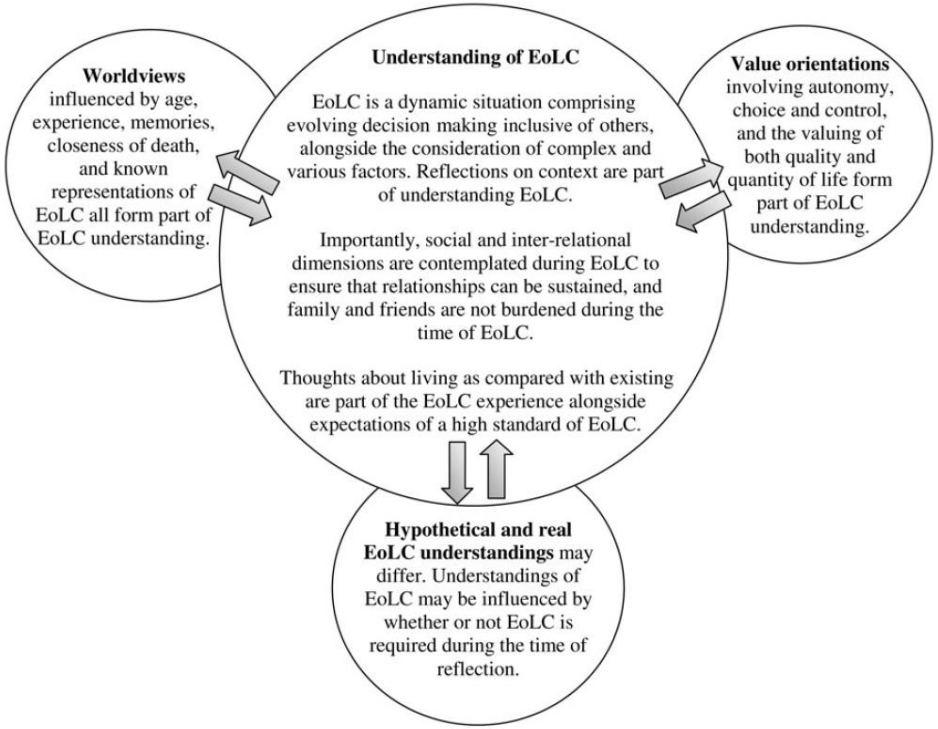

Worldviews influenced by age, experience, memories, closeness of death, and known representations of EoLC all form part of EoLC understanding.

Understanding of EoLC

EoLC is a dynamic situation comprising evolving decision making inclusive of others, alongside the consideration of complex and various factors. Reflections on context are part of understanding EoLC.

Importantly, social and inter-relational dimensions are contemplated during EoLC to ensure that relationships can be sustained, and family and friends are not burdened during the time of EoLC.

Thoughts about living as compared with existing are part of the EoLC experience alongside expectations of a high standard of EoLC.

Value orientations involving autonomy, choice and control, and the valuing of both quality and quantity of life form part of EoLC understanding.

Hypothetical and real EoLC understandings may differ. Understandings of EoLC may be influenced by whether or not EoLC is required during the time of reflection.

Glossary

Abbreviations	Terms in full
.ab	Boolean search term for abstract
.kw	Boolean search term for keyword
.ti	Boolean search term for title
AIDS	Acquired Immunodeficiency Syndrome
ANOVA	Analysis of Variance
AXIS	Appraisal tool for cross-sectional studies
CAPC	Center to Advance Palliative Care
CASP	The Critical Appraisal Skills Programme
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CIS	Critical Interpretive Synthesis
CRD	Centre for Reviews and Dissemination
CSS	Cross-sectional survey
CVH	Canadian Virtual Hospice
EAPC	European Association of Palliative Care
EMBASE	Excerpta Medica dataBASE
EOL	End of Life
EoLC	End of life care
F	Female
HBAS	Hospice Beliefs and Attitudes Scale
HC	Hospice care
HCP	Healthcare professional
HINTS	Health Information National Trends Survey
HKT	Hospice Knowledge Test
HL	Health Literacy
HPC	Hospice Palliative Care
HPS-8	Hospice Philosophy Scale
IAHPC	International Association for Hospice and Palliative Care
IAPC	Indian Association of Palliative Care

Abbreviations	Terms in full
M	Male
MEDLINE	Medical Literature Analysis and Retrieval System Online
MMAT	Mixed methods appraisal tool
N	number
NCPC	National Council for Palliative Care, UK
NHS	National Health Service
NICE	National Institute for Health and Care Excellence, UK
NK	Not known
non-MESH	non-Medical Subject Headings
OPTIM	Outreach Palliative Care Trial of the Integrated Regional Model
OR	Odds ratio
PaCKS	Palliative Care Knowledge Scale
PC	Palliative care
PCA	Palliative Care Australia
PCNZ	Palliative Care New Zealand
PCU	Palliative care unit
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	The International Prospective Register of Systematic Reviews
SPC	Specialist Palliative Care
TV	Television
UK	United Kingdom
US	United States
WHO	World Health Organisation