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Inappropriate treatment at the end of life:

a systematic review of qualitative evidence

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2021

The NIHR Policy Research Programme Reviews Facility is a collaboration between the following:

EPPI Centre Evidence for Policy & Practice

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

UNIVERSITY of York

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Draft report following peer review
December 2021

This report should be cited as:

Lorenc T, Raine G, Khouja C, Rees R, Hinds K, Wright K, Sowden A, Sutcliffe K, Thomas J (2021)
Inappropriate treatment at the end of life: a systematic review of qualitative evidence
London: EPPI Centre, UCL Social Research Institute, UCL Institute of Education,
University College London.

Funding

This report is independent research commissioned by the National Institute for Health Research (NIHR) Policy Research Programme (PRP) for the Department of Health and Social Care (DHSC). It was funded through the NIHR PRP contract with the EPPI Centre at UCL (Reviews facility to support national policy development and implementation, PR-R6-0113-11003). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the DHSC.

Funder involvement

Department of Health and Social Care (DHSC) policy team members were consulted to understand the context of the issue under study, and collaborated on the development of the research question(s) and focus of the review.

Advisory Group membership

The review team were advised by Freddie Lewis (DHSC). There was no patient or public involvement work carried out as part of this review.

Acknowledgements and conflict of interest

There were no conflicts of interest in the writing of this report.

Guarantor of the review

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Editorial & design by: Lionel Openshaw

ISBN: 978-1-911605-27-0

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How to read this report

Because this is the technical report of a systematic review that uses transparent methods, some sections are necessarily detailed. Without compromising on the transparency that is expected of a systematic review, we have structured this report to help those who are more concerned with the findings than the methods. Part I contains the review's findings and implications, preceded by the background and a brief section on methods. The findings are split between two chapters. Chapter 3 presents an overview of the types of studies informing the review's findings. Chapter 4 contains the review's synthesis of these studies. Part I concludes with a discussion of the review's findings in the context of other existing work and an analysis of the review's strengths, limitations and implications. Part II contains additional detail about the review's methods and processes. A set of appendices contains the full details of the review's search strategy and study appraisal, as well as structured evidence tables for each included study.

Executive summary

Background

Population ageing is increasingly putting pressure on health and social care services towards the end of people's lives. However, a body of evidence identifies that a significant proportion of medical treatments given at the end of life in hospital may be inappropriate because they are non-beneficial. Failure to provide beneficial treatment is also a concern. This over- and undertreatment may lead to less than optimal care for patients near the end of life. The Department of Health and Social Care for England commissioned this systematic review of research evidence to explore potential explanations for the occurrence of over- and undertreatment. The review focuses in particular on patient, family and clinician views about influential factors.

Strategy documents to support high quality end of life care have been produced by various national bodies. The UK Department of Health's 2008 End of Life Care Strategy was one of the first produced by a national government. Along with other steps, the strategy emphasised that clinicians should discuss end of life care with patients as the end approaches, assess needs and plan care. They should also review these plans regularly, coordinate care and deliver high quality services. In 2016, in response to a review of the 2008 strategy, the government committed to ensuring that every person nearing the end of their life should receive attentive, high quality, compassionate care, so that their pain is eased, their spirits lifted and their wishes for their closing weeks, days and hours are respected.

Progress with end of life care in the UK since the 2008 strategy has been questioned and it appears that much is still to be done. Despite an increased focus on Advance Care Plans and Statements, many patients in end of life situations in the UK and elsewhere are still unlikely to have such a plan. Furthermore, the ageing of populations in many countries is expected to put increasing pressure on health and social care services, both in hospital and other care settings.

For the purposes of this review, inappropriate treatment is used as a catch-all term to refer both to overtreatment (delivery of treatments which are unlikely to be beneficial, in particular aggressive treatment with limited impact on survival or future quality of life) and undertreatment (failure to deliver beneficial treatments, for example, for pain or other symptoms).

Methods

We searched eight electronic databases and included any qualitative study focusing on over- or undertreatment for patients at or near the end of life. We conducted a thematic synthesis of the data. We assessed study reliability using a standardised tool and excluded less reliable studies from the synthesis. The synthesis was structured using the idea of influencing factors operating at different socio-economic levels. Themes were developed using findings from all the studies, but needed to be supported by at least two studies that were relatively recent (published within the last ten years) and from an OECD country (to help findings have greater relevance to a UK policy context).

Results

Twenty-nine studies were included in the synthesis. Twenty five studies collect views from clinicians, often (n=14) from those working in intensive care; four collect views from either patients (n=2) or carers (n=2). Just under half of the studies were conducted in the USA and only three studies contain findings from the UK. The kinds of patients being discussed by clinicians are often not described, but they include those who have been receiving treatment for cancer, who have end-stage or chronic kidney disease, or are comatose survivors of cardiac arrest. In terms of the life-span, two studies of clinicians' views limit their study to care for older patients, and two are focused on end of life treatments for children. The themes identified through synthesis of these studies are outlined below.

This review finds that inappropriate treatment, particularly overtreatment, at the end of life is recognised as a problem by patients and family members and as a substantial problem by many clinicians. Overtreatment is seen by clinicians as including treatments which do not improve quality of life, or where the benefit is outweighed by the suffering produced. This is seen to have negative consequences in terms of avoidable suffering for patients and distress for clinicians. However, it is recognised that judgements of what constitutes overtreatment are challenging to make in practice, and cannot be fully objective.

A range of factors are seen as contributing to overtreatment. Views from patients or families focus on interpersonal and individual influences related to attempts to minimise suffering in a context of uncertainty.

Clinicians refer to societal and organisational influences, as well as factors that are interpersonal and individual in nature. Their accounts also show how these influences can be interlinked. Clinicians report that they are sometimes unwilling to limit treatment due to their professional culture and sense of their own role, and see more palliative approaches to care as an admission of defeat. However, they are also aware of their own responsibility for life-and-death decisions, and aware of the limits to clinical knowledge, so that they can almost never rule out the possibility of recovery with total certainty. Some clinicians are also reluctant to limit treatment due to possible legal repercussions. They may also continue treatment which they know to be futile for a few days to allow family members to come to terms with the patient's imminent death.

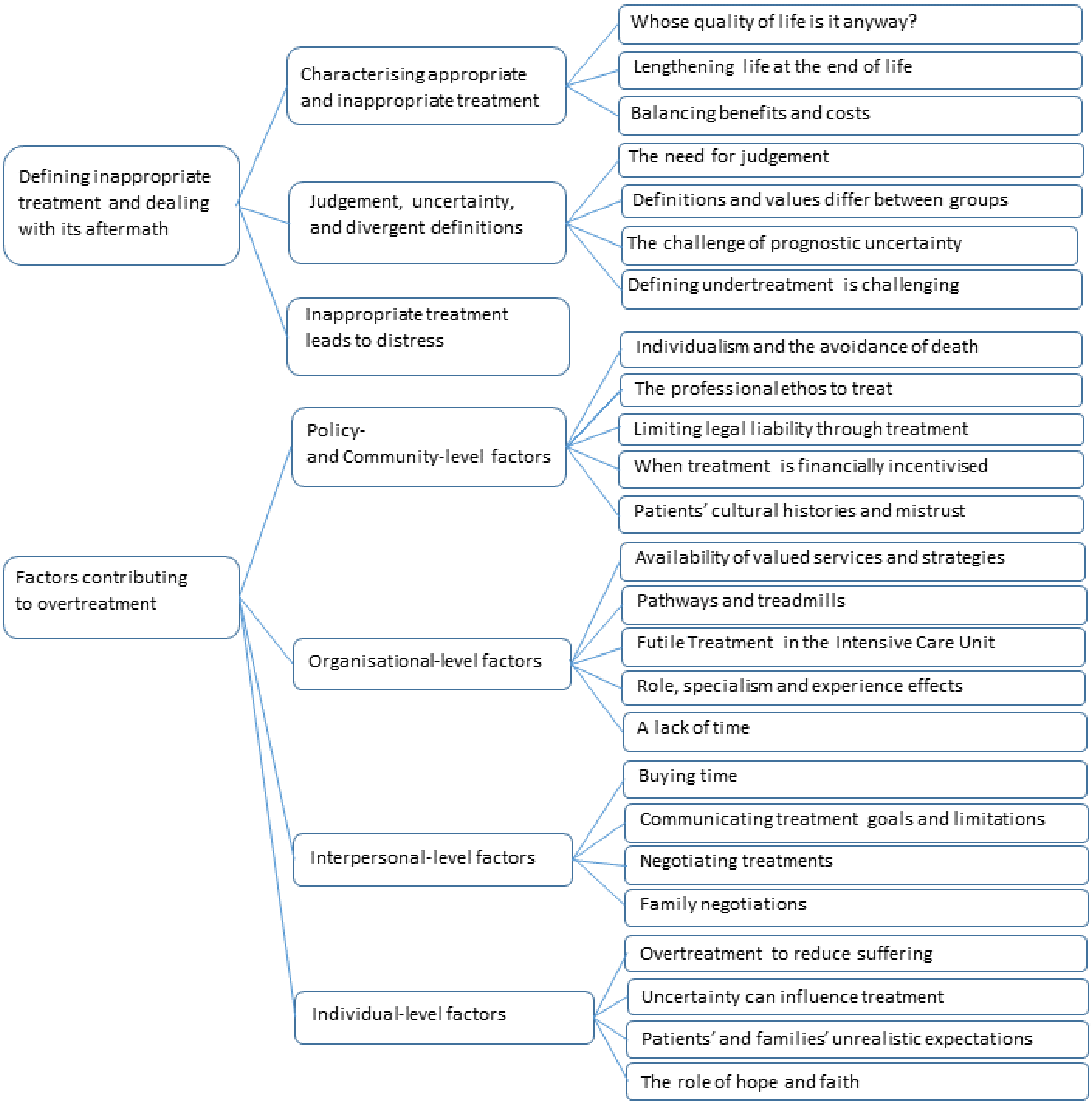
Doctors describe how they can have limited contact with patients due to their caseloads, and how nurses (who are closer to the patient and more aware of the negative impacts of continued treatment) can have limited input into decision-making. Patients with complex needs are often treated by multiple specialists, focusing on specific problems rather than overall quality of life, which can create a 'treadmill' effect whereby aggressive treatment creates a demand for more treatment further along the pathway. The Intensive Care Unit (ICU) is identified as a particular site for futile treatment.

The decision to limit or withdraw treatment requires communication with patients and families, which is both personally uncomfortable and time-consuming for clinicians. It is recounted how inaccurate information or vague communication may leave patients or families little choice but to request continued treatment. Clinicians report how patients and family members may be unwilling to give up hope, even when they recommend limiting treatment, and describe limits to understanding about the implications of continuing with treatment, or the probability of recovery.

Several of the same themes recur as potential causes of undertreatment (although the data is very limited). In particular, inadequate communication or limited contact between clinicians and patients may lead to poor pain management or early withdrawal of treatment.

It is important to recognise that the very limited data available on patients' and family members' own views means that this synthesis represents, in the main, the views of clinicians about inappropriate treatment at the end of life.

Figure 1. Structure of thematic codes



Discussion

To our knowledge this is the first review to synthesise study findings about people's views on inappropriate treatment. In terms of its strengths, we looked across a diverse range of sources and used a wide number of search terms to find potentially relevant studies. It is nonetheless possible that some studies will have been missed despite their containing relevant findings about inappropriate treatment, for example when the study's focus was broader and key terms relating to inappropriate treatment were missing from the study's title or abstract. This would only be of concern if the missing studies differed in significant ways from the ones we did identify. Very few studies were found that focused on undertreatment. Again, additional data might be gleaned from searches targeting specific clinical areas linked with undertreatment, such as pain management.

The review identifies considerable gaps in the evidence base. Particularly lacking are views from patients and family members, recent studies of nurses' perspectives, and studies conducted in the UK and in other settings outside the USA. The views of study participants were almost exclusively related to hospital settings, with no specific reference to treatment in residential or home care settings and only one study involving clinicians in hospices. The scarcity of studies from the UK means there may be issues of generalisability to the UK due to the different organisation of healthcare systems particularly in the USA.

Our synthesis of qualitative data suggests a range of factors that may lead to inappropriate treatment at the end of life and so contributes to discussions about potential targets for intervention. Further research could usefully explore, in particular, guidelines for ICU intervention, opportunities for enabling improved communication, both between clinicians and patients and within clinical teams, access to specialist services, improved coordination of care, and professional and public education initiatives.

Part I: Background, brief methods, findings and implications

1 BACKGROUND

The Office for National Statistics (ONS) predicts that annual deaths in England and Wales will increase by 27% between 2014 and 2040 (Bone et al., 2018). Population ageing is expected to put increasing pressure on health and social care services towards the end of people's lives, and has the potential to reverse recent trends away from deaths in hospital (Bone et al., 2018). There is also a body of evidence showing that medical treatments at the end of life in hospital may frequently be inappropriate, either being judged as overtreatment (Cardona-Morrell et al., 2016), or as insufficient (Rodriguez et al., 2010). The NIHR Policy Research Programme-funded Reviews Facility to support national policy development and implementation was commissioned by the Department of Health and Social Care for England to further explore research evidence in this area. We were asked to look at the qualitative research evidence to identify factors thought important by clinicians, patients and their friends and families.

1.1 Concepts and definitions

Inappropriate medical treatment can be defined as treatment not in accordance with best practice or applicable guidelines. It also contravenes accepted medical ethics, broadly conceived as following principles of non-maleficence (do no harm), beneficence, patient autonomy and justice. What this means in practice will vary widely depending on the clinical population in question, and on the setting and context of the delivery of care. In addition, what constitutes appropriate or inappropriate treatment may often be the subject of disagreement between clinicians and patients, and among clinicians (Bosslet et al., 2015; Wilkinson and Savulescu, 2011). Such decisions may not be consistently based on empirical evidence (Gabbay et al., 2010), and will also require a consideration of medical ethics (White and Pope, 2016). Many of these ethical debates happen over cases in ICUs since questions as to when to turn off life support systems have become increasingly complex in the light of technological advances and improvements in drug therapy (Almerud et al., 2008; Hofmann, 2002; Lewis and McConnell, 2018). Nonetheless, in the abstract, we can classify inappropriate treatment as consisting either of:

- **overtreatment,** or treatment which is unlikely to benefit the patient (including **futile** treatments, which are known to be of no benefit); or
- **undertreatment**, or the failure to deliver treatment which is likely to benefit the patient.

This project focuses on overtreatment and undertreatment at the end of life. Several documents help define End of Life Care for the UK context (see Section 1.2. below), although identifying when a patient may be near the end of their life continues to be clinically challenging in all settings (White et al., 2017). For the purposes of this review, where we explore a relatively sparse qualitative literature, we deliberately define end of life broadly to include patients in any setting who are near the end of life, and any patients in a care setting specialised for life-threatening or terminal illnesses, including both:

- **intensive care** or **critical care** services, which provide intensive treatment and monitoring for patients with life-threatening conditions; and

- **palliative care** or **hospice** services, which provide holistic care and relief from symptoms and improving quality of life.

Such services vary widely in terms of their underlying goals and philosophy of care, and in terms of the care pathways through which they are accessed by patients. They may be delivered in a range of clinical or non-clinical settings, and some in patients' homes (Dixon et al., 2015; Gao et al., 2018; Mosenthal et al., 2012).

Both overtreatment and undertreatment can occur when people are nearing the end of life, and clinicians, patients and their family members face challenges in determining the point at which treatments focused on sustaining life should give way to treatments focused on relieving pain and other symptoms. Overtreatment has been found to be widespread, with one systematic review finding that around 35% of patients near the end of life receive non-beneficial treatments (Cardona-Morrell et al., 2016); some evidence suggests that more aggressive treatments are associated with poorer quality of life for both patients and carers (Wright et al., 2008). Conversely, pain and other symptoms at the end of life may be undertreated (Rodriguez et al., 2010), leading to avoidable suffering for patients. Thus, both overtreatment and undertreatment may lead to worse outcomes for patients and their families or carers.

These issues raise complex ethical and social questions. Clinicians' judgements of what constitutes appropriate care may not always be made in consultation with patients and families; where they are, these judgements may conflict with patients' and families' wishes regarding treatment, and the latter may change over time (Auriemma et al., 2014). The question of how far patient autonomy should be respected in such situations, and whether futile treatments can be justified, has received considerable attention in the ethical and legal literature (Winkler et al., 2012; Moratti, 2009; Billings and Krakauer, 2011; White and Pope, 2016). Overtreatment may also incur substantial costs and mean that resources are unavailable for beneficial treatments (Huynh et al., 2013).

1.2 Policy context

Strategy documents to support high quality end of life care have been produced by various national bodies (for example, Australian Medical Association, 2014; Department of Health, 2008; Department of Health, 2016; Institute of Medicine, 2014). Other national level documents focused on end of life care that are relevant to the UK include those from the General Medical Council and the National Centre for Health and Care Excellence (General Medical Council, 2010; National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016; National Institute for Health Care Excellence, 2011).

The UK Department of Health's 2008 End of Life Care Strategy was one of the first produced by a national government. It defines end of life care as care that 'helps all those with advanced, progressive, incurable illness to live as well as possible until they die'. It continues, 'The strategy aims to enable the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support' (Department of Health, 2008). The 2008 strategy specifies a care pathway with various steps. As part of these, clinicians should discuss end of life care with patients as the end approaches, assess needs and plan care. They should also review these plans regularly, coordinate care and deliver high quality services. Separate steps in the pathway relate to care in the last days of life and care after death. The strategy emphasises the need for support for carers and families, and information and spiritual care for patients and families throughout. There is an emphasis in the strategy on the drawing up of Advance Care Plans or Advance Statements which set out the care that a patient would like to receive (for example, for the management of symptoms) over their last months, weeks, days or hours of life.

In 2016, in response to a review of the 2008 strategy, the government made the following commitment: 'every person nearing the end of their life should receive attentive, high quality, compassionate care, so that their pain is eased, their spirits lifted and their wishes for their closing weeks, days and hours are respected.' (Department of Health, 2016). They also committed to digital palliative and end of life care records by 2020; rating services for end of life care; supporting trusts to improve care; testing 'personal health budgets' to allow patients to choose care; measures to assess care; and changes to medical education to improve choice and care.

Many have questioned progress with end of life care in the UK since the 2008 strategy. Since its publication, several reports have highlighted high degrees of variation in the quality of end of life care services (Care Quality Commission, 2016; House of Commons Health Committee, 2015; Neuberger et al., 2013; Parliamentary Health Service Ombudsman, 2015). In particular, the review of the Liverpool Care Pathway identified a number of concerns with end of life care, including perceptions of inappropriate treatment (Neuberger et al., 2013). A 2012 report by the UK's National Confidential Enquiry into Patient Outcome and Death (2012) made clear the limitations of cardiopulmonary resuscitation and called for the appropriate use of do not attempt cardiopulmonary resuscitation (DNACPR) orders to reduce patient suffering and futile care (Findlay et al., 2012). Treatment withdrawal and futile treatment have been contributing factors in complaints about end of life care, as well as issues about communication and shared decision-making (NHS Improving Quality, 2013). Concerns continue, following the devolution of England's health and social care to local Government Authorities with the 2012 Health and Social Care Act (Sleeman et al., 2018). Initiatives to promote palliative care education for health care providers report progress (for example, Paal et al., 2019), but there appears much still to be done. Despite an increased focus on Advance Care Plans and Statements, many patients in end of life situations in the UK and elsewhere are still unlikely to have such a plan, especially if they are experiencing an illness without a clear terminal prognosis (De Vleminck et al., 2015; Detering et al., 2019; Garand et al., 2011).

1.3 Previous research

There is a substantial body of systematic review evidence (both quantitative and qualitative) on interventions to improve end of life care, particularly those focused on clarifying and communicating patient preferences. These include, for example, decision aids (Cardona-Morrell et al., 2017), Advance Care Planning programmes (Johnson et al., 2016; Lund et al., 2015; Jimenez et al., 2018), and broader initiatives to promote discussion of care preferences (Abba et al., 2013). These systematic reviews suggest that such interventions are broadly acceptable but tend to find mixed results on their effectiveness. They also identify a number of barriers to effective implementation, including lack of resources or organisational support, and the emotional difficulty of talking about death.

Reviews of qualitative evidence can add to this evidence base by illuminating the processes which may give rise to over- or undertreatment, and the ways inappropriate treatment is understood and experienced. A number of previous systematic reviews have included qualitative evidence relating to end of life care, focusing for example on: patients' preferences for place of death (Wahid et al., 2018); patient and carer experiences of withdrawing life-sustaining treatment (Coventry, 2017; Meeker and Jezewski, 2009); and clinician-patient communication (Barclay et al., 2011; Slort et al., 2011). However, they have not looked specifically at views or experiences relating to inappropriate intervention at the end of life. The aim of this review was to identify, assess and synthesise data from qualitative research about views or experiences of patients, clinicians, families or other stakeholders regarding under- and overtreatment at the end of life.

2 BRIEF METHODS

This section provides a brief overview of the methods used to conduct the review. A more complete description of the methods is provided in Part II of this report. Plans for this review were developed in consultation with members of the policy team at the Department of Health and Social Care.

Studies were identified in August 2018 from searching eight bibliographic databases and websites of key UK research groups, checking references within relevant systematic reviews and by identifying studies citing and cited by included studies. Databases were searched using a combination of controlled vocabulary and free-text terms.

Inclusion criteria were applied to identify relevant studies. To be included, studies needed to be reported in English and use qualitative methods. The studies also needed to explore views about or experiences of care delivered to patients who are near the end of life; and to report data about views related to treatment intensity, and about over- or undertreatment, inappropriate treatment or futile treatment.

Individual reviewers initially screened studies using titles and abstracts. Full texts of all citations included on title and abstract were retrieved and then screened again. Studies meeting the inclusion criteria were assessed for reliability and included only if they met our minimum standard for reliability. Information about study features, such as the population, study setting and research methods used, were captured from each included study and study findings were synthesised thematically. An initial framework was used to classify findings into those contributing to over- and undertreatment and factors helping to reduce each; further domains were added as coding progressed. Ultimately, the narrative was organised so as to group factors roughly by socio-ecological level – societal, organisational, interpersonal and individual (Bronfenbrenner, 1977).

A total of 6,968 references were screened. After screening on abstract and full text, 41 studies were included in the review. After application of the reliability assessment threshold a total of 29 studies was finally included in the synthesis.

3 THE EVIDENCE BASE FOR VIEWS ABOUT INAPPROPRIATE TREATMENT AT THE END OF LIFE – OVERVIEW OF IDENTIFIED STUDIES

The focus of most of the 29 included studies (n=27) is overtreatment, with only five studies exploring undertreatment (Belcher, 2013; Dale et al., 2016; Jablonski and Duke, 2012; Sheard et al., 2012; Workman et al., 2003). Just under half (n=14, 48%) of the studies report data from the USA. Three are from the UK (Grubbs et al., 2017; Kitzinger and Kitzinger, 2013; Sheard et al., 2012) with one – Grubbs et al. (2017) – reporting from both the UK and USA. Countries from the OECD are otherwise represented by Canada (n=4) Australia (n=2), Germany (n=2), The Netherlands (n=1), Norway (n=1) and Ireland (n=1). Perspectives are provided also by studies from Iran (n=1) and from Malta (n=1).

Most of the studies (n=25) investigate the views of clinicians solely. Between them these studies address a range of hospital settings, but only one (Sheard et al., 2012) sought the views of clinicians based outside of hospitals (these participants include those based in general practice and hospices as well). Just under half (n=14) of the studies recruited clinicians are working in Intensive Care or focus upon that setting.

The kinds of patients being discussed by clinicians are not always described, but they include those who have been receiving treatment for cancer (n=4), who have end-stage or chronic kidney disease (n=2), or are comatose survivors of cardiac arrest (n=1). In terms of patients' life-span, two studies of clinicians' views limit their study to care for older patients, and two are focused on end of life treatments for children.

Only four studies report views data from patients (n=2) or family members (n=2). The two studies of patients' views recruited people with Motor Neurone disease (Foley et al., 2014) and older patients from an outpatient clinic (Rodriguez et al., 2010). The views of family members had been sought in relation to patients with severe brain-injury (Kitzinger and Kitzinger, 2013) or to those who were more generally critically ill (Zier et al., 2009). One of these studies also interviewed clinicians (Rodriguez et al., 2010).

A good proportion (n=20, 69%) of the 29 studies have been conducted in the last ten years, but noticeably, relatively few of these more recent studies (n=3) have focused on nurses' views. Full study characteristics are presented in the evidence tables in Appendix D; Table 1 below provides a summary.

Table 1. Summary of study characteristics

Reference	**Topic focus and population from whom views were sought** (focus was overtreatment only, unless otherwise indicated)	**Country**
Aghabarary and Nayeri (2017)	Futile treatment Interviews with nurses (primarily) and doctors	Iran
Belcher (2013)	Futile treatment; moral distress (very premature neonates)** Interviews with nurses working in Intensive Care	USA
Bellmore (1995)	Futile treatment Interviews with nurses working in Intensive Care	USA
Bluhm et al. (2016)	Late chemotherapy Interviews with Oncologists	USA
Cauley et al. (2016)	Non-beneficial surgery Interviews with Emergency general surgeons	USA
Dale et al. (2016)	Early withdrawal of life support following cardiac arrest** Interviews with nurses and doctors working in Intensive Care	Canada
Dzeng et al. (2016)	Futile treatment; moral distress Interviews with trainee doctors (internal medicine)	USA
Dzeng et al. (2018)	Influences of systems and individuals on resuscitation, and end of life treatment more generally Interviews with doctors (internal medicine)	USA
Foley et al. (2014)	Engagement with healthcare services Interviews with patients	Ireland
Gallois et al. (2015); White et al. (2016); Willmott et al. (2016)	Futile treatment Interviews with doctors from a range of specialities that routinely deliver end-of-life care	Australia
Grech et al. (2018)	End of Life care Interviews with nurses	Malta

Grubbs et al. (2017)	System-level barriers and facilitators for foregoing or withdrawing dialysis Interviews with nephrologists	England and USA
Heland (2006)	Futile treatment Interviews with nurses working in Intensive Care	Australia
Jablonski and Duke (2012)	Effective pain management in rural settings* Interviews with nurses	USA
Jox et al. (2012)	Futile treatment Interviews with nurses and doctors	Germany
Kitzinger and Kitzinger (2013)	Use of life-sustaining treatments against family wishes Interviews with family members	England and Wales
Ladin et al. (2018a); Ladin et al. (2018b)	Conservative management in advanced chronic kidney disease Interviews with nephrologists	USA
Laryionava et al. (2018)	Reasons for aggressive chemotherapy treatment Interviews with nurses in Intensive/Palliative Care and oncologists	Germany
Meyers (1994)	Moral distress Interviews with nurses working in Intensive Care	USA
Morris et al. (2018)	Shared decision-making about surgery Interviews with surgeons of varied types	USA
Oerlemans et al. (2015)	Ethical dilemmas relating to ICU admission and discharge Interviews with doctors and nurses	Netherlands
Rodriguez and Young (2006)	Futile treatment Interviews with older patients	USA
Saettele and Kras (2013)	Futile treatment Interviews with trainee and attending anaestheologists	USA
Sheard et al. (2012)	Diagnostic and treatment barriers** Interviews with doctors in oncology, palliative medicine and general practice	England and Wales

Sibbald et al. (2007)	Futile treatment Interviews with nurses, doctors and respiratory therapists (all working in Intensive Care)	Canada
Simmonds (1996a); Simmonds (1996b); Simmonds (1997)	Experiences of work in the ICU Interviews with nurses and doctors (trainee and attending)	Canada
Sørlie et al. (2000)	Ethical reasoning in difficult situations Interviews with female Paediatricians	Norway
Workman (1998); Workman et al. (2003)	Treatment withdrawal; futile treatment** Interviews with nurses and doctors working in Intensive Care	Canada
Zier et al. (2009)	Surrogates' attitudes to doctors' judgements of futility and treatment withdrawal Interviews with family members	USA

Key: ICU – Intensive Care Unit; * study focuses on undertreatment only;
** study focuses on both over- and undertreatment

4 FINDINGS ABOUT PEOPLES' VIEWS OF INAPPROPRIATE TREATMENT

The analysis is presented here in two parts. The first contains findings about how people define inappropriate treatment and talk about its impacts. Notably, nearly all the participants providing definitions are clinicians, and most of these clinicians are doctors, rather than nurses. The second contains findings about factors that are implicated in such treatment. Each part contains further themes and sub-themes. Figure 1 below lists the themes and the following sections discuss each theme in turn. In each section, patient and family/carer views are presented first when these are available, before those of clinicians.

4.1 Defining inappropriate treatment, and dealing with its aftermath

4.1.1 Characterising appropriate and inappropriate treatment

As the themes below illustrate, when participants describe end of life treatment, they identify valued experiences and goals, as well as aspects to be avoided. Judgements about potential futility are recognised to be partly subjective. Quality of life and brief extensions of life are emphasised as aims that can make treatment appropriate, but harms to patients and other costs are also identified as important considerations.

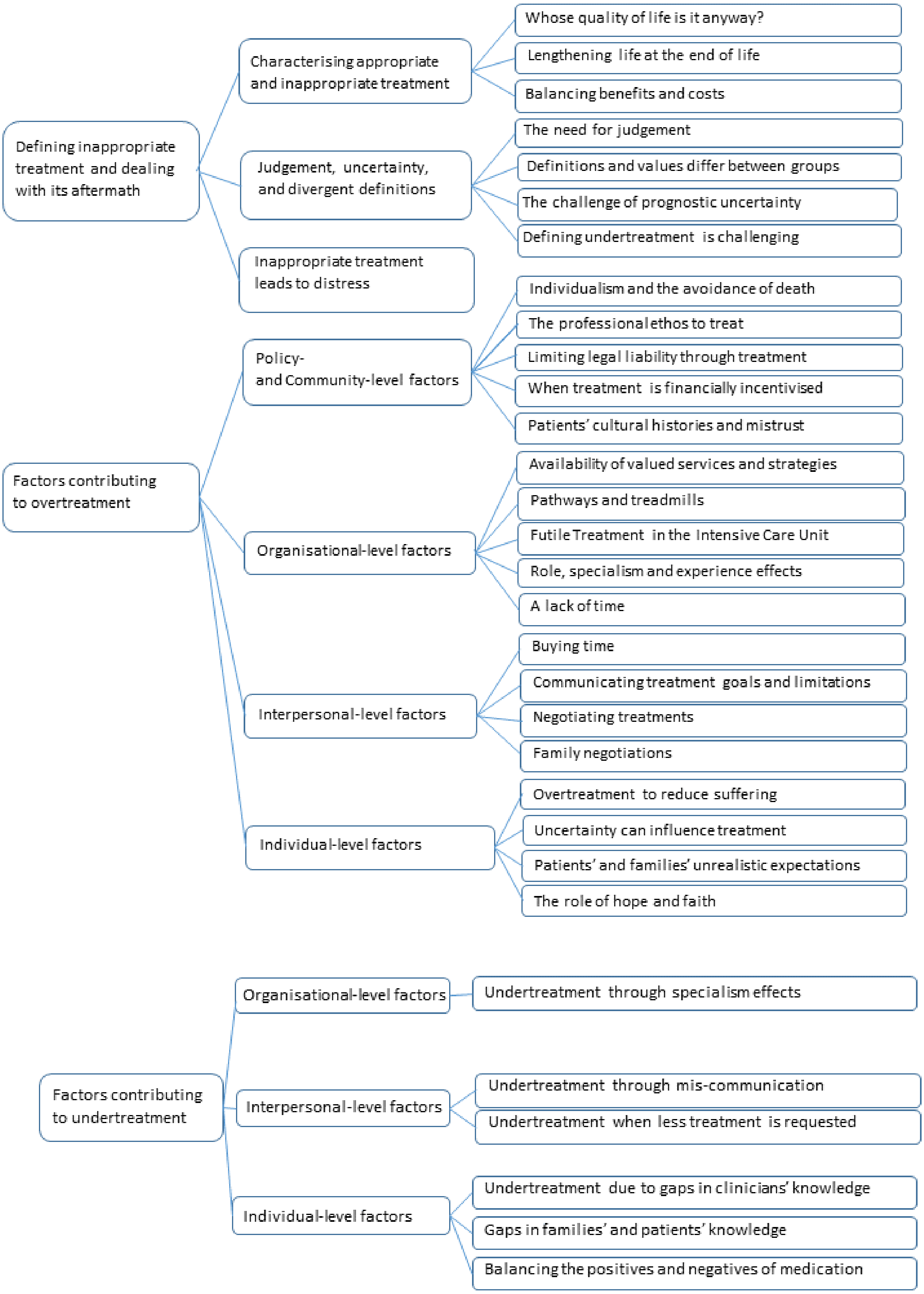
4.1.1.1 Whose quality of life is it anyway?

In one study of patients which focused on treatment futility, older primary care patients are reported as emphasising the importance of quality of life, using phrases such as 'not what I would consider life', and 'nothing to look forward to' (Rodriguez and Young, 2006). Futile treatment is defined by these patients in terms of not allowing function at a level that a person would personally find acceptable. Many clinicians also focus on quality of life in descriptions of what constitutes overtreatment (Cauley et al., 2016; Dale et al., 2016; Heland, 2006; Jox et al., 2012; Ladin et al., 2018b; Oerlemans et al., 2015; Saettele and Kras, 2013; Sibbald et al., 2007; White et al., 2016). Similarly, many clinicians view the patient's wishes and values around life quality to be the most important consideration, but note that these might not be immediately obvious:

'Well, the absolute indication, I think, is quality of life, and this can only be decided by the patient herself' [Intensive Care Nurse, Germany] (Jox et al., 2012).

'To a large extent it is our interpretation of such an existence, or of that quality of life, of which we think – well, is that worth the effort? Even though at such an acute time, that could be completely different for the family or the patient. I have a couple of patients that, well, literally are unable to do anything but lie in bed all day without consciousness but the family still considers it to be very meaningful.' [General Ward Physician, Netherlands] (Oerlemans et al., 2015).

Figure 1. Structure of thematic codes



4.1.1.2 Lengthening life at the end of life

In the two studies of patients' perspectives, little support is expressed for certain life-sustaining treatments. In one, patients with motor neurone disease question the use of treatments such as assisted ventilation (Foley et al., 2014). Some consider both gastrostomy and non-invasive ventilation to be overtreatment, and none wish to be kept alive long-term with these techniques:

'I felt I was rushed into it [gastrostomy feed]. I would have liked more time to have thought about it... when you get to that stage, what's the point... It's just a life line for the medics to put in food and drugs... to sustain life beyond what it should be.' [Person with Motor Neurone Disease, Ireland] (Foley et al., 2014).

In the other study, older primary care patients generally express support for short-term treatment in order to improve the chance of survival, but in many cases regard long-term life-sustaining treatment as overtreatment:

'If I only need oxygen, okay, and not a defibrillator or any drastic measures to keep me alive, ... okay, I'd go along with that. I don't want to go to anything too drastic, like the breathing machine that breathes for you, the ventilator, and things like that. If there is no hope for me to get better, ... then I would like to have it end.' [Primary care patient aged 60+, USA] (Rodriguez and Young, 2006).

Treatment impacts on survival and length of life are also mentioned by clinicians as defining characteristics of inappropriate treatment. Some clinicians suggest that overtreatment includes any treatment with little benefit either in terms of survival or quality of life (Bluhm et al., 2016; Grubbs et al., 2017; Jox et al., 2012; Meyers, 1994; Sheard et al., 2012; White et al., 2016; Workman, 1998).

'Treatment that's not going to improve a patient's longevity or quality of life essentially. [...] I don't think you should provide it just for the sake of providing it... you've got to provide treatment that's actually going to have some benefit, and if you can't achieve that, then what are you doing it for?' [Cardiology Consultant, Australia] (White et al., 2016).

4.1.1.3 Balancing benefits and costs

Overtreatment is also commonly referred to as a balancing act. In one study family members describe a desire to prevent short-term distress and pain but fear life-sustaining interventions could in the long-term work against a loved one's best interests (Kitzinger and Kitzinger, 2013). In another, patients emphasise the need to balance the potential for increased longevity with reduced quality of life [also see 'Inappropriate treatment leads to distress' below].

'She's had a lung collapsed, she's had C Diff [clostridium difficile] five times... She's had pneumonia. She had to have a defib [defibrillator] fitted. She had a NG [nasal gastric] tube pushed down her nose for five months which kept coming out. And that's traumatic in itself. Having that pushed down all the time you know... Amy feels pain.' [Family member of patient with severe brain injury, UK] (Kitzinger and Kitzinger, 2013).

'I do wonder a lot, I'm saying why are they [healthcare professionals] keeping me alive for longer, why don't they just let me fade away, you know the end is going to be the same when it comes, so why prolong the suffering.' [Person with Motor Neurone Disease, Ireland] (Foley et al., 2014).

The idea of futile treatments is often associated with concerns about wasted resources. This is seen among the patients in one study who use phrases such as, 'corpse lying there taking up space' and 'a waste of time and money' (Rodriguez and Young, 2006), and in a number of studies of clinician's views (Jox et al., 2012; Saettele and Kras, 2013; White et al., 2016).

Clinicians also suggest that overtreatment occurs when any benefits to patients are outweighed by the harms they experience (Cauley et al., 2016; Jox et al., 2012; White et al., 2016; Workman, 1998). Several studies also find that clinicians are aware of the cost impacts of overtreatment, and may be frustrated by the misdirection of scarce resources to futile care – both money and other resources such as blood – (Aghabarary and Nayeri, 2017; Bellmore, 1995; Dzeng et al., 2016; Gallois et al., 2015; Grech et al., 2018; Meyers, 1994).

4.1.2 Judgement, uncertainty, and divergent definitions

A range of participants point out the subjectivity involved in defining treatments as futile. Clinicians and patients, or their families, or even different types of clinician might take different positions on what constitutes inappropriate treatment. Clinicians describe how uncertainty over treatment effects can add to this complicated mix.

4.1.2.1 The need for judgement

Patients and healthcare providers alike report that value judgements about what constitutes an acceptable quality of life are a necessary part of decisions on whether to attempt or forgo the initiation of life sustaining interventions, and that different aspects of quality of life would be valued by different people (Rodriguez and Young, 2006).

Similarly, many clinicians observe that deciding whether a given treatment constitutes overtreatment involves an irreducible element of subjectivity or clinical judgement, and that placing emphasis on different factors may lead to different decisions (Bluhm et al., 2016; Heland, 2006; Morris et al., 2018; Oerlemans et al., 2015; White et al., 2016).

'[F]or me it's kind of a slippery slope, because they're not really well-defined terms you know, what futility is. I think futility is a very subjective concept and what you consider futile can be very meaningful for me, very valuable, just, ... that's the way it is for such a patient too.' [General ward physician, Netherlands] (Oerlemans et al., 2015).

'Even within our department we have different views on what is futility. You may think it is futile, but the family may not. So where we draw the line: that is the basic problem. There is a conflict everywhere.' [Renal physician, Australia] (White et al., 2016).

4.1.2.2 Definitions and values differ between groups

Not surprisingly, given views on the need for judgement, there seem to be differences between the views of clinicians and others as to what constitutes futility. In this body of literature, patients, but not clinicians, are reported to emphasise the value of avoiding end of life treatments that could add to the burden or financial strain for family members (Rodriguez and Young, 2006). Clinicians, but not patients or carers mention that continued treatment may generate clinical knowledge, either in the sense of offering learning experiences for individual clinicians or understanding of new clinical techniques, even where it is not of benefit to the patient (Aghabarary and Nayeri, 2017; Dzeng et al., 2016; Saettele and Kras, 2013; Simmonds, 1996b).

Similarly clinicians alone mention the probability of success or failure of interventions (Rodriguez and Young, 2006), or specific patient characteristics as indicators of the futility of continued treatment, such as the severity of their disease or the presence of extensive comorbidities (Heland, 2006; Jox et al., 2012; Morris et al., 2018; Saettele and Kras, 2013; Sibbald et al., 2007; White et al., 2016). These participants suggest that appropriateness of treatment needs to be viewed in the context of a complete clinical picture which may reflect factors such as the patient's age, frailty and general status.

'Futile would mean that there is no chance that the intervention will alter the outcome, and the outcome is death.' [Surgeon, USA] (Morris et al., 2018).

4.1.2.3 The challenge of prognostic uncertainty

Clinicians recount being aware of the limitations of clinical knowledge, identifying that judgements of futility are never absolutely certain:

'You don't know if something is going to fail or succeed until you try it. We haven't got anywhere near a lens of 100 per cent prediction to determine whether a treatment is going to be a benefit or not. Sometimes, not often, but sometimes you're surprised at what does work or doesn't work.' [Oncology consultant, Australia] (Willmott et al., 2016).

Similarly, several clinicians point to cases (either in their own experience or heard second hand) where further treatment was judged to be futile, and then the patient made a full recovery:

'You hear the attending physicians talk about that one person who really wanted treatment and they thought, there's no way they're ever gonna benefit from this. And sure enough, their disease responds and they have control, and the lung cancer patient that you thought was gonna be dead in two months is now alive at two years. I mean they're not many here. You can count [them] on one hand. But there's always that story.' [Oncologist, USA] (Bluhm et al., 2016).

4.1.2.4 Defining undertreatment is challenging

Participants report challenges in distinguishing between over- and undertreatment. This is particularly evident in the study by Sheard et al. (2012), which focuses on doctors' experiences of treating cancer patients at risk of deep-vein thrombosis (DVT); pulmonary embolism (PE) or venous thromboembolism (VTE). Some doctors report the perception that where death is certain, a PE is a relatively 'good' way to die and preventive treatment is not appropriate, while others argue that it should be avoided, and that PE or DVT should be actively managed. In other words, some participants argue that not managing DVT is undertreatment, and others that managing it actively is overtreatment.

‘Do you want to be treating people with VTE and PE and do you want to be running around and looking for it in cancer patients with very bad prognosis and very little time to live? No. Should I be giving them all low molecular weight heparin injections into their stomach when they are dying? No, I don’t think so.’ [Oncology consultant, UK] (Sheard et al., 2012).

‘I’m actively looking to treat anybody who has a PE or DVT because obviously my perspective is that I see people with either horribly unmanaged DVTs or who become very, very breathless with what I presume is a PE and I don’t see that as a good way to die.’ [Palliative Medicine Consultant, UK] (Sheard et al., 2012).

It should also be borne in mind that over- and undertreatment can also happen at the same time, for example when a patient is receiving both overly aggressive treatment, and also has pain which is inadequately managed (Belcher, 2013).

4.1.3 Inappropriate treatment leads to distress

Running through the studies are accounts of the difficult consequences and dilemmas of overtreatment. Views on the consequences of futile treatment from those other than clinicians are scarce, although in one study, family members report regretting their past decisions to pursue treatment, and some expressed anger at clinicians (Kitzinger and Kitzinger, 2013).

Many studies report extensive data on clinicians’ (and in a few cases patients’ or family members’) views of the impacts of overtreatment. Clinicians in ten studies discuss the suffering caused to patients by overtreatment, using words such as ‘*cruelty*’ and ‘*torture*’ to characterise impacts (Aghabarary and Nayeri, 2017; Belcher, 2013; Bellmore, 1995; Dzeng et al., 2016; Grech et al., 2018; Sheard et al., 2012; Simmonds, 1996b; Sørlie et al., 2000; Workman, 1998; Kitzinger and Kitzinger, 2013).

‘We spend a lot of time at the end of life in the ICU torturing our patients and so, I can’t in good conscience say that our current system really seems to serve the best interests of the patient because, we torture them before they die, even though we know that they are going to die.’ [USA Internal Medicine trainee] (Dzeng et al., 2016).

Overtreatment is seen as a needless prolonging of the dying process (Aghabarary and Nayeri, 2017; Bellmore, 1995; Sheard et al., 2012; Simmonds, 1996b). Suffering may arise from pain, or where pain is well controlled, for other reasons such as bed sores and thirst (Workman, 1998).

Clinician participants discuss the emotional impacts of delivering care they perceive to be futile, including a sense of anger, frustration or guilt, which is referred to in the literature as ‘moral distress’ (Belcher, 2013; Bellmore, 1995; Dale et al., 2016; Dzeng et al., 2016; Grech et al., 2018; Heland, 2006; Ladin et al., 2018a; Meyers, 1994; Simmonds, 1996a; Workman, 1998). Clinicians in three studies report that they had left or considered leaving their jobs due to ‘burnout’ caused at least partly by moral distress (Heland, 2006; Meyers, 1994; Simmonds, 1996b).

The infliction of needless suffering on patients would be distressing to witness in any case, but the sense that one is complicit in perpetuating this suffering creates an additional dimension of conflict and guilt. For many clinicians, it also goes against their education and values as professionals dedicated to the reduction of suffering (Workman, 1998). This may be exacerbated where clinicians feel powerless to address the situation, or feel that they have limited autonomy within the clinical team (Belcher, 2013; Dzeng et al., 2016; Meyers, 1994).

The limitations of clinical knowledge may also be a driver of the distress experienced by clinicians:

‘I mean, when it’s clearly futile then there’s never any problem, either for me or for the families... unless they’re totally obstinate, you know, you’ve lost trust and they don’t believe you and they are hostile and have other issues. But the difficult ones for me personally are the ones of prognostic uncertainty.’ [Intensive Care Physician, Canada] (Workman, 1998).

4.2 Factors contributing to overtreatment

The following section describes the factors seen as influencing overtreatment by either patients or their family members, or clinicians.

4.2.1 Policy and community-level factors

This sub-section presents themes that relate to views about influences arising from the societal contexts in which end of life care is set. Two studies aimed explicitly to identify views on system-level influences on futile care (Dzeng et al., 2018; Grubbs et al., 2017) and these studies feature in this and the following section (on features related to hospital organisation and practices) in particular. Views are available only from clinicians; no studies capture patient or family views on influences acting at the societal level. As the sub-sections below illustrate, doctor and nurse participants in studies conducted both inside and outside the USA, relate overtreatment pressures to societal attitudes to death, and to technological advances and a fear of lawsuits. They report that clinicians’ professional ethos can lead to a focus on active treatment, and some see limiting or withdrawing treatment as failure. The lure of financial rewards and mistrust among certain patient groups is also raised by physicians working mainly in the USA.

4.2.1.1 Individualism and the avoidance of death

Physicians identify several factors in the broader culture which may influence the use of treatments inappropriately. Two USA studies suggest that acceptance of patient or family demands for aggressive treatment reflect a more general set of norms around patient autonomy (Dzeng et al., 2016; Dzeng et al., 2018); the authors suggest this may be linked to a more general set of ‘*values of liberal individualism and the primacy of choice, which is oftentimes equated with autonomy*’ (authors (Dzeng et al., 2018)).

‘I think it’s really tough. It’s this American value that patients get to dictate. I do think you should have some say in how you end your life, that’s the right of the patient. But it’s difficult when the decision is to have everything done. And you’re wondering, what are we doing? We’re spending all of these resources, all of this money on somebody that is clearly not going to benefit from it.’ [Internal Medicine trainee, USA] (Dzeng et al., 2016).

A few participants also implicate a more general social pattern of avoidance of death:

‘There’s a fear of death and people will do something driven by the desire to do something for the patient, driven by the desire for them to look a bit smarter. People will concentrate on a small issue and treat them.' [Emergency Medicine consultant, Australia] (Willmott et al., 2016).

More broadly, the default presumption of aggressive care may reflect a broader set of values which prioritise saving life over the avoidance of suffering, although the data do not explore this idea in any detail.

'There is the medical culture, academic culture and then the bigger cultural picture of Western medicine and kind of this life at all costs.' [Surgeon, USA] (Morris et al., 2018).

4.2.1.2 The professional ethos to treat

Physicians, but also nurses, in 11 studies report drivers of overtreatment that have to do with their professional culture or ethos, or their sense of their own role (Bellmore, 1995; Bluhm et al., 2016; Cauley et al., 2016; Grubbs et al., 2017; Jox et al., 2012; Ladin et al., 2018a; Morris et al., 2018; Saettele and Kras, 2013; Simmonds, 1996b; Willmott et al., 2016; Workman, 1998). Clinicians see their training and professional values as focused on taking action to help patients, which can be a barrier to accepting that treatment is no longer worth continuing. Taking the decision to limit treatment is sometimes seen as an abdication of their role, or as contradicting their professional ethos.

'[Doctors are] trained to treat. You don't learn – you learn how to treat and it's easy to treat.' [Geriatric Medicine consultant, Australia] (Willmott et al., 2016).

This may be a driver of aggressive treatment, particularly in conjunction with the perception that conservative and palliative care amount to failure or to giving up hope. It may often also be linked with an institutional culture in which the default setting is to provide aggressive care, and to a focus on narrowly disease-led treatment endpoints, rather than broader goals of care (see 'Organisational-level factors' below).

'The thought that conservative care is no treatment is a [stopping] point for conservative care. It sort of feels like… giving up.' [Nephrologist, USA] (Ladin et al., 2018a).

'I wonder if some of it is just a failure… a terrible failure of their skills, that they're there to save people and get people better and every death is a failure. I know a consultant who will do anything to avoid having the patient die in their service, and will preferably give them to someone else to die.' [Internal Medicine consultant, USA] (Willmott et al., 2016).

Some clinicians also link this culture to an overemphasis on advanced technology, where the availability of drugs or devices leads to a presumption in favour of their use, even where the chance of real benefit is limited (Belcher, 2013; Dzeng et al., 2018; Gallois et al., 2015; Grubbs et al., 2017; Oerlemans et al., 2015; Simmonds, 1996b). There is a perception that patients who would at one time have received palliative care are now undergoing aggressive treatment simply because it is technically possible (Belcher, 2013; Grubbs et al., 2017; Oerlemans et al., 2015).

4.2.1.3 Limiting legal liability through treatment

Participants in nine studies suggest that clinicians may aggressively treat patients at the end of life because they fear the potential legal implications of limiting treatment (Aghabarary and Nayeri, 2017; Dzeng et al., 2016; Dzeng et al., 2018; Meyers, 1994; Morris et al., 2018; Saettele and Kras, 2013; Sibbald et al., 2007; Simmonds, 1996b; Willmott et al., 2016; Workman, 1998). Participants in two studies mention that hospital management may exert pressure on clinicians to continue treatment due to a fear of legal liability and/or negative public perceptions (Grubbs et al., 2017; Workman, 1998). In some cases, this appears based on direct experience of threats of legal action, although in most cases it appears to be largely a hypothetical concern:

‘[T]he hospital does not want to create a scene. They never say lawsuit. You do not want to upset the family members for even patients who are in all senses dead already. And so you just, if the family still pushes for it to go ahead, do as much as you do, not necessarily wanting to.’ [Internal Medicine physician, USA] (Dzeng et al., 2018).

One participant suggests that the concern about legal liability needs to be seen in the context of managing relationships with patients and families, rather than a direct fear of being sued:

‘I wanted to avoid escalation, yeah. I know that you could argue, well why should you produce – you know, ... we shouldn’t have people telling doctors to provide futile care simply to avoid a legal confrontation. But well that’s all nice sitting in the ivory tower, but I think you’ve got to take it into context... If we think okay, let’s just give these people another week and have further discussions with them and get them to understand that this is the way to go, I think then that’s a better outcome. Because then they don’t lose, you know, there’s not a complete disruption in the relationship between us. In fact if anything we parted on, I think, pretty amicable terms.’ [Internal Medicine Consultant, Australia] (Willmott et al., 2016).

4.2.1.4 When treatment is financially incentivised

Surgeons in one USA study mention a sense that they are largely insulated from the financial impacts of clinical decisions:

‘[W]e’re pretty separated from the financial impact of most of these operations [...] I know from my own experience and family members that there’s a bill at the end of all of that. And some can afford it and some can’t. But we’re somewhat isolated from it.’ [Surgeon, USA] (Morris et al., 2018).

However other clinicians identify that clinicians can have a vested financial interest in continuing to treat patients (Aghabarary and Nayeri, 2017; Grubbs et al., 2017; Ladin et al., 2018a; Ladin et al., 2018b; Simmonds, 1996b). These findings are from Iran and the USA. One study comparing USA and UK nephrologists finds that this is a substantial theme for the former but not an issue for the latter (Grubbs et al., 2017). Most of these studies also are focused on dialysis (Grubbs et al., 2017; Ladin et al., 2018a; Ladin et al., 2018b). End-stage kidney disease is one of the only disease-specific entitlements to USA government healthcare.

‘There is a huge conflict of interest from the nephrology perspective, because frankly we’re getting paid for this and at times, I think that really gets in the way’ [Nephrologist, USA] (Grubbs et al., 2017).

While this point is made explicitly only in a handful of studies, it is possible that it is under-reported due to social desirability bias. One Canadian study reports that one participant ‘ask[ed] to have the tape recorder turned off, prior to discussing the significant financial incentive for some physicians to continue treatment’ [Authors] (Workman, 1998).

Related to this are concerns about the structure of reimbursement. In one study, USA participants mention that the quality metrics used to determine payment do not pay sufficient attention to patient experience, and in particular disincentivise doctors from spending time having conversations with patients (Grubbs et al., 2017).

‘We’re focused on hitting guidelines and targets but until very recently, the patient experience isn’t part of anything that we get incentivized for’ [Nephrologist, USA] (Grubbs et al., 2017).

4.2.1.5 Patients’ cultural histories and mistrust

Clinicians in four studies report that patients and families’ distrust of clinicians or the healthcare system in general may be a factor in overtreatment (Dzeng et al., 2018; Grubbs et al., 2017; Ladin et al., 2018a; Workman, 1998). Much of this evidence is descriptive and does not clarify why trust breaks down. However, two USA studies find that mistrust is seen to be particularly an issue with black and minority ethnic patients (Dzeng et al., 2018; Grubbs et al., 2017).

‘There’s a large Ethiopian and Somalian population around this area. I’ve had families tell me that their loved ones want to be DNR but their families absolutely refuse to allow it. Once they are no longer able to make their own decisions, they quickly reverse their loved one’s wishes. People in their community [and] church told them, ‘do not let the doctors kill off your loved one’ because they’re poor and black and do not speak English.’ [Internal Medicine Physician, USA] (Dzeng et al., 2018).

‘[U]p until the late 1960s or 1970s, people of African American heritage were not very trusting for a good reason... It’s not that way anymore, but there are people still alive today that remember the 60s and find it very difficult to give their trust in a physician that comes out of that system.’ [Nephrologist, USA] (Grubbs et al., 2017).

4.2.2 Organisational-level factors

This sub-section presents themes that relate to perceptions of hospital and health service organisation as influences on inappropriate treatment. Views are available only from clinicians. The sub-sections illustrate how valued services, including those that provide palliative care, are sometimes said to be unavailable. Physicians identify how rapid, cascading treatments can reduce options for palliative approaches and how the ICU is a particular site for futile treatment. Nurses contrast their role with that of doctors, seeing the latter as more oriented towards treatment and less aware of patient suffering, but differences between types of doctors are also reported. Doctors report having a lack of time for patients who are at the end of life, due to caseloads.

4.2.2.1 Availability of valued services and strategies

Participants in one study identify the availability of dedicated palliative care or hospice services as an important factor in reducing overtreatment (Grubbs et al., 2017). However, problems with referral to appropriate services may discourage clinicians from moving towards palliative care and clinical palliative services may be unavailable (Aghabarary and Nayeri, 2017; Cauley et al., 2016). Clinicians in departments treating end of life patients, such as intensive care or oncology can be unaware of the services which exist (Cauley et al., 2016; Grech et al., 2018; Jox et al., 2012). More specifically, USA data in one study suggest that the hospices' policy of requiring abrupt withdrawal of dialysis treatment is a barrier for those who prefer a more gradual transition (Grubbs et al., 2017).

Several strategies at an organisational level are mentioned as potentially helpful. Most of these aim to improve communication with patients, including: dedicated full-time care managers who specialise in having treatment discussions with patients (Ladin et al., 2018a); 'rapid response teams' which allow early discussion of treatment options and can help to avoid patients moving to the ICU (Sibbald et al., 2007); and consensus meetings between staff involved in providing care (Grubbs et al., 2017). However, there is limited information in the studies about how these interventions work (see also a discussion of guidelines in 'Futile treatment in the ICU' below).

Clinicians in several studies report that there is limited support available to help them work through problems dealing with the emotional impacts of futile care, either formally or informally (Bellmore, 1995; Meyers, 1994; Sørlie et al., 2000). However, some participants express positive views of services such as counselling, ethics consultations or discussions in group meetings (Dzeng et al., 2016).

4.2.2.2 Pathways and treadmills

A driver of overtreatment may be that patients' pathways through the healthcare system generate path dependencies, where aggressive care or lack of communication at one stage create a need for more aggressive treatment further down the line. Surgeons and others talk in depersonalised, systemic terms of a '*cascade*' or '*treadmill*' of interventions [USA and Australian consultant surgeons respectively] (Cauley et al., 2016; Willmott et al., 2016) which, once begun, make it difficult for them to divert into a more palliative approach:

'Often we're just left with no option to at least provide short terms of futile care because someone has already started the process... so a 90 year old is in ED, they've got a tummy problem, I [a surgeon] can fix it, I've got the skills to fix it. So someone decides to do an operation. But if you don't think about the whole scenario of this 90 year old with 100 other problems, who can potentially be stuck in hospital for another two months with no realistic outcome, then it becomes tricky.' [ICU surgeon, Australia] (Gallois et al., 2015).

'If a cardiac surgeon does an open heart [surgery] in an 85-year-old and the patient develops renal failure tomorrow how can I come and say, 'I don't want to dialyze this patient because she's 85,' or something like that. So, what am I supposed to do at that time?' [Nephrologist, USA] (Grubbs et al., 2017).

In particular, clinicians in acute or emergency situations may need to make rapid decisions which then generate a demand for further treatment (Dzeng et al., 2018; Oerlemans et al., 2015; Sibbald et al., 2007; Sørlie et al., 2000; Workman, 1998). Information needed to inform treatment decisions in medical records may also be hard to access in such situations (Cauley et al., 2016).

The typical patient is post-arrest. The patient is being cooled in an ICU. After a certain point, there's some neurological recovery. We're not sure about the neurological recovery but in the meantime, the creatinine is this or the potassium is that. We start CVVH [continuous veno-venous hemofiltration] until we determine, so we sort of get stuck and we take that path. Suddenly, we have a vegetative patient on CVVH. [Internal Medicine Physician, USA]' (Dzeng et al., 2018).

4.2.2.3 Futile Treatment in the ICU

Physicians identify that the ICU is a particular place where futile treatment is given to patients who had little prospect of recovery:

'This person with advanced dementia had been in and out of the ICU multiple times that month at baseline, and had very poor cognitive functioning. She had no quality of life. She was septic. I forget how many other comorbidities on board. Just kind of a remote family member was making the decisions, and had spent a week in the ICU remaining full code despite everybody's efforts, and ultimately coded again and didn't survive. But I think that's a pretty common scenario, especially in the ICUs and everything.' [Internal Medicine Physician, USA] (Dzeng et al., 2018).

Some had found this distressing and thought that this treatment amounted to torture [also see 'Inappropriate treatment leads to distress' above]. Others voice regret at wasted resources (Jox et al. 2012). However, others see treatment in the ICU as the place where new boundaries of medical science are created:'Participant 5... noted the role of surgeons in pushing the envelope of what was possible. "And if you don't take cases that others may view as futile and make an effort, we're never going to learn how to do X, Y, or Z." [Anaestheologist, USA] (Saettele and Kras 2013).

Admission to the ICU for some patients is questioned by some, and others see themselves as a part of a much bigger hospital machine where they feel obliged to accept patients referred by other departments:

'I think we sometimes admit people we shouldn't admit, and I think that sometimes we can say in advance that we shouldn't have let this patient go to the ICU, but we're too afraid that we judge things too negatively and we do it anyway, but with the result that we treat the patient for too long.' [ICU Physician, Nertherlands] (Oerlemanns et al. 2015).

Respondents also identify that admission to the ICU is often dependent on individual clinicians and their willingness to treat, sometimes at the expense of discussions with the family about the goals of care:

'Differing outlooks of different ICU attending staff was also noted to affect how far care was pushed. Participant 2 (M, <5, religious) said, "...it depends week to week who the ICU attending is. If you happen to get a very aggressive attending who wants to provide all care then that patient will get care and... the family discussion may not happen."' [Anaestheologist, USA] (Saettele and Kras 2013).

Oerlemanns et al. (2015) discuss the ethical problems associated with admission and discharge, and in particular consider the use of a guideline, published in the Netherlands, created to support decisions about admission when the ICU is full. They find that most physicians ignore the guideline which privileges those already admitted and prefer to move patients with a lower risk profile than the new patient to other hospitals or units.

‘In the beginning, I had a lot of problems with it [the guideline on an admission request for a patient near the end of life in case of full bed occupancy], the way it was drawn up. It went completely against my own way of thinking. I took the risks as a starting point. Which patient can you help the most here, who will suffer most from not being admitted at that moment?’ [ICU Physician, Netherlands] (Oerlemanns et al. 2015).

4.2.2.4 Role, specialism and experience effects

Clinicians involved in patient care may have differing perspectives on overtreatment that relate to differing roles.

Nurses tend to see their culture and role as more holistic or patient-centred, as against doctors’ focus on treating symptoms (Belcher, 2013; Bellmore, 1995; Meyers, 1994). In some cases, they take the view that doctors’ treatment decisions made on the basis of such a narrow perspective are not in the best interests of the patient. Participants describe how this can fragment and interrupt responsibility for care. Some link this symptom-focused approach to the challenges of communication between clinicians and patients or their carers (see ‘Communicating treatment goals and limitations’ below) (Meyers, 1994; Simmonds, 1996b; Willmott et al., 2016).

‘[T]hey become so focused on their subspecialty that perhaps they lose the big picture of the patient and they might be fighting to keep the hand attached without realising the body it’s attached to is no longer happy with life and functioning.’ [Emergency Medicine Consultant, Australia] (Willmott et al., 2016).

In particular, nurses are seen to be closer to patients than doctors and more aware of their suffering (Belcher, 2013; Bellmore, 1995; Dzeng et al., 2016; Grech et al., 2018; Meyers, 1994; Oerlemans et al., 2015; Workman, 1998). This perception is reported both by doctors and by nurses:

‘[T]he nursing staff [...] are the ones who have to carry out the doctor’s orders and who are at bedside seeing the effects of our treatment – seeing patients suffer. That translates to the interns who are seeing the patients suffer, then the residents, fellows, and sometimes even attendings. So it goes up the chain, but I feel that each step is slightly further removed from the patient so they’re seeing less.’ [Internal Medicine trainee, USA] (Dzeng et al., 2016).

In some cases, nurses may approach families without doctors’ knowledge (Belcher, 2013; Bellmore, 1995; Jox et al., 2012):

‘Mostly, it is the case that we nurses and the relatives say “this does not make sense any more”, the physicians, however, say “yes, yes, we can manage this, he will go to rehab.” Then we just say to the relatives, rather secretly, “say that your husband would not want this.”’ [Intensive Care Nurse, Germany] (Jox et al., 2012).

As well as differences between doctors and nurses, there may be differences among doctors, for example between different clinical specialties. Surgeons and intensive care doctors criticise oncologists and cardiologists for being over-optimistic about treatment (Gallois et al., 2015; Sibbald et al., 2007). Surgeons report a sense that referring doctors do not wish them to exercise clinical judgement as to the benefit of treatment (Cauley et al., 2016; Morris et al., 2018).

Several studies also report differences between older and younger (or more and less experienced) doctors, with the latter sometimes seen by nurses to have a more collaborative style of decision-making (Grech et al., 2018; Meyers, 1994). However, the influence of age or experience on judgements of futility varies: some studies report that doctors are more confident in making judgements of futility as they become more experienced (Ladin et al., 2018a; Sørlie et al., 2000; Willmott et al., 2016), while others report that older doctors are more prone to the default assumption of aggressive care (Grubbs et al., 2017), or more aware of the prognostic uncertainty which may argue in favour of continued treatment (Sørlie et al., 2000; Willmott et al., 2016). These factors interact with the medical hierarchy. Several junior doctors report feeling uncomfortable with decisions made by supervising doctors to continue treatment (Dzeng et al., 2016; Dzeng et al., 2018; Gallois et al., 2015; Simmonds, 1996b; Willmott et al., 2016). In addition, like nurses, junior doctors sometimes feel that senior doctors' limited familiarity with patients means they err on the side of overtreating (Willmott et al., 2016).

4.2.2.5 A lack of time

Doctors involved in end of life care report they have limited time to speak to patients due to their caseloads (Belcher, 2013; Bellmore, 1995; Cauley et al., 2016; Dzeng et al., 2018; Grubbs et al., 2017; Ladin et al., 2018a; Ladin et al., 2018b; Saettele and Kras, 2013; Sørlie et al., 2000; Willmott et al., 2016). This limits the possibility of effective communication about goals of care or treatment decisions (see 'Communicating treatment goals and limitations' below), and may hinder the development of trust and relationships between doctors and patients or families. It may also contribute to patients' and families' lack of information. Doctors' lack of time combines with other barriers to communication discussed below:

'this institutional reality subsequently serves as justification for a cultural primacy of an unreflective conception of autonomy rather than making time to have in-depth conversations to achieve consensus' [Authors] (Dzeng et al., 2018).

'There were several pressures to not have that conversation in depth. One was just a time pressure. You have less time than you had before [...] In the past, I had been more aggressive about getting the ethics consults. Now, I've given up because of the time constraints.' [Internal Medicine Physician, USA] (Dzeng et al., 2018).

'It takes time. I think it does require a longitudinal type of system... We don't have somebody who's dedicated towards long-term education and follow-up and repeated discussions about goals of care.' [Nephrologist, USA] (Ladin et al., 2018b).

4.2.3 Interpersonal-level factors

This sub-section presents themes where participants describe human interactions that can lead to treatment that might be judged futile. Doctors describe using clinically futile treatments so as to give sufficient time for patients or families to come to terms with an imminent death. They identify how effective communication about treatment goals and limitations at the end of life is time consuming and challenging, but if lacking can result in patients or their families having unrealistic expectations of treatment options. Family members report wanting consistency in communication. Doctors describe resorting to what they judge to be inappropriate treatments after difficult negotiations with patients or their families, who they can view as insufficiently informed or as struggling emotionally.

4.2.3.1 Buying time

Clinician participants in several studies report continuing treatment for a few days beyond the point of clinical futility in order to help patients or, more often, family members come to terms with a death (Bluhm et al., 2016; Gallois et al., 2015; Ladin et al., 2018a; Sørlie et al., 2000; White et al., 2016; Willmott et al., 2016; Workman, 1998; Cauley et al., 2016).

Sometimes continued treatment can allow family members to visit and see the patient for a last time (Aghabarary and Nayeri, 2017; Heland, 2006; Saettele and Kras, 2013). The authors of one study find that participants disagreed about whether to think of such treatments as 'futile' – while they may constitute overtreatment from a narrowly medical point of view, they do serve a broader purpose (White et al., 2016).

'Well, there are times when I think that you can do a nonbeneficial procedure that's not gonna benefit the patient, per se, but may allow time for the family to come to terms with the realities of that patient's care.' [Emergency general surgeon, USA] (Cauley et al., 2016).

4.2.3.2 Communicating treatment goals and limitations

Clinicians identify effective communication with patients and families, and ideally shared decision-making, as helpful in reducing overtreatment (Aghabarary and Nayeri, 2017; Cauley et al., 2016; Ladin et al., 2018a; Morris et al., 2018; Sibbald et al., 2007). Participants suggest that communication which is open and honest, appropriately timed, and which gives patients and families as full an understanding as possible of the different treatment options and their likely costs and benefits, is likely to reduce overtreatment. Patients and families may need a few days to fully take on board information about treatments and prognosis (Sibbald et al., 2007).

However, clinicians report great difficulty in communicating effectively with patients and families (also see 'Negotiating treatments' below). Discussing goals of care or treatment limitation with patients is emotionally challenging. In conjunction with a culture of care which focuses on active treatment (see 'The professional ethos to treat' above), this may mean that clinicians do not discuss treatment limitation with patients as long as active treatment remains an option (Bluhm et al., 2016; Dzeng et al., 2018; Laryionava et al., 2018; Oerlemans et al., 2015).

For most of the respondents, telling patients that they have no further treatment to offer is one of their most difficult tasks. They characterised the discussion about stopping chemotherapy as 'stomach turning,' 'emotionally draining,' and 'horribly sad.' Moreover, they reported that it is easier on everyone to bypass 'the talk' and to offer the next round of chemotherapy. [Authors] (Bluhm et al., 2016)

'That is driving up healthcare costs, giving the family false hope, causing the nursing staff to become demotivated because they already know it's not going to work. But it takes guts and that's a problem. It takes guts to decide this, it takes guts to go and talk to the family and say it out loud, it takes guts to explain to your colleagues that you're not going to continue.' [ICU Physician, Netherlands] (Oerlemans et al., 2015).

Clinicians also report having limited time to engage in conversations about the goals of care (see 'Organisational-level factors' above). This may contribute to patients' and families' misperceptions about the nature of aggressive care, and the likely prospects for improvement (see 'Negotiating treatments' and 'Family negotiations' below). When clinicians do discuss treatment options with patients, they may consciously or unconsciously do so in a way which is vague and overly optimistic, or which perpetuates the default assumption of aggressive care. In such cases they may feel they have fulfilled their responsibility to communicate, even though the patient remains ill-prepared to make decisions.

'And when he did finally talk to the family, he hedged and couched things in such vague terms that it was not at all clear to the family what he was talking about... he was just so vague about the way he presented things and it was like he sort of gave them options or choices that they really didn't have.' [ICU Nurse, USA] (Meyers, 1994).

In particular, overly general framing of questions around treatment may distort patients' and families' perceptions and choices (Simmonds, 1996b; Willmott et al., 2016; Workman, 1998). The binary option of either 'doing everything' or limiting treatment nudges decisions towards aggressive treatment. Where patients' or families' wishes are not based on a realistic understanding of the treatment options, clinicians may assume that they wish to attempt all available treatments:

'So if you give a smorgasbord to the patient's family and say, 'do you want everything done?', the answer is always going to be yes. If you're going to address the issue like, everything reasonable will be done, do you want x, y and z, it's a slightly different issue.' [Intensive Care Consultant, Australia] (Willmott et al., 2016).

The content and timing of conversations also needs to take into account patients' and families' existing attitudes and preferences:

'Timing is crucial, and that's difficult because if you approach the family too early [for permission to withdraw] they think 'are they going to try everything for my loved one? Like why are they talking to me about this now?' And if you approach them too late, then they get the feeling like well you know, we've come this far, why are we quitting now?' [ICU nurse, Canada] (Workman, 1998).

4.2.3.3 Negotiating treatments

Given differences in views about futility among clinicians, it is perhaps not surprising that family members in two studies emphasise a wish for consistency amongst clinicians when seeking judgements about treatment utility (Kitzinger and Kitzinger, 2013) (Zier et al., 2009).

'I always want a second opinion ... In other words, I'm not going to believe everything that [the physician] tells me ... I still need a second opinion. Another expert opinion tells me that, yeah, you know, he's right and there's no hope.' [Family member of a critically ill patient, USA] (Zier et al., 2009).

Indeed, several clinician participants mention cases where a decision to discontinue treatment was made by one clinician, discussed with the patient or family, and then reversed by another (Heland, 2006; Willmott et al., 2016). And yet clinicians' reports of continuing treatment reflect a high degree of ambivalence about cases in which patient or family requests for treatment have gone beyond what they consider worthwhile (Bluhm et al., 2016; Dzeng et al., 2018; Morris et al., 2018; Willmott et al., 2016). Clinicians in a large number of studies state that patients' or their family members' desires to continue treatment actually drive overtreatment (Aghabarary and Nayeri, 2017; Belcher, 2013; Bellmore, 1995; Bluhm et al., 2016; Dzeng et al., 2016; Dzeng et al., 2018; Gallois et al., 2015; Jox et al., 2012; Laryionava et al., 2018; Meyers, 1994; Morris et al., 2018; Saettele and Kras, 2013; Sibbald et al., 2007; Simmonds, 1996b; Sørlie et al., 2000; Willmott et al., 2016; Workman, 1998). In a minority of cases, patients or families may be highly insistent on their desire to continue treatment and apply pressure to clinicians, up to and including legal action (see also 'Limiting legal liability through treatment' above). Clinicians may experience such requests as threatening, and feel that they do not have the personal ability or institutional support to resist them.

'Usually I think if physicians end up treating to the death bed, which we sometimes do, it's because the family or the patient [is] very insistent.' [Oncologist, USA] (Bluhm et al., 2016).

'Another thing will be patient and family expectation because again the doctors aren't really – that's not their skill, arguing up those things. Their skill is providing treatments and medicine so that's what they're going to go for. If somebody is quite adamant saying I want this treatment, I want this treatment, I pay my taxes so I deserve this treatment.' [Palliative Medicine Consultant, Australia] (Willmott et al., 2016).

In many of the cases described, pressure is reported to come from patients themselves (Aghabarary and Nayeri, 2017; Bluhm et al., 2016; Dzeng et al., 2018; Laryionava et al., 2018; Morris et al., 2018; Willmott et al., 2016; Workman, 1998) (see 'Family negotiations' below for cases where communication with family members is described as problematic). This may depend on individuals' personalities, with some patients more likely to '*fight*' than others, and hence to request aggressive treatment (Bluhm et al., 2016; Dzeng et al., 2018; Laryionava et al., 2018); one study suggests that this is more often true of young adults than older patients (Laryionava et al., 2018).

Communicating that further treatment is futile can be seen as a process that may take a considerable time, both for clinicians to prepare themselves and for patients or families to come to terms with the reality of death (Simmonds, 1996a, Willmott et al., 2016).

Doctors said it often took several conversations to negotiate how and when to withdraw futile treatment from dying patients and that they were comfortable providing futile treatment for a limited time to allow this to occur. [Authors] (Willmott et al., 2016).

4.2.3.4 Family negotiations

Family participants in one study (Kitzinger and Kitzinger, 2013) suggest that treatment of comatose patients is sometimes pursued, despite family members suggesting it might not be appropriate – given their knowledge of the patient's prior views and values. Several members of different families in this study report cases where clinicians undertook treatments of comatose patients without consulting the family. In one case a family member reports being told by a clinician that ‘because he’s an adult we don’t need your permission’ to perform surgery ([Family member, UK] (Kitzinger and Kitzinger, 2013)). Others describe cases in which they had concerns that treatment was not consistent with the wishes and values of the patient.

‘Her husband reports saying to the surgeon “let her die if you think the prognosis is bad”; her adult daughter [...] recalls explaining to the surgeon that her mother’s strong religious faith coupled with her views about brain injury meant that “this isn’t a complicated or fearful situation. You must let her die if that’s a better outcome for her.”’ [Authors] (Kitzinger and Kitzinger, 2013).

Doctors report difficulties when negotiating with family members. Pressure from family members for treatment considered futile by clinicians, is reported even where the patient does not strongly wish to continue treatment. In some cases, clinicians feel that patients may go along with family demands for treatment; in others, family members of incapacitated or unconscious patients are said to have overridden the patient’s previously expressed wishes (Bellmore, 1995; Ladin et al., 2018a; Morris et al., 2018; Sibbald et al., 2007; Workman, 1998). There may also be disagreement and conflict between different members of the family (Bellmore, 1995; Dzeng et al., 2016; Saettele and Kras, 2013).

‘Even in patients who have had multiple complications, prolonged hospital stays, and subsequent setbacks, family members are still unwilling to say, ‘enough is enough.’ They still want to press on and do the procedure and go to the nursing home, regardless of what that means for the patient. And in some of these scenarios, the patient is in a physiologic state where they can’t agree or disagree. They’re basically just being swept along by the tide.’ [Surgeon, USA] (Morris et al., 2018).

As in this case, critically ill patients can be unable to make their own decisions. And in the absence of, or quick access to, a legally valid and binding Advance Decision (‘living will’), clinicians will consult the next of kin. Many clinicians report that, where patients are unable to communicate, they regard it as appropriate that families should be ultimately responsible for treatment decisions, even when their request for treatment goes against the clinician’s own judgement (Gallois et al., 2015; Laryionava et al., 2018; Morris et al., 2018; Workman, 1998).

Clinician participants in four studies suggest that patient and family decisions may be mainly influenced by emotional factors, due to the extreme emotional demands of the situation, and to patients’ suffering (Belcher, 2013; Cauley et al., 2016; Saettele and Kras, 2013; Sørlie et al., 2000). In particular, doctors and nurses in several studies report feeling that demand for continued treatment comes when family members struggle with a sense of guilt (Aghabarary and Nayeri, 2017; Saettele and Kras, 2013; Simmonds, 1996b; Workman, 1998).

‘[M]y experience with families in these situations is that the angst comes not over the fact that somebody is sick and dying, but the angst comes over the fact that they don’t want to be responsible for the death.’ [Anaestheologist, USA] (Saettele and Kras, 2013)

One trainee physician links families not seeing the full picture of care to this challenge (Dzeng et al., 2016; Saettele and Kras, 2013; Workman, 1998).

‘It is infuriating when the family is not there and they cannot see. I feel like it’s morally wrong. [...] I agree with giving the patients choice, but oftentimes it’s the family member. If the patient says, ‘Torture me, I want everything done.’ Fine. The family member is doing it for other reasons. Like guilt; they can’t let go.’ [Internal Medicine trainee, USA] (Dzeng et al., 2016).

4.2.4 Individual-level factors

This sub-section presents themes that relate to perceptions of individuals’ needs, knowledge, expectations and beliefs. It illustrates perceptions that treatments that might otherwise be judged inappropriate by family members can turn into a necessary continuation of treatment so as to reduce a loved-one’s suffering. Doctors emphasise the impact on treatment of uncertainty around prognosis and family members show awareness of this uncertainty. Otherwise, views on factors that operate at the level of the individual are largely restricted to those from clinicians. Clinicians in many studies evaluate patients and families’ understanding and attitudes. They judge their expectations for many intensive care treatments to be unrealistic and also identify the emphasis placed by some on hope and faith.

4.2.4.1 Overtreatment to reduce suffering

Family members in one study report that a desire to prevent short-term distress and pain in patients can act as a driver for the administration of additional medical procedures (Kitzinger and Kitzinger, 2013). Several family member participants report that they did not initially challenge the medical decision to provide life sustaining treatment for their severe brain injured relatives, but then agreed reluctantly at a later time to additional treatments such as tracheostomy in order to reduce suffering.

‘She needed ... either to die or to be made more comfortable, and since no one was going to let her die, she had to be made more comfortable.’ [Family member of patient with severe brain injury, UK] (Kitzinger and Kitzinger, 2013).

Findings from this study also indicate that families sometimes reluctantly tolerate the continuation of treatment because they do not consider there to be any other acceptable alternative for their relative. For example, withdrawing artificial nutrition and hydration is considered by some participants to be abhorrent and they are horrified by the prospect of ‘starving and dehydrating’ their relative to death, but others consider it the ‘least worst’ option: ‘[it’s] barbaric – but then being kept living that way is barbaric.’ [Family member of patient with severe brain injury, UK] (Kitzinger and Kitzinger, 2013).

4.2.4.2 Uncertainty can influence treatment

The clinical uncertainty referred to earlier surfaces in accounts that link it directly to further treatment for the critically ill. In one study, family members express an unwillingness to simply accept physicians’ prognostic assessments and judgements that life sustaining treatment would be futile (Zier et al., 2009). This is linked to a belief that physicians are unable to predict prognosis with the necessary level of certainty. For some family members, their distrust of physicians’ futility judgements results from previous experience of receiving an inaccurate prognosis.

In addition, making a personal assessment about their relative's condition plays a key role in families deciding that there is no realistic expectation of recovery and in accepting physicians' futility predictions (Kitzinger and Kitzinger, 2013; Zier et al., 2009). A process of 'triangulating' information from multiple sources is reported in one study (Zier et al. 2009).

In a large number of studies clinicians report that, where there is doubt about the prognosis and prospects for recovery, they are unwilling to limit treatment (Aghabarary and Nayeri, 2017; Bluhm et al., 2016; Cauley et al., 2016; Grubbs et al., 2017; Morris et al., 2018; Oerlemans et al., 2015; Saettele and Kras, 2013; Simmonds, 1996b; Sørlie et al., 2000; Willmott et al., 2016; Workman, 1998). Doctors report giving patients the '*benefit of the doubt*' [Australian and Canadian Physicians] (Simmonds, 1996b; Willmott et al., 2016). Particularly where further treatment is desired by the patient or by family members, even a small probability of recovery may justify undertaking it.

'And so when the patient and their family [are] saying, 'Well, is there anything else,' you sort of feel like who are you to close that door, [be]cause you actually don't know with 100% certainty.' [Oncologist, USA] (Bluhm et al., 2016).

The irreversible consequences of limiting or withdrawing treatment lead clinicians to err on the side of caution by continuing treatment:

'I've come to an age where I've become careful. I've been wrong too many times. You can only stop once.' [ICU Physician, Netherlands] (Oerlemans et al., 2015).

However, a few clinicians are critical of this reasoning, and express discomfort with the tendency to see any possibility of recovery as justifying treatment. These participants argue that outside chances of recovery need to be seen in the context of a realistic judgement of probabilities.

'[M]ostly you have to in medicine go with the odds. If the odds are very much swayed in the fact that this isn't going to help the person, this person is going to die almost no matter what I do, then you've got to expect that that's what is going to happen. It's wrong to try and build false hope in people when really there is very little... hope there.' [Geriatric Medicine Consultant, Australia] (Willmott et al., 2016).

4.2.4.3 Patients and families' unrealistic expectations

While there were no views found on this from patients or families, clinicians in 12 studies report that patients and families often have, in their view, mistaken views about the likely outcomes of treatment and the potential negative effects (Aghabarary and Nayeri, 2017; Belcher, 2013; Bellmore, 1995; Cauley et al., 2016; Grubbs et al., 2017; Laryionava et al., 2018; Meyers, 1994; Saettele and Kras, 2013; Sibbald et al., 2007; Simmonds, 1996b; Willmott et al., 2016; Workman et al., 2003). For example, they may overestimate the success rate of interventions like cardiopulmonary resuscitation, and underestimate the potential for complications. In conjunction with the other factors mentioned, this may be a driver of requests for continued treatment which clinicians feel to be futile.

Clinicians in two studies identify the education of patients and families as a priority to address overtreatment (Belcher, 2013; Sibbald et al., 2007). However, others express a broader view, arguing that inadequate understanding of treatment is influenced by a number of factors, such as inaccurate information on websites or social media (Belcher, 2013) or language barriers (Bellmore, 1995; Grubbs et al., 2017) (also see ‘Communicating treatment goals and limitations’ above). Distorted views of the likely efficacy of treatment are also thought by clinicians to relate to psychological attitudes of ‘denial’, ‘wishful thinking’ or ‘cling[ing] to life’ (Ladin et al., 2018b; Laryionava et al., 2018). Several clinicians express discomfort with the way patients and families are expected to make treatment decisions without understanding the implications of these decisions.

‘And I think it is really not fair to make the family make calls... The family has no idea of what the complexities are, and I think at some point, if you’ve gotten into that ground that I don’t think it’s fair to ask them anymore what they think.’ [Anaestheologist, USA] (Saettele and Kras, 2013).

4.2.4.4 The role of hope and faith

Family members in two studies express the belief that it is important not to give up prematurely, and to provide their relatives with a fighting chance of recovery (Kitzinger and Kitzinger, 2013; Zier et al., 2009).

Some clinicians take this idea of allowing time, or optimal conditions for a possible recovery further. They emphasise how some patients and families want to maintain hope for a positive outcome, and may grasp at any chance of a miraculous recovery (Aghabarary and Nayeri, 2017; Bellmore, 1995; Bluhm et al., 2016; Jox et al., 2012; Workman, 1998). As noted above, this may contribute to unrealistic expectations of treatment, but may in turn be perpetuated by the way clinicians communicate to patients (see ‘Communicating treatment goals and limitations’).

‘They equate chemotherapy with hope. I don’t think it’s going to necessarily do something. But it’s giving them hope.’ [Oncologist, USA] (Bluhm et al., 2016).

Clinicians in four studies describe cases where patients or families did not wish to limit treatment due to their religious beliefs (Aghabarary and Nayeri, 2017; Belcher, 2013; Dzeng et al., 2018; Saettele and Kras, 2013; Sibbald et al., 2007; Workman, 1998). Faced with the overwhelming responsibility of taking end of life treatment decisions, family members may see the decision as being ‘in God’s hands’ [Intensive Care Nurses, USA] (Belcher, 2013; Bellmore, 1995). However, one participant suggests that such concerns are sometimes overstated by clinicians, and reports that religious families are able to accept treatment limitation with the support of community leaders (Dzeng et al., 2018).

4.3 Factors contributing to undertreatment

Five studies report data relevant to undertreatment (Belcher, 2013; Dale et al., 2016; Jablonski and Duke, 2012; Sheard et al., 2012; Workman et al., 2003); all these studies report only the views of clinicians and Sheard et al. (2012) is the only one from the UK. Two studies contribute the most data for this review: one looks at what authors judged to be early decisions to withdraw treatment after cardiac arrest (Dale et al., 2016), and one looks at pain management for end of life patients in rural areas (Jablonski and Duke, 2012). No policy or community-level factors were reported in multiple studies as influencing undertreatment. Otherwise, the themes that arise are noticeably similar to those relating to overtreatment.

4.3.1 Organisational-level factors

As with views on overtreatment, nurses see themselves as more able than doctors to avoid undertreatment.

4.3.1.1 Undertreatment through specialism effects

Some differences are reported between doctors and nurses' perspectives on undertreatment. Nurses perceive that they are closer to the patient, and see themselves as having an advocacy role. In some cases they feel that doctors' limited contact with patients can lead them to undertreat pain (Belcher, 2013; Jablonski and Duke, 2012; Workman, 1998).

'Babies do not have the voice to say they are in pain. I cannot be the patient advocate I want to be when doctors will not listen to me about the pain experienced by extremely immature babies.' [Intensive Care Nurse, USA] (Belcher, 2013).

'[Sometimes] what you are using is not working for the patient... [and] the doctors may not think that the patient needs any more medication.' [Nurse, Rural hospital USA] (Jablonski and Duke, 2012).

4.3.2 Interpersonal-level factors

As with overtreatment, both miscommunication involving clinicians and family members and directives from family members are cited by clinicians as contributing to undertreatment.

4.3.2.1 Undertreatment through miscommunication

Inadequate communication between clinicians and family members may lead to inappropriate treatment. Inadequate information may lead to a lack of understanding of patient prognosis, or lead to families not realising that the patient is in pain, or not realising that they are at the end of life, and so not accepting pain medication or palliative care for them. Clinicians identify communication as an important gap in their training, and express a desire for better patient information materials (Dale et al., 2016).

'[F]amilies don't get enough information prewarming from the team.' [Intensive Care Nurse, Canada] (Dale et al., 2016).

'Doctors may have the knowledge but lack the skill to teach patients and families. Nurses can be the same.' [Nurse, Rural hospital, USA] (Jablonski and Duke, 2012).

These communication problems can be exacerbated by language and cultural differences.

'When you are talking about the ethnic[ally] diverse community, you will have communication barriers, you know. We have to look for hospital translators.' [Intensive Care Nurse, Canada] (Dale et al., 2016).

'[I] have had female patients of a Middle Eastern background where only the husband would speak and he would say if the patient is in pain or not, or how much pain.' [Nurse, Rural hospital, USA] (Jablonski and Duke, 2012).

The stresses experienced by family members are also implicated:

‘Family-team communication in the first 72 hours after OHCA [out-of-hospital cardiac arrest] was described as emotionally charged [...] highly stressed surrogates were perceived to ‘hear every third or fourth word’ [Authors] (Dale et al., 2016).

4.3.2.2 *Undertreatment when less treatment is requested*

Clinicians report that family members may want the patient to remain responsive so that they can interact with them, which may lead them to be less favourable to pain management or sedation.

‘[F]amily members [want their loved ones] to be comfortable, but not always to the point of unresponsive... want to spend the last days... hoping that the patient can respond right up until death.’ [Nurse, Rural hospital USA] (Jablonski and Duke, 2012).

They may also be reluctant to allow treatments which could hasten death:

‘[T]he family refused to let us give him morphine, because they knew that if we gave him morphine his blood pressure would probably drop and he was already on epinephrine and all these other drugs, so there was no other drug we could really give him to combat that. So they had said no, don’t want him to have any morphine.’ [ICU Nurse, Canada] (Workman, 1998).

Nurses report that, in some cases, patients and/or families may have a fear of addiction to pain medication, but they also report reluctance because they feel patients are asking for it for reasons other than pain.

‘One nurse believed that some patients want ‘routine’ pain medication [...] ‘...to make them sleep until it is time [for death] because they are depressed’ [Authors] (Jablonski and Duke, 2012).

In one study focusing on reasons why treatment is withdrawn after cardiac arrest earlier than guidelines recommend, clinician participants report that family members are sometimes ‘impatient’ to withdraw treatment early [participant] (Dale et al., 2016). Family members may wish not to prolong the patient’s suffering, or feel that the patient would not wish to be resuscitated, for example if there is a risk that they would be cognitively impaired.

Having their loved one’s cognitive status intact was very important, so that was another reason why they didn’t want to pursue this. [Nurse, Rural hospital USA] (Dale et al., 2016).

4.3.3 Individual-level factors

As with overtreatment, prognostic uncertainty featured in clinician’s accounts. Clinicians, similarly again, critique family members’ understanding. They also cite the challenges of balancing of positive and negative side-effects of medication.

4.3.3.1 *Undertreatment due to gaps in clinicians’ knowledge*

In one study, participants report that uncertainty and an inability to predict the outcome could lead families to choose early withdrawal of treatment after a cardiac arrest. Not knowing whether their relative would recover may lead families to want to withdraw treatment early, as they do not want to prolong the patient’s suffering. This choice may be reinforced by pessimistic evaluations of prognosis by clinicians:

‘People want to do the right thing. They don’t want to prolong [life support] if someone is not going to have a meaningful recovery. Unfortunately, we just don’t know. We don’t have the evidence to say one way or the other.’ [ICU Fellow, Canada] (Dale et al., 2016).

A lack of skills, knowledge, or experience on the part of clinicians is also reported:

‘Poor assessment skills and knowledge about pain and treatment for pain are ... definitely ... big barriers.’ [Nurse, Rural hospital, USA] (Jablonski and Duke, 2012)

4.3.3.2 Gaps in families and patients’ knowledge

Clinicians perceive that family members can misjudge their loved ones’ levels of suffering. Families can think that where the patient is not visibly showing signs of suffering, they are not in pain, and hence underestimate the need for pain management. Conversely, families may infer from patients’ appearance that they are in pain or have a poor prognosis, leading them to wish to withdraw treatment.

‘[F]airly benign patient signs or symptoms could be perceived negatively; shivering, which may have been misinterpreted as seizures or other types of life threatening events, appeared to communicate ‘pain and suffering’ to families.’ [Authors] (Dale et al., 2016).

‘They think that because the patient is unconscious that they do not need pain medications… [nurses should acknowledge] nonverbal cues of pain… when family is in the room.’ [Nurse, Rural hospital, USA] (Jablonski and Duke, 2012).

They also argue that patients themselves may underestimate the need for pain management because of inadequate understanding of their condition:

‘[P]atients do not understand the progression of their diseases and are unable to prepare themselves for increases in pain intensity.’ [Nurse, Rural hospital, USA] (Jablonski and Duke, 2012).

4.3.3.3 Balancing the positives and negatives of medication

Nurses report their own concerns about side-effects, overdose or addiction which may lead to undertreatment, particularly the underuse of pain medication. While clinicians are concerned about patients’ suffering and want to manage it appropriately, they need to balance this against these potential negative effects.

‘[I do] not want to see anyone get too dependent on medication.’ [Nurse, Rural hospital, USA] (Jablonski and Duke, 2012).

5 DISCUSSION

5.1 Summary of findings

This review finds that inappropriate treatment, particularly overtreatment, at the end of life is recognised as a problem area by patients and family members. It is reported to be a substantial problem by many clinicians. Overtreatment is seen by clinicians largely as including treatments which do not improve quality of life, or where the benefit is outweighed by the suffering produced. This is seen to have negative consequences in terms of avoidable suffering for patients and distress for clinicians. However, it is recognised that judgements of what constitutes overtreatment are challenging to make in practice and cannot be fully objective.

A range of factors is seen as contributing to overtreatment. Views from patients or families focus on interpersonal and individual influences related to attempts to minimise suffering in a context of uncertainty.

Clinicians refer to societal and organisational influences, as well as factors that are interpersonal and individual in nature. Their accounts also show how these influences can be interlinked. Clinicians report that they are sometimes unwilling to limit treatment due to their professional culture and sense of their own role, and see more palliative approaches to care as an admission of defeat. However, they are also aware of their own responsibility for life-and-death decisions, and aware of the limits to clinical knowledge, so that they can almost never rule out the possibility of recovery with total certainty. Some clinicians are also reluctant to limit treatment due to possible legal repercussions. They may also continue treatment which they know to be futile for a few days to allow family members to come to terms with the patient's death.

Doctors describe how they can have limited contact with patients due to their caseloads, and nurses (who are closer to patients and more aware of the negative impacts of continued treatment) how they can have limited input into decision-making. Patients with complex needs are often treated by multiple specialists, focusing on specific problems rather than overall quality of life, which can create a 'treadmill' effect whereby aggressive treatment creates a demand for more treatment further along the pathway. The ICU is identified as a particular site for futile treatment.

The decision to limit or withdraw treatment requires communication with patients and families, which is both personally uncomfortable and time-consuming for clinicians. It is recounted how inaccurate information or vague communication may leave patients or families little choice but to request continued treatment. Clinicians report how patients and family members may be unwilling to give up hope, even when they recommend limiting treatment, and describe limits to understanding about the implications of continuing with treatment, or the probability of recovery.

Several of the same themes recur as potential causes of undertreatment (although the data is very limited). In particular, inadequate communication or limited contact between clinicians and patients may lead to poor pain management or early withdrawal of treatment.

It is important to recognise that the very limited data available on patients' and family members' own views mean that this summary represents in the main, the views of clinicians about inappropriate treatment at the end of life.

5.2 Differences between patient groups

Studies presenting clinician views suggest that the main issues regarding end of life care are not dependent on the characteristics of specific patients. Although the data is limited because most studies do not clearly differentiate patient groups, those studies which do focus on specific clinical specialisms or units (for example, oncology, nephrology, neonatal intensive care), and hence implicitly on specific patient populations, are broadly consistent with the data from the studies that include a range of populations. (There are one or two exceptions, such as the finding in the studies on kidney disease about the financial implications of continued dialysis versus conservative management.) The age of the patient may make a difference, in that it enters into clinicians' judgments of futility along with other information about the likely benefits of treatment; in addition, one study suggests that young adult patients may be more likely to demand aggressive care than older people, and clinicians may be more willing to provide it (Laryionava et al., 2018).

Studies reporting patient and family data are too few and heterogeneous to draw strong conclusions. In particular, the data gives little sense of how patient and family views might differ between subgroups, for example by ethnicity or religion. One possible difference concerns how the trajectory of disease onset and progression may impact on attitudes (Murray et al., 2005; Barclay et al., 2014; Bailey et al., 2011). The study by Kitzinger and Kitzinger (2013) on family members of brain-injured patients finds that participants' views evolved over time, such that they were often supportive of life-sustaining treatment initially, but later came to see it as overtreatment. This contrasts with the findings of Foley et al. (2014) on patients with a progressive condition (motor neurone disease), who had often considered their preferences for end of life care long in advance.

5.3 Strengths and weaknesses of the review and gaps in the evidence

This review was conducted according to systematic review principles, with comprehensive searching and *a priori* procedures to minimise bias in study selection, reliability assessment and data extraction. As with any systematic review, this involves drawing a sharp boundary around the topic, and specific decisions as to inclusion may appear arbitrary. This is particularly true of this review, since the question of inappropriate treatment needs to be seen in a broader context of the processes and pathways governing the delivery of care at the end of life. While focusing on inappropriate treatment helps to draw out the most relevant messages from the evidence, it is to some extent artificial, and the findings of this review should be interpreted in the light of the broader literature on experiences of end of life care and the process of decision-making about treatment.

The review found only three studies from the UK, with around half the studies from the USA and the remainder from a range of other countries. There may be barriers to the applicability of non-UK evidence in the UK, particularly due to the organisation of the healthcare system: for example, one study which includes both USA and UK data suggests that financial factors may be a more important driver of overtreatment in the former (Grubbs et al., 2017). There are clearly differences in the broader policy context. For example, the availability of specialist services (hospices and palliative care), and the funding structures and clinical guidelines which determine who can access those services, varies widely both within and between countries. For example, in the USA much palliative care in community settings is not covered by Medicare, and access to services varies widely between states (Meier et al., 2017). All of these factors are likely to play some role in clinicians' decisions about treatment and referral, and would merit more detailed investigation.

The applicability of this evidence to specific settings may also be limited by differences between countries in prevailing social and cultural norms, and in the legal frameworks in force. For example, there may be differences in the relative value attached to the autonomy of the patient (or their surrogate decision-maker) and the clinician's judgement of the patient's best interest. As well as differences between countries, the heterogeneity of patient populations and their clinical contexts needs highlighting. While our synthesis has aimed to draw out common themes, as described in the previous section, it should be borne in mind that the broad notion of 'end of life' can include a wide range of different patients and the clinical questions involved may be very different.

The evidence in the review largely focuses on overtreatment with few studies addressing undertreatment. This may be partly because studies addressing undertreatment are not explicitly focused on end of life populations. In addition, this data is likely to be found in qualitative studies with a broader focus which are not explicitly reported in terms of undertreatment, and which consequently would not have been located by our searches; this is particularly true of the literature on pain management. There is no direct analogue to the 'futile treatment' literature on the undertreatment side. A more detailed exploration of undertreatment would need to adopt a somewhat different approach, and probably a broader focus in terms of population. Further review using broader search terms and inclusion criteria, but focusing on specific treatment options and possibly on specific diseases, would enable syntheses addressing treatment decision-making in a more holistic way, and potentially enable more contextually sensitive exploration of over- and undertreatment. Our finding that the same factors may drive both under- and overtreatment suggests that the overarching construct of 'inappropriate treatment' may be a better way to conceptualise the issue, but it is challenging to operationalise in a review.

The studies we found mostly collected data from clinicians rather than patients or family members. This may be partly an artefact of the topic focus and review's methods – in that patients are less likely to talk in terms of over- or undertreatment – but the few studies which report data from patients and families indicated that many do have clear views and preferences regarding over- and undertreatment at the end of life, and that these may diverge from clinicians' views. The lack of data on patients or families is an important gap in the qualitative evidence.

Almost all the studies focus on healthcare settings, mainly hospitals. There is a particular gap around care homes and residential care: given that a substantial and growing proportion of deaths (over 20%) occur in these settings (Public Health England, 2018), the absence of studies on inappropriate treatment in care homes is a clear gap in the evidence.

We did not place a date limit on inclusion and a handful of studies (n=4) are 20 to 30 years old; there may be issues with the applicability of these studies due to advances in technology or changes in clinical practice, although changes in perceptions over time are not immediately apparent from the data. As Section 7.6 explains, steps have been taken to reduce the influence of the oldest studies in the synthesis so as to make the findings more relevant for current contexts.

Many studies report limited information on sampling or recruitment, and most use self-selected samples. This may introduce selection bias, in that participating clinicians may have more interest in the issues, or more awareness or experience of the challenges around over- and undertreatment, than the broader population. The review also does not explore the potential for interview effects in the included studies. Without careful attention to participant anonymity, it is quite possible that responses might sometimes have been provided because they were judged by an interviewee to be socially desirable, especially when, as was the case for some studies, clinicians were reflecting upon differences between specialisms.

5.4 Implications

This review of qualitative data does not allow us to objectively measure or quantify how far inappropriate treatment is a problem, or compare it to other potential issues, for example in terms of costs. While there are findings from quantitative studies on this (see ‘Background’ above), our findings suggest these should be interpreted with caution, since it may be impossible to define over- and undertreatment objectively: for example, it may depend on value judgements about quality of life, or on whether one focuses on purely clinical indicators or a broader conception of care.

The focus in the literature upon Intensive Care could reflect perceptions among researchers that ICUs comprise an important testing ground for the treatment of extremely ill patients likely to be nearing the end of their lives. ICUs may in part be singled out for attention because of their use of technologically advanced equipment and the visibility of ICU treatments, while the dedicated and specialised care provided in other settings, particularly hospices and care homes, remains less studied.

Nonetheless, there appears to be an ever increasing demand for ICU beds, as people are admitted to hospitals later in life with more co-morbidities (Oerlemans et al., 2015). Recent mixed-methods research from the UK identifies the many complexities surrounding ICU referral and admission (Bassford et al., 2019). However, medical ethicists have argued that those who work in Intensive Care should be present for discussions with patients and their treating physicians about the patients’ wishes at the end of life, so as to discuss the opportunities and consequences of a stay in an ICU. Indeed, Brooks et al. (2017) suggest that Intensive Care specialists should take a leadership role in end of life decision making that involves the ICU. There is likely to be value in evaluating the existing guidance for admissions into ICU that has been developed in some countries. Examples can be found for the Netherlands (Oerlemans et al., 2016), Scandinavian countries and the USA (Fleck and Murphy, 2018; Jesus et al., 2018). In addition, France has passed a legislative framework to guide physicians when they make decisions about admission to the ICU. Here it is argued that the presumption that there would be no readmission to ICU after discharge may encourage a conversation about end of life planning and advance directives (Rigaud et al., 2018).

Data from clinicians in this review suggest workloads and time pressures as a major barrier to effective communication, which may contribute to both over- and undertreatment. Relationships within clinical teams may also be an issue; in particular, some nurses feel that their views of patients' situations, based on more in-depth experience than doctors', are not adequately reflected in clinical decision-making. A lack of coordination between different clinicians and units involved in the care of patients with highly complex needs may contribute to inappropriate treatment, due to fragmentation of responsibilities and a lack of clarity about the goals of care. There may be issues with access and referral to specialist hospice or palliative care services. Strategies to promote more 'joined-up' care and information sharing at the end of life, to coordinate and plan care over time for patients with long-term conditions, and to facilitate shared decision-making within clinical teams and between clinicians, patients and families, could be evaluated to examine their potential for addressing some of these issues. Relevant recent work from the UK includes the national rollout and evaluation of the 'Quality End of Life Care for All' (QELCA) programme (Gillett and Bryan, 2016). Funded by the NHS National End of Life Care Programme, this scheme enables professionals from acute NHS trusts to experience hospice care and then conduct action learning in their trust settings. In response to concerns about resuscitation policy, the ReSPECT process has been developed to provide clinicians with support for conversations about goals of care and with guidance for when patients do not have capacity to make decisions themselves (Friz et al 2017). To date the process has been rolled out to over 130 NHS Trusts.

Requests from patients and family members are seen by clinicians to be a driver of inappropriate treatment, particularly overtreatment (although this is largely not borne out by the data from patients and families themselves). Some clinicians recommend education or public information campaigns to shape more realistic expectations of end of life care and reduce inappropriate treatment. However, this may be over-simplified. The data suggest that patients and families' wishes for care are shaped by the healthcare environment, in particular by communication with clinicians – as well as by cultural and social norms – and may shift over time. The studies suggest that unrealistic demands for treatment are likely to be reduced by communication about treatment decisions which is informative, honest and timely, and by trusting clinician-patient relationships, and that the main barriers to such communication are more a matter of clinician behaviour and the healthcare system than of patients' and families' attitudes. Thus, patient and family demand for treatment might be better seen as evolving within the interpersonal and organisational context of care delivery, rather than as a pre-given set of expectations which are fulfilled or disappointed in the encounter with the care system.

The data also suggests a number of possible policy interventions that could be targeted at clinicians, particularly relating to overtreatment. Clinicians identify a professional culture, particularly among doctors, which prioritises active problem-solving and sees aggressive treatment as the default option. In this context, the adoption of a more palliative approach to care is sometimes seen as 'giving up', and clinicians may lose sight of the patient's overall wellbeing in the effort to address specific problems. Clinicians report feeling uncomfortable with talking to patients and their families about treatment decisions and goals of care, particularly where this means facing up to the likelihood of death, which may lead them to see overtreatment as the easier option. Public and professional educational or engagement activities focusing on these needs, particularly around communication between clinicians and patients, may be a promising area to explore.

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Part II Technical description of the review

7 DETAILED METHODS

This chapter describes in more detail the methods that were used to search for, identify and review the studies relevant to the systematic review of the research literature. The protocol was published on PROSPERO and is available to view at: http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42018107805. EPPI-Reviewer 4 software was used for data management (Thomas et al., 2010).

Plans for this review were developed in consultation with members of the policy team at the Department of Health and Social Care. The review question was:

What is known from qualitative research about the views or experiences of patients, clinicians, families or other stakeholders regarding under- and overtreatment at the end of life?

7.1 Search strategy

Databases were searched using a combination of controlled vocabulary and free-text terms (the latter restricted to the title or abstract fields). The search strategy for MEDLINE is set out in Appendix A; this was translated for searches of other sources. The sets of terms were grouped in the search as follows:

Terms for end of life care
AND
Terms for over- and undertreatment
AND
Terms for qualitative research methods

The following sources were searched in August 2018:

- ASSIA (Proquest)
- British Nursing Index (Proquest)
- CINAHL (Ebsco)
- Embase (OVID)
- MEDLINE (OVID)
- Proquest Dissertations & Theses (Proquest)
- Science Citation Index (Web of Science)
- Social Science Citation Index (Web of Science)

The following additional search methods were used:

- Backwards citation chasing from all included studies
- Backwards citation chasing from systematic reviews meeting criteria (1)-(4) (below)
- Forwards citation chasing from all included studies, using Google Scholar
- Website searches of key UK research groups working on end of life care (see Appendix B).

7.2 Inclusion criteria

The following criteria were developed so as to identify studies relevant for answering the review's research question:

1) Does the study report primary qualitative data (for example, interviews, free-text responses to surveys, ethnography) or a systematic review including such data?
2) Does the study concern views or experiences of care delivered to patients who are near the end of life?

Include any study concerning care for patients who are near the end of life, critically or terminally ill, in any setting, *or* for patients in palliative care, hospices, intensive care or critical care units. *Include* patients in any setting who are on a supportive or palliative care register, or who have community palliative care team involvement. *Exclude* studies concerning care for older people generally (for example, nursing homes), unless specified to be near the end of life.

3) Does the study report data on views relating to treatment intensity?

Exclude studies of general preferences or experiences relating to end of life care. *Include* views on withdrawal or withholding of life-sustaining treatment, limitation of therapeutic effort or aggressiveness of treatment, or on transitions from curative to palliative care. *Include* views on advanced care plans or do-not-resuscitate orders.

4) Does the study mainly focus on views relating to over- or undertreatment, inappropriate treatment or futile treatment?

Exclude studies which may present some data on these topics but whose main focus is on other questions.

5) Does the study report primary data?

Exclude systematic reviews. *Include* any primary study design.

6) Is the study available in English?

In addition to these screening criteria, at a later stage of the review, studies of lower reliability were excluded from the synthesis (see under ‘Reliability assessment results’ below).

7.3 Screening

All study records identified by searches were uploaded to specialist systematic review software where duplicate studies were identified and removed.

A random sample of 10% of titles and abstracts were screened against the above criteria by two reviewers independently, and disagreements reconciled by discussion and reference to a third reviewer when necessary. Initial agreement on this sample was 98.8% and inter-rater reliability (Cohen’s kappa) $\kappa=0.687$. The remaining 90% of titles and abstracts were screened by one reviewer alone.

The full text of all records meeting the criteria were retrieved and screened by two reviewers independently.

7.4 Reliability assessment

The reliability of findings was assessed using Hawker et al.’s tool for qualitative studies (Hawker et al., 2002). The assessment was conducted by one reviewer and checked in detail by a second reviewer. We converted the results for each question (good, fair, poor, very poor) into a score from 0 to 3, giving each study an overall score from 0 to 27. After completion of the reliability assessment, we judged that the exclusion of less reliable studies would produce a more robust synthesis, since they are both less reliable and provide limited data. The threshold for inclusion was set at a score of 17 or higher.

7.5 Data extraction

Data was extracted on contextual features of the studies including the population, setting, and study design and methods. This data was extracted by one reviewer and checked in detail by a second reviewer.

7.6 Data synthesis

Data was synthesised thematically (Thomas and Harden, 2008). Qualitative data (both direct participant quotes and primary study authors' interpretations) were coded line-by-line using the coding function in EPPI-Reviewer. Our initial framework was based on a binary classification of factors contributing to over- and undertreatment and factors helping to reduce each; further domains were added as coding progressed. The coding process was iterative, with new codes which emerged during the process re-applied to the whole data set. Given variations in context, thematic groupings were kept only if supported by findings of studies conducted in an OECD country within the last ten years. Finally, the narrative was organised so as to group factors roughly by socio-ecological level (Bronfenbrenner, 1977).

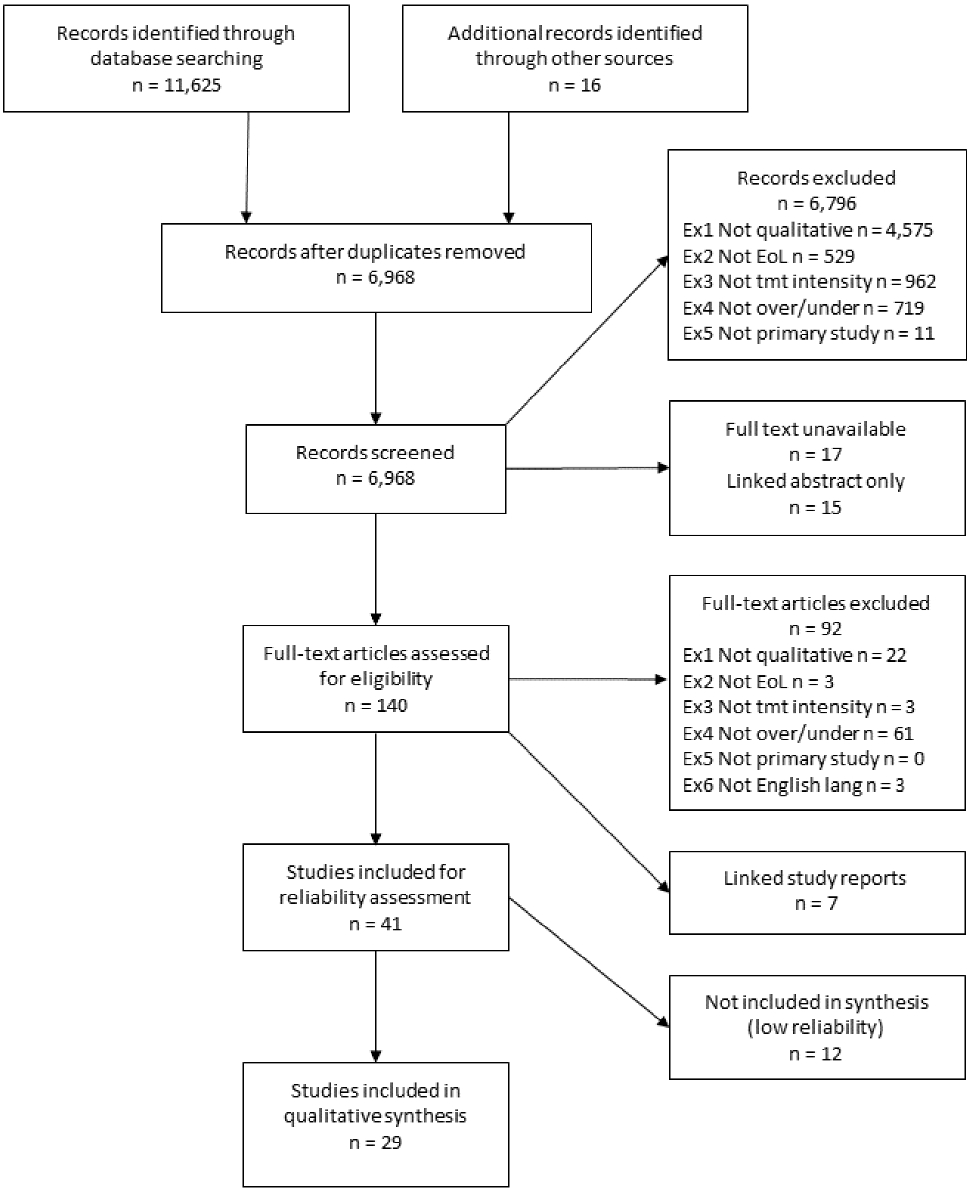
7.7 Contextual analysis

The participants, study focus and setting for each included study were examined by two reviewers working together so as to identify the overall contextual nature of this body of research. This, and reference by authors to recent policy was noted so as to inform the background and discussion sections of this report.

8 FLOW OF LITERATURE THROUGH THE REVIEW

A total of 6,952 unique records were identified by the database searches. An additional 16 potentially relevant records were retrieved through the supplementary searches. For a small number of records no full text was available (most of these were conference abstracts for which full data had not been published). After screening on abstract and full text, a total of 41 studies (48 study reports) were included in the review. After application of the reliability assessment threshold (see below), 29 records were included in the synthesis.

Figure 2. Flow of literature through the review



9 RELIABILITY ASSESSMENT RESULTS

The full results of reliability assessment are presented in Appendix C. The application of a threshold of a score of 17 for inclusion led to the exclusion of 12 studies (13 study reports) from the synthesis (Aghabarary and Nayeri, 2016; Bowser, 2016; de Carvalho and Lunardi, 2009; de Menezes et al., 2009; Ferrell, 2006; Hefferman and Heilig, 1999; Mondragon, 1987; Moratti, 2010; Peter et al., 2014; Porto Gois dos Santos et al., 2016; Yekefallah et al., 2015; Yekefallah et al., 2018; Zuzelo, 2007), leaving a total of 29 studies (35 study reports). It is acknowledged that the simple summing of scores in this way to produce a single overall rating suggests that each of the dimensions assessed are considered equally important. We note, however, that the approach seems in this review mainly to have separated the studies on the basis of the reporting of their findings – the clarity of the authors' statement of their findings (dimension 7 in Appendix C) has been assessed as 'poor' in all but one (Peter et al., 2014) of the above excluded studies, while the clarity of reporting of the findings in all of the included studies is rated as either 'fair' or 'good'.

Appendices

Appendix A: MEDLINE search strategy

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to August 07, 2018>

Search Strategy:

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1. Terminal Care/ (25590)
2. Terminally Ill/ (6168)
3. (terminal$ adj2 (care or cares or cared or caring or ill or illness or therap$ or treat$)).ti,ab. (8845)
4. "end of life".ti,ab. (18755)
5. "end-of-life".ti,ab. (18755)
6. EOL.ti,ab. (1436)
7. Palliative Care/ (48825)
8. (palliative adj2 (care or therap$ or treatment$)).ti,ab. (32936)
9. Hospices/ (4799)
10. hospice$.ti,ab. (11013)
11. ((death or dying) adj2 (care or cares or cared or caring)).ti,ab. (1934)
12. Critical Care/ (47334)
13. Intensive Care Units/ (47152)
14. intensive care.ti,ab. (122936)
15. ICU.ti,ab. (45975)
16. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 (270618)
17. Withholding Treatment/ (10765)
18. (appropriate$ adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (62523)
19. (futile adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (686)
20. (futility adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (172)
21. (excessive$ adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (1584)
22. (aggressive$ adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (25734)
23. (unnecessar$ adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (4730)
24. (intensity$ adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (6494)
25. (inappropriate$ adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (5289)

26. (limit$ adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (24505)
27. (unwanted adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (312)
28. (inadequate$ adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (7124)
29. (insufficient$ adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (2690)
30. ((non-beneficial or nonbeneficial) adj2 (care or caring or intervention$ or therap$ or treat$)).ti,ab. (71)
31. medical futility.ti,ab. (386)
32. medical$ futile.ti,ab. (52)
33. (withhold$ adj2 (therap$ or treatment$)).ti,ab. (1039)
34. (withdraw$ adj2 (therap$ or treatment$)).ti,ab. (6305)
35. (withdraw$ adj2 (practice$ or instruction$)).ti,ab. (119)
36. do-not-start.ti,ab. (81)
37. do-not-increase.ti,ab. (2346)
38. perceptions of excessive care.ti,ab. (1)
39. perceived excessive care.ti,ab. (1)
40. letting-go decision$.ti,ab. (1)
41. disruptive medical events.ti,ab. (1)
42. (overtreatment$ or over-treatment$ or over treatment$).ti,ab. (5115)
43. (undertreatment$ or under-treatment$ or under treatment$).ti,ab. (9160)
44. untreated.ti,ab. (158624)
45. "not treated".ti,ab. (13559)
46. (non-treatment or nontreatment or non treatment).ti,ab. (2729)
47. underuse$.ti,ab. (5409)
48. overuse$.ti,ab. (9546)
49. ((chang$ or limit$ or reduc$ or remov$ or restrict$ or withdraw$ or withhold$) adj2 life ustain$).ti,ab. (898)
50. ((chang$ or limit$ or reduc$ or remov$ or restrict$ or withdraw$ or withhold$) adj2 life prolong$).ti,ab. (124)
51. ((chang$ or limit$ or reduc$ or remov$ or restrict$ or withdraw$ or withhold$) adj2 life extend$).ti,ab. (16)
52. ((chang$ or limit$ or reduc$ or remov$ or restrict$ or withdraw$ or withhold$) adj2 life preserv$).ti,ab. (11)
53. oligoanalgesi$.ti,ab. (53)

54. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 (354400)
55. 16 and 54 (13537)
56. Qualitative Research/ (40359)
57. qualitative$.af. (244534)
58. focus group.af. (19886)
59. interview$.af. or interviews/ (340522)
60. ((interpretive or interpretative) adj research).af. (119)
61. ethnography.af. (2711)
62. narrative.af. (24516)
63. ((interpretive or interpretative) adj phenomenolog$).af. (2048)
64. (mixed method$ or multimethod$ or multi-method$ or multi method$).mp. (17402)
65. Attitude of Health Personnel/ (111513)
66. (attitude$ or belief$ or believ$ or choice$ or choos$ or experienc$ or feeling$ or opinion$ or perceiv$ or percept$ or prefer$ or reflect$ or view$).ti. (588101)
67. 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 (1141242)
68. 55 and 67 (2046)

Appendix B. Websites searched

Cambridge Palliative & End of Life Care Group
http://www.phpc.cam.ac.uk/pcu/research/research-groups/end-of-life-care/publications/

Glasgow End of Life Studies Group
https://www.gla.ac.uk/research/az/endoflifestudies/publications/

International Observatory on End of Life Care, Lancaster University
http://www.lancaster.ac.uk/fhm/research/ioelc/#publications

Nottingham Centre for the Advancement of Research into Supportive, Palliative and End-of-life Care (NCARE)
https://www.nottingham.ac.uk/research/groups/ncare/publications.aspx

Wolfson Palliative Care Research Centre, Hull York Medical School
https://www.hyms.ac.uk/research/research-centres-and-groups/wolfson/projects

Appendix C. Reliability assessment: full results

Hawker et al.’s (2002) assessment tool was applied to the studies. Each question is scored as ‘good’, ‘fair’, ‘poor’ or ‘very poor’. We converted these scores into a number from 0 to 3, to generate an overall score between 0 and 27. Studies with a total score less than 17 (shaded grey in the table) were not included in the synthesis.

Reference	**1. Abstract and title**	**2. Introduction and aims**	**3. Method and data**	**4. Sampling**	**5. Data analysis**	**6. Ethics and bias**	**7. Results**	**8. Transferability / generalizability**	**9. Implications and usefulness**	**TOTAL**
Aghabarary and Nayeri (2016)	2	2	2	2	2	2	1	1	2	16
Aghabarary and Nayeri (2017)	3	3	3	3	2	2	2	2	2	22
Belcher (2013)	3	3	3	3	1	2	3	2	3	23
Bellmore (1995)	3	3	2	2	2	2	2	1	1	18
Bluhm et al. (2016)	3	3	3	3	2	1	3	1	2	21
Bowser (2016)	3	2	3	1	1	1	1	0	2	14
Cauley et al. (2016)	3	3	2	2	2	1	2	1	2	18
Dale et al. (2016)	3	3	2	2	2	1	3	2	3	21
de Carvalho and Lunardi (2009)	2	1	2	1	1	1	1	1	1	11
de Menezes et al. (2009)	2	1	2	1	1	1	1	1	0	10
Dzeng et al. (2016)	3	3	3	2	3	2	3	1	2	22
Dzeng et al. (2018)	3	3	3	2	3	2	3	1	2	22
Ferrell (2006)	3	1	1	1	2	0	1	1	0	10
Foley et al. (2014)	3	3	2	3	3	1	3	2	2	22
Gallois et al. (2015); White et al. (2016); Willmott et al. (2016)	3	3	2	2	2	1	3	2	2	20
Grech et al. (2018)	3	3	3	2	2	2	3	2	2	22
Grubbs et al. (2017)	3	3	3	2	2	1	3	2	1	20

Hefferman and Heilig (1999)	0	1	1	1	0	0	1	1	0	5
Heland (2006)	3	3	2	1	2	1	3	1	3	19
Jablonski and Duke (2012)	2	3	3	2	2	2	3	2	3	22
Jox et al. (2012)	3	2	3	2	2	1	3	2	2	20
Kitzinger and Kitzinger (2013)	3	3	1	2	2	1	3	1	2	18
Ladin et al. (2018a; 2018b)	3	3	3	2	2	1	3	1	3	21
Laryionava et al. (2018)	3	3	2	1	2	1	2	1	2	17
Meyers (1994)	3	3	3	3	3	3	3	2	3	26
Mondragon (1987)	2	3	1	1	1	0	1	0	2	11
Moratti (2010)	1	2	1	1	2	0	1	1	0	9
Morris et al. (2018)	3	3	3	2	2	1	2	1	2	19
Oerlemans et al. (2015)	3	3	3	3	2	2	3	1	2	22
Peter et al. (2014)	3	3	1	1	2	1	2	1	1	15
Porto Gois dos Santos et al. (2016)	3	2	1	0	1	1	1	0	0	9
Rodriguez and Young (2006)	3	3	3	3	2	1	3	2	2	22
Saettele and Kras (2013)	3	3	3	1	1	1	2	1	2	17
Sheard et al. (2012)	3	2	3	2	2	1	3	1	1	18
Sibbald et al. (2007)	3	3	3	2	2	1	3	1	2	20
Simmonds (1996a; 1996b; 1997)	2	3	2	1	2	2	2	1	3	18
Sørlie et al. (2000)	3	3	2	2	2	1	3	1	1	18
Workman (1998); Workman et al. (2003)	3	3	3	1	2	2	2	1	3	20
Yekefallah et al. (2015; 2018)	3	3	1	1	2	1	1	1	0	13
Zier et al. (2009)	3	2	2	2	3	1	2	1	2	18
Zuzelo (2007)	2	3	1	2	1	1	1	1	2	14

Appendix D. Evidence tables

Reference	Aghabarary and Nayeri (2017)
Research question / aim	To explore nurses' and physicians' perceptions of the reasons behind providing futile medical treatments
Theoretical approach	NR
Date data collected	2014-15
Country / location	Iran (Tehran)
Data collection methods	Semi-structured individual interviews; questions focused on experiences of delivering futile treatments
Population	Nurses (primarily) and doctors working in hospitals in Iran
Setting for care under discussion	Focus on Intensive Care and End-of-life care centres
Types of patient under discussion	No limits set
Sampling methods	Sampling of site unclear. Individuals sampled for variation in age, gender, experience etc. Recruitment NR. Sampling continued until data saturation.
Inclusion criteria	Healthcare work experience ≥2 years
Sample size	30
Sample characteristics	70% nurses, 30% doctors; 53% male; mean age 37 (nurses), 43 (doctors); mean years experience 12 (nurses), 14 (doctors); range of specialisms
Site / institution characteristics	Teaching hospitals; range of units including critical care and general wards
Data analysis methods	Thematic analysis (conventional content analysis); 'supervised' by second coder
Limitations (author)	NR
Limitations (reviewer)	Some unclarity re sampling; data appear somewhat shallow and remote from experience
Funding	Tehran University of Medical Sciences

Reference	**Belcher (2013)**
Research question / aim	"1. What are the perceptions and lived experiences of nurses regarding futile care of extremely immature newborns? 2. What are the perceptions and lived experiences related to moral distress of nurses who care for extremely immature newborns?" p19
Theoretical approach	Hermeneutic-phenomenological
Date data collected	NR
Country / location	USA (Illinois)
Data collection methods	Face-to-face semi-structured individual interviews; interview questions focused on futile care and moral distress / ethical dilemmas. Data collection piloted with first n=5 participants recruited.
Population	Nurses in neonatal ICU
Setting for care under discussion	Neonatal ICU
Types of patient under discussion	Extremely immature newborns
Sampling methods	Sampling of site (n=1 hospital) convenience / unclear. All NICU nurses in study site emailed and asked to contact researcher (response rate NR)
Inclusion criteria	≥3 years experience caring for critically ill newborns born at ≤24 weeks gestation; not pregnant at time of study
Sample size	15 (5 in pilot, 10 in main study)
Sample characteristics	All female; mean years working as nurse 25.4; modal age 50-59
Site / institution characteristics	Neonatal ICU in non-faith-based acute care hospital; limited further information
Data analysis methods	Hermeneutic data analysis following van Manen's method
Limitations (author)	Small and homogeneous sample; only one site; possible recruitment bias; possible bias in themes due to researcher's own background

Limitations (reviewer)	No major limitations
Funding	NR

Reference	**Bellmore (1995)**
Research question / aim	"to explore the lived experience of nurses providing futile care" (abstract)
Theoretical approach	Sociotechnical systems theory; phenomenology
Date data collected	NR
Country / location	USA (Connecticut)
Data collection methods	Open-ended individual interview; focused on recalling situations where the participant provided futile care (based on an explicit definition provided to participants at the outset) and the impact of this experience; validated by clinical advisory group
Population	Critical care nurses
Setting for care under discussion	ICU
Types of patient under discussion	Patients considered to have received futile care
Sampling methods	Sampling of sites (n=3) unclear. Sampling of individuals stated to be "purposeful" (*sic*; p36) but no information provided beyond this; recruitment NR.
Inclusion criteria	At least 5 years experience as Registered Nurse, of which 3 in critical care; at least 2 experiences of providing futile care; "the ability to describe events and express thoughts richly and fully" [?] (pp36-7). Nurses who were on the clinical advisory group or employed at the same institution as the researcher were excluded.
Sample size	5
Sample characteristics	Mean age 37.4; 100% female; mean years experience 12.4, in critical care 10.3
Site / institution characteristics	Teaching hospitals in urban areas

Data analysis methods	Thematic analysis based on method of Giorgi
Limitations (author)	NR
Limitations (reviewer)	Sampling and recruitment very unclear. Data arguably biased by presentation of detailed definition of futile care.
Funding	NR

Reference	**Bluhm et al. (2016)**
Research question / aim	"the self-reported factors that influence oncologists' decisions about late chemotherapy" (abstract)
Theoretical approach	NR
Date data collected	NR
Country / location	USA ("the Midwest")
Data collection methods	Individual face-to-face semi-structured interviews; questions focused on experiences of late chemotherapy decisions
Population	Oncologists
Setting for care under discussion	Varied practice settings
Types of patient under discussion	Patients with varied cancer diagnoses
Sampling methods	Sites sampled for variation in practice setting. Participants identified by key informants at each site and invited by post; response rate 89%. Cash incentive offered to participants (US$100).
Inclusion criteria	Oncologists who routinely prescribed cytotoxic chemotherapy
Sample size	17
Sample characteristics	71% male; mean age 47; 82% White; mean years in practice 18
Site / institution characteristics	Academic tertiary care, private practice, oncology fellowship programme; no further information

Data analysis methods	Thematic analysis (conventional content analysis); double coding of first n=6 interviews
Limitations (author)	Results cannot be generalised beyond study population. Possible selection bias due to recruitment by key informants. Findings not confirmed with reference to other data sources (for example, medical records, other clinicians, patients, families).
Limitations (reviewer)	No major limitations. Not clear that all participants understood late chemotherapy as overtreatment (but this is the focus of analysis).
Funding	University of Michigan Rackham Graduate School

Reference	**Cauley et al. (2016)**
Research question / aim	"to (1) describe how surgeons approach treatment decisions and discussions about EOL care for older seriously ill patients with surgical emergencies and (2) identify modifiable factors to reduce nonbeneficial surgery near the EOL." p530
Theoretical approach	NR
Date data collected	2014
Country / location	USA (nationwide sample)
Data collection methods	Individual semi-structured interview by telephone. Questions focused on experience of making treatment decisions at EoL and communication with patients and surrogates; interviews also included vignettes asking surgeons to make clinical recommendations.
Population	Emergency general surgeons
Setting for care under discussion	Surgical settings
Types of patient under discussion	Seriously ill older patients with acute surgical conditions
Sampling methods	Direct recruitment from researchers' professional contacts to obtain a "national" sample; snowballing. No further information.
Inclusion criteria	General surgeons
Sample size	24

Sample characteristics	Mean age 43; 67% male; most undertook surgical training 2000-09; most practice >50% consists of emergency surgery
Site / institution characteristics	NR
Data analysis methods	Thematic analysis using grounded theory; double coding of sample of data
Limitations (author)	Only surgeons sampled; participants mainly early career; limited generalizability.
Limitations (reviewer)	Very limited information on sampling.
Funding	NR

Reference	**Dale et al. (2016)**
Research question / aim	“To explore clinicians’ experiences and perceptions of early withdrawal of life support decisions and barriers to guideline-concordant neurological prognostication in comatose survivors of OHCA treated with targeted temperature anagement.” (abstract)
Theoretical approach	NR
Date data collected	NR
Country / location	Canada (Ontario)
Data collection methods	Individual interviews by telephone
Population	ICU doctors and nurses
Setting for care under discussion	ICU
Types of patient under discussion	Comatose survivors of out of hospital cardiac arrest
Sampling methods	Study nested within an RCT. Sampling of sites unclear (sites were hospitals allocated to active arm of RCT). Participants recruited from hospitals that had been allocated to the active intervention phase of the RCT (stepped wedge design). After any withdrawal of life-sustaining treatment for patient with out-of-hospital cardiac arrest, ICU doctors

	and nurses involved in the case were contacted. Response rate NR. Sampling ended with thematic saturation.
Inclusion criteria	"ICU physicians and nurses directly involved in [a] case [of treatment withdrawal for patient with cardiac arrest]" p1116
Sample size	21
Sample characteristics	52% female; 43% doctors, 57% nurses; mean 10.5 years ICU experience
Site / institution characteristics	ICUs; community (48%) and academic (52%) hospitals
Data analysis methods	"Focused thematic analysis" (essentially a framework analysis) with aim to identify barriers to implementing guidelines and potentially modifiable factors. Double coding of 30% of transcripts.
Limitations (author)	Limited generalizability to other jurisdictions; study did not include surrogates.
Limitations (reviewer)	No major limitations. Interview questions do not focus on undertreatment as such; this is study authors' interpretation based on guidelines, and unclear whether participants understood cases as undertreatment.
Funding	Heart and Stroke Foundation of Canada; Canadian Institute of Health Research; Physicians' Services Incorporated Foundation

Reference	**Dzeng et al. (2016)**
Research question / aim	"how medical physician trainees perceive and respond to ethical challenges arising in the context of treatments at the end of life that they perceive to be futile and how these challenges may contribute to moral distress" p94
Theoretical approach	NR
Date data collected	NR
Country / location	USA ("medium to large cities", not specified)
Data collection methods	Open-ended (semi-structured) interviews with interview guide, conducted in person or via Skype

Setting for care under discussion	Academic medical centres, not further specified
Types of patient under discussion	No limits set but quotes refer often to ICU treatments
Population	Trainee doctors (internal medicine)
Sampling methods	Sites purposively sampled for variation in EoL care. Individuals sampled for variation in stage of training; recruited through various means (email, personal invitation, snowballing); response rate NR. Sampling ceased with theoretical saturation.
Inclusion criteria	Physicians who had attended medical school and residency in the USA
Sample size	22
Sample characteristics	59% female; mean years experience 3.7; 45% fellows, 55% residents
Site / institution characteristics	Academic medical centres (n=3); all had palliative care and ethics consultation services; limited further information
Data analysis methods	Thematic coding; focus on disconfirming cases; double coding of 20% of interviews; member checking through discussion with physicians
Limitations (author)	Possible social desirability bias (and concern among participants about confidentiality); excluded community hospital-based residency programmes
Limitations (reviewer)	No major limitations
Funding	Health Resources and Service Administration Training Grant; Gates Cambridge Scholarship; Society of General Internal Medicine Founders Grant; Ho-Chiang Palliative Care Research Fellowship

Reference	**Dzeng et al. (2018)**
Research question / aim	To explore how institutional and system-level factors influence perceptions and behaviour on the part of clinicians, patients and surrogates [as perceived by clinicians], leading to overly aggressive treatment
Theoretical approach	interpretivist symbolic interactionism

Date data collected	NR
Country / location	USA (“New England, the Mid-Atlantic, and the Pacific Northwest")
Data collection methods	Semi-structured individual interviews, in person or via Skype. Questions focused on views and experiences relating to resuscitation and DNR orders.
Population	internal medicine physicians
Setting for care under discussion	Academic medical centres, not further specified
Types of patient under discussion	No limits set but quotes refer often to ICU treatments
Sampling methods	Sampling of sites unclear. Individuals sampled purposively for diversity in experience and specialty. Recruitment via email, individual approach and snowballing. Response 100% for those approached individually.
Inclusion criteria	"general and subspecialty internal medicine physicians"
Sample size	42
Sample characteristics	55% male; mean 13.9 years experience; range of specialties
Site / institution characteristics	Academic medical centres (n=3); no further information
Data analysis methods	Thematic analysis; focus on disconfirming cases; double coding of 20% of interviews; member checking through conversations and formal presentations of findings to doctors
Limitations (author)	Sample did not include patients, families, nurses or others involved in care; interview data do not allow assessment of actual practice; data from academic medical centres in urban settings may not be generalizable to other healthcare settings
Limitations (reviewer)	No major limitations. Relation between original theme of interviews (resuscitation and DNR) and focus of paper (overly aggressive care) is not clarified, and unclear how far all participants understood the situations described as overtreatment
Funding	Health Resources and Service Administration; Gates Cambridge Scholarship; Ho-Chiang Palliative Care Research Fellowship; UCSF Pepper Center for Older Adults; Society of General Internal Medicine

Reference	**Foley et al. (2014)**
Research question / aim	‘To identify key psycho-social processes that underpin how people with motor neurone disease engage with healthcare services.’ (abstract)
Theoretical approach	NR
Date data collected	2011-12
Country / location	Ireland (nationwide sample)
Data collection methods	Individual unstructured interviews; questions focused on experiences of healthcare
Setting for care under discussion	No limits set
Types of patient under discussion	Patients with motor neurone disease
Population	People with motor neurone disease (MND)
Sampling methods	Recruited from a national population-based register. Purposive sampling for diversity in healthcare experience. Response rate 72%.
Inclusion criteria	People with MND
Sample size	34
Sample characteristics	modal age 60-69; 50% male; mean disease duration 31 months
Site / institution characteristics	N/A
Data analysis methods	Thematic coding based on grounded theory, focusing on ‘psycho-social processes’ in different contexts. Second author ‘interrogated’ the data analysis (p320). Analysis not validated with participants due to rapid disease progression.
Limitations (author)	Findings may not be generalisable to other countries. Participants only interviewed at one time point.
Limitations (reviewer)	No major limitations. The research question is broad and over-/undertreatment is not the primary goal (but is a theme of much of the data).

Funding	Health Research Board of Ireland

Reference	**Gallois et al. (2015); White et al. (2016); Willmott et al. (2016)**
Research question / aim	To investigate the reasons why doctors provide futile treatment at the end of life (Willmott et al.); to investigate the intergroup language associated with futile treatment (Gallois et al.); to explore definitions of futility (White et al.)
Theoretical approach	NR (Willmott et al.); communication accommodation theory and linguistic intergroup bias theory (Gallois et al.)
Date data collected	2013
Country / location	Australia (Brisbane)
Data collection methods	Individual semi-structured interviews using convergent interviewing technique. Interview guide informed by clinical advisory group and piloted; questions focused on recalling cases of futile treatment (or where futile treatment had been avoided, or where there was disagreement about whether treatment was beneficial).
Population	Doctors (in range of specialties routinely involved in EoL care)
Setting for care under discussion	A teaching hospital
Types of patient under discussion	No limits set
Sampling methods	Sampling of sites unclear. Sampling of individuals for variation in specialty and seniority, with quotas for specialty; sampling informed by clinical advisory group. Recruitment by word of mouth and emails from heads of departments; participants contacted the research team directly. Sample also included at least one medical administrator from each (of n=3) site.
Inclusion criteria	Doctors involved in EoL care (implicit)
Sample size	96
Sample characteristics	71% male; mean age 49; mean years working in Australia 19; "almost all" Australian-trained; range of specialties, with focus on emergency care, intensive care, palliative care, oncology, and renal medicine.
Site / institution characteristics	public tertiary hospitals; no further information

Data analysis methods	Thematic coding (framework analysis) with double-coding and focus on disconfirming cases; analysis validated with clinical advisory group and other clinicians. Discourse analysis in Gallois et al.
Limitations (author)	Findings may not be generalizable to other specialties, private hospitals, or rural areas. Data focus on general perceptions of futile treatment rather than doctors' own practice. Participants volunteered so there may be selection bias.
Limitations (reviewer)	None to add to authors
Funding	Australian Research Council; Royal Brisbane and Women's Hospital

Reference	**Grech et al. (2018)**
Research question / aim	'to explore the experiences of nurses providing end-of-life care to patients with hematologic malignancies' (abstract)
Theoretical approach	Interpretative Phenomenological Analysis
Date data collected	NR
Country / location	Malta
Data collection methods	Semi-structured individual interview [or unstructured]; questions focused on experiences of providing EoL care for patients with haematological cancers
Population	Nurses providing EoL care in a haematology oncology unit
Setting for care under discussion	Haematology oncology unit in an acute general hospital
Types of patient under discussion	Patients with haematologic malignancies
Sampling methods	Sampling of sites unclear. Sampling of individuals stated to be 'purposive', but details NR. No information on recruitment.
Inclusion criteria	Nurses working in haematology oncology unit with >1 year experience
Sample size	5
Sample characteristics	100% female; age 25-55

Site / institution characteristics	hematology oncology unit in acute general hospital; no formal palliative care service available
Data analysis methods	Thematic coding of interviews and field notes.
Limitations (author)	Small sample size; only female participants.
Limitations (reviewer)	Very limited information on sampling. Overtreatment is not the research question (but emerged as a predominant theme in the analysis).
Funding	NR

Reference	**Grubbs et al. (2017)**
Research question / aim	To investigate nephrologists' views and experiences of foregoing or withdrawing dialysis, and factors related to decision-making
Theoretical approach	NR
Date data collected	2013-14
Country / location	UK (England, nationwide sample); USA (nationwide sample)
Data collection methods	Individual semi-structured interviews, in person or by telephone / Skype. Questions focused on experiences of treatment decisions for patients with chronic kidney failure.
Population	Nephrologists
Setting for care under discussion	Various (nationally drawn samples)
Types of patient under discussion	Patients with end-stage kidney disease
Sampling methods	Key informants identified (NR how) and asked to identify other nephrologists representing variation in demographics, location and practice types / payment structures. Recruitment process and response rate NR.
Inclusion criteria	Nephrologists caring for adult patients with end-stage renal disease in dialysis units; excluded trainees, those without clinical practice and paediatric nephrologists.

Sample size	59 (n=41 in USA sample, n=18 in England sample)
Sample characteristics	58% ≤45 years old; 76% male; 59% White; mean years since completing nephrology training 14.2
Site / institution characteristics	All UK sample in NHS settings; for USA sample, 61% academic practice, 29% private practice, 7% VA or other 'closed' system, 1% other. For UK sample, 56% metropolitan, 8% town/rural. For USA sample, 66% paid by salary only, 17 % fee for service only, 17% both. Most settings <20 nephrologists.
Data analysis methods	Thematic coding using constant comparative analysis; double coding of n=9 cases; analysis determined by thematic saturation.
Limitations (author)	Sample may not capture views of all nephrologists.
Limitations (reviewer)	Some unclarity in sampling. Over-/undertreatment is not the *a priori* focus, but was a major theme.
Funding	National Institute of Diabetes and Digestive and Kidney Diseases; Robert Wood Johnson Foundation.

Reference	**Heland (2006)**
Research question / aim	"to investigate the perceptions and experiences of nurses practising in adult intensive care units (ICUs) with regard to medical futility" (abstract)
Theoretical approach	Qualitative exploratory descriptive method
Date data collected	NR
Country / location	Australia (location NR)
Data collection methods	Semi-structured interviews
Population	Nurses in ICUs
Setting for care under discussion	ICUs, varied hospitals
Types of patient under discussion	No limits set

Sampling methods	"purposeful sampling using the snowball technique" (p26); no further information on sampling or recruitment
Inclusion criteria	Registered nurse; ≥12 months experience in ICU; experience of participating in treatment which they believed to be futile
Sample size	7
Sample characteristics	Mean 11 years practice experience (7 years as ICU nurse); 71% female
Site / institution characteristics	NR
Data analysis methods	Thematic coding; emergent themes presented to subsequent participants
Limitations (author)	Small sample size
Limitations (reviewer)	Very limited information on sampling or data collection.
Funding	NR

Reference	**Jablonski and Duke (2012)**
Research question / aim	to explore "nurses' perceptions of barriers and facilitators for effective pain management in rural acute care" (pp533-4)
Theoretical approach	NR
Date data collected	NR
Country / location	USA (Texas)
Data collection methods	Initial data collection via email (two rounds with open-ended questions and then further clarification of themes); second round of data collection by individual interviews further exploring themes from emails. Interviews not recorded but detailed notes taken. Questions focused on concerns about pain management and barriers to advocating for patients in pain.
Population	Nurses
Setting for care under discussion	A 100-bed, rural hospital

Types of patient under discussion	Patients acutely or terminally ill
Sampling methods	Sampling of site unclear. Individuals sampled on a convenience basis; recruitment by email to n=40 (unclear how selected), response rate 27.5%.
Inclusion criteria	"any licensed nurse who worked in the hospital and who cared on a regular basis for persons who were terminally ill" (p534)
Sample size	10
Sample characteristics	100% female; age range 23-58; years of experience range 1-33
Site / institution characteristics	Hospital in rural community; mainly adult patients, 70% white and 30% Hispanic; most participants in general medical-surgical units
Data analysis methods	Thematic coding using barriers-facilitators framework; findings verified with participants
Limitations (author)	Small sample size; limited generalizability; no audio recording of interviews; no piloting of interview tool
Limitations (reviewer)	Some unclarity in sampling. Study does not expressly focus on undertreatment, but much of the data are relevant.
Funding	NR

Reference	**Jox et al. (2012)**
Research question / aim	"to elucidate how clinicians define futility, when they perceive life-sustaining treatment (LST) to be futile, how they communicate this situation and why LST is sometimes continued despite being recognised as futile." (abstract)
Theoretical approach	NR
Date data collected	NR
Country / location	Germany (location NR)
Data collection methods	Semi-structured interviews; interview guide based on analysis of ethics consultations and piloted with experts; questions focused on definitions of futility, how judgements about futility are made and communicated, and reasons why futile life-sustaining treatment is

	provided. Data collected in German and translated to English for publication.
Population	Doctors and nurses in intensive care and palliative care
Setting for care under discussion	Intensive and Palliative Care Units at a tertiary hospital
Types of patient under discussion	No limits set
Sampling methods	Sampling of site (n=1) unclear. Sampling of participants based on ethics consultation records (stated that n=17 consultations were analysed from a 12-month period in given site, although unclear if this was all consultations or if there was further selection). All doctors and nurses from intensive care medicine and palliative care medicine present at the selected consultation meetings were sampled; response rate "all but one" (=97%).
Inclusion criteria	doctors and nurses from intensive care medicine or palliative care medicine
Sample size	29
Sample characteristics	62% doctors, 38% nurses; 59% intensive care, 41% palliative care; no further information
Site / institution characteristics	"a large tertiary referral centre" (p540)
Data analysis methods	Thematic coding; double coding of 30% of records
Limitations (author)	Data not representative; sample from a single hospital and setting.
Limitations (reviewer)	No major limitations
Funding	NR

Reference	**Kitzinger and Kitzinger (2013)**
Research question / aim	To explore the delivery of life-sustaining treatments to brain-injured patients whose families believe they would not wish to be kept alive.
Theoretical approach	"Realist" / "interpretive autobiography" (p1100)

Date data collected	NR
Country / location	UK (location NR)
Data collection methods	Interviews; no further information
Population	Family members of brain-injured patients who believe the patient would prefer to die than continue to receive treatment
Setting for care under discussion	Not described
Types of patient under discussion	Patients with severe brain-injury
Sampling methods	Participants sampled though brain injury support groups and websites, personal contacts, and snowballing. This report presents a subgroup of a broader sample of relatives (n=26 of 34 participants, n=14 of 21 families), namely those who believe their relative would prefer to be dead.
Inclusion criteria	Family members of patients with severe brain injury; interviews containing explicit statement that they believe the patient would prefer to be dead. (Inclusion did not require that all family members agreed on this point, although authors report that none disagreed.)
Sample size	26 (from n=14 different families)
Sample characteristics	Patient age range from teens-70s; patient diagnoses of permanent vegetative state, minimally conscious state and/or profound neurological deficit. Participants' relation to patient: parent n=9, sibling n=5, spouse/partner n=5, adult child n=4, other relative n=3; no further information
Site / institution characteristics	NR
Data analysis methods	Thematic analysis focusing on decision-making regarding medical interventions at critical periods, "to identify moments where the opportunity to die was taken or missed" (p1099).
Limitations (author)	Non-representative sample.
Limitations (reviewer)	Some unclarity on sampling / recruitment
Funding	Rockefeller Foundation; Wellcome Trust

Reference	Ladin et al. (2018a; 2018b)
Research question / aim	To examine nephrologists’ views and experiences of discussing and decision-making regarding conservative management [i.e. avoiding aggressive treatment with little survival benefit] with older patients with advanced chronic kidney disease
Theoretical approach	NR
Date data collected	2016-17
Country / location	USA (various locations)
Data collection methods	Semi-structured individual interview, in person or by telephone
Population	Nephrologists
Setting for care under discussion	Academic and Community practice settings (nationally drawn sample)
Types of patient under discussion	Older patients with chronic kidney disease
Sampling methods	Purposive sampling for diversity in sex, years in practice, practice type, and location; purposive sampling of practices "to capture a range of perspectives" (p628); sampling of individuals unclear although "at 50% of sites we used snowball sampling" (p628); response rate NR
Inclusion criteria	NR explicitly
Sample size	35
Sample characteristics	80% male; most >10 years since completion of training; 51% were medical directors of dialysis facility
Site / institution characteristics	Large academic centres (69%), small academic centres (11%), community practices (20%); n=18 sites total
Data analysis methods	Thematic inductive coding; double coding of n=7 transcripts; attention given to confirmatory and contradictory narratives
Limitations (author)	Oversampling of academic medical centres
Limitations (reviewer)	Some unclarity in sampling and recruitment

Funding	National Institutes of Health; Dialysis Clinic Inc

Reference	**Laryionava et al. (2018)**
Research question / aim	To investigate treatment decisions for young adults with advanced cancer, and whether age was a factor in these decisions.
Theoretical approach	NR
Date data collected	NR
Country / location	Germany (Munich)
Data collection methods	Semi-structured individual face-to-face interviews; questions based on literature review and piloted. Interview themes / questions NR.
Population	Oncologists and oncology nurses
Setting for care under discussion	Intensive and Palliative Care Units and an Oncology ward, in a University hospital
Types of patient under discussion	Young adult patients with advanced cancer
Sampling methods	Stated to be purposive for heterogeneity, but no information on sampling process or recruitment reported
Inclusion criteria	Oncologists and nurses in intensive and palliative care
Sample size	29
Sample characteristics	76% doctors, 24% nurses; ages 22-64 years; work experience 8 months - 34 years.
Site / institution characteristics	university hospital; palliative care unit (n=1), intensive care unit (n=1) and general oncology wards (n=4)
Data analysis methods	Thematic coding (by three coders) on grounded theory principles, guided by thematic saturation; preliminary results informed by feedback from academic conference presentation
Limitations (author)	NR
Limitations (reviewer)	Very little information on sampling or data collection (specifically to what extent participants were asked about overtreatment, or whether this theme emerged from more general lines of questioning).

Funding	Deutsche Krebshilfe (German Cancer Aid)

Reference	**Meyers (1994)**
Research question / aim	To describe moral suffering experienced by critical care nurses, and its impact on them and on patient care
Theoretical approach	Phenomenology
Date data collected	NR
Country / location	USA (“Pacific Northwest”)
Data collection methods	Individual unstructured interviews; focused on describing situations where patient care involved ethical problems.
Population	Critical care nurses
Setting for care under discussion	ICUs in Tertiary medical centres
Types of patient under discussion	No limits set
Sampling methods	Sampling of sites (n=5 units in n=4 hospitals) unclear. Sampling purposive for ‘intensity’, i.e. for individuals whose experience supported in-depth inquiry. Individuals recruited through posters, handouts, unit meetings after meeting with unit manager; participants contacted researcher (n=1 also contacted researcher after hearing about the study from a colleague). Author estimates that n=150 nurses saw invitation [which would give a response rate of 6%].
Inclusion criteria	NR explicitly
Sample size	9
Sample characteristics	100% female; age 25-43; mean years experience in critical care 11
Site / institution characteristics	Large critical care units (16-24 beds) in tertiary medical centres; urban setting; range of units including coronary, trauma, surgical critical care, bone marrow transplant
Data analysis methods	Thematic analysis; validated by advisory group (n=1 interview); emergent themes validated with participants.

Limitations (author)	Low response rate and potential selection bias as a result; no male participants; possible researcher bias
Limitations (reviewer)	Some unclarity in sampling and self-selected sample. Over-/under–treatment is not the *a priori* research question (but is a major theme in the data).
Funding	Laura C. Dustan Research Award

Reference	**Morris et al. (2018)**
Research question / aim	To investigate surgeons' perceptions of shared decision-making in emergency situations, treatment decisions and communication with patients and families
Theoretical approach	NR
Date data collected	NR
Country / location	USA (Milwaukee; Baltimore)
Data collection methods	Semi-structured interviews in person or by telephone; interview guide piloted with key informant surgeons; included 2 case vignettes and questions about surgical decision-making in patients with acute illness (i.e. who were expected to die without surgery).
Population	Surgeons
Setting for care under discussion	Surgical settings in academic medical centres
Types of patient under discussion	Patients with acute surgical illness
Sampling methods	Sampling of sites (n=2) unclear. Individuals stated to be "randomly selected" (p785) [but unclear what this means, or what the sampling frame was]; also stated that sample was intended "to provide increased opportunity for thematic saturation" (p785). No information on recruitment.
Inclusion criteria	"Participants were required to speak English, actively practice at the main academic hospital or a community affiliate of these institutions, and practice general surgery or a subspecialty of general surgery" (p785)
Sample size	20

Sample characteristics	median age 45; median years experience 9; 90% male; 80% White; 30% trauma surgeons, 20% vascular surgeons, 50% other subspecialties
Site / institution characteristics	Academic medical centres
Data analysis methods	Thematic coding using grounded theory approach, guided by thematic saturation; double coding of all data
Limitations (author)	Mostly male participants; only one time point
Limitations (reviewer)	Some unclarity on sampling. Over-/undertreatment is not the *a priori* research question (but was found to be a major theme).
Funding	AHRQ

Reference	**Oerlemans et al. (2015)**
Research question / aim	To explore ethical dilemmas relating to ICU admission and discharge
Theoretical approach	NR
Date data collected	2012-13
Country / location	Netherlands (location NR)
Data collection methods	Individual face-to-face interviews; interview guide piloted; questions related to ethical dilemmas and disagreements / problems relating to admission or discharge to ICU. Four focus groups (ICU doctors, ICU nurses, general ward doctors, general ward nurses) led by moderator; questions focused on fictional cases based on interview data and literature.
Population	Doctors and nurses in ICUs, and in general wards admitting post-ICU patients
Setting for care under discussion	ICUs and general wards of varied types of hospital
Types of patient under discussion	No limits set
Sampling methods	Sampling of sites unclear. For individual interviews, individuals invited by email; recruitment process not described in detail; response rate

	95%. For focus groups, snowball sampling via key contacts in sampled sites; recruitment not described in detail; response rate 24%.
Inclusion criteria	Doctors and nurses in ICUs or in general wards admitting post-ICU patients; involvement in (post-)ICU patient care
Sample size	19 for individual interviews; 25 for focus groups
Sample characteristics	57% ICU, 43% general ward; 55% nurses, 45% doctors; 57% female; 48% had >10 years' experience in current specialty
Site / institution characteristics	General hospitals, teaching hospitals, academic hospitals (n=2 each); ICUs and general wards; no further information
Data analysis methods	Focus group transcripts sent to participants for comment. Thematic analysis using grounded theory; double-coding for first five interviews and one focus group
Limitations (author)	Possible social desirability bias; small sample size
Limitations (reviewer)	Some unclarity in sampling. Study does not focus primarily on over/undertreatment although there are substantial data.
Funding	Netherlands Organisation for Health Research and Development (ZonMw)

Reference	**Rodriguez and Young (2006)**
Research question / aim	To understand patients' views on the utility or futility of EoL treatment
Theoretical approach	NR
Date data collected	2000-02
Country / location	USA (Pittsburgh)
Data collection methods	Individual semi-structured face-to-face interviews; interview included open-ended questions focusing on the terms life-sustaining treatment, terminal condition, state of permanent unconsciousness and decision-making capacity; participants were asked about their understanding of the term and associations with it.
Population	Older people receiving primary care [population also includes healthcare providers, but qualitative data from these participants are NR and they are not considered in this data extraction]

Setting for care under discussion	Recruitment conducted in Veterans Affairs medical centre Outpatient clinic
Types of patient under discussion	No limits set
Sampling methods	Sampling of site (n=1) unclear. All healthcare providers at sampled site invited to participate and first n=30 to respond were enrolled. All patients who met inclusion criteria scheduled for appointment with each provider within 2 months were approached in person; response rate 32%.
Inclusion criteria	>60 years, ambulatory, able to speak and read English, residing in the community, receiving outpatient care from the Veterans Administration, not cognitively impaired and not acutely ill
Sample size	30
Sample characteristics	93% male; 90% white; 13% no high school education; mean age 70.5. [Healthcare provider data not extracted.]
Site / institution characteristics	"a large, urban, outpatient primary care clinic"; part of Veterans Administration system (pp444-5)
Data analysis methods	Constant comparison analysis based on grounded theory, analysed in 'conversational turn' units, guided by theoretical saturation. (Analysis did not focus on futility *a priori* but this emerged as a core theme from the data.) Double coding of 20% of transcripts.
Limitations (author)	Limited generalisability due to small sample size, 'nonprobability' sampling, use of a single site and homogeneity of sample characteristics
Limitations (reviewer)	No major limitations. The concept of utility/futility is introduced in the analysis and was not explicitly used by most participants.
Funding	Department of Veterans Affairs

Reference	**Saettele and Kras (2013)**
Research question / aim	to "characterize the current attitudes and clinical practices regarding futile care by ... United States [anaesthetists] who frequently care for critically ill patients."
Theoretical approach	NR

Date data collected	NR
Country / location	USA (location NR)
Data collection methods	Semi-structured group interviews (mean n=4 participants), led by two researchers. Participants were presented with a definition of futility and asked whether they agreed with it, and about experiences of futile care
Population	Anaesthetists (trainee and attending)
Setting for care under discussion	Operating room and ICU, University hospital
Types of patient under discussion	No limits set
Sampling methods	Sampling of site unclear (presumably convenience – "our institution"). All attendings, fellows and residents of Departments of Anesthesiology and Surgery at selected institution were invited to participate by email and at meetings. Response rate NR.
Inclusion criteria	NR
Sample size	16
Sample characteristics	63% male; 69% aged 20-40; all employed in Dept of Anesthesiology
Site / institution characteristics	NR
Data analysis methods	Thematic coding using grounded theory with broad *a priori* framework; no double coding; no participant validation
Limitations (author)	NR
Limitations (reviewer)	Some unclarity in sampling. Data may be biased by presentation of definition of futility. The RQ and data collection do not mention EoL, but almost all of the data appears to be about this (the fact that participants understood 'futility' to be about EoL is not explored in the paper).
Funding	NR

Reference	**Sheard et al. (2012)**
Research question / aim	To explore the barriers for doctors diagnosing and treating advanced cancer patients with venous thromboembolism
Theoretical approach	NR
Date data collected	2010-11
Country / location	UK (Yorkshire; South Wales)
Data collection methods	Semi-structured interview. Questions focused on barriers to diagnosis and treatment of cancer patients with venous thromboembolism. Interview guide amended to take account of emergent themes.
Population	Doctors treating patients with advanced cancer (in oncology, palliative medicine and general practice)
Setting for care under discussion	Hospitals, hospices and GP surgeries
Types of patient under discussion	Advanced cancer patients with venous thromboembolism
Sampling methods	Individuals identified initially by websites of hospitals / trusts / practices and professional directories and invited by post or email, with further recruitment by snowballing; sampling guided by diversity in specialty and seniority; response rate NR.
Inclusion criteria	Doctors involved in treating patients with advanced cancer with venous thromboembolism
Sample size	45
Sample characteristics	Age 28-58; 58% female; 44% oncologists, 33% palliative medicine doctors, 22% GPs
Site / institution characteristics	Teaching hospitals, oncology hospitals, district general hospitals, hospices, GP practices.
Data analysis methods	Framework analysis; double coding of all data
Limitations (author)	Sample may be biased to those who had a higher level of interest in or knowledge of the topic.

Limitations (reviewer)	Some unclarity in sampling / recruitment.
Funding	National Institute for Health Research

Reference	**Sibbald et al. (2007)**
Research question / aim	To explore ICU staff's definitions of futile care, reasons why futile care is provided, and potential strategies to reduce futile care
Theoretical approach	NR
Date data collected	NR
Country / location	Canada (Ontario)
Data collection methods	Individual semi-structured interviews; questions focused on describing cases of inappropriate or excessive care, perceived good and bad outcomes for patients, and strategies for reducing inappropriate care. Interviewers deliberately did not use term 'futility' or 'futile care' in interviews.
Population	Doctors, nurses and respiratory therapists working in ICUs (including medical directors / nursing managers)
Setting for care under discussion	ICUs, Community and Teaching hospitals
Types of patient under discussion	No limits set
Sampling methods	Sites (n=16) sampled randomly from a total of 50 ICUs in Ontario, to include at least 1 from each Local Health Integration Network. From each site, recruited medical director, nurse manager and senior respiratory therapist. Response rate 100% (although n=4 participants were not interviewed in time to be included in the analysis).
Inclusion criteria	For sites: closed or semi-closed (some or all patients under care of trained intensivists) and ≥12 beds (to ensure participants had sufficient intensive care experience). For individuals: NR explicitly
Sample size	44
Sample characteristics	32% doctors, 36% nurses, 32% respiratory therapists; no further information

Site / institution characteristics	ICUs in community hospitals (n=10) or teaching hospitals (n=6); included both rural and urban settings and a range of patient types
Data analysis methods	Thematic coding using grounded theory approach; double coding of all data
Limitations (author)	May not be generalisable to other ICUs or ICU staff
Limitations (reviewer)	No major limitations
Funding	Ontario Ministry of Health and Long-Term Care

Reference	**Simmonds (1996a; 1996b; 1997)**
Research question / aim	"to explore the experience of intensive care physicians and nurses working with dying patients whom they perceive to be over or undertreated." (abstract)
Theoretical approach	Not clearly stated; based on theological ethics
Date data collected	1994
Country / location	Canada (Toronto)
Data collection methods	Individual face-to-face interviews; questions focused on what participants liked or found difficult about working in intensive care; over-/undertreatment not introduced explicitly by researcher.
Population	Doctors (trainee and attending) and nurses in intensive care
Setting for care under discussion	An ICU
Types of patient under discussion	No limits set
Sampling methods	Sampling of site (n=1) unclear; sampling stated to aim for diversity in age, experience, gender and nationality, but limited further information on sampling; no information on recruitment
Inclusion criteria	NR explicitly
Sample size	21

Sample characteristics	57% male; 33% nurses, 29% house physicians, 38% staff physicians; ages 26-55; ICU experience from ‘months’ – 26 years
Site / institution characteristics	ICU in teaching hospital; urban setting; diverse patient population
Data analysis methods	Thematic coding using grounded theory approach
Limitations (author)	Analysis carried out by one researcher alone, possibly leading to bias; all respondents from single site
Limitations (reviewer)	Some unclarity on sampling. Not all data relate to over-/undertreatment despite this being the stated research question.
Funding	NR

Reference	**Sørlie et al. (2000)**
Research question / aim	To explore the ethical reasoning of female doctors relating to ethically difficult care situations
Theoretical approach	Phenomenological hermeneutics (Ricoeur); also makes reference to the distinction between action ethics and relation ethics
Date data collected	NR
Country / location	Norway (location NR)
Data collection methods	Individual interview focused on narrating situations that participants had found ethically difficult.
Population	Women doctors working in paediatrics
Setting for care under discussion	Paediatric Clinics in university hospitals
Types of patient under discussion	Children
Sampling methods	Unclear. Study aimed to sample both more and less experienced doctors; aimed to sample n=10 (actual sample n=9). Invitations to participate made “at various meetings”. No other information on sampling or recruitment.
Inclusion criteria	NR explicitly

Sample size	9
Sample characteristics	Median age 39; median years experience in paediatric clinics 9, in healthcare 11
Site / institution characteristics	Paediatric clinics in university hospitals (n=2)
Data analysis methods	Thematic analysis based on phenomenological hermeneutics
Limitations (author)	NR
Limitations (reviewer)	Unclarity regarding sampling. Research question is very broad and not focused on over-/undertreatment (although this is a major theme in the data).
Funding	NR

Reference	**Workman (1998); Workman et al. (2003)**
Research question / aim	To investigate ICU nurses' and doctors' experiences of treatment withdrawal and futile care
Theoretical approach	Phenomenology
Date data collected	NR
Country / location	Canada (location NR)
Data collection methods	Individual semi-structured interviews; focused on recalling cases where participants had been required to continue life-sustaining treatment because family members refused to allow treatment to be withdrawn
Population	ICU doctors and nurses
Setting for care under discussion	ICUs at University hospitals
Types of patient under discussion	No limits set
Sampling methods	Sampling of sites based on their participation in a task force with which the researcher was involved. The sample was stated to be one ICU director (doctor) and one nurse from each of n=6 sites (2003 p18), but

	unclear how nurses were sampled – appears that involvement in the task force played a role. Recruitment by letter from task force chair (requiring participants to opt out of study if they did not wish to participate).
Inclusion criteria	NR explicitly; non-medical members of the task force were excluded
Sample size	12
Sample characteristics	50% doctors, 50% nurses; 50% male; age 30-50; years of critical care experience 5-25
Site / institution characteristics	ICUs (n=6) in teaching hospitals; urban setting
Data analysis methods	Thematic analysis
Limitations (author)	Small and unrepresentative sample; family members not included; data only on perceptions and not actual behaviour; participants' selection of cases may be 'archetypal' or unusually dramatic and not reflect more typical cases; homogeneous selection of settings
Limitations (reviewer)	Some unclarity on sampling. The prompt for data collection is rather specific and arguably could introduce bias.
Funding	University of Toronto; Canadian Institutes of Health Research

Reference	**Zier et al. (2009)**
Research question / aim	To explore surrogates' attitudes to doctors' judgements of futility, and how these relate to willingness to withdraw treatment.
Theoretical approach	NR
Date data collected	2006-07
Country / location	USA (California)
Data collection methods	Semi-structured interview using "techniques of cognitive interviewing" (p111) using a vignette prompt. (Also a quantitative component; data from this not extracted here.)
Population	Surrogates of critically ill patients

Setting for care under discussion	ICUs at hospitals of various types
Types of patient under discussion	Critically ill patients
Sampling methods	Sampling of sites unclear. Researchers went through each ICU once per week and assessed the first patient-surrogate pair they encountered for inclusion. Response rate 86%.
Inclusion criteria	English speaking; ≥18 years old; involved in decision-making for a patient who was critically ill and incapacitated
Sample size	50 (representing n=31 patients)
Sample characteristics	(for participants) mean age 55.2; 68% female; 40% White, 24% Black, 20% Hispanic; relationship to patient 28% spouse/partner, 22% sibling, 16% child, 13% parent; education level some college or above 62%; first language English 96%. (patients) mean age 65.2; 68% male; 48% White, 19% Black, 13% Hispanic; most common diagnoses cardiac failure, aneurysm or haemorrhage.
Site / institution characteristics	One Veterans Affairs hospital, one academic hospital, and one public county hospital
Data analysis methods	Constant comparison analysis; double coding for a subset of data; preliminary framework validated by checking with participants; analysis focused on doubt about doctors' predictions of futility.
Limitations (author)	Small sample size; findings may depend upon specific prompt used; possible social diversity bias; non-English-speaking surrogates excluded; data not collected over time to investigate variation over illness trajectory; surrogate-doctor relationships not investigated
Limitations (reviewer)	Mixed-methods study with fairly limited qualitative data. The topic is arguably marginal in terms of inclusion in the review, as the focus is on judgements of futility rather than experiences of care as such.
Funding	University of California; National Institutes of Health; Greenwall Foundation

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The NIHR Policy Research Programme Reviews Facility collaboration has grown out of a previous 'reviews facility' in Health Promotion and Public Health based at the EPPI Centre, and has been funded by the Department of Health and Social Care since 1995.

The views expressed in this work are those of the authors and do not necessarily reflect the views of the collaborating centres or the funder. All errors and omissions remain those of the authors.

First produced in 2021 by:

Evidence for Policy and Practice Information Centre (EPPI Centre)
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UCL Institute of Education, University College London
18 Woburn Square
London WC1H 0NR

https://eppi.ioe.ac.uk
https://www.ucl.ac.uk/ioe/departments-and-centres/departments/ucl-social-research-institute

ISBN: 978-1-911605-27-0

Editorial & design by: Lionel Openshaw

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