

O'CONNOR, T., PATERSON, C., GIBSON, J. and STRICKLAND, K. 2022. The conscious state of the dying patient: an integrative review. *Palliative supportive care* [online], 20(5), pages 731-743. Available from: <https://doi.org/10.1017/S1478951521001541>

# The conscious state of the dying patient: an integrative review.

O'CONNOR, T., PATERSON, C., GIBSON, J. and STRICKLAND, K.

2022

*This article has been published in a revised form in Palliative Supportive Care, <http://doi.org/10.1017/S1478951521001541>. This version is published under a Creative Commons CC-BY-NC-ND. No commercial re-distribution or re-use allowed. Derivative works cannot be distributed. © The Author(s), 2021.*

# **The Conscious State of the Dying Patient: An Integrative Review**

## **Introduction**

Dying is not a new phenomenon, nor is caring for the dying as their physical and conscious state declines. As death approaches there is a gradual failure of all the major organs. This progressive failure of the body's systems and organs, together with the resulting physiological and metabolic changes, are precipitating factors contributing to altered consciousness in people nearing the end of their life (Freeman, 2015; Matzo, 2019). This reduction in consciousness suggests that dying patients are less able, or completely unable, to communicate their own symptoms, needs, or levels of distress. (Benedetti et al., 2013; Hui, dos Santos, Chisholm, & Bruera, 2015; Azhar & Bruera, 2018; Campbell et al., 2018; Krooupa et al., 2019). This review aims to explore the care needs of the dying as their levels of consciousness change. Understanding how these care needs are determined when the dying patient's conscious state changes as they progress closer to death will also be investigated.

For the purpose of this paper, and in line with the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), consciousness is considered as a state of alertness (American Psychiatric Association, 2013). A more precise definition for consciousness remains elusive and has variably been described in terms of levels of awareness and intellectual function (Sarà & Pistoia, 2010; Naccache, 2017; Koch, 2018; Brown et al., 2019). The related term, cognition, is the ability to think, reason and respond (American Psychiatric Association, 2013). The two terms – consciousness and cognition – are used largely interchangeably in the literature due to a lack of definitional precision (Van Gulick, 2012).

Improved end-of-life care and individualised care planning are fundamental to meet the specific needs of the dying individual and their family, and are recognised and championed

internationally (The Institute of Medicine Committee on Approaching Death: Addressing key end-of-life issues, 2014; NICE, 2017; Palliative Care Australia, 2018). Poor symptom control can be traumatic for patients and a significant source of emotional and psychological distress for their families (Donnelly et al., 2018; Coelho et al., 2020). How people die remains in the long lasting memories of their families and loved ones (Saunders, 2006). Those who have witnessed inadequate symptom palliation in the context of their dying loved ones are often the people who are active advocates for legislative change to allow assisted dying (Feigin et al., 2019; Roest et al., 2019).

As the patient's conscious level deteriorates so too does their ability to reason, to process information and instructions, and articulate their needs or a response to stimuli (Hui, dos Santos, Chisholm, & Bruera, 2015). This deterioration may impact on care delivery, as the dying patient may encounter difficulties articulating their own care needs. The 'gold standard' for assessing symptoms for example, is to ask the patient, because they are the ones experiencing the symptom (McColl, 2004; Hui & Bruera, 2017; Wiegand et al., 2018). Identifying and diagnosing distressing symptoms can therefore be problematic once the dying adult is no longer able to verbalise or communicate their own care needs. Contemporary research indicates that existing assessment tools to assess dyspnoea, levels of consciousness and pain may not be appropriate for cognitively impaired dying patients (Campbell et al., 2018; Krooupa et al., 2019; Tapp et al., 2019). Further, existing reviews and studies do not provide insights into how healthcare professionals should assess the dying patients' care needs (Plonk & Arnold, 2005; Eychmüller et al., 2013; Kehl & Kowalkowski, 2013; Kennedy et al., 2014; Hui, dos Santos, Chisholm, & Bruera, 2015; Campbell et al., 2018; Krooupa et al., 2019; Tapp et al., 2019). There is therefore a clinical need to appraise current evidence to understand the conscious state of the dying patient.

This integrative review therefore aimed to examine the existing evidence to better understand:

- the conscious state of the dying adult patient,
- whether the conscious state of the dying adult changes over time as patients progress closer to death
- what the care needs of dying adults associated with altered levels of consciousness are; and
- how individual care needs are determined when the dying patient's conscious state changes.

## **Methods**

An integrative review (Whittemore & Knafl, 2005) was conducted and has been reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). An a priori review protocol was developed and registered with PROSPERO (registration number CRD42020160475), available from: [https://www.crd.york.ac.uk/prospero/display\\_record.php?ID=CRD42020160475](https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020160475).

## **Theoretical Framework**

Although palliative care has more recently been associated with care needs early in a progressive life-limiting illness (Waller et al., 2020), it is traditionally associated with optimum care in the last days of life. The World Health Organisation (WHO) definition for palliative care (World Health Organization, 2020) provided a conceptual framework to guide this review. Specifically, the following palliative care concepts were used to guide data extraction and analysis: quality of life, suffering, assessment and treatment, pain, physical, psychosocial and spiritual problems, and the family (World Health Organization, 2020).

## **Eligibility Criteria**

Inclusion and exclusion criteria were developed to identify studies of interest that addressed the review's aims (see Table 1 for inclusion and exclusion criteria with rationales). A systematic electronic literature search of CINAHL, MEDLINE (OVID), Scopus, PsycINFO, Cochrane Library, and PubMed, was conducted in collaboration with a professional university research librarian. Subject headings and keywords were adapted according to the nuances of each database using MESH subject headings and other key search terms (see Table 2).

## **Search Outcome**

All references were uploaded to EndNote™ (X9.3) and then exported to Covidence™ (Covidence systematic review software) where duplicates were removed. Covidence™ was used to complete the title and abstract screening based on the inclusion and exclusion criteria across the reviewers. Relevant titles and abstracts meeting the inclusion criteria were moved to full text review screening. Full text publications were reviewed by three researchers. Where required, consultation with a fourth reviewer resolved any disagreements. Authors of one study (Geijteman et al., 2018) were contacted seeking more complete data. It was later identified that this study did not meet the inclusion criteria (Geijteman et al., 2018). Citation tracking was used in the Scopus database, hand searches of reference lists, and review of existing systematic reviews. Searches of grey literature was conducted via Google Scholar to increase inclusiveness.

## **Quality Appraisal**

The included studies were assessed for methodological quality using the Joanna Briggs Institute's (JBI) Critical Appraisal Tool: the 'Checklist for Case Series' (Moola, 2017). The Case Series appraisal tool is to be applied to studies where all participants have a specific disease or specific disease-related outcome (Moola, 2017, p. 4). This appraisal tool enabled

assessment of differing study designs and was considered appropriate as the disease-related outcome for all the studies was death. The JBI Critical Appraisal Tool allocates ‘yes’, ‘no’, ‘unclear’, or ‘not applicable’ for ten quality appraisal questions. Studies were not eliminated based on methodological quality; but rather, all studies were included with the evidence summarised and recorded noting concerns about quality or risk of bias.

### **Data Abstraction**

Data abstraction was informed by the WHO definition for palliative care (World Health Organization, 2020) and the aims of the review. The following information was extracted and tabulated in an MS Excel™ spreadsheet: primary author, publication year, country, purpose, sample size, design, assessment tools, data collection, and data analysis. Details describing any change in conscious state, care needs, quality of life, assessment, treatments or interventions, pain, and any other details of suffering (physical, psychosocial, or spiritual) were also extracted. Any references to family within the individual studies were also extracted. Data was extracted from all included studies and double-checked for accuracy and completeness. Any disagreement or uncertainty in data extraction was resolved by discussion among the four reviewers.

### **Data Synthesis**

Extracted data were synthesised using a narrative approach. A thematic analysis was undertaken following the process outlined by Braun and Clarke (2006) (see Supplement 1) and guided by the WHO definition for palliative care (World Health Organization, 2020).

## **Results**

### **Search results**

The search identified 5136 studies, of which 105 studies were assessed in full text according to the inclusion and exclusion criteria. A further five articles were identified from backward and forward citation tracking, and hand search processes. A total of 11 studies fully met the inclusion criteria (see Figure 1).

### **Quality appraisal results**

Based on the JBI Level of Evidence (The Joanna Briggs Institute Levels of Evidence and Grades of Recommendation Working Party, 2014) all included studies were classified as level four, namely, observational descriptive studies. No studies were graded level one to three, suggesting that robust, higher levels of evidence in this area are currently lacking. The quality appraisal identified several limitations among the included studies. All studies received low to moderate scores for methodological quality (see Table 3). The most common limitation across the studies was poor reporting of the independent variables (demographics [n=9] and clinical information [n=7]). There is therefore a risk that confounding factors may have introduced bias in these studies and as such, the results should be viewed with caution. Secondly, six of the eleven studies were published more than 15 years ago. Thus, some of the data may not be representative of contemporary clinical practice. Thirdly, the included studies had small sample sizes, and many were retrospective case series studies. The lack of qualitative studies meant the voices of the patients, and the staff providing for their care needs were not fully reflected in the literature. The findings of this review should be viewed in this context.

### **Study characteristics**

All 11 studies used quantitative designs (see Table 4). None of the studies reported a theoretical model or conceptual framework. Non-probability sampling methods were used across all the

studies. The studies represented clinical settings in eight different countries: Australia [n=3], Japan [n=2], Austria [n=1], Canada [n=1], New Zealand [n=1], Portugal [n=1], United Kingdom [n=1], and United States of America [n=1]. The studies were published between 1990 (Lichter & Hunt, 1990) and 2019 (White et al., 2019). There was a combined total of 822 participants, ranging from 12 to 200 participants (Lichter & Hunt, 1990; Fainsinger et al., 1991; Turner et al., 1996; Morita et al., 1998; Barbato, 2001; Bruera et al., 2003; Thier et al., 2016; Barbato et al., 2018; Matsunami et al., 2018; Pereira et al., 2018; White et al., 2019). Generally, the studies had representation of both males and females, with slightly more male participants represented (56%). The average age was 64 years with a range of 25 years to 102 years. One study did not record age nor gender (Lichter & Hunt, 1990). Studies either exclusively or predominantly focused on participants with a diagnosis of cancer. All studies discussed dying patients with an altered level of consciousness, however not all participants died. Two studies compared nurses' and families' perceptions of patient comfort and did not indicate if any participants died during the studies (Bruera et al., 2003; Barbato et al., 2018). A further study compared the clinical condition of those who died within 72 hours (48% [n=24]) with those who lived longer than 72 hours (52% [n=26]) (White et al., 2019). Use of various assessment tools and scales were reported (see Table 4). One study did not specify any particular assessment tool or scale (Lichter & Hunt, 1990).

### **Conscious state, awareness, and change over time**

Two themes addressing the conscious state of the dying adult were identified in the thematic analysis, namely: the conscious state and change over time, and awareness.

#### *Conscious state and change over time*

Various terms were used across the studies to describe the conscious state of the dying patient prior to death: 'conscious' or 'unconscious' state (55% [n=6]) (Lichter & Hunt, 1990; Turner



et al., 1996; Barbato, 2001; Thier et al., 2016; Matsunami et al., 2018; White et al., 2019), ‘unresponsive’ (27% [n=3]) (Fainsinger et al., 1991; Bruera et al., 2003; Barbato et al., 2018), and ‘comatose’ (18% [n=2]) (Morita et al., 1998; Pereira et al., 2018) (see Supplement 2). In three studies, 100% of participants were reported as unconscious/unresponsive prior to death (Barbato, 2001; Bruera et al., 2003; Barbato et al., 2018).

Only one study provided a definition for ‘unconscious’, stating that “patients responded lethargically or not at all to their name being spoken, and had infrequent or no spontaneous movements” (Barbato, 2001, p. 104). Three studies described or implied that ‘unconscious’ was being unable to respond to questions regarding symptoms (Turner et al., 1996; Bruera et al., 2003; White et al., 2019). Morita et al. (1998) provided a categorical scale to measure the patients’ level of consciousness which described states between awake and coma, where coma was defined as “does not awaken to any stimuli” (Morita et al., 1998, p. 218).

Despite the lack of definitions used across the studies, five different tools were used to assess the conscious state of dying patients, namely: a modified Consciousness Scale (Barbato, 2001), Bispectral Index monitoring (Barbato, 2001; Barbato et al., 2018), Richmond Agitation-Sedation Scale (Barbato et al., 2018; White et al., 2019), Glasgow Coma Scale (Matsunami et al., 2018), and a Categorical Scale designed to measure patients’ level of consciousness (Morita et al., 1998). An assessment of behaviour and consciousness was completed in 96.4% [80] of patients in another study but the assessment tool used was not reported (Pereira et al., 2018).

A gradual decline in conscious levels over a period of seven days to death was identified in three studies (Lichter & Hunt, 1990; Fainsinger et al., 1991; Morita et al., 1998). Morita et al. (1998) found that none of the participants in their study were in a coma seven days prior to death. An increase of 12% [n=12] of the participants were in a coma one day prior to death, with 50% [n=50] of the participants in a coma on the day of death (Morita et al., 1998) (see

Supplement 2). Similarly, Fainsinger et al. (1991) reported that 57% [n=57] of participants were unresponsive on the day of death. In contrast, a lesser number of study participants (38%, n=76) were described by Lichter and Hunt (1990) as unconscious on the day of death.

Four studies referred to delirium (Lichter & Hunt, 1990; Fainsinger et al., 1991; Turner et al., 1996; White et al., 2019). In one study delirium was included as a key prognostic feature in a table with no mention elsewhere (White et al., 2019). Another reported that delirium did not frequently occur (Turner et al., 1996). The third study reported that 39% [39] of participants experienced delirium, and 26% [10] of those that developed a delirium required additional treatment to relieve their symptoms (Fainsinger et al., 1991). Fainsinger et al. (1991) reported that delirium was the most difficult symptom to control without using sedation. A cause for delirium in the dying was difficult to find (Lichter & Hunt, 1990). Four studies (Lichter & Hunt, 1990; Bruera et al., 2003; Barbato et al., 2018; Pereira et al., 2018) used related terms such as restlessness, agitation, confusion, and disorientation without being definitive about whether they were referring to delirium or not.

Eighteen percent of participants [n=15] were reported to suffer agitation and 19% [n=16] disorientation or confusion in the chart review by Pereira et al. (2018). Together with delirium, the table presented in the study by White et al. (2019) revealed that 20% [n=5] of participants who died within 72 hours of assessment were agitated, while 70% [n=18] of those who did not die within 72 hours had mild agitation or were sedated. Lichter and Hunt (1990) found that 42% [n=84] of the participants experienced restlessness and agitation in the last 48 hours of life.

### ***Awareness***

Despite a decline in consciousness related to dying, and associated medication administration for symptom management, results from two studies found evidence of participants experiencing signs of awareness (Lichter & Hunt, 1990; Barbato, 2001). These authors reported that

apparently unconscious patients demonstrated an awareness of pain and discomfort during care activities, such as repositioning or during the provision of fundamental care interventions (Lichter & Hunt, 1990; Barbato, 2001).

Awareness was recorded via bispectral index monitoring (Barbato, 2001) and staff observation (Lichter & Hunt, 1990). Bispectral index monitoring is described by Barbato (2001) as a non-invasive method of electroencephalography monitoring, where two small sensors are applied to the head. The higher the index value, the higher the likelihood of awareness (Barbato, 2001). Barbato (2001) reported values fluctuating above basal levels in response to pain and nursing procedures. In Lichter and Hunt (1990) study, staff recorded all symptoms and observations using strict criteria. The nature of the criteria were not reported.

Several studies noted that sedation secondary to medication was a cause for an altered conscious state in the dying patient (Lichter & Hunt, 1990; Fainsinger et al., 1991; Turner et al., 1996; Barbato et al., 2018). This induced reduction in cognition and awareness was variously viewed as justifiable (Barbato et al., 2018), defensible (Barbato et al., 2018), unavoidable (Lichter & Hunt, 1990), and preferable (Turner et al., 1996).

### **Care needs of the dying adult with an altered level of consciousness**

Four themes were identified which described the care needs of the dying adult with an altered level of consciousness, namely: pain, absence of holistic care, the voiceless patient, and signs and symptoms of dying.

#### *Pain*

Pain was mentioned in 81.8% [n=9] of studies (Lichter & Hunt, 1990; Fainsinger et al., 1991; Turner et al., 1996; Barbato, 2001; Bruera et al., 2003; Thier et al., 2016; Barbato et al., 2018; Pereira et al., 2018; White et al., 2019). Physical and observable indications associated with

pain were only described in four of the 11 studies (Lichter & Hunt, 1990; Barbato, 2001; Bruera et al., 2003; Pereira et al., 2018).

The terms narcotics, opioids, or morphine were specifically mentioned in eight of the 11 studies (Lichter & Hunt, 1990; Fainsinger et al., 1991; Turner et al., 1996; Morita et al., 1998; Barbato, 2001; Thier et al., 2016; Barbato et al., 2018; Pereira et al., 2018). Between 86% [n=480] and 100% [n=558] of patients were recorded as receiving opioids before their death (Lichter & Hunt, 1990; Fainsinger et al., 1991; Turner et al., 1996; Morita et al., 1998; Barbato, 2001; Thier et al., 2016; Barbato et al., 2018). Two studies indicated that 92% [n=48] to 100% [n=52] of dying patients were on a continuous infusion of opioids (Barbato, 2001; Barbato et al., 2018).

### *Absence of holistic care*

There was no reference made to the emotional, psychological, spiritual, or social issues in relation to the dying patient in five of the 11 studies (Morita et al., 1998; Barbato, 2001; Thier et al., 2016; Barbato et al., 2018; Matsunami et al., 2018). Two studies commented on the lack of documentation in patient records regarding emotional, psychological, spiritual, or social care needs (Pereira et al., 2018; White et al., 2019). Although emotional distress was one of the checklist reasons suggested for discomfort in Bruera et al. (2003) study, there was no further mentioned of emotional care or distress in the study. Reported psychosocial and spiritual issues for the patient (Lichter & Hunt, 1990) and the emotional distress of the family (Fainsinger et al., 1991) were considered resolved once medical treatment was administered in two other studies. Turner et al. (1996) also listed emotional distress as a symptom, however actions to manage or treat this symptom were not discussed.

### *The voiceless patient*

All the included studies were quantitative in design, consequently, the voice and experience of the patient with altered levels of consciousness is silent. Perspectives and information were sought from nurses, family members, and equipment being trialled, (Barbato, 2001; Bruera et al., 2003; Barbato et al., 2018). Data regarding pain on the day death for 90% [n=90] of patients was completed by the nurse (Fainsinger et al., 1991). The retrospective study designs adopted by some researchers also resulted in the voice of the patient not being reported (Fainsinger et al., 1991; Turner et al., 1996; Pereira et al., 2018).

Research consent is an important area of note across the 11 studies. Only 27% [n=3] of studies documented obtaining consent from patients and/or next of kin (Barbato, 2001; Barbato et al., 2018; White et al., 2019). Four of the studies did not mention research consent (Lichter & Hunt, 1990; Fainsinger et al., 1991; Turner et al., 1996; Morita et al., 1998), and a further four studies stated that consent was waived at their institution due to the study design for chart reviews and observational studies (Bruera et al., 2003; Thier et al., 2016; Matsunami et al., 2018; Pereira et al., 2018). One study referred to legislation and mental capacity in the context of informed consent (White et al., 2019).

### *Signs and symptoms of dying*

The patients' signs and symptoms varied and were widely discussed as predictors of dying. Respiratory changes were the most dominant sign and symptom reported by 91% [n=10] of authors (Lichter & Hunt, 1990; Fainsinger et al., 1991; Turner et al., 1996; Morita et al., 1998; Bruera et al., 2003; Thier et al., 2016; Barbato et al., 2018; Matsunami et al., 2018; Pereira et al., 2018; White et al., 2019). The prevalence of dyspnoea was reported by Fainsinger et al. (1991) in 46% [n=46] of participants, Lichter and Hunt (1990) 22% [n=44], Pereira et al. (2018)

61% [n=51], Turner et al. (1996) 26% [n=13] and White et al. (2019) as 8% [n=2]. Difficult and noisy respirations were also recorded as being problematic in between 31% [n=26] (Pereira et al., 2018) and 56% [n=112] (Lichter & Hunt, 1990) of participants. The main indication for breakthrough medication was respiratory in nature (Barbato et al., 2018). Several studies (n=4, 36.3%) indicated that respiratory issues in the dying patient were likely to cause suffering for the patient, family, and staff (Lichter & Hunt, 1990; Turner et al., 1996; Bruera et al., 2003; Barbato et al., 2018).

One of the physical signs that indicated imminent death on the last day of life is respiration with mandibular movement, according to Matsunami et al. (2018) and White et al. (2019). Thier et al. (2016) described a decreased level of consciousness, fever, dysphagia, and seizures as the most frequently reported symptoms in people dying with a glioblastoma. Elsewhere, Lichter and Hunt (1990) identified that symptoms such as twitching, jerking, restlessness, agitation, and 'plucking' were observed in the period before death. White et al. (White et al., 2019) documented a decrease in oral intake, a rapid decline in health, and decreased level of consciousness as indications of dying. Although White et al. (2019) identified increased care needs, this was not the aim of their study. The study aimed to detect and document signs and symptoms of dying as prognostic markers with view to improving the skill level of staff in identifying patients whose death was imminent (White et al., 2019).

Cognisant of the variation in findings, Morita et al. (1998, p. 220) concluded that there was diversity among individual dying patients signs and symptoms which made it difficult to predict the time of death.

## Discussion

This integrative review identified and confirmed changes over time in the conscious state of dying adults prior to death. Although the aims and purposes of the 11 selected studies were diverse, the timeframes, prognosis, and symptoms that predict dying in the selected studies were congruent with other reported results (Eychmüller et al., 2013; Kennedy et al., 2014; Hui, dos Santos, Chisholm, Bansal, et al., 2015; Clark et al., 2016; Sandvik et al., 2016). This review extends our current knowledge by tabulating the gradual but consistent deterioration in the cognitive state of dying patients in the last days of life. A lack of definitional clarity for terms such as consciousness was evident within the studies but consistent with other literature (Sarà & Pistoia, 2010; Naccache, 2017; Koch, 2018; Brown et al., 2019).

There is currently significant clinical uncertainty about what the dying person is experiencing. Due to the physiological process of dying, loss of both motor function and verbal response is common. However, the findings of this integrative review identified that patients may have periods of heightened awareness during, for example, repositioning or during the provision of hygiene care (Lichter & Hunt, 1990; Barbato, 2001). Anecdotal evidence suggests that apparent unconscious patients may maintain the ability to hear until the last moments of life (Freeman, 2015; Matzo, 2019). Emerging scientific research confirms this, indicating that dying patients may in fact have a level of awareness, even when that awareness cannot be physically communicated during the last hours of life (Rady, 2016; Blundon et al., 2020). Awareness indicates not only the ability to hear but also to maintain a perception of self and the environment (Rady, 2016). The dying patient should therefore be considered ‘unresponsive’ rather than ‘unconscious’ (Rady & Verheijde, 2013; Barbato et al., 2015). Noxious stimuli, such as movement after several hours of inertia, may therefore cause pain and discomfort in the dying. The inability to self-express, combined with an absence of visible markers of pain and

discomfort could mean that pain and suffering are not being recognised or considered in the dying patient with an altered or diminished level of consciousness. These findings have significant implications for the care needs of dying patients.

This review also highlighted a further cohort of patients who may be unable to convey their own care needs: those who develop delirium or become terminally restless or agitated due to the dying process (Lichter & Hunt, 1990; Fainsinger et al., 1991; Turner et al., 1996; Bruera et al., 2003; Barbato et al., 2018; Pereira et al., 2018; White et al., 2019). The incidence of delirium is reported elsewhere, varying from 58-88% in dying patients, with the prevalence increasing closer to death (Hosie et al., 2013; Lawlor et al., 2014; Hosie et al., 2019; Maeda et al., 2020; Watt et al., 2021). Delirium affects perception, attention, and communication, leading to a reduced ability to express symptoms (Hosie et al., 2019; Hui, 2019). Despite delirium being an important area of concern at end-of-life, only three of the 11 studies mentioned delirium (Fainsinger et al., 1991; Turner et al., 1996; White et al., 2019). This is consistent with other recent research suggesting that delirium is often not recognised or not identified in palliative care patients (Watt et al., 2021), despite the availability of both diagnostic criteria (American Psychiatric Association, 2013) and validated delirium screening tools (Watt et al., 2021). This may account for the limited discussion of delirium in the reviewed studies. Given that delirium is perceived as a very distressing condition by those who have experienced it and recovered (Kuusisto-Gussmann et al., 2021), it is possible that the dying patient with an altered level of consciousness is equally distressed. The findings of this integrative review agree with the previous reported findings regarding the lack of available guidance, and the difficulty in assessing the care needs of the voiceless and vulnerable dying patient with delirium (Gao et al., 2013; Lawlor et al., 2014; Blinderman & Billings, 2015; Mah et al., 2017).



Various assessment tools and scales were reported across 10 of the 11 included studies. Only two studies reported the use of pain assessment tools: VAS and PCS (Fainsinger et al., 1991; Barbato et al., 2018). Other research comparing the VAS and Numeric Rating Scale found that both these subjective pain assessment tools require some level of cognitive ability to comprehend the questions and formulate an opinion (Hjermstad et al., 2008; Hjermstad et al., 2011). Importantly, this integrative review has provided evidence that across eight of the 11 studies that more than half of the study participants had a decreased conscious state prior to death. Recorded pain assessment scores may therefore have been the subjective evaluation by the nurse, that is, the recorded pain assessment scores describe the nurse's perception of the patient's level of pain. High rates of pain prevalence were reported in most of the studies, yet only four of the 11 studies documented pain markers (Lichter & Hunt, 1990; Barbato, 2001; Bruera et al., 2003; Pereira et al., 2018). A correspondingly high prevalence of opioid use was recorded, indicating that healthcare professionals were prescribing and administering opioids for unresponsive patients. This would suggest a level of patient awareness was observed and/or, that a degree of assessment, diagnosis, and decision-making had taken place, yet evidence of this decision-making remains unrecorded and unknown.

Respiratory changes were the most dominant sign and symptom reported across 10 of the 11 studies, yet there was no evidence of assessment of care needs nor documentation of assessment tools or scales. Equally, nausea, vomiting and other gastrointestinal issues were reported as problematic with no reporting on assessment. This too is consistent with other studies which report a lack of appropriate tools suitable for assessing the needs of the dying patient, such as levels of consciousness (Krooupa et al., 2019), dyspnoea (Campbell et al., 2018), and pain (Tapp et al., 2019).

Given the intrinsic value of dignity in dying and the inherent importance of a ‘good death’, being free from pain and suffering is imperative for all dying patients (Kastbom et al., 2016; Meier et al., 2016; Rodríguez-Prat et al., 2016). For the dying adult, sources of pain can be numerous (Herr et al., 2019). Compounding the problem, pain markers may not be a sign of physical pain but of emotional or existential pain (Herr et al., 2011; McGuire et al., 2016), yet emotional, psychological, spiritual, or social issues in relation to the dying patient was not addressed across the studies. There was no mention or discussion of referral to other members of the multidisciplinary team.

An increased need for assistance with activities of daily living would be expected as the dying patient deteriorates both physically and cognitively as death approaches. Fundamental care activities, such as, the patient’s personal care and oral hygiene, were only mentioned in one study (Pereira et al., 2018). In this study nearly 98% of patients did not have oral hygiene care documented during their admission (Pereira et al., 2018). Perhaps these caring activities had in fact been provided and were not documented, but ultimately this will remain unknown. Kitson et al. (2019) believe that nursing notes regarding patient care are commonly deemed as ‘fluffy notes’ (p2). In this context, fundamental caring activities or basic nursing care has been devalued by nurses themselves and has become invisible (Zwakhaleh et al., 2018). Yet, nursing documentation provided the foundational data utilised by the authors across the studies included in this review. ‘Care’ is at the core of what nursing is, with care for the dying being an integral component of nursing care (Robinson et al., 2019) and is embedded within the multidisciplinary team (Epstein, 2014; Hickman et al., 2015). Nurses provide the most direct patient care to dying adults across all healthcare professional groups (Sekse et al., 2018), yet, across the 11 studies there was only one nurse-led research study (Pereira et al., 2018).

The findings reported here are dominated by cancer diagnoses, which is consistent with previous studies (Moens et al., 2014; Etkind et al., 2017; Quinn et al., 2020). Although cancer and non-cancer patients have different disease trajectories (Lunney et al., 2003; Murray et al., 2005), non-cancer patients have equally complex symptoms and care needs (Stiel et al., 2015). As life expectancy increases so too does the incidence and prevalence of chronic diseases, such as organ failure and neurological diseases (Moens et al., 2014; Etkind et al., 2017). Although the lack of non-cancer related studies and the increasing need for further research in this area have previously been reported (Moens et al., 2014; Etkind et al., 2017; Quinn et al., 2020), this integrative review reiterates this call for further research.

Although physical care needs such as pain and dyspnoea have been highlighted, insights on how to best identify and assess these needs in the dying patient with an altered conscious state was missing. Equally, other obvious care needs such as quality of life, suffering, psychosocial and spiritual problems, and the family (World Health Organization, 2020) were absent. Minimal guidance was therefore detected in this integrative review on how best to care for the dying patient in the last hours to days of life when they have an altered conscious state due to the dying process.

## **Limitations**

This review has several key limitations. A meta-analysis was precluded due to the broad range of outcome variables across the studies, and therefore the findings of this review are constrained by the current state of the evidence. Combining heterogeneous methodologies, with various study designs, sizes, setting, and characteristics of the population studied, was also a limitation. Despite these limitations this review followed a rigorous, clear, and transparent process which has provided valuable directions for future research, education, and practice.

## **Conclusion**

This integrative review focussed on the alteration and gradual deterioration of the conscious state of the dying adult patient, and their care needs as they progress toward death. As death approaches the conscious state of many patients decline and they become unresponsive. Although unable to respond, the findings of this integrative review identified that the dying patient may retain a level of awareness, including awareness of pain and other forms of discomfort. This review highlighted the prevalence of distressing physical symptoms such as pain and dyspnoea as the patient nears death. A biomedical model of care was apparent, dominated by medications and in particular, by opioids. The lack of suitable assessment tools to determine and assess care needs when the dying patient's conscious state changes was also highlighted. Assessment of emotional, psychological, spiritual, or social care needs were largely absent from the literature. These issues raise significant uncertainty and challenges for the patient, healthcare professionals, and families in relation to the delivery of person-centred care; and raise significant questions about the delivery of holistic care for patients who are unable to communicate their own individual needs due to the dying process. This review adds to the call for urgent development of assessment tools to determine the care needs of dying adults with an altered level of consciousness to ensure holistic, patient-centric care.

**Acknowledgements:** The authors wish to acknowledge and thank librarians, Murray Turner, who assisted in developing the search strategies and Sonny Chandra for technical advice.

Conflicts of Interest: None

**Funding Statement:** This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

## References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). Arlington, VA: American Psychiatric Association.
- Azhar, A., & Bruera, E. (2018). Outcome measurement and complex physical, psychosocial and spiritual experiences of death and dying. *Annals of Palliative Medicine*, 7(Suppl 3), S231-S243. <https://doi.org/10.21037/apm.2018.07.04>
- Barbato, M. (2001). Bispectral index monitoring in unconscious palliative care patients. *Journal of Palliative Care*, 17(2), 102-108. <https://doi.org/10.1177/082585970101700206>
- Barbato, M., Barclay, G., Potter, J., & Yeo, W. (2015). Sedation and analgesia in unconscious palliative care patients: Can bispectral index monitoring add to our understanding? *Journal of Palliative Care*, 31(1), 57-59. <https://doi.org/10.1177/082585971503100109>
- Barbato, M., Barclay, G., Potter, J., & Yeo, W. (2018). Breakthrough medication in unresponsive palliative care patients: Indications, practice, and efficacy. *Journal of Pain and Symptom Management*, 56(6), 944-950. <https://doi.org/10.1016/j.jpainsymman.2018.08.020>
- Benedetti, F. D., Ostgathe, C., Clark, J., Costantini, M., Daud, M. L., Grossenbacher-Gschwend, B., Latten, R., Lindqvist, O., Peternelj, A., Schuler, S., Tal, K., van der Heide, A., & Eychmueller, S. (2013). International palliative care experts' view on phenomena indicating the last hours and days of life. *Supportive Care in Cancer*, 21(6), 1509-1517. <https://doi.org/10.1007/s00520-012-1677-3>
- Blinderman, C. D., & Billings, A. J. (2015). Comfort care for patients dying in the hospital. *The New England Journal of Medicine*, 373(26), 2549-2561. <https://doi.org/10.1056/NEJMra1411746>
- Blundon, E. G., Gallagher, R. E., & Ward, L. M. (2020). Electrophysiological evidence of preserved hearing at the end of life. *Scientific Reports*, 10(1), 10336. <https://doi.org/10.1038/s41598-020-67234-9>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Brown, R., Lau, H., & LeDoux, J. E. (2019). Understanding the higher-order approach to consciousness. *Trends in Cognitive Sciences*, 23(9), 754-768. <https://doi.org/10.1016/j.tics.2019.06.009>

- Bruera, E., Sweeney, C., Willey, J., Palmer, J. L., Strasser, F., & Strauch, E. (2003). Perception of discomfort by relatives and nurses in unresponsive terminally ill patients with cancer: A prospective study. *Journal of Pain and Symptom Management*, 26(3), 818-826. [https://doi.org/10.1016/S0885-3924\(03\)00286-0](https://doi.org/10.1016/S0885-3924(03)00286-0)
- Campbell, M. L., Kiernan, J. M., Strandmark, J., & Yarandi, H. N. (2018). Trajectory of dyspnea and respiratory distress among patients in the last month of life. *Journal of Palliative Medicine*, 21(2), 194-199. <https://doi.org/10.1089/jpm.2017.0265>
- Clark, K., Connolly, A., Clapham, S., Quinsey, K., Eagar, K., & Currow, D. (2016). Physical symptoms at the time of dying was diagnosed: A consecutive cohort study to describe the prevalence and intensity of problems experienced by imminently dying palliative care patients by diagnosis and place of care. *Journal of Palliative Medicine*, 19(12), 1288-1295. <https://doi.org/10.1089/jpm.2016.0219>
- Coelho, A., de Brito, M., Teixeira, P., Frade, P., Barros, L., & Barbosa, A. (2020). Family caregivers' anticipatory grief: A conceptual framework for understanding its multiple challenges. *Qualitative Health Research*, 30(5), 693-703. <https://doi.org/10.1177/1049732319873330>
- Covidence systematic review software. *Veritas Health Innovation*. Melbourne, Australia. [www.covidence.org](http://www.covidence.org)
- Donnelly, S., Prizeman, G., Ó Coimín, D., Korn, B., & Hynes, G. (2018). Voices that matter: End-of-life care in two acute hospitals from the perspective of bereaved relatives. *BMC Palliative Care*, 17(1), 117-113. <https://doi.org/10.1186/s12904-018-0365-6>
- Epstein, N. E. (2014). Multidisciplinary in-hospital teams improve patient outcomes: A review. *Surgical Neurology International*, 5(Suppl 7), S295-S303. <https://doi.org/10.4103/2152-7806.139612>
- Etkind, S. N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I. J., & Murtagh, F. E. M. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine*, 15, 102. <https://doi.org/10.1186/s12916-017-0860-2>
- Eychmüller, S., Benedetti, F. D., Latten, R., Tal, K., Walker, J., & Costantini, M. (2013). 'Diagnosing dying' in cancer patients: A systematic literature review. *European Journal of Palliative Care*, 20(6), 292-296.
- Fainsinger, R., Miller, M. J., Bruera, E., Hanson, J., & Maceachern, T. (1991). Symptom control during the last week of life on a palliative care unit. *Journal of Palliative Care*, 7(1), 5-11.

- Feigin, S., Owens, R. G., & Goodyear-Smith, F. (2019). Helping a loved one die: The act of assisted dying in New Zealand. *Mortality*, 24(1), 95-110. <https://doi.org/10.1080/13576275.2017.1382461>
- Freeman, B. (2015). *Compassionate person-centered care for the dying: an evidence-based palliative care guide for nurses*. Springer Publishing Company, LLC.
- Gao, X., Prigerson, H. G., Diamond, E. L., Zhang, B., Wright, A. A., Meyer, F., & Maciejewski, P. K. (2013). Minor cognitive impairments in cancer patients magnify the effect of caregiver preferences on end-of-life care. *Journal of Pain and Symptom Management*, 45(4), 650-659. <https://doi.org/https://doi.org/10.1016/j.jpainsymman.2012.03.003>
- Geijteman, E. C. T., van der Graaf, M., Witkamp, F. E., van Norden, S., Stricker, B. H., van der Rijt, C. C. D., van der Heide, A., & van Zuylen, L. (2018). Interventions in hospitalised patients with cancer: The importance of impending death awareness. *BMJ Supportive & Palliative Care*, 8(3), 278-281. <https://doi.org/10.1136/bmjspcare-2017-001466>
- Herr, K., Coyne, P. J., Ely, E., Gélinas, C., & Manworren, R. C. B. (2019). Pain assessment in the patient unable to self-report: Clinical practice recommendations in support of the ASPMN 2019 position statement. *Pain Management Nursing*, 20(5), 404-417. <https://doi.org/https://doi.org/10.1016/j.pmn.2019.07.005>
- Herr, K., Coyne, P. J., McCaffery, M., Manworren, R., & Merkel, S. (2011). Pain assessment in the patient unable to self-report: Position statement with clinical practice recommendations. *Pain Management Nursing*, 12(4), 230-250. <https://doi.org/10.1016/j.pmn.2011.10.002>
- Hickman, L. D., Phillips, J. L., Newton, P. J., Halcomb, E. J., Al Abed, N., & Davidson, P. M. (2015). Multidisciplinary team interventions to optimise health outcomes for older people in acute care settings: A systematic review. *Archives of Gerontology and Geriatrics*, 61(3), 322-329. <https://doi.org/https://doi.org/10.1016/j.archger.2015.06.021>
- Hjermstad, M. J., Fayers, P. M., Haugen, D. F., Caraceni, A., Hanks, G. W., Loge, J. H., Fainsinger, R., Aass, N., & Kaasa, S. (2011). Studies comparing numerical rating scales, verbal rating scales, and visual analogue scales for assessment of pain intensity in adults: A systematic literature review. *Journal of Pain and Symptom Management*, 41(6), 1073-1093. <https://doi.org/10.1016/j.jpainsymman.2010.08.016>
- Hjermstad, M. J., Gibbins, J., Haugen, D. F., Caraceni, A., Loge, J. H., & Kaasa, S. (2008). Pain assessment tools in palliative care: An urgent need for consensus. *Palliative Medicine*, 22(8), 895-903. <https://doi.org/10.1177/0269216308095701>



- Hosie, A., Davidson, P. M., Agar, M., Sanderson, C. R., & Phillips, J. (2013). Delirium prevalence, incidence, and implications for screening in specialist palliative care inpatient settings: A systematic review. *27*, 486-498. <https://doi.org/10.1177/0269216312457214>
- Hosie, A., Siddiqi, N., Featherstone, I., Johnson, M., Lawlor, P. G., Bush, S. H., Amgarth-Duff, I., Edwards, L., Cheah, S. L., Phillips, J., & Agar, M. (2019). Inclusion, characteristics and outcomes of people requiring palliative care in studies of non-pharmacological interventions for delirium: A systematic review. *Palliative Medicine*, *33*(8), 878-899. <https://doi.org/10.1177/0269216319853487>
- Hui, D. (2019). Delirium in the palliative care setting: “Sorting” out the confusion. *Palliative Medicine*, *33*(8), 863-864. <https://doi.org/10.1177/0269216319861896>
- Hui, D., & Bruera, E. (2017). The Edmonton Symptom Assessment system 25 years later: Past, present, and future developments. *Journal of Pain and Symptom Management*, *53*(3), 630-643. <https://doi.org/10.1016/j.jpainsymman.2016.10.370>
- Hui, D., dos Santos, R., Chisholm, G., Bansal, S., Souza Crovador, C., & Bruera, E. (2015). Bedside clinical signs associated with impending death in patients with advanced cancer: Preliminary findings of a prospective, longitudinal cohort study. *Cancer*, *121*(6), 960-967. <https://doi.org/10.1002/cncr.29048>
- Hui, D., dos Santos, R., Chisholm, G. B., & Bruera, E. (2015). Symptom expression in the last seven days of life among cancer patients admitted to acute palliative care units. *Journal of Pain and Symptom Management*, *50*(4), 488-494. <https://doi.org/10.1016/j.jpainsymman.2014.09.003>
- Kastbom, L., Milberg, A., & Karlsson, M. (2016). A good death from the perspective of palliative cancer patients. *Supportive Care in Cancer*, *25*(3), 933-939. <https://doi.org/10.1007/s00520-016-3483-9>
- Kehl, K. A., & Kowalkowski, J. A. (2013). A systematic review of the prevalence of signs of impending death and symptoms in the last 2 weeks of life. *American Journal of Hospice and Palliative Medicine®*, *30*(6), 601-616. <https://doi.org/10.1177/1049909112468222>
- Kennedy, C., Brooks-Young, P., Brunton Gray, C., Larkin, P., Connolly, M., Wilde-Larsson, B., Larsson, M., Smith, T., & Chater, S. (2014). Diagnosing dying: An integrative literature review. *BMJ Supportive & Palliative Care*, *4*(3), 263-270. <https://doi.org/10.1136/bmjspcare-2013-000621>
- Kitson, A., Carr, D., Conroy, T., Feo, R., Grønkjær, M., Huisman-de Waal, G., Jackson, D., Jeffs, L., Merkley, J., Muntlin Athlin, Å., Parr, J., Richards, D. A., Sørensen, E. E., & Wengström, Y. (2019). Speaking up for fundamental care: The ILC Aalborg Statement. *BMJ Open*, *9*(12). <https://doi.org/10.1136/bmjopen-2019-033077>

- Koch, C. (2018). What is consciousness? *Nature (London)*, 557(7704), S8-S12. <https://doi.org/10.1038/d41586-018-05097-x>
- Krooupa, A.-M., Vivat, B., McKeever, S., Marcus, E., Sawyer, J., & Stone, P. (2019). Identification and evaluation of observational measures for the assessment and/or monitoring of level of consciousness in adult palliative care patients: A systematic review for I-CAN-CARE. *Palliative Medicine*, 34(1), 83–113. <https://doi.org/10.1177/0269216319871666>
- Kuusisto-Gussmann, E., Höckelmann, C., von der Lühe, V., Schmädig, R., Baltes, M., & Stephan, A. (2021). Patients' experiences of delirium: A systematic review and meta-summary of qualitative research. *Journal of Advanced Nursing*. <https://doi.org/10.1111/jan.14865>
- Lawlor, P. G., Davis, D. H. J., Ansari, M., Hosie, A., Kanji, S., Momoli, F., Bush, S. H., Watanabe, S., Currow, D. C., Gagnon, B., Agar, M., Bruera, E., Meagher, D. J., de Rooij, S. E. J. A., Adamis, D., Caraceni, A., Marchington, K., & Stewart, D. J. (2014). An analytical framework for delirium research in palliative care settings: Integrated epidemiologic, clinician-researcher, and knowledge user perspectives. *Journal of Pain and Symptom Management*, 48(2), 159-175. <https://doi.org/10.1016/j.jpainsymman.2013.12.245>
- Lichter, I., & Hunt, E. (1990). The last 48 hours of life. *Journal of Palliative Care*, 6(4), 7-15. <http://ezproxy.canberra.edu.au/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1991-19379-001&site=ehost-live>
- Lunney, J. R., Lynn, J., Foley, D. J., Lipson, S., & Guralnik, J. M. (2003). Patterns of functional decline at the end of life. *JAMA*, 289(18), 2387-2392. <https://doi.org/10.1001/jama.289.18.2387>
- Maeda, I., Ogawa, A., Yoshiuchi, K., Akechi, T., Morita, T., Oyamada, S., Yamaguchi, T., Imai, K., Sakashita, A., Matsumoto, Y., Uemura, K., Nakahara, R., & Iwase, S. (2020). Safety and effectiveness of antipsychotic medication for delirium in patients with advanced cancer: A large-scale multicenter prospective observational study in real-world palliative care settings. *General Hospital Psychiatry*, 67, 35. <https://doi.org/10.1016/j.genhosppsy.2020.09.001>
- Mah, K., Rodin, R. A., Chan, V. W. S., Stevens, B. J., Zimmermann, C., & Gagliese, L. (2017). Health-care workers' judgments about pain in older palliative care patients with and without delirium. *American Journal of Hospice & Palliative Medicine*, 34(10), 958-965. <https://doi.org/10.1177/1049909116672641>
- Matsunami, K., Tomita, K., Touge, H., Sakai, H., Yamasaki, A., & Shimizu, E. (2018). Physical signs and clinical findings before death in ill elderly patients. *American Journal of*

*Hospice & Palliative Medicine*, 35(4), 712-717.  
<https://doi.org/10.1177/1049909117733661>

Matzo, M., Hill, J.A. (2019). Peri-death nursing care. In M. Matzo & D. W. Sherman (Eds.), *Palliative care nursing: Quality care to the end of life* (Fifth edition. ed.). New York, NY : Springer Publishing Company.

McColl, E. (2004). Best practice in symptom assessment: A review. *Gut*, 53 suppl 4, iv49-iv54.

McGuire, D. B., Kaiser, K. S., Haisfield-Wolfe, M. E., & Iyamu, F. (2016). Pain assessment in noncommunicative adult palliative care patients. *Nursing Clinics of North America*, 51(3), 397-431. <https://doi.org/10.1016/j.cnur.2016.05.009>

Meier, E. A., Gallegos, J. V., Thomas, L. P. M., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): Literature review and a call for research and public dialogue. *The American journal of geriatric psychiatry*, 24(4), 261-271.

Moens, K., Higginson, I. J., Harding, R., Brearley, S., Caraceni, A., Cohen, J., Costantini, M., Deliens, L., Francke, A. L., Kaasa, S., Linden, K., Meeussen, K., Miccinesi, G., Onwuteaka-Philipsen, B., Pardon, K., Pasmán, R., Pautex, S., Payne, S., & Van den Block, L. (2014). Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. *Journal of Pain and Symptom Management*, 48(4), 660-677. <https://doi.org/10.1016/j.jpainsymman.2013.11.009>

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *British Medical Journal*(2009:), 2535.

Moola, S. M., Z.; Tufanaru, C.; Aromataris, E.; Sears, K.; Sfetcu, R.; Currie, M.; Lisy, K.; Qureshi, R.; Mattis, P.; Mu, P. (2017). Chapter 7: Systematic reviews of etiology and risk. In E. Aromataris, Munn, Z.; (Ed.), *JBI Manual for Evidence Synthesis*. The Joanna Briggs Institute. <https://reviewersmanual.joannabriggs.org/>

Morita, T., Ichiki, T., Tsunoda, J., Inoue, S., & Chihara, S. (1998). A prospective study on the dying process in terminally ill cancer patients. *American Journal of Hospice and Palliative Medicine*, 15(4), 217-222. <https://doi.org/10.1177/104990919801500407>

Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *BMJ (Clinical research ed.)*, 330(7498), 1007-1011. <https://doi.org/10.1136/bmj.330.7498.1007>

Naccache, L. (2017). Minimally conscious state or cortically mediated state? *Brain*, 141(4), 949-960. <https://doi.org/10.1093/brain/awx324> %J Brain

- NICE. (2017). *Care of dying adults in the last days of life: Quality standard* National Institute for Health and Care Excellence. <https://www.nice.org.uk/guidance/qs144>
- Palliative Care Australia. (2018). *National Palliative Care Standards*. <https://palliativecare.org.au/>
- Pereira, M. E. D., Barbosa, A., & Dixe, M. d. A. (2018). Palliative care for end-of-life patients in a basic emergency service. *Scandinavian Journal of Caring Sciences*, 32(3), 1056-1063. <https://doi.org/10.1111/scs.12551>
- Plonk, W. M., & Arnold, R. M. (2005). Terminal care: The last weeks of life. *Journal of Palliative Medicine*, 8(5), 1042. <https://doi.org/10.1089/jpm.2005.8.1042>
- Quinn, K. L., Shurrab, M., Gitau, K., Kavalieratos, D., Isenberg, S. R., Stall, N. M., Stukel, T. A., Goldman, R., Horn, D., Cram, P., Detsky, A. S., & Bell, C. M. (2020). Association of receipt of palliative care interventions with health care use, quality of life, and symptom burden among adults with chronic noncancer illness: A systematic review and meta-analysis. *JAMA*, 324(14), 1439-1450. <https://doi.org/10.1001/jama.2020.14205>
- Rady, M. Y., & Verheijde, J. L. (2013). Deep Sedation at the End of Life: Life-Shortening Effect and Palliative Efficacy [Editorial]. *American Journal of Hospice and Palliative Medicine*, 30(1), 100-101. <https://doi.org/10.1177/1049909112462863>
- Rady, M. Y., Verheijde, J. L. . (2016). Neuroscience and awareness in the dying human brain: Implications for organ donation practices. *Journal of Critical Care*, 34, 121-123. <https://doi.org/10.1016/j.jcrc.2016.04.016>
- Robinson, J., Moeke-Maxell, T., Parr, J., Slark, J., Black, S., Williams, L., & Gott, M. (2019). Optimising compassionate nursing care at the end of life in hospital settings. *Journal of Clinical Nursing*, 29(11-12), 1788-1796. <https://doi.org/10.1111/jocn.15050>
- Rodríguez-Prat, A., Monforte-Royo, C., Porta-Sales, J., Escribano, X., & Balaguer, A. (2016). Patient perspectives of dignity, autonomy and control at the end of life: Systematic review and meta-ethnography. *PloS One*, 11(3), e0151435-e0151435. <https://doi.org/10.1371/journal.pone.0151435>
- Roest, B., Trappenburg, M., & Leget, C. (2019). The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: A systematic mixed studies review. *BMC Medical Ethics*, 20(1), 1-21. <https://doi.org/10.1186/s12910-019-0361-2>
- Sandvik, R. K., Selbaek, G., Bergh, S., Aarsland, D., & Husebo, B. S. (2016). Signs of imminent dying and change in symptom intensity during pharmacological treatment in dying

- nursing home patients: A prospective trajectory study. *Journal of the American Medical Directors Association*, 17(9), 821-827. <https://doi.org/10.1016/j.jamda.2016.05.006>
- Sarà, M., & Pistoia, F. (2010). Defining consciousness: Lessons from patients and modern techniques. *Journal of Neurotrauma*, 27(4), 771. <https://doi.org/10.1089/neu.2008.0804>
- Saunders, C. (2006). The Problem of Euthanasia (Care of the Dying—1) In *Cicely Saunders: Selected Writings 1958-2004* (pp. 133-138). Oxford University Press. <https://doi.org/10.1093/acprof:oso/9780198570530.001.0001>
- Sekse, R. J. T., Hunskaar, I., & Ellingsen, S. (2018). The nurse's role in palliative care: A qualitative meta-synthesis. *Journal of Clinical Nursing*, 27(1-2), e21-e38. <https://doi.org/10.1111/jocn.13912>
- Stiel, S., Heckel, M., Frauendorf, T., Hanke, R., & Ostgathe, C. (2015). Comparison of terminally ill cancer-vs. non-cancer patients in specialized palliative home care in Germany - A single service analysis. *BMC Palliative Care*, 14, 34. <https://doi.org/10.1186/s12904-015-0033-z>
- Tapp, D., Chenacher, S., Gérard, N. P. A., Bérubé-Mercier, P., Gelinas, C., Douville, F., & Desbiens, J. F. (2019). Observational pain assessment instruments for use with nonverbal patients at the end-of-life: A systematic review. *Journal of Palliative Care*, 34(4), 255-266. <https://doi.org/10.1177/0825859718816073>
- The Institute of Medicine Committee on Approaching Death: Addressing key end-of-life issues. (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. National Academies Press. <https://doi.org/10.17226/18748>
- The Joanna Briggs Institute Levels of Evidence and Grades of Recommendation Working Party. (2014). *Supporting document for the Joanna Briggs Institute Levels of Evidence and Grades of Recommendation*. The Joanna Briggs Institute. [https://joannabriggs.org/sites/default/files/2019-05/JBI-Levels-of-evidence\\_2014\\_0.pdf](https://joannabriggs.org/sites/default/files/2019-05/JBI-Levels-of-evidence_2014_0.pdf)
- Thier, K., Calabek, B., Tinchon, A., Grisold, W., & Oberndorfer, S. (2016). The last 10 days of patients with glioblastoma: Assessment of clinical signs and symptoms as well as treatment. *American Journal of Hospice & Palliative Medicine*, 33(10), 985-988. <https://doi.org/10.1177/1049909115609295>
- Turner, K., Chye, R., Aggarwal, G., Philip, J., Skeels, A., & Lickiss, J. N. (1996). Dignity in dying: A preliminary study of patients in the last three days of life. *Journal of Palliative Care*, 12(2), 7-13.

- Van Gulick, R. (2012). Consciousness and cognition. In E. Margolis, R. Samuels, & S. P. Stich (Eds.), *The Oxford handbook of philosophy of cognitive science*. Oxford: Oxford University Press.
- Waller, A., Chan, S., Chan, C. W. H., Chow, M. C. M., Kim, M., Kang, S. J., Oldmeadow, C., & Sanson-Fisher, R. (2020). Perceptions of optimal end-of-life care in hospitals: A cross-sectional study of nurses in three locations. *Journal of Advanced Nursing*. <https://doi.org/10.1111/jan.14510>
- Watt, C. L., Scott, M., Webber, C., Sikora, L., Bush, S. H., Kabir, M., Boland, J. W., Woodhouse, R., Sands, M. B., & Lawlor, P. G. (2021). Delirium screening tools validated in the context of palliative care: A systematic review. *Palliative Medicine*, 35(4), 683-696. <https://doi.org/10.1177/0269216321994730>
- White, N., Reid, F., Harries, P., Harris, A. J. L., Minton, O., McGowan, C., Lodge, P., Tookman, A., & Stone, P. (2019). The (un)availability of prognostic information in the last days of life: A prospective observational study. *BMJ Open*, 9(7), Article e030736. <https://doi.org/10.1136/bmjopen-2019-030736>
- Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing*, 52(5), 546-553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>
- Wiegand, D. L., Wilson, T., Pannullo, D., Russo, M. M., Kaiser, K. S., Soeken, K., & McGuire, D. B. (2018). Measuring acute pain over time in the critically ill using the multidimensional objective pain assessment tool (MOPAT). *Pain Management Nursing*, 19(3), 277-287. <https://doi.org/10.1016/j.pmn.2017.10.013>
- World Health Organization. (2020). *WHO Definition of Palliative Care*. <https://www.who.int/cancer/palliative/definition/en/>
- Zwakhalen, S. M. G., Hamers, J. P. H., Metzelthin, S. F., Ettema, R., Heinen, M., Man-Van Ginkel, J. M., Vermeulen, H., Huisman-De Waal, G., & Schuurmans, M. J. (2018). Basic nursing care: The most provided, the least evidence based – A discussion paper. *Journal of Clinical Nursing*, 27(11-12), 2496-2505. <https://doi.org/10.1111/jocn.14296>

**Table: 1 Inclusion and exclusion criteria**

Inclusion criteria	Exclusion criteria
Published from inception to October 2019 - to obtain complete coverage of the literature	Adults who are receiving palliative sedation, euthanasia or physician assisted suicide - involves alteration to the natural dying process
Published in English - funding was not available for language translation	Editorials, opinions, and letters - non-primary studies and not peer reviewed
Adults ≥18 years of age – there are unique differences in paediatric and adult populations	Adults who are receiving curative treatment or life prolonging treatment (such as artificial hydration and nutrition)
Dying within two weeks - previous literature (Clark et al., 2016; Sandvik et al., 2016) indicate that two weeks prior to death was a significant timeframe for understanding changes in the level of consciousness	Adults who are unconscious due to disease such as stroke, head injuries, etc.
Cared for in a health care setting where continuous health care is provided, and care needs documented	Adults who are dying in intensive care units - conscious level may be altered due to intentional sedation
	Adults with a diagnosis of dementia or aging associated cognitive decline because they may not be able to communicate their needs regardless of the dying process

Clark, K., Connolly, A., Clapham, S., Quinsey, K., Eagar, K., & Currow, D. (2016). Physical symptoms at the time of dying was diagnosed: A consecutive cohort study to describe the prevalence and intensity of problems experienced by imminently dying palliative care patients by diagnosis and place of care. *Journal of Palliative Medicine, 19*(12), 1288-1295.

Sandvik, R. K., Selbaek, G., Bergh, S., Aarsland, D., & Husebo, B. S. (2016). Signs of imminent dying and change in symptom intensity during pharmacological treatment in dying nursing home patients: A prospective trajectory study. *Journal of the American Medical Directors Association, 17*(9), 821-827.



**Table 2: Example of database search strategy for CINAHL and MEDLINE**

Search no.	Concept	Search Terms
1	Dying adult	(MH "Death+") OR (MH "Palliative Care") OR death OR dying OR "end of life" OR passing OR palliative OR terminal*
2	Prior to death	Imminent* OR "final stage*" OR actively OR "close to" OR "last day*" OR "final day*"
3	Dying adult prior to death	#1 AND #2
4	Conscious state	(MH "Consciousness") OR (MH "Coma+") OR awareness OR alert* OR responsive OR cognit* OR coma* OR "semi-coma*" OR unresponsive OR consciousness OR unconscious OR "semi-conscious"
5	Conscious state in dying adults prior to death	#3 AND #4
6	Care needs	Need* OR "end of life care" OR "care intervention*" OR "needs assessment"
7	Care needs of the dying adult	#5 AND #6



**Table 3: JBI Risk of Bias Results**

Author (Date)	Q1. Were there clear criteria for inclusion in the case series?	Q2. Was the condition measured in a standard, reliable way for all participants included in the case series?	Q3. Were valid methods used for identifying the condition for all participants included in the case series?	Q4. Did the case series have consecutive inclusion of participants?	Q5. Did the case series have complete inclusion of participants?	Q6. Was there clear reporting of the demographics of the participants in the study?	Q7. Was there clear reporting of clinical information of the participants?	Q8. Were the outcomes or follow up results of cases clearly reported?	Q9. Was there clear reporting of the presenting site(s) / clinic(s) demographic information?	Q10. Was statistical analysis appropriate?
White et al. (2019)	Y	Y	Y	N	N	Y	Y	Y	N	Y
Barbato et al. (2018)	N	Y	Y	UC	N	N	Y	Y	N	Y
Matsunami et al. (2018)	UC	Y	UC	Y	N	N	N	Y	N	Y
Pereira et al. (2018)	UC	UC	Y	Y	Y	N	N	Y	N	UC
Their et al. (2016)	Y	UC	UC	UC	Y	N	Y	N	N	Y
Bruera et al. (2003)	Y	Y	Y	N	N	Y	N	Y	N	Y
Barbato (2001)	UC	Y	Y	N	N	N	N	UC	N	Y
Morita et al. (1998)	N	N	UC	UC	UC	N	N	Y	UC	Y
Turner et al. (1996)	N	N	N	Y	UC	N	Y	UC	Y	N
Fainsinger et al. (1991)	N	Y	Y	Y	N	N	N	Y	Y	N

Lichter and Hunt (1990)	N	N	UC	Y	Y	N	N	Y	Y	Y
-------------------------	---	---	----	---	---	---	---	---	---	---

**Note:** Levels of quality assessment

Y = Yes, low risk of bias

UC = Unclear, risk of bias

N = no, high risk of bias

NA = not applicable

**Table 4: Overview of the included studies**

Author (year) Country	Purpose	Sample size mean age (SD, years), gender diagnosis (% with cancer)  Study design	1. Assessment Tools 2. Data collection 3. Time points 4. Data analysis	Major findings
White et al. (2019) UK	<ul style="list-style-type: none"> <li>to prospectively document the clinical condition of patients considered to be in the last 2 weeks of life</li> <li>to compare the clinical condition of patients who did or did not survive within 72 hours</li> </ul>	<p>n=50 72 years ± 16 Female = 20 (40%) Cancer = 33 (66%)</p> <p>prospective observational study</p>	<ol style="list-style-type: none"> <li>RASS, PPS, Charlson Comorbidity Index score, skin integrity assessments, swallowing assessments</li> <li>prognostic variables, clinical signs and symptoms</li> <li>one-off assessment and followed up 7 days later,</li> <li>Mean, SD, IQR, descriptive statistics, no statistical tests</li> </ol>	<ul style="list-style-type: none"> <li>a large volume of data was recorded as missing for patients who died within 72 hours</li> <li>symptoms prevalent in patients who died imminently; rapid decline in global condition, decreased urine output, increased anxiety, incontinence, noisy respiratory secretions, Cheyne-Stoke breathing and peripheral cyanosis</li> <li>Participants who died within 72 hours had a lower level of consciousness and had more care needs</li> </ul>
Barbato et al. (2018) Australia	<ul style="list-style-type: none"> <li>to examine the indications, nature, and frequency of breakthrough medication and their</li> </ul>	<p>n=40 74 years (range 41-97) Female = 15 (37.5%) Cancer = 35 (87.5%)</p>	<ol style="list-style-type: none"> <li>RASS, PCS, BIS scores</li> <li>nurse assessment and documentation, BIS recording, family completion of PCS</li> </ol>	<ul style="list-style-type: none"> <li>changes occurred in RASS, PCS and BIS scores of unresponsive patients after the administration of breakthrough medication</li> </ul>

Author (year) Country	Purpose	Sample size mean age (SD, years), gender diagnosis (% with cancer)	1. Assessment Tools 2. Data collection 3. Time points 4. Data analysis	Major findings
	<p>effectiveness in unresponsive patients</p> <ul style="list-style-type: none"> <li>compare family PCS assessments with synchronous PCS assessments made by nurses</li> </ul>	<p>prospective experimental study</p>	<p>3. from the time they became unresponsive until death, time-matched BIS score related to breakthrough medication administration at 0-, 30-, and 60-minute assessments</p> <p>4. analysis of variance, paired t-tests, probability plots, Mann-Whitney tests</p>	<p>indicating their efficacy and effectiveness</p> <ul style="list-style-type: none"> <li>therapeutic effect of breakthrough medication takes place at or before 30 minutes after injection</li> <li>54% of the PCS assessments made by family and nurses were identical, and 81% were within a range of <math>\pm 1</math></li> </ul>
Matsunami et al. (2018) Japan	<ul style="list-style-type: none"> <li>to determine the physical signs and clinical findings of impending death</li> <li>to examine the association between signs and clinical findings with the profile and timing of ECG, and SpO<sub>2</sub> changes prior to death</li> </ul>	<p>n=70</p> <p>82 years (range 42-102 years)</p> <p>Female = 23 (33%)</p> <p>Cancer = 20 (29%)</p> <p>prospective observational study</p>	<p>1. ECG, SpO<sub>2</sub>, Sequential Organ Failure Assessment, Glasgow Coma Scale</p> <p>2. physical signs and clinical findings were systematically documented</p> <p>3. every 6 hours from admission to death</p> <p>4. statistical analyses using SPSS software: median, Kolmogorov-Smirnov test / Mann-Whitney U test, Fisher's exact / chi-</p>	<ul style="list-style-type: none"> <li>decline in consciousness, loss of oral intake and respiration with mandibular movement were observed prior to death</li> <li>a decline in consciousness occurred (100%), with a median of 1.3 days</li> <li>findings did not support universal ECG and SpO<sub>2</sub> monitoring in the last days of life</li> </ul>

Author (year) Country	Purpose	Sample size mean age (SD, years), gender diagnosis (% with cancer)	1. Assessment Tools 2. Data collection 3. Time points 4. Data analysis	Major findings
		<b>Study design</b>		
			square test, and descriptive analysis	
Pereira et al. (2018) Portugal	<ul style="list-style-type: none"> <li>to describe the care provided by the nursing staff for end-of-life patients at a Basic Emergency Service</li> </ul>	<p>n=83 78 years ± 11 Female = 45 (54.2%) multiple oncological and non-oncological pathologies</p> <p>retrospective, quantitative, exploratory, and descriptive study</p>	<ol style="list-style-type: none"> <li>data collection instrument created based on the Liverpool Care Pathway, including Braden Scale, unspecified pain scale, skin integrity assessments, swallowing assessments</li> <li>clinical data, admission and death records, nursing clinical documentation</li> <li>from admission to death</li> <li>SPSS and the answers to open-ended questions were subjected to content analysis, mean</li> </ol>	<ul style="list-style-type: none"> <li>nursing interventions favoured technical-instrumental care</li> <li>the end-of-life therapeutic approach was centred on the biomedical model. Care focused on the patient's functional status and symptomatic relief</li> <li>a gap in the documentation of interventions regarding the psycho-emotional, spiritual, and social support provided to patients and families was noted</li> </ul>
Thier et al. (2016) Austria	<ul style="list-style-type: none"> <li>to investigate signs and symptoms in patients with glioblastoma</li> <li>therapeutic strategies in caring for patients with glioblastoma</li> </ul>	<p>n=57 59 years ± 11 Female = 18 (32%) Cancer = 100%</p>	<ol style="list-style-type: none"> <li>Karnofsky Performance Status</li> <li>clinical chart data, signs, symptoms, and treatment strategies were collected</li> </ol>	<ul style="list-style-type: none"> <li>decrease in level of consciousness, fever, dysphagia, and seizures were the most frequent symptoms</li> <li>high need for opioids (95%)</li> </ul>

Author (year) Country	Purpose	Sample size mean age (SD, years), gender diagnosis (% with cancer)	1. Assessment Tools 2. Data collection 3. Time points 4. Data analysis	Major findings
		prospective study	3. assessed on a daily basis using the standardized protocol 4. analysed descriptively – calculation of frequency, mean value, and SD	<ul style="list-style-type: none"> <li>assessment of clinical signs and symptoms at the end of life is difficult due to a decrease in levels of consciousness and cognitive impairment</li> <li>discussion of end-of-life decisions and advance directives need to occur earlier</li> </ul>
Bruera et al. (2003) USA	<ul style="list-style-type: none"> <li>to compare family members' and nurses' perceptions of discomfort in unresponsive patients with cancer</li> <li>to assess the association between patient behaviour and family perception of patient discomfort</li> </ul>	<p>n=60 64 years (range 28–88) Female = 31 (52%) Cancer = 60 (100%)</p> <p>comparative study</p>	<ol style="list-style-type: none"> <li>assessment questionnaire - Patient Comfort Assessment Form</li> <li>questionnaires were completed by 60 relatives and 15 nurses on 60 unresponsive patients</li> <li>one assessment only</li> <li>Student's t tests, McNemar's test, Fisher's exact test, Kappa statistics, analyses of variance</li> </ol>	<ul style="list-style-type: none"> <li>discomfort levels reported by relatives and nurses were similar</li> <li>the most common reasons cited by nurses and family for discomfort were pain and difficulty breathing</li> <li>findings suggest that factors other than observed behaviours influenced relatives' perceptions</li> </ul>

Author (year) Country	Purpose	Sample size mean age (SD, years), gender diagnosis (% with cancer)	1. Assessment Tools 2. Data collection 3. Time points 4. Data analysis	Major findings
Study design				
Barbato (2001) Australia	<ul style="list-style-type: none"> <li>to assess whether BIS monitoring is relevant in palliative care</li> <li>to obtain data on the level of awareness in unconscious dying patients</li> <li>factors, if any, that influence levels of awareness</li> </ul>	<p>n=12</p> <p>73 years (range 36-91 years)</p> <p>Female = 7 (58%)</p> <p>Cancer = 10 (83%)</p> <p>experimental pilot study</p>	<ol style="list-style-type: none"> <li>a modified CS and BIS monitoring</li> <li>photographic records of the BIS recordings from continuous monitoring, using two small sensors applied to the head. The higher the index value, the higher the likelihood of awareness, medication administration was recorded</li> <li>every four hours from the onset of unconsciousness until death</li> <li>mean, SD, df, p-value</li> </ol>	<ul style="list-style-type: none"> <li>BIS values reflected: heightened awareness caused by pain associated with turning or other procedures, hearing, relationship to REM sleep, and awareness at the "point of death"</li> <li>conventional medications in commonly used doses do not contribute significantly to the onset of unconsciousness, nor alter normal processes during the terminal phase of a person's life</li> </ul>
Morita et al. (1998) Japan	<ul style="list-style-type: none"> <li>to investigate the change of physical signs in patients whose death was presumed imminent</li> <li>to investigate the medical interventions for terminally ill cancer patients</li> </ul>	<p>n=100</p> <p>67 years ± 14</p> <p>Female = 45 (45%)</p> <p>Cancer = 100 (100%)</p> <p>prospective observational study</p>	<ol style="list-style-type: none"> <li>a categorical scale to measure level of consciousness</li> <li>observation and recording of signs, and symptoms, and medication dosage until time of death</li> <li>four weeks, two weeks, one week, 48 hours, 24 hours,</li> </ol>	<ul style="list-style-type: none"> <li>death rattle followed by respiration with mandibular movement, cyanosis on extremities and pulselessness on the radial artery resulted in death within a few hours, but timing of signs varied</li> </ul>

Author (year) Country	Purpose	Sample size mean age (SD, years), gender diagnosis (% with cancer)  Study design	1. Assessment Tools 2. Data collection 3. Time points 4. Data analysis	Major findings
			12 hours, and 6 hours prior to death  4. mean, analysis of variance, Fisher's LSD method, Mann-Whitney U-test, chi-square test, Friedman test	<ul style="list-style-type: none"> <li>because of the large variance among individuals, prediction of the time of death was not easy</li> <li>87% required opioids in the last 48 hours before death</li> <li>50% of patients were considered to be in a coma in the final six hours</li> </ul>
Turner et al. (1996) Australia	<ul style="list-style-type: none"> <li>to describe and evaluate the concept of "dying with dignity"</li> </ul>	<p>n=50</p> <p>64 years (range 25 to 87 years)</p> <p>Female = 22 (44%)</p> <p>Cancer = 49 (98%)</p> <p>retrospective study</p>	<ol style="list-style-type: none"> <li>NRS: medical and nursing staff were each asked to assign a score out of 10, 10 being totally dignified</li> <li>clinical chart data collected</li> <li>retrospective chart review of documented symptoms over the last three days of life</li> <li>mean, scatter plot, descriptive analysis</li> </ol>	<ul style="list-style-type: none"> <li>dignity remains an elusive concept, ultimately dignity is an intrinsic quality</li> <li>good levels of symptom control can be achieved in most patients without inducing dense somnolence in the last 3 days of life</li> </ul>
Fainsinger et al. (1991)	<ul style="list-style-type: none"> <li>to assess the prevalence and severity</li> </ul>	<p>n=100</p> <p>62 years ± 12</p>	<ol style="list-style-type: none"> <li>VAS</li> <li>VAS was completed twice daily by the patient if</li> </ol>	<ul style="list-style-type: none"> <li>symptom control improved from the day of admission</li> </ul>



Author (year) Country	Purpose	Sample size mean age (SD, years), gender diagnosis (% with cancer)	1. Assessment Tools 2. Data collection 3. Time points 4. Data analysis	Major findings
Study design				
Canada	<p>of symptoms during the last week of life</p> <ul style="list-style-type: none"> <li>to assess the need to administer treatment for the relief of symptoms that may result in sedation</li> </ul>	<p>Female = 49 (49%) Cancer = 100 (100%)</p> <p>retrospective descriptive study</p>	<p>possible, or by a relative or nurse, to collect data on nausea, drowsiness, and symptom distress</p> <p>3. twice a day for the last seven days of life</p> <p>4. mean, paired t-tests, chi-square test, descriptive analysis of chart documentation</p>	<p>and continued to improve during the last week of life</p> <ul style="list-style-type: none"> <li>there was no "crescendo of pain" for most patients. VAS showed that mean pain and nausea scores decreased as death approached</li> <li>six patients with pain were probably sedated by the treatment they received</li> </ul>
Lichter and Hunt (1990) New Zealand	<ul style="list-style-type: none"> <li>to document the problems that may arise in the last 48hrs of life</li> <li>to record problem frequency and management</li> </ul>	<p>n=200</p> <p>not recorded</p> <p>longitudinal study</p>	<p>1. none mentioned</p> <p>2. nurses record of symptoms and observations following strict criteria</p> <p>3. in the last 48 hours (frequency not reported)</p> <p>4. descriptive analysis, frequency</p>	<ul style="list-style-type: none"> <li>91% were on opioids with 51% of patients suffering pain in the last 48 hours</li> <li>18% suffered from activity or "disturbance pain", even when apparently deeply unconscious</li> <li>22% suffered from dyspnea, 25% had noisy respirations, 14% suffered nausea or vomiting, 9% had confusion, 42% had restlessness and agitation,</li> </ul>

Author (year) Country	Purpose	Sample size mean age (SD, years), gender diagnosis (% with cancer)	1. Assessment Tools 2. Data collection 3. Time points 4. Data analysis	Major findings
Study design				requiring medication in the last 48 hours of life. <ul style="list-style-type: none"> <li>an awareness of the problems is required to ensure comfort at the end of life</li> </ul>

**Abbreviations:** *BIS*, Bispectral Index Score; *CS*, Consciousness Score; *df*, degrees of freedom; *ECG*, *electrocardiogram*; *Fisher's LSD method*, Fisher's least significant difference; *IQR*, interquartile range; *NRS*, Numerical Rating Scale; *PCS*, Patient Comfort Score; *PPS*, Palliative Performance Scale; *REM*, rapid eye movement; *RASS*, Richmond Agitation-Sedation Scale; *SpO<sub>2</sub>*, peripheral capillary oxygen saturation; *SPSS software*, Statistical Package for the Social Sciences; *SD*, standard deviation; *VAS*, Visual Analogue Scale.

**Supplementary Table 1: Thematic data analysis**

Thematic analysis	
Steps	Action
(i) familiarisation with data	Immersion in the data by reading and re-reading full-text papers
(ii) systematic coding of the data	Maintenance of notes on all studies Extraction of data using excel spread sheet was based on the research questions and the WHO definition (World Health Organization, 2020) Extracted data was coded All decisions were considered and documented
(iii) grouping codes under potential themes	Codes were grouped and collated. Relevant illustrative quotes were recorded as evidence. Codes that were similar were collated together. After reading and re-reading the extracted data, potential themes were generated. Data was rearranged to fit into each theme coherently. Revisions were made and discussed across all researchers
(iv) validating themes	The data was reviewed and considered by means of mapping for themes and sub-themes. Working titles for themes were considered by all reviewers. Data that diverged from the main narrative was noted and separately included
(v) defining and naming themes	The meaning and essence of the data as a whole was considered in relation to the validated themes to ensure it reflected the theme name. Theme names were validated by all reviewers. Revisions were made. Final thematic map and definition for each theme was created
(vi) producing the final report with selected extracts	Final analysis and write up of report with examples from the data

**Supplementary Table 2: Conscious state and changes over time prior to death**

Author (date)	Timing (days prior to death)	Timing (average days prior to death)	Term used	% of study participants with a changed conscious state
White et al. (2019)	3 days	Not reported	deeply unconscious	62.5%
Barbato et al. (2018)	<1-3.8 days	Mean 1.1 ± 0.8 days	unresponsive	100%
Matsunami et al. (2018)	0.1-11 days	Median 1.3 days	decline in consciousness	100%
Pereira et al. (2018)	<0.1 to 5 days	Not reported	comatose state	44.6%
Thier et al. (2016)	0-7 days	Not reported	decrease in level of consciousness	95%
Bruera et al. (2003)	Not reported	Not reported	unresponsive	100%
Barbato (2001)	1-8 days	Mean 3.1 days	unconscious	100%
Morita et al. (1998)	0.25 day 1 day 7 days	Not reported	comatose	50% 12% 0%
Turner et al. (1996)	3 days	Not reported	unconscious	8%
Fainsinger et al. (1991)	≤1 day 6 days	Not reported	unresponsive	57% 2 %
Lichter and Hunt (1990)	0-0.5 day 0.5-1 day 1-2 days >2 days	Not reported	became unconscious	38% 24% 7% 1%