

# Physicians' Conceptions of the Dying Patient: Scoping Review and Qualitative Content Analysis of the United Kingdom Medical Literature

Qualitative Health Research  
2022, Vol. 32(12) 1881–1896  
© The Author(s) 2022



Article reuse guidelines:

[sagepub.com/journals-permissions](https://sagepub.com/journals-permissions)  
DOI: 10.1177/10497323221119939  
[journals.sagepub.com/home/ghr](https://journals.sagepub.com/home/ghr)



Shaun Peter Qureshi<sup>1</sup> , Derek Jones<sup>1</sup>, and Avril Dewar<sup>1</sup>

## Abstract

Most people in high income countries experience dying while receiving healthcare, yet dying has no clear beginning, and contexts influence how dying is conceptualised. This study investigates how UK physicians conceptualise the dying patient. We employed Scoping Study Methodology to obtain medical literature from 2006-2021, and Qualitative Content Analysis to analyse stated and implied meanings of language used, informed by social-materialism. Our findings indicate physicians do not conceive a dichotomous distinction between dying and not dying, but construct conceptions of the dying patient in subjective ways linked to their practice. We argue that the focus of future research should be on exploring practice-based challenges in the workplace to understanding patient dying. Furthermore, pre-Covid-19 literature related dying to chronic illness, but analysis of literature published since the pandemic generated conceptions of dying from acute illness. Researchers should note the ongoing effects of Covid-19 on societal and medical awareness of dying.

## Keywords

death, dying, end-of-life issues, healthcare professional, social construction, work environment

## Introduction

Most people in high income countries experience dying while receiving healthcare (Broad et al., 2013). Modern literature places importance on physicians providing high quality care for dying patients (National Institute for Health and Care Excellence [NICE], 2020), including cognisance of the length of the patient's remaining life (Finucane et al., 2017). This suggests physicians should understand when a patient will die soon; however, this understanding is not straightforward. This article presents a study analysing how UK physicians conceptualise the dying patient. No previous study has taken such a broad, inductive scope in establishing how physicians understand patient dying.

## Dying and Not Dying

In the UK there is no statutory definition of death (Academy of Medical Royal Colleges [AOMRC], 2008). A dualistic view of the difference between living and dead is presented by the Department of Health (2019) which

indicates that life is extinct when there is cessation of spontaneous breathing, circulation, cardiac activity, and reflexes. The physician's aim is to find objective evidence of death, and texts do not acknowledge the influence of social and organisational factors in this (Holland, 2010). In contrast to these clear definitions of the dead/not dead binary, we have found that this binary perspective is not found in medical literature pertaining to physician's understandings of *dying*, as we will present in this article.

It is obvious that all people who are currently alive will die at some time, yet it is only in certain contexts that living people are considered as dying. In medicine, this is reflected in the emphasis on end-of-life care as a discrete

---

<sup>1</sup>Edinburgh Medical School, The University of Edinburgh Edinburgh Medical School, Edinburgh, UK

## Corresponding Author:

Shaun Peter Qureshi, Edinburgh Medical School, The University of Edinburgh Medical School, Chancellor's Building, Little France Crescent, Edinburgh EH164TJ, UK.  
Email: [shaunqureshi@doctors.org.uk](mailto:shaunqureshi@doctors.org.uk)

mode of care (NICE 2020). Unlike the identification of death, constituent factors which inform the understanding of dying are not widely agreed, and physicians may reach different conclusions (Willmott et al., 2016).

Since most in high income countries die in a healthcare environment (Broad et al., 2013), this is not a question for purely academic interest; it is relevant to the experience of dying for most people in our society. Healthcare professionals, including physicians, will influence how most people experience dying. Reports of poor care have led to criticism of physicians, including perceived failures to identify dying patients (UK Parliamentary and Health Ombudsman, 2014). Conversely, instances when physicians have deemed patients were dying have led to criticism that doctors should have continued to pursue life-prolonging treatment (Seymour & Clark, 2018). Physicians' understandings are therefore crucial to the dying patient, but complex and subjective.

### *Defining the Research Problem*

Based on the challenges identified in the existing literature, we theorised that the dying patient would not be conceptualised as solely biomedical. We therefore aligned our analysis with socio-materiality. This practice-based epistemology considers the social relations between humans, and the role of matter and physical and psychological tools. It is therefore an appropriate lens for analysing how the dying patient is understood by physicians, and how these understandings are shared (Fenwick & Nimmo, 2015).

Previous studies have explored understandings of specific pre-determined concepts related to care of the dying (Bausewein & Higginson, 2012; Ewert et al., 2016; Pastrana et al., 2008). However, no previous studies have taken our inductive, comprehensive approach which examines conceptions without pre-defining them.

### **Methods**

We aimed to explore UK physicians' conceptions of dying. This study employed Scoping Study Methodology (SSM) and Qualitative Content Analysis (QCA). The SSM facilitated answering a broad research question and was conducted broadly according to the Arksey and O'Malley (2005) framework. The methodology allowed for iterative refinement of search strategy, which was appropriate as we had established there are no universally accepted terms for the dying patient.

In reporting our methods, we aim to meet the PRISMA-ScR (PRISMA extension for Scoping Reviews) criteria (Tricco et al., 2018) and SRQR (Standards for Reporting Qualitative Research) criteria (O'Brien et al.,

2014) to ensure we are being as transparent and complete as possible. We did not publish a review protocol before commencement. The researchers are SPQ, who is a physician, AD, who is a registered nurse, and DJ a health professions education academic.

We have described the context and rationale for our study (see Introduction). As described in the section 'Defining the Research Problem', we aligned our analysis, using QCA methodology, with our epistemology, socio-materiality. In line with our inductive approach, we did not use a pre-formed analytical framework. Nevertheless, in presenting our findings, we have aimed to demonstrate how the conceptions have been generated in relationships with the tangible and intangible tools of the physicians' practice (Fenwick & Nimmo, 2015). Like previous socio-material studies which have utilised QCA, our analysis considered social and material influences on creation of knowledge and understandings (Hawley, 2021; Mehto et al., 2020).

Combining SSM with qualitative analysis has been previously established. SSM methodology allows exploration to identify relevant texts from a broad area of academic literature, and further combining with qualitative analysis facilitates pattern identification and analysis of meanings contained within the identified texts (Brydges et al., 2017; Martimianakis et al., 2015).

The SSM was initially conducted in September 2016 (as part of SPQ's doctoral thesis) and then the process was repeated in April 2021, providing a dataset of literature from January 2006 to April 2021 on which to perform QCA. For simplicity, we present an amalgamation of the findings from these scoping studies. The results presented in this article represent analysis of the combined findings of these scoping searches. This study was conducted over the following three phases.

### *Phase One – Construction of Search Strategy and Inclusion Criteria*

We reviewed 11 documents, which SPQ and AD were aware of as relevant to UK medical practitioners involved in the care of dying patients (Carey et al., 2015; Chan et al., 2016; General Medical Council, 2010; NICE, 2015; NHS Scotland, 2008; Royal College of General Practitioners, 2011; Royal College of Physicians et al., 2009; Scottish Intercollegiate Guidelines Network, 2014; The Scottish Government, 2015; Tucker et al., 2016a; Tucker et al., 2016b). We used terms these documents contained to develop search terms. We then generated further keywords by group discussion. These were used to conduct a systematic search of Web of Science and EbscoHOST (the keywords used are listed in Supplementary Table 1).

We also conducted a systematic search of PubMed using MeSH headings related to the keywords in the previously described search. MeSH terms in PubMed return all literature on a particular heading even if the terminology used by authors varies. In this way, we were able to cover a broad range of literature in a simpler search. The MeSH terms identified as relevant and used in the PubMed search are listed in [Supplementary Table 1](#). The MeSH terms were not applied in the general search of Ebscohost or Web of Science.

We limited the scope to UK literature. The scoping search was originally conducted on 18th September 2016, and then updated on 14th April 2021. Altogether, the database searches resulted in 6024 items. To cover a range of data sources, a hand search of other sources was performed including non-database websites ([Cochrane Library, 2000](#); [NICE, 1997](#); [NHS Scotland, 2015](#)), and ancestry searching ([Poirier & Behnen, 2014](#)) resulting in 193 further results. These, combined with the systematic search, gave a result of 6217. References were collated on EndNote ([Clarivate Analytics, 2016](#)).

Fifty documents were initially reviewed to iteratively develop inclusion criteria. Included publications were those written in English language for clinical education or guidance of physicians; published 2006 and after; discussed dying patients in the UK. Publications were excluded if they were written for veterinary surgeons; were relevant only to one clinical site; were economic evaluations; discussed processes after death; were non-written materials, anecdotal, or non-clinical reflections. Our research focuses on physicians' conceptions; therefore, we excluded literature written for the intended audience of non-medical healthcare professionals. As our familiarity with the literature increased, we decided to exclude literature which discussed deaths in nursing homes. Physicians' language when discussing dying patients can differ from that of nursing colleagues ([Charman & Esterhuizen, 2016](#)), and we recognised that the texts discussing deaths in nursing homes, which emerged from our search, generally did not relate to physicians' conceptions, nor contain descriptions of the dying patient which we believed would be used by or acceptable to UK physicians.

### Phase Two – Document Selection and Data Extraction

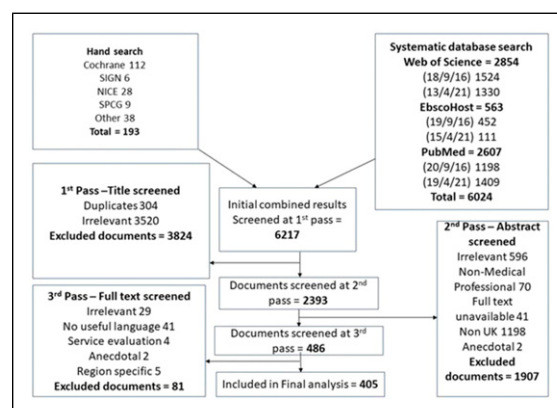
Our initial combined searches from 2016 to 2021 resulted in 6217 documents collectively. The documents were screened individually by SPQ and AD, without the aid of any specialist software. Documents were screened first by reading the titles to exclude any duplicates and obviously irrelevant documents, leading to 3824 exclusions.

Secondly the remaining documents were screened by reading the abstracts and excluding according to the inclusion and exclusion criteria, leading to 1907 exclusions. Thirdly, the remaining documents were screened by reading the documents in full and this resulted in 81 further exclusions. SPQ and AD compared results to ensure consistency. At any point, if there was dubiety over whether a document should be included, it was carried over to the next stage of document selection until there could be a definitive decision about whether it met the inclusion criteria. [Figure 1](#) summarises the selection process and the break-down of reasons for exclusion at each pass. The documents which were included in analysis are listed in [Supplementary Table 2](#). Throughout the screening process, we iteratively developed a template to extract and chart the characteristics of included documents, the results of which are displayed in [Table 1](#).

### Phase Three – Qualitative Content Analysis of Key Concepts

Analysis was managed using the software package NVivo ([QSR International, 2015](#)). We sought for analysis to be based on language in the documents and developed inductively; therefore, we did not use a pre-established framework. The qualitative analysis was led by SPQ with support from AD, and oversight from DJ.

SPQ began with initial coding of identified concepts related to the dying patient using in vivo terms generated from the text ([Saldana, 2015](#)) and discussed these with the other authors. We recognised there were few simple definitions of terms in use. QCA examines not only usage of terms, but also the concepts represented and implied in language, by examining both manifest (stated definitions) and latent meanings (implied by context) ([Elo & Kyngäs, 2008](#); [Hsieh & Shannon, 2005](#)). We were informed by the epistemology of socio-materiality. This facilitated us in



**Figure 1.** PRISMA chart (Moher et al., 2009) demonstrating document selection process.

**Table 1.** Characteristics of Included Documents (n = 405)

Document characteristic document	No
Type	
Research Study	276
Research study protocol	5
Clinical guideline	50
Review	20
Commentary or opinion	11
Editorial	6
Letters to the Editor	9
Case Study	5
Government white paper	3
Reports of consultations or consensus agreements	8
News article	2
Transcripts from lectures or symposia	2
Policy or position document	2
Quality Improvement Project report	1
Clinical audit report	2
Clinical questionnaire	1
Book Chapter	1
Ethical Discussion	1
Research Type (n = 276)	
Qualitative study	111
Cross-sectional questionnaire	42
Retrospective analysis of case notes	20
Other observational study	22
Systematic review	40
Other review type	17
Mixed methods study	12
Randomised Controlled Trial	7
Other experimental study	2
Modified Delphi study	2
Other	1
Publishing Institution (determined by address of corresponding author)	
University	236
Hospital/secondary care department	96
Hospice/specialist palliative care department	26
Community health centre/primary care department	5
Medical Royal Colleges	6
NHS Scotland	4
National Institute for Health and Clinical Excellence	8
Medical professional society or association	4
UK Government Department of Health	1
Scottish Government	1
General Medical Council	1
Cochrane Library	3
Scottish Intercollegiate Guidelines Network	1
National Clinical Guidelines Centre	1
UK Resuscitation Council	3
Charity	1
NHS England	1
House of Lords	1
Postgraduate medical training deanery	1
Scottish Palliative Care Guidelines	5

(continued)

**Table 1.** (continued)

Document characteristic	document	No
Disease or body system discussed	Cancer (including haematological and other body systems)	56
	Covid-19	9
	Other respiratory non-cancer conditions (including cystic fibrosis)	17
	Liver failure	4
	Renal non-cancer conditions	8
	Cardiac non-cancer conditions	22
	Dementia	15
	Other neurological non-cancer conditions	18
	Frailty	2
	Intellectual disability	4
	Diabetes Mellitus	2
	Rheumatological non-cancer conditions	1
	Burns	
	Stroke	1
	Mental illness	1
	Non-specific	244
	Age group of patients discussed	Specified as adults
Specified as children and young people		29
Specified as older adults		17
Not specified		346

considering the conceptions as existing in relationships between people, and relationships between people and materials (Fenwick & Nimmo, 2015). Therefore, we adapted our methods to include *descriptive coding* (Saldana, 2015) of the data which was conducted by SPQ and AD. This allowed us to examine the context in which these concepts were found, and, in particular, how the idea of the dying patient was latent in the descriptions of interpersonal interactions, and in elements of practice. Grouping similar codes together allowed us to begin categorising under higher level headings and developing descriptions of ways of considering the dying patient within categories and subcategories (Elo & Kyngäs, 2008). We held frequent meetings to discuss the generated conceptions, discuss any differences in understanding between us, and ensure the analysis being generated was understandable and justified to others, for the purposes of triangulation (Denzin, 2012). The research group provided useful balance: the group agreed that the first author and lead analyst, SPQ, as a physician was well placed to interpret physicians' conceptions; however, the two non-physician authors challenged SPQ to ensure his analysis was justified by the available data. This increased the trustworthiness of our work.

We continued this process until we agreed we reached saturation of varying forms. We achieved *data saturation* by the time we had finished analysing the included documents, as no new conceptions were being generated and we were therefore satisfied no further data was needed. We were also satisfied that we had achieved

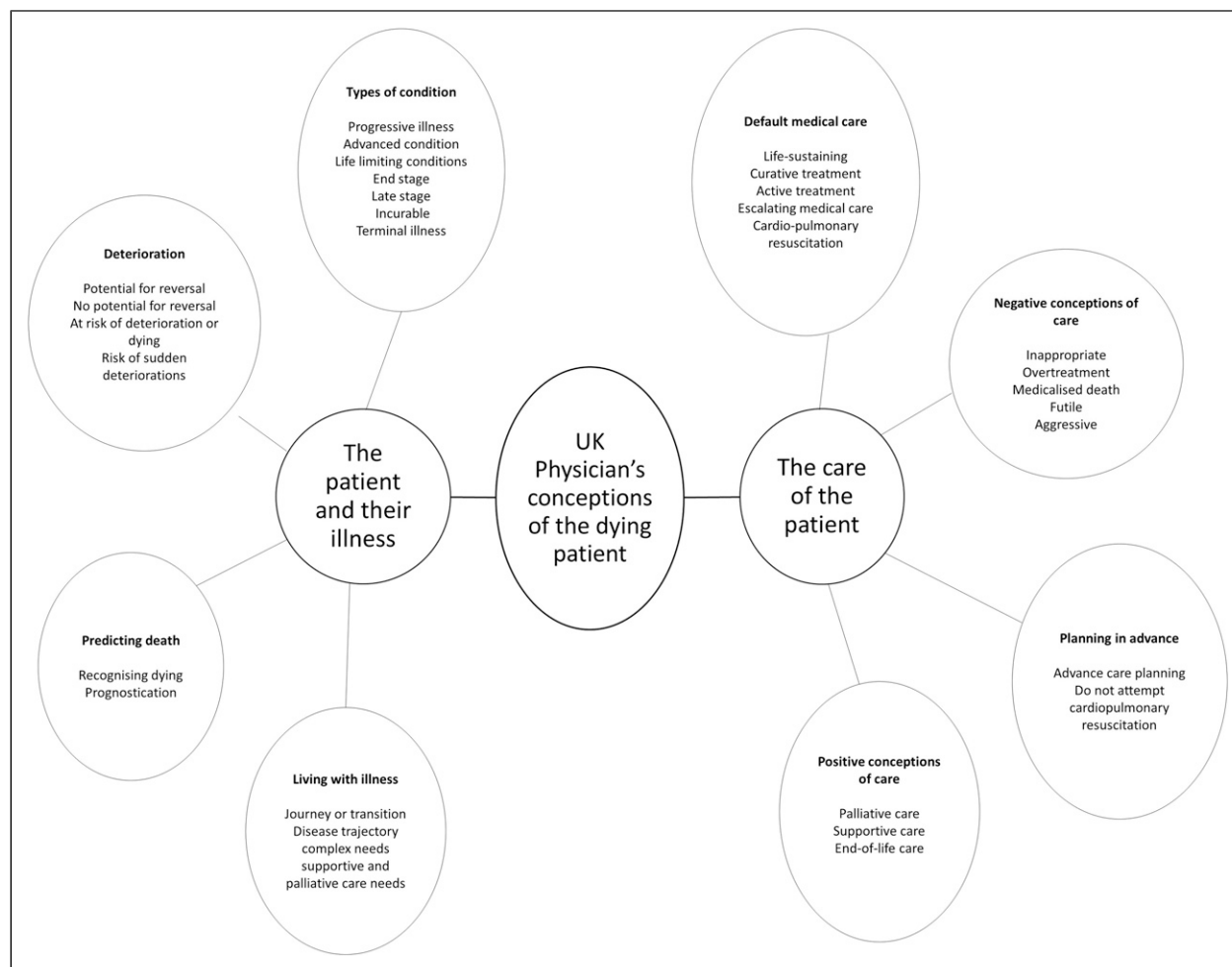
sufficient *theoretical saturation* for the purposes of the study: the conceptions generated from our analysis were completely represented by the data, and, from an alternative perspective, we had sufficient data to illustrate the conceptions we had generated (Saunders et al., 2018). The resulting analysis and discussion within the research group generated a hierarchy of generated conceptions, which formed our results (see Figure 2).

## Results

### Document Characteristics

Four hundred and five documents were included. Among these included documents the most common types were research studies (276), clinical guidelines (50), review articles (20), and commentaries or opinion articles (11). Most included documents (236) had been published by universities, while 96 had been published by hospital/secondary care clinical departments and 26 by specialist palliative care services or departments. Most documents (244) did not specifically relate to dying from one single disease or group of diseases, but most documents where this was specified (56) related to cancer. Most documents (346) did not relate to dying people of a specified age range, while 13 were specified as referring to adults only, 29 as children and young people only, and 17 as older adults only. Further characteristics are tabulated (Table 1).

Included documents are listed in [Supplementary Table 2](#), which displays the results of the literature search, but



**Figure 2.** Results of Qualitative Content Analysis of UK medical literature: Conceptions of the dying patient presented in categories and subcategories.

not the results of the Qualitative Content Analysis which are described below.

### Results of Analysis

We identified no simple definitions or biologically essentialist conceptions of the dying patient. We found conceptions were generated in how the literature discussed patients and their illnesses, and care which was available to or administered to patients. In QCA terms, conceptions of the dying patient were interpreted from latent meanings, that is, those derived from context. In socio-material terms, conceptions existed in relationships and between people and materials. The materials are often intangible, including psychological tools, for example, knowledge of illness pathologies.

In presenting the results, references are provided as representative examples. Furthermore, our description of findings demonstrates how conceptions are constructed in

relation to aspects of physicians' practice. Figure 2 provides an overview of the conceptions presented here and indicates the corresponding section of the article where these results are explained.

*The Patient and Their Illness.* We have broadly categorised the results of our analysis into two over-arching categories. This section presents physicians' conceptions of the dying patient, generated from our analysis, which broadly relate to the patient, and the perceived effects of the illness on the patient.

*Types of Condition.* The dying patient was often conceptualised in the context of the condition affecting them. This included progressive illness, describing chronic illness progressing over time until reaching death. Progression from diagnosis may be variable and lead to reduced quality of life, for example, Motor Neurone Disease (Hobson & Mcdermott, 2016).



Advanced condition was a further conception, typically describing late disease stages (British Medical Association, 2016). For example, Idiopathic Pulmonary Fibrosis was conceptualised as ‘advanced’ when there was no further opportunity for treatment options and lung transplantation is unsuitable (Bajwah et al., 2015).

The conception of life limiting conditions (LLCs) was evident where the focus is shortened life expectancy, most often discussions of children, with the expectation of not reaching adulthood. Beecham et al. (2015, p.3) described LLCs as ‘any condition from which there is no reasonable hope of cure and from which the child or young adult will die prematurely’. However, Boland et al. (2013) highlighted that LLCs encompass conditions with potential for cure.

Similarly, the conditions affecting a dying patient may be conceptualised as being end stage (Bloom et al., 2019), late stage (Read et al., 2019), incurable (Sheridan et al., 2021), and terminal illness (Lazenby et al., 2017). However, Seymour et al. (2010) describe ‘terminal’ as representing a phase of disease rather than a category of illness itself. These conceptions were often used together, without clear boundaries between meanings.

**Deteriorations.** Episodes of worsening physical condition were conceptualised as deteriorations. These may lead to death or have potential for reversal (Cocks et al., 2016). Being close to death may be described in terms of there being no (or limited) potential for reversibility, and that cases with no reversibility should be identified as unpreventable dying (Bennett et al., 2015). In contrast, Cocks et al. (2016) advise that physicians attempting to reverse deteriorations is not always in the patient’s interests. This indicates a conception of the dying patient in terms of deterioration but more broadly than whether reversible or not. Some suggested it is those at risk of deterioration or dying for whom the possibility of dying should be considered (Blackwood et al., 2015).

Authors also advised that physicians should be conscious of the risk of sudden deteriorations that may lead to death in patients with chronic disease (Barnes & Campbell, 2010). However, from 2020 onwards, Covid-19 was identified and discussed as an acute disease in which sudden deterioration may take place when there is no underlying chronic disease (Association for Palliative Medicine, 2021), and which may precipitate sudden deterioration in those with another chronic disease (Scottish Palliative Care Guidelines, 2020).

**Predicting Death.** The literature espouses the importance of predicting death (NICE, 2020). This relies on the concept that patients will experience a period of ill health prior to death (Knight et al., 2020). Analysis generated

various conceptions of recognising dying. However, we identified discrepancies regarding what should constitute this, for example, those likely to die within the next 12 months (Royal College of General Practitioners, 2011); patients in the last few months of life (Royal College of General Practitioners, 2016); patients in the last days or hours of life (Brooks, 2014); patients for whom recovery is uncertain (Carey et al., 2015).

Prognostication is a further conception related to predicting dying and encompasses when a patient may be expected to die, and likely responses to treatments (Boland et al., 2013). Some advocate prognostic accuracy (White et al., 2016). In contrast, one commonly promoted aid to prognostication is the ‘Surprise Question’: ‘Would you be surprised if this patient were to die in the next 6–12 months?’ (Royal College of General Practitioners, 2011). The promoted benefit of the Surprise Question was that it does not rely on certainty (Burke et al., 2018).

**Living with Illness.** Some described living with a disease leading to death as a journey or transition (Wolff & Whitehouse, 2017). This describes events which occur for the patient living with disease until there is an eventual transition to an end stage leading to death. The journey may be affected by medical interventions and advances (Taylor et al., 2016).

Disease trajectory is a concept describing the course of a patient’s life with a condition which will lead to death, from point of developing the disease until death, including rate of decline and deteriorations, and having elements of time and shape (Taylor & Pagliari, 2018). Trajectories are influenced by available treatments. Typical trajectories have been defined: cancer; organ failure; frailty (Murray and Yang Kok, 2008). Despite this, the unpredictability of a patient’s disease trajectory is acknowledged (Hopkins et al., 2020). Alternative trajectories were described, for example, for those who die in hospital (Campling et al., 2018).

Dying patients were often conceptualised in terms of their needs while living with their disease. These differ from the conceptions above which describe dying in terms of length of life or disease stage. For example, patients may be described as having complex needs. No specific set of needs are demarcated as ‘complex’ (Finucane et al., 2021), but may include the needs of those who need to access specialist palliative care services, unpredictability, those who lack capacity for making decisions about their own care, and having needs across multiple dimensions (Carduff et al., 2018). The concept of supportive and palliative care needs also described needs of patients (Adam et al., 2020). Supportive care and palliative care were referred to as separate concepts, but we were unable to identify how they differ.

*The Care of the Patient.* The previous section presented conceptions which relate to the patient and the illnesses which affect patients. In this section, we present physicians' conceptions of the dying patient which relate to care which is available to or administered to patients, and the perceived effects of this care or these treatments on patients.

*Default Medical Care.* The dying patient was conceptualised in relation (and often in opposition) to default medical care. The default role of the physician was often perceived as to provide treatments which are life-sustaining (Birchley et al., 2017). The distinction between what is a curative treatment and supportive care is not always clear (Murray et al., 2017).

Active treatment describes a conception of treatments given with the aim of prolonging life, in contrast to symptomatic relief (Howell et al., 2015). This includes surgical and medical interventions (Field et al., 2014). Patients may receive active treatments concurrently with symptomatic treatments (Puckey & Bush, 2011).

Default care involves clinical actions being made to increase the intensiveness of attempts to prolong the patient's life, representing the conception of escalating medical care (Campling et al., 2018). For example, patients in hospital may be referred to critical care for more intensive treatment (Beckett et al., 2013). The escalation will occur by default until/unless there are specific decisions to limit this.

One example of a life-prolonging intervention is cardiopulmonary resuscitation (CPR). The default presumption is that CPR will be performed on patients who experience cardiorespiratory arrest unless decided against specifically (Perkins & Fritz, 2019).

*Negative Conceptions of Care.* Care was often conceived negatively when dying patients received default medical care. Failure to alter the treatment plan accordingly for a dying patient was conceptualised as inappropriate, and may result in patients receiving overtreatment (Ryan et al., 2012) and having a medicalised death (Boland et al., 2019). It is often not possible to determine overtreatment until considering events retrospectively (Dehnel, 2014). Certain treatments were also conceptualised as futile (Danbury & Waldmann, 2006) or aggressive (Lowton, 2009).

*Planning in Advance.* Advance care planning (ACP) was conceptualised as a means to reduce likelihood of dying patients receiving poor care and facilitate them having a better quality of life (Lund et al., 2015). Often this involved plans to prevent default medical care being applied to dying patients (Lazenby et al., 2017). Definitions and

understanding of ACP varied, for example, a conversation (Blackwood et al., 2015); an ethical framework (Lund et al., 2015).

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions are declarations made by physicians that CPR should not be performed. The aim is prevention of CPR unwanted by the patient and/or which would not lead to a perceived successful outcome. DNACPR decisions are influenced by, for example, patient's diagnosis, prognosis, age, quality of life, opinions of physicians, and the wishes of patients and relevant others (Hawkes et al., 2020).

*Positive Conceptions of Care.* Palliative care for dying patients was conceived positively. There was no standard, consistent meaning of palliative care (Bausewein & Higginson, 2012) but it was generally described as an approach to increasing quality of life of patients and their families (Allsop et al., 2018). Howell et al. (2015) described palliative care as part of a transition from active treatments, others that it is compatible with active treatments (Puckey & Bush, 2011), or that palliative care itself is active (Latorraca et al., 2019).

Supportive care was a further conception lacking universal or consistent meaning, and the distinction between supportive care and palliative care is unclear. Supportive care may be care where disease-modifying treatment is no longer provided (Barclay & Maher, 2010), or care where patient's comfort is the priority (Fritz et al., 2014). In contrast, NICE (2019) stated that supportive care is disease-modifying and potentially life-prolonging treatment. These results concern conceptions of types of care provided to patients, named in the literature as 'Palliative care' and 'Supportive care'. These differ from the conceptions of needs of patients described in the Results section *Living with illness*, named in the literature as 'supportive and palliative care needs'.

End-of-life care (EOLC) arose as a separate concept from palliative or supportive care (Adam et al., 2020). Papavasiliou et al., (2013) related EOLC to care of dying patients in the last few hours or days of life, and Frank (2009) related it to impending death. In contrast, the British Medical Association (2016) defined EOLC as the total care of patients with 'advanced incurable illness', and stated that it may last for days, weeks or longer. Good quality EOLC included timely recognition of dying (Lancaster et al., 2018) and stopping non-essential drugs (Sleeman & Collis, 2013).

## Discussion

This scoping study and QCA is the first study to examine such a broad scope of conceptions of the dying patient in



medical literature, without pre-determining concepts of interest. In doing so, we have made significant contributions to the literature, discussed below. In addition, we discuss the implications of our findings for the dying person.

### *Conceptualising the Dying Patient through and in Practice*

Among UK physicians, the difference between living and dead is normally perceived as a straightforward dichotomy (AOMRC, 2008; Lock 2002). In contrast, our analysis has found that dying is not conceptualised as a discrete, easily understood entity. Instead, the dying patient is conceptualised subjectively, in relation to wider meanings ascribed to the patient and the actions of the physician. The construction of these conceptions through social and cultural factors related to medical practice align with socio-materiality (Fenwick & Nimmo, 2015).

Like previous authors (Bausewein & Higginson, 2012; Ewert et al., 2016; Maciasz et al., 2013; Pastrana et al., 2008), we note lack of agreement of what the dying patient is. Despite ambiguities, common messages were interpreted across findings. There is strong agreement of the importance of excellent care for dying patients. Positively conceived care reduced distressing symptoms and was minimally invasive. Furthermore, our findings indicate challenges faced by physicians, for example, it is important not to continue inappropriate treatments, but it is difficult to know if a physician is over-treating until after patient death. Moreover, physicians operate within a system which is designed to provide life-prolonging care by default, which is negative for dying people.

Previous authors have emphasised the importance of unambiguous, consistent language, and multiple terms may cause confusion (Bausewein & Higginson, 2012). However, the findings of the present study call into question any clinical guidance which presents conceptions of the dying patient as straightforward and clearly defined, when this does not reflect the subjectivities of medical practice. Our analysis has not led to identification of a single, unified way of physicians thinking about the dying patient, nor discrete modes of understanding, but conceptions which are linked to the physician's practice. For this reason, we believe it is more helpful to consider that understanding the dying patient is something that physicians *do* through and in practice, rather than something that is *known* in cognitive terms. Instead of focusing on developing and refining processes which ostensibly facilitate the cognition of dying in biomedical terms (Royal College of General Practitioners, 2011; University of Edinburgh, 2016), we argue the focus should be on better understanding of the physician's

practice, including organisational and systems-based influences. For example, researchers in Canada (Chan et al., 2017) have conducted practice-based studies investigating how organisation of the hospital often does not facilitate good care of dying patients, including understanding when/if a patient is dying. We believe that by taking a practice-based approach similar to Chan et al.'s (2017), researchers can take the valuable next step of exploring influences of the workplace on UK physicians' understandings, and how these facilitate or hinder understanding the dying patient. This may include examination of tangible tools of the workplace such as clinical documentation, and intangible tools such as distribution of workload, and inter-professional communication, and how these influence doctors in understanding if/when patients are dying.

### *Acute or Chronic Illness*

In our study, the results demonstrate that the dying patient has been conceived generally in terms of a period in the person's life preceding death, with qualities meaning that the person's death could be anticipated. No conceptions related to traumatic or sudden death in otherwise healthy individuals were generated. We consider this to be reasonable, as we believe the period of healthy life preceding very sudden death, for example, from a road traffic accident, would not normally be considered a period of dying. Such people could therefore be seen to go from not dying to dead, without having an intermediate period of dying.

Furthermore, most deaths in high income countries follow a chronic illness, such as heart disease, cancer, stroke, or dementia (Hyde et al., 2011). It is therefore acceptable that in our study of the UK context conceptions related only to deaths which could be anticipated. This contrasts with other cultural contexts, where deaths may occur more often as a result of war or inter-personal violence (Matzopoulos et al., 2008). Although most included literature did not relate to a specific body system or disease, when this was specified, it mostly related to cancer or other chronic diseases such as non-cancerous organ dysfunction (see Table 1).

In literature prior to 2020, we noted a dearth of conceptions of dying from acute illnesses. This may indicate that some patients who die from acute illness may not have had a preceding period of being considered as 'dying'. For example, a patient with no underlying chronic disease who develops systemic sepsis then dies, while still being treated with antibiotics, may not have been considered as dying by the physician before the time of death. For such patients, there may have been no period where there was outward acknowledgement of dying to the patient, the patient's relatives and carers, and within

the medical team. We theorise, that it is only in certain contexts that patients may be perceived as dying by UK physicians, and medical discussions of patients with life-threatening acute illness (such as severe sepsis) are likely the focus on improved ways to treat these conditions, rather than discuss these patients in terms of dying.

However, it is noteworthy that Covid-19 became a subject of discussion in literature published since 2020. Our analysis led to conceptions of dying in patients with Covid-19, even when there was no underlying chronic illness. For example, Covid-19 was the only acute disease for which palliative care was discussed, and was provided as an example of an acute illness from which patients may suddenly deteriorate. This may reflect a larger paradigm shift in medical views of the threat of death which emerged from the Covid-19 pandemic, for people in high income countries where risks of death from acute illness have historically been relatively low ([World Health Organization, 2021](#)). The Covid-19 pandemic may have brought considerations of risks to health and potential for death in normally healthy people to the fore, in a way which has not previously been seen in recent history. It will be interesting to see how the Covid-19 pandemic continues to influence public, academic, and medical discourse over death and dying, throughout the remainder of the pandemic and beyond.

### *Implications for the Dying Person*

This study has wide relevance to medical education and healthcare, as most people in high income countries die in healthcare settings ([Broad et al., 2013](#)). Differing understandings of significant concepts can lead to patients not receiving appropriate care ([Gibbins et al., 2009](#); [Maciasz et al., 2013](#)). Language also influences patients' perspectives and choices ([Nickel et al., 2017](#)) and the lack of a lingua franca between health professionals and patients may empower staff preferentially over patients ([O'Connor et al., 2010](#)). Based on the present study, it would be prudent for clinicians and policy makers to be careful with language, and not assume understandings are shared. This is particularly concerning for care of dying patients, where patients should be actively included in treatment decisions ([The Scottish Government, 2015](#)).

It is important to note our findings represent the perspective of physicians. Medical knowledge (as socially constructed) has been criticised as exerting power imbalance over patients ([Kitzinger & Kitzinger, 2014](#)). The patient is likely to have different perspectives on the effects of their condition on their life, and construct meanings differently. Understanding how physicians conceptualise the dying patient therefore does not necessarily advance our understanding of how patients

conceptualise their own dying. Future research should consider conceptions of dying through the lens of the patient.

### *Strengths and Limitations*

The scoping study benefited from its clear and replicable design. The search strategy was systematic, robust, and guided by language found in the literature from its earliest stages. The search yielded a broad sample of language used in discussion of UK medical practice, as the sample includes varied document types, which discuss a wide range of patient ages and disease types (see [Table 1](#)). Furthermore, this analysis incorporated literature from a range of years. We therefore consider that we have conducted a comprehensive search of the existing literature. The QCA of included data went further than the analysis generally possible in a scoping study and allowed for analysis of heterogenous data sources.

We must also consider our study's limitations. Scoping studies do not include consideration of quality, and documents which met the inclusion criteria were considered regardless of their quality (although this study analysed only language used). Furthermore, we included terms in regardless of how frequently they appeared, because we sought to explore the breadth of conceptions rather than only those most used. Additionally, the scope of included documents was limited to the UK, as medical language and meanings varied too widely to lead to useful analysis across nations, cultural contexts, and health services. Furthermore, as we are British and based in the UK, our interpretation is grounded in knowledge of UK medical practice. We must also acknowledge that the decision to exclude documents which discussed deaths in nursing homes is a potential weakness. We made this decision to exclude conceptions of non-physician health care professionals in our results; however, it is possible that we inadvertently excluded some conceptions of physician deaths by introducing this exclusion criterion. These factors may limit transferability of findings.

Although we believe the terms in use are acceptable and understood by UK physicians, there will certainly be further conceptions which are not captured here. QCA does not assume objectivity ([Elo & Kyngäs, 2008](#)) but we aimed to achieve findings which can be inter-subjectively understood. We have not yet tested the results outside the scope of this study, although many scoping studies do not include this stage ([Levac et al., 2010](#)).

### *Conclusions*

This article has demonstrated differences in conceptions of the dying patient among physicians. The importance of physicians recognising dying is affirmed in the literature;

however, analysis demonstrates there is no linear, single means by which this is achieved. Despite physicians ostensibly favouring objectivity and biomedical understandings, our study has demonstrated physicians' understanding of the dying patient is not a single disembodied way of knowing. Instead, this understanding is constructed by physicians in subjective ways linked to their practice. Furthermore, we tentatively suggest that Covid-19 pandemic may have led to more awareness and conceptions of dying after illness with no pre-existing chronic disease. Researchers should note the ongoing effects of Covid-19 on societal and medical conceptions of death and dying.

Although the analysed literature agrees in the vital importance of understanding when/if a patient is dying, there is lack of agreement of what this means. Conceptions of the dying patient are heavily influenced by subjectivities related to the tangible and intangible tools available to the practicing physician. Since most in our society experience death in a healthcare environment as a patient, we believe these challenges for physicians in understanding when/if a patient is dying are likely to have significant effects for most dying people. It is therefore appropriate to shift the focus from processes which aim to aid recognition of dying in cognitive terms. Future research should investigate how the lay person conceptualises dying, in order to explore ways in which care of the dying person can be empowered in their experience as a patient. Furthermore, we suggest that it may be fruitful to improve elements needed for successful medical practice. Future work should investigate systemic factors which influence physicians in understanding the dying patient in practice.

### Acknowledgement

We gratefully acknowledge the contribution of Marshall Dozier, health services librarian at University of Edinburgh, for the useful guidance she provided on comprehensive literature searching. SPQ acknowledges that Professor Morwenna Wood and Dr Janet Skinner attended regular supervision meetings during his time as a doctoral student at University of Edinburgh during which he reported on the earlier version of this scoping study after it had been designed, developed, the results analysed, and the first iteration was completed. SPQ also thanks Jessica Bytautas for proof-reading the manuscript and providing valuable suggested references.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article:

This work was supported by a grant from the University of Edinburgh Principal's Teaching Award Scheme.

### Ethical Approval

This study involved systematic searching and analysis of existing literature only. No data was generated using living subjects and no confidential material was accessed. For this reason, approval from a Research Ethics Committee was not required.

### ORCID iD

Shaun Peter Qureshi  <https://orcid.org/0000-0001-6743-8494>

### Supplemental Material

Supplemental material for this article is available online.

### References

- Academy of Medical Royal Colleges [AOMRC]. (2008). *A code of practice for the diagnosis and confirmation of death*. <https://www.aomrc.org.uk/reports-guidance/ukdec-reports-and-guidance/code-practice-diagnosis-confirmation-death/>
- Adam, E., Sleeman, K. E., Brearley, S., Hunt, K., & Tuffrey-Wijne, I. (2020). The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review. *Palliative Medicine*, 34(8), 1006–1018. <https://doi.org/10.1177/0269216320932774>
- Allsop, M. J., Ziegler, L. E., Mulvey, M. R., Russell, S., Taylor, R., & Bennett, M. I. (2018). Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study. *Palliative Medicine*, 32(8), 1322–1333. <https://doi.org/10.1177/0269216318781417>
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Association for Palliative Medicine. (2021). *Covid-19 and palliative and end of life in secondary care*. <https://apmonline.org/wp-content/uploads/2021/02/COVID-19-Palliative-and-End-of-Life-Care.pdf>
- Bajwah, S., Ross, J. R., Wells, A. U., Mohammed, K., Oyeboode, C., Biring, S. S., Patel, A. S., Koffman, J., Higginson, I. J., & Riley, J. (2015). Palliative care for patients with advanced fibrotic lung disease: A randomised controlled phase II and feasibility trial of a community case conference intervention. *Thorax*, 70(9), 830–839. <https://doi.org/10.1136/thoraxjnl-2014-206583>
- Barclay, S., & Maher, J. (2010). Having the difficult conversations about the end of life. *British Medical Journal*, 431(sep16 2), c4862. <https://doi.org/10.1136/bmj.c4862>
- Barnes, J., & Campbell, C. (2010). Palliative care in multiple sclerosis and motor neurone disease. *British Journal of Hospital Medicine*, 71(1), 21–25. <https://doi.org/10.12968/hmed.2010.71.1.45968>

- Bausewein, C., & Higginson, I. J. (2012). Challenges in defining “palliative care” for the purposes of clinical trials. *Current Opinion in Supportive and Palliative Care*, 6(4), 471–482. <https://doi.org/10.1097/SPC.0b013e32835998f5>
- Beckett, D. J., Inglis, M., Oswald, S., Thomson, E., Harley, W., Wilson, J., Lloyd, R. C., & Rooney, K. D. (2013). Reducing cardiac arrests in the acute admissions unit: A quality improvement journey. *BMJ Quality and Safety*, 22(12), 1025–1031. <https://doi.org/10.1136/bmjqs-2012-001404>
- Beecham, E., Candy, B., Howard, R., McCulloch, R., Laddie, J., Rees, H., Vickerstaff, V., Bluebond-Langer, M., & Jones, L. (2015). Pharmacological interventions for pain in children and adolescents with life-limiting conditions. *Cochrane Database of Systematic Reviews*, 3, CD010750. <https://doi.org/10.1002/14651858.CD010750.pub2>
- Bennett, F., Brodrick, R., & Stirling, L. C. (2015). Dying for a change: Junior doctors and care of the dying patient. *British Journal of Hospital Medicine*, 76(1), C6–C9. <https://doi.org/10.12968/hmed.2015.76.1.c6>
- Birchley, G., Gooberman-Hill, R., Deans, Z., Fraser, J., & Huxtable, R. (2017). Best interests” in paediatric intensive care: An empirical ethics study. *Archives of Disease in Childhood*, 102(10), 930–935. <https://doi.org/10.1136/archdischild-2016-312076>
- Blackwood, D., Santhirapala, R., Mythen, M., & Walker, D. (2015). End of life decision planning in the perioperative setting: The elephant in the room? *British Journal of Anaesthesia*, 115(5), 648–650. <https://doi.org/10.1093/bja/aev209>
- Bloom, C. I., Ricciardi, F., Smeeth, L., Stone, P., & Quint, J. K. (2019). Predicting COPD 1-year mortality using prognostic predictors routinely measured in primary care. *BMC Medicine*, 17, 1–10. <https://doi.org/10.1186/s12916-019-1310-0>
- Boland, J., Martin, J., Wells, A. U., & Ross, J. R. (2013). Palliative care for people with non-malignant lung disease: Summary of current evidence and future direction. *Palliative Medicine*, 27(9), 811–816. <https://doi.org/10.1177/0269216313493467>
- Boland, J. W., Barclay, S., & Gibbins, J. (2019). Twelve tips for developing palliative care teaching in an undergraduate curriculum for medical students. *Medical Teacher*, 41(12), 1359–1365. <https://doi.org/10.1080/0142159X.2018.1533243>
- British Medical Association [BMA]. (2016). *End-of-life care and physician-assisted dying*. <https://www.bma.org.uk/advice-and-support/ethics/end-of-life/physician-assisted-dying/end-of-life-care-and-physician-assisted-dying-project>
- Broad, J. B., Gott, M., Kim, H., Boyd, M., Chen, H., & Connolly, M. J. (2013). Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *International Journal of Public Health*, 58(2), 257–267. <https://doi.org/10.1007/s00038-012-0394-5>
- Brooks, D. (2014). Care of the dying: Priorities for the future. *British Journal of Hospital Medicine*, 75(7), 364–365. <https://doi.org/10.12968/hmed.2014.75.7.364>
- Brydges, R., Stroud, L., Wong, B. M., Holmboe, E. S., Imrie, K., & Hatala, R. (2017). Core competencies or a competent core? A scoping review and realist synthesis of invasive bedside procedural skills training in internal medicine. *Academic Medicine*, 92(11), 1632–1643. <https://doi.org/10.1097/ACM.0000000000001726>
- Burke, K., Coombes, L. H., Menezes, A., & Anderson, A. K. (2018). The ‘surprise’ question in paediatric palliative care: A prospective cohort study. *Palliative Medicine*, 32(2), 535–542. <https://doi.org/10.1177/0269216317716061>
- Campling, N., Cummings, A., Myall, M., Lund, S., May, C. R., Pearce, N. W., & Richardson, A. (2018). Escalation-related decision making in acute deterioration: A retrospective case note review. *BMJ Open*, 8, 1–11. <https://doi.org/10.1136/bmjopen-2018-022021>
- Carduff, E., Johnston, S., Winstanley, C., Morrish, J., Murray, S. A., Spiller, J., & Finucane, A. (2018). What does “complex” mean in palliative care? Triangulating qualitative findings from 3 settings. *BMC Palliative Care*, 17, 1–7. <https://doi.org/10.1186/s12904-017-0259-z>
- Carey, I., Smith, R., & Shouls, S. (2015). *Transforming end of life care in acute hospitals AM workshop 2: AMBER care bundle*. NHS England. <https://www.slideshare.net/NHSIQ/workshop-2-amber-care-bundle>
- Chan, L. S., Macdonald, M. E., Carnevale, F. A., & Cohen, S. R. (2017). ‘I’m only dealing with the acute issues’: How medical ward ‘busyness’ constrains care of the dying. *Health*, 22(5), 451–468. <https://doi.org/10.1177/1363459317708822>
- Chan, R. J., Webster, J., & Bowers, A. (2016). End-of-life care pathways for improving outcomes in caring for the dying. *Cochrane Database of Systematic Reviews*, 2(11), CD008006. <https://doi.org/10.1002/14651858.CD008006.pub4>
- Charman, L. A., & Esterhuizen, P. (2016). A nurse’s phenomenological enquiry into doctors’ end-of-life decision making. *Journal of Research in Nursing*, 21(2), 82–93. <https://doi.org/10.1177/1744987116628327> ClarivateAnalytics <https://www.cochranelibrary.com/> (11th January 2017)
- Cochrane Library (2000). Cochrane Library. <https://www.cochranelibrary.com/>
- Cocks, H., Ah-See, K., Capel, M., & Taylor, P. (2016). Palliative and supportive care in head and neck cancer: United Kingdom national multidisciplinary guidelines. *Journal of Laryngology and Otology*, 130(S2), S198–S207. <https://doi.org/10.1017/S0022215116000633>
- Clarivate Analytics (2016). EndNote. <https://endnote.com/>



- Danbury, C. M., & Waldmann, C. S. (2006). Ethics and law in the intensive care unit. Best practice and research. *Clinical Anaesthesiology*, 20(4), 589–603. <https://doi.org/10.1016/j.ccc.2008.10.002>
- Dehnel, T. (2014). Should intensive care medics be palliative specialists? *The Lancet Respiratory Medicine*, 2, 96–97. [https://doi.org/10.1016/S2213-2600\(14\)70023-2](https://doi.org/10.1016/S2213-2600(14)70023-2)
- Denzin, N. K. (2012). Triangulation 2.0. *Journal of Mixed Methods Research*, 6(2), 80–88. <https://doi.org/10.1177/1558689812437186>
- Department of Health. (2019). *Guidelines for verifying life extinct*. <https://www.health-ni.gov.uk/publications/guidelines-verifying-life-extinct>
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Ewert, B., Hodiament, F., Wijngaarden, J. van, Payne, S., Groot, M., Hasselaar, J., Menten, J., & Radbruch, L. (2016). Building a taxonomy of integrated palliative care initiatives: Results from a focus group. *BMJ Supportive and Palliative Care*, 6(1), 14–20. <https://doi.org/10.1136/bmjspcare-2014-000841>
- Fenwick, T., & Nimmo, G. R. (2015). Making visible what matters: Sociomaterial approaches for research and practice in healthcare education. In J. Cleland, & S. J. Durning (Eds.), *Researching medical education* (pp. 67–80). Wiley-Blackwell.
- Field, R. A., Fritz, Z., Baker, A., Grove, A., & Perkins, G. D. (2014). Systematic review of interventions to improve appropriate use and outcomes associated with do-not-attempt-cardiopulmonary-resuscitation decisions. *Resuscitation*, 85(11), 1418–1431. <https://doi.org/10.1016/j.resuscitation.2014.08.024>
- Finucane, A., Carduff, E., Lugton, J., Fenning, S., Johnston, B., Fallon, M., Clark, D., Spiller, J., & Murray, S. (2017). Palliative care research in Scotland 2006–2015: A scoping review. *BMC Palliative Care*, 17(1), 19. <https://doi.org/10.1186/s12904-017-0266-0>
- Finucane, A. M., Swenson, C., MacArtney, J. I., Perry, R., Lamberton, H., Hetherington, L., Graham-Wisener, L., Murray, S. A., & Carduff, E. (2021). What makes palliative care needs “complex”? A multisite sequential explanatory mixed methods study of patients referred for specialist palliative care. *BMC Palliative Care*, 20, 1–11. <https://doi.org/10.1186/s12904-020-00700-3>
- Frank, R. K. (2009). Shared decision making and its role in end of life care. *British Journal of Nursing*, 18(10), 612–618. <https://doi.org/10.12968/bjon.2009.18.10.42466>
- Fritz, Z., Cork, N., Dodd, A., & Malyon, A. (2014). DNACPR decisions: Challenging and changing practice in the wake of the Tracey judgment. *Clinical Medicine*, 14(6), 571–576. <https://doi.org/10.7861/clinmedicine.14-6-571>
- General Medical Council. (2010). *GMC treatment and care towards the end of life: Good practice in decision making*. [http://www.gmc-uk.org/guidance/ethical\\_guidance/end\\_of\\_life\\_care.asp](http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp)
- Gibbins, J., Smith, G. S., & Forbes, K. (2009). Lesson of the week: Life saving treatment for a “palliative care” patient. *British Medical Journal*, 337(jul29 1), a428. <https://doi.org/10.1136/bmj.39563.581377.80>
- Hawkes, C. A., Fritz, Z., Deas, G., Ahmedzai, S. H., Richardson, A., Pitcher, D., Spiller, J., & Perkins, G. D. (2020). Development of the recommended summary plan for eEmergency care and treatment (ReSPECT). *Resuscitation*, 148, 98–107. <https://doi.org/10.1016/j.resuscitation.2020.01.003>
- Hawley, S. (2021). *Doing sociomaterial studies: The circuit of agency*. Learning, Media and Technology. <https://doi.org/10.1080/17439884.2021.1986064>
- Hobson, E. V., & Mcdermott, C. J. (2016). Supportive and symptomatic management of amyotrophic lateral sclerosis. *Nature Reviews Neurology*, 12(9), 526–538. <https://doi.org/10.1038/nrneuro.2016.111>
- Holland, S. (2010). On the ordinary concept of death. *Journal of Applied Philosophy*, 27(2), 109–122. <https://doi.org/10.1111/j.1468-5930.2010.00478.x>
- Hopkins, S. A., Bentley, A., Phillips, V., & Barclay, S. (2020). Advance care plans and hospitalized frail older adults: A systematic review. *BMJ Supportive and Palliative Care*, 10(2), 164–174. <https://doi.org/10.1136/bmjspcare-2019-002093>
- Howell, D. A., Wang, H. I., Roman, E., Smith, A. G., Patmore, R., Johnson, M. J., Garry, A. C., & Howard, M. R. (2015). Variations in specialist palliative care referrals: Findings from a population-based patient cohort of acute myeloid leukaemia, diffuse large B-cell lymphoma and myeloma. *BMJ Supportive and Palliative Care*, 5, 496–502. <https://doi.org/10.1136/bmjspcare-2013-000578>
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. <https://doi.org/10.1177/1049732305276687>
- Hyde, V., Skirton, H., & Richardson, J. (2011). Palliative day care: A qualitative study of service users’ experiences in the United Kingdom. *Nursing and Health Sciences*, 13(2), 178–183. <https://doi.org/10.1111/j.1442-2018.2011.00598.x>
- Kitzinger, C., & Kitzinger, J. (2014). This in-between”: How families talk about death in relation to severe brain injury and disorders of consciousness. In L. Leen Van Brussel, & N. Carpentier (Eds.), *The social construction of death: Interdisciplinary perspectives* (pp. 239–258). <https://doi.org/10.1057/9781137391919>
- Knight, T., Malyon, A., Fritz, Z., Subbe, C., Cooksley, T., Holland, M., & Lasserson, D. (2020). Advance care planning in patients referred to hospital for acute medical care: Results of a national day of care survey. *EclinicalMedicine*, 19, 100235. <https://doi.org/10.1016/j.eclinm.2019.12.005>



- Lancaster, H., Finlay, I., Downman, M., & Dumas, J. (2018). Commissioning of specialist palliative care services in England. *BMJ Supportive and Palliative Care*, 8(1), 93–101. <https://doi.org/10.1136/bmjspcare-2016-001119>
- Latorraca, C. O. C., Martimbianco, A. L. C., Pachito, D. V., Torloni, M. R., Pacheco, R. L., Pereira, J. G., & Riera, R. (2019). Palliative care interventions for people with multiple sclerosis. *Cochrane Database of Systematic Reviews*, CD012936(10), CD012936. <https://doi.org/10.1002/14651858.CD012936.pub2>
- Lazenby, S., Edwards, A., Samuriwo, R., Riley, S., Murray, M. A., & Carson-Stevens, A. (2017). End-of-life care decisions for haemodialysis patients – ‘We only tend to have that discussion with them when they start deteriorating.’ *Health Expectations*, 20(2), 260–273. <https://doi.org/10.1111/hex.12454>
- Levac, D., Colquhoun, H., & O’Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, 5(1), 69. <https://doi.org/10.1186/1748-5908-5-69>
- Lock, M. (2002). *Twice dead: Organ transplants and the re-invention of death*. University of California Press.
- Lowton, K. (2009). A bed in the middle of nowhere?: Parents’ meanings of place of death for adults with cystic fibrosis. *Social Science and Medicine*, 69(7), 1056–1062. <https://doi.org/10.1016/j.socscimed.2009.07.007>
- Lund, S., Richardson, A., & May, C. (2015). Barriers to advance care planning at the end of life: An explanatory systematic review of implementation studies. *Plos One*, 10(2), e0116629. <https://doi.org/10.1371/journal.pone.0116629>
- Maciasz, R., Arnold, R., Chu, E., Park, S., White, D., Vater, L., & Schenker, Y. (2013). Does it matter what you call it? A randomized trial of language used to describe palliative care services. *Supportive Care in Cancer*, 21(12), 3411–3419. <https://doi.org/10.1007/s00520-013-1919-z>
- Martimianakis, M. A. T., Michalec, B., Lam, J., Cartmill, C., Taylor, J. S., & Hafferty, F. W. (2015). Humanism, the hidden curriculum, and educational reform: A scoping review and thematic analysis. *Academic Medicine*, 90, S5–S13. <https://doi.org/10.1097/ACM.0000000000000894>
- Matzopoulos, R., Bowman, B., Butchart, A., & Mercy, J. A. (2008). The impact of violence on health in low- to middle-income countries. *International Journal of Injury Control and Safety Promotion*, 15(4), 177–187. <https://doi.org/10.1080/17457300802396487>
- Mehto, V., Riikonen, S., Hakkarainen, S., Kangas, K., & Seitamaa-Hakkarainen, P. (2020). Epistemic roles of materiality within a collaborative invention project at a secondary school. *British Journal of Educational Technology*, 51(4), 1246–1261. <https://doi.org/10.1111/bjet.12942>
- Murray, S., & Yang Kok, J. (2008). Internationally, it is time to bridge the gap between primary and secondary healthcare services for the dying. *Annals Academy of Medicine Singapore*, 37(2), 142–144.
- Murray, S. A., Kendall, M., Mitchell, G., Moine, S., Amblàs-Novellas, J., & Boyd, K. (2017). Authors’ reply to Wise’s letter on including palliative care doctors in treatment discussions. *British Medical Journal*, 357, 2432. <https://doi.org/10.1136/bmj.j2432>
- National Institute for Health and Care Excellence [NICE]. (1997). *NICE guidance*. <https://www.nice.org.uk/guidance>
- National Institute for Health and Care Excellence [NICE]. (2015). *Care of dying adults in the last days of life*. <https://www.nice.org.uk/guidance/ng31>
- National Institute for Health and Care Excellence [NICE]. (2019). *End of life care for adults: Service delivery, end of life care for adults: Service delivery*. <https://www.nice.org.uk/guidance/ng142>
- National Institute for Health and Care Excellence [NICE]. (2020). *End of life care for people with life-limiting conditions overview*. <https://pathways.nice.org.uk/pathways/end-of-life-care-for-people-with-life-limiting-conditions>
- NHS Scotland. (2008). *Living and dying well: A national action plan for palliative and end of life care in Scotland*. <https://www.cen.scot.nhs.uk/wp-content/uploads/2017/01/LivingDyingWell.pdf>
- NHS Scotland. (2015). *Scottish palliative care guidelines*. <http://www.palliativecareguidelines.scot.nhs.uk/>
- Nickel, B., Barratt, A., Copp, T., Moynihan, R., & McCaffery, K. (2017). Words do matter: A systematic review on how different terminology for the same condition influences management preferences. *BMJ Open*, 7, e014129. <https://doi.org/10.1136/bmjopen-2016-014129>
- O’Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, 89(9), 1245–1251. <https://doi.org/10.1097/ACM.0000000000000388>
- O’Connor, M., Davis, M. P., & Abernethy, A. (2010). Language, discourse and meaning in palliative medicine. *Progress in Palliative Care*, 18(2), 66–71. <https://doi.org/10.1179/096992610X12624290276421>
- Papavasiliou, E. S., Brearley, S. G., Seymour, J. E., Brown, J., & Payne, S. A. (2013). From sedation to continuous sedation until death: How has the conceptual basis of sedation in end-of-life care changed over time? *Journal of Pain and Symptom Management*, 46(5), 691–706. <https://doi.org/10.1016/j.jpainsymman.2012.11.008>
- Parliamentary, Health Service Ombudsman. (2014). *Dying without dignity: Investigations by the parliamentary and health service ombudsman into complaints about end of life care*. [https://www.ombudsman.org.uk/sites/default/files/Dying\\_without\\_dignity.pdf](https://www.ombudsman.org.uk/sites/default/files/Dying_without_dignity.pdf)
- Pastrana, T., Jünger, S., Ostgathe, C., Elsner, F., & Radbruch, L. (2008). A matter of definition - Key elements identified in a discourse analysis of definitions of palliative care.

- Palliative Medicine*, 22(3), 222–232. <https://doi.org/10.1177/0269216308089803>
- Perkins, G. D., & Fritz, Z. (2019). Time to change from do-not-resuscitate orders to emergency care treatment plans. *JAMA Network Open*, 2(6), e195170. <https://doi.org/10.1001/jamanetworkopen.2019.5170>
- Poirier, T., & Behnen, E. (2014). Where and how to search for evidence in the education literature: The WHEEL. *American Journal of Pharmaceutical Education*, 78(4), 70. <https://doi.org/10.5688/ajpe78470>
- Puckey, M., & Bush, A. (2011). Passage to Paradise” Ethics and end-of-life decisions in children. *Paediatric Respiratory Reviews*, 12(2), 139–143. <https://doi.org/10.1016/j.prrv.2010.10.003>
- QSR International. (2015). *NVivo 11*.
- Read, J., Cable, S., Löfqvist, C., Iwarsson, S., Bartl, G., & Schrag, A. (2019). Experiences of health services and unmet care needs of people with late-stage Parkinson’s in England: A qualitative study. *Plos One*, 14(12), 1–17. <https://doi.org/10.1371/journal.pone.0226916>
- Royal College of Physicians. (2009). British geriatric society. In: *Concise guidance to good practice number 12: Advance care planning*. The National Council for Palliative Care, British Society of Rehabilitation Medicine, Alzheimer’s Society, Royal College of Nursing, Royal College of Psychiatry, Help the Aged, Royal College of General Practitioners. <https://www.bgs.org.uk/sites/default/files/content/attachment/2018-04-18/AdvanceCarePlanningGuideline.pdf>
- Royal College of General Practitioners. (2011). *The gold standards framework prognostic indicator guidance*. <https://www.goldstandardsframework.org.uk/cd-content/uploads/files/GeneralFiles/PrognosticIndicatorGuidanceOctober2011.pdf>
- Royal College of General Practitioners. (2016). *Palliative and end of life care toolkit*. <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/palliative-and-end-of-life-care-toolkit.aspx>
- Ryan, T., Gardiner, C., Bellamy, G., Gott, M., & Ingleton, C. (2012). Barriers and facilitators to the receipt of palliative care for people with dementia: The views of medical and nursing staff. *Palliative Medicine*, 26(7), 879–886. <https://doi.org/10.1177/0269216311423443>
- Saldana, J. (2015). *The coding manual for qualitative researchers*. Sage Publications.
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality and Quantity*, 52(4), 1893–1907. <https://doi.org/10.1007/s11135-017-0574-8>
- Scottish Palliative Care Guidelines. (2020). *Alternatives to regular medication normally given via a syringe pump when this is not available*. <https://www.palliativecareguidelines.scot.nhs.uk/guidelines/symptom-control/alternatives-to-regular-medication-normally-given-via-a-syringe-pump-when-this-is-not-available.aspx>
- Scottish Intercollegiate Guidelines Network. (2014). *Care of deteriorating patients*. <https://www.sign.ac.uk/assets/sign139.pdf>
- Seymour, J., & Clark, D. (2018). The Liverpool care pathway for the dying patient: A critical analysis of its rise, demise and legacy in England. *Wellcome Open Research*, 3, 15. <https://doi.org/10.12688/wellcomeopenres.13940.2>
- Seymour, J., French, J., & Richardson, E. (2010). Dying matters: Let’s talk about it. *British Medical Journal*, 341(sep16 2), c4860. <https://doi.org/10.1136/bmj.c4860>
- Sheridan, R., Roman, E., Smith, A. G., Turner, A., Garry, A. C., Patmore, R., Howard, M. R., & Howell, D. A. (2021). Preferred and actual place of death in haematological malignancies: A report from the UK haematological malignancy research network. *BMJ Supportive and Palliative Care*, 11(1), 7–16. <https://doi.org/10.1136/bmjspcare-2019-002097>
- Sleeman, K. E., & Collis, E. (2013). Caring for a dying patient in hospital. *British Medical Journal*, 346(apr17 1), f2174. <https://doi.org/10.1136/bmj.f2174>
- Taylor, F., Taylor, C., Baharani, J., Nicholas, J., & Combes, G. (2016). Integrating emotional and psychological support into the end-stage renal disease pathway: A protocol for mixed methods research to identify patients’ lower-level support needs and how these can most effectively be addressed. *BMC Nephrology*, 17(1), 111. <https://doi.org/10.1186/s12882-016-0327-2>
- Taylor, J., & Pagliari, C. (2018). #Deathbedlive: The end-of-life trajectory, reflected in a cancer patient’s tweets. *BMC Palliative Care*, 17, 1–10. <https://doi.org/10.1186/s12904-018-0273-9>
- The Scottish Government. (2015). *Realistic medicine*. <https://www.gov.scot/binaries/content/documents/govscot/publications/progress-report/2016/01/chief-medical-officers-annual-report-2014-15/documents/chief-medical-officers-annual-report-2014-15/chief-medical-officers-annual-report-2014-15/govscot%3Adocument/00492520.pdf>
- Tricco, A. C., Lillie, E., Zarin, W., O’Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garrity, C., & Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473. <https://doi.org/10.7326/M18-0850>
- Tucker, C., Turner, J., Scott, H., & Taylor, R. (2016a). *Discussing dying*. <https://vimeo.com/170436673>
- Tucker, C., Turner, J., & Scott, H. (2016b). *Understanding the processes following a sudden or unexplained death*. <https://vimeo.com/167901377>
- University of Edinburgh. (2016). *Supportive and palliative care indicators tool (SPICT)*. <https://www.spict.org.uk/>

- White, N., Reid, F., Harris, A., Harries, P., & Stone, P. (2016). A systematic review of predictions of survival in palliative care: How accurate are clinicians and who are the experts? *Plos One*, *11*(8), 1–20. <https://doi.org/10.1371/journal.pone.0161407>
- Willmott, L., White, B., Gallois, C., Parker, M., Graves, N., Winch, S., Callaway, L. K., Shepherd, N., & Close, E. (2016). Reasons doctors provide futile treatment at the end of life: A qualitative study. *Journal of Medical Ethics*, *42*(8), 496–503. <https://doi.org/10.1136/medethics-2016-103370>
- Wolff, T., & Whitehouse, W. P. (2017). Time to ReSPECT personal resuscitation plans for adults? *British Medical Journal*, *356*, j1634. <https://doi.org/10.1136/bmj.j1634>
- World Health Organization. (2021). *World health statistics 2021: A visual summary*. <https://www.who.int/data/gho/publications/world-health-statistics>