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The perspective of professional caregivers working in generalist palliative care on ‘good dying’: An integrative review

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ABSTRACT

In today’s industrial societies, many people die receiving professional care. Although specialist palliative and hospice care have often been identified as ideal care approaches to promote good dying, more people die receiving generalist palliative care. This integrative review examines how professional caregivers providing generalist palliative care in hospitals, nursing or private homes define good dying. Furthermore, through comparative analysis of existing empirical studies, it explores conceptual aspects in researching good dying that better reflect the social complexity of this phenomenon. Three databases (Scopus, MEDLINE, and CINAHL) were searched for peer-reviewed studies published between January 2000 and April 2020. Studies were selected if they presented original empirical findings from qualitative or quantitative studies on the perspective of professional caregivers in generalist palliative care (nurses, physicians, surgeons, clergy, and other staff) on good dying or related concepts (e.g., good death, dignity in dying, or quality of life at the end of life). 42 studies were included in the review. They identified good dying as expected, accepted and prepared dying, as free from pain and suffering, as socially embedded, as being at peace with one’s life and situation, as supported with individualised and holistic care, as based upon professional cooperation and communication, and as in a peaceful and private environment. The paper concludes that the perspective of professional caregivers in generalist palliative care shares many elements of good dying with societal and specialist palliative care discourses around good dying. Through comparing the different studies, the review found that studies that explicated who benefitted from ideals and practices of good dying, questioned the dichotomous categorisation of good/bad dying, or discussed the compatibility of elements of good dying, provided more nuanced perspectives on this topic. Thus, the review calls for a more systematic analysis of these aspects in research of good dying.

1. Introduction

Social meaning and practices of dying and good dying are socially contingent (Kellehear, 2007). Good dying can be understood as ‘complex set of relations and preparations’ and as ‘a series of social events’ (McNamara et al., 1994, p. 1501). As a social phenomenon, it is constructed through discourses (Lang, 2020; Van Brussel and Carpentier, 2012) but also co-created and negotiated in social situations (Munday et al., 2009; Seymour, 2000). Research on good dying has not only been conducted to improve our understanding of society, but also to inform care policy and practices by identifying needs and values of those involved in and affected by end-of-life care situations (Asano et al., 2019; Meier et al., 2016).

In industrial countries, dying regularly happens in institutional contexts under the care of professionals (Broad et al., 2013). Even dying in private homes often involves the presence of professional caregivers in addition to family and relatives (Emanuel et al., 1999; Gott et al., 2004). Thereby, contemporary societal debates have often discussed hospice and palliative care as paramount professional care approaches to promote good dying (Lang, 2020). The concept of good death is identified as fundamental for the hospice movement (Hart et al., 1998; McNamara et al., 1994), but in palliative care it has also transformed towards a ‘good enough death’ (Masson, 2002; McNamara, 2004). Yet, many people do not have access to specialised palliative and hospice care (Woitha et al., 2016) and die receiving ‘generalist palliative care’ (Ryan and Johnston, 2019) in hospitals, nursing homes, or at home. Generalist palliative care can be defined as care provided to people with life-threatening diseases and dying as part of standard care and clinical

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practice outside of specialised palliative care organisations, departments, or teams. As in specialised hospice and palliative care, professionals working in generalist palliative care – together with families, relatives, or community members – strive for accomplishing good care, the well-being of the patient, and ultimately, good dying. Their values and beliefs, as well as their work experiences and practices, are important aspects in creating the conditions, social interactions, and meanings related to good dying.

Against this background, our integrative review (Whittemore and Knafl, 2005) had two aims: First, we wanted to examine empirical insights into the perspectives of professional caregivers who do not work in specialised palliative or hospice care but nonetheless experience end-of-life care situations. Existing reviews on the perspective of professional caregivers on good dying focus on specific care contexts, e.g., the emergency department (McCallum et al., 2018) or intensive care units (Mu et al., 2019), particular causes of death, e.g., heart failure (Asano et al., 2019), or certain concepts related to good dying such as dignity (Guo and Jacelon, 2014). Others have reviewed studies on the perspective of different groups of social actors concurrently, including professional caregivers but also relatives or patients (Meier et al., 2016). However, the present review focused on professional caregivers working in different healthcare contexts — but not in specialised palliative care — and considered various concepts to grasp good dying. We identified key elements of good dying as analysed by a diversity of quantitative and qualitative studies empirically investigating the perspectives of these professional caregivers in non-specialised/generalist palliative care (see 3.2).

Second, we aimed to explore differences in how empirical studies have approached good dying. Scholars have already discussed research approaches to investigate dying and good dying, often focusing on practical challenges regarding the study design and methodology, ethical aspects of doing research on sensitive topics, and emotional challenges on behalf of researchers (Kendall et al., 2007; Koenig et al., 2003). There is also a considerable body of work on operationalising and measuring 'good dying' (Hales et al., 2010). We wanted to detect ways to better capture the social complexity of good dying in empirical research by comparing the different approaches and findings of existing studies. Through comparing the different studies, we identified a number of broader conceptual issues concerning research on good dying that can inform future scientific endeavours in this field (see 3.3). The integrative review method allowed us to scrutinise a large number of empirical studies, thus increasing the chance of finding these uncommon ways of researching and framing good dying.

2. Methods and data

The integrative review is a method of compiling, summarising, and analysing existing insights of studies 'to provide a more comprehensive understanding of a particular phenomenon' (Whittemore and Knafl, 2005, p. 546). It can serve different purposes including 'to define concepts, to review theories, to review evidence, and to analyse methodological issues of a particular topic' (Whittemore and Knafl, 2005, p. 547). Thereby it 'looks more broadly at a phenomenon of interest than a systematic review' (Toronto, 2020, p. 2), but is more systematic in its design and implementation than a narrative review (for a comparison see Toronto, 2020, p. 2–3).

2.1. *Inclusion and exclusion criteria*

The integrative review allows the inclusion of scientific studies with different designs (experimental, non-experimental) and types of data (quantitative, qualitative) and can be aligned with different research interests and questions (Whittemore and Knafl, 2005). In our review we included empirical qualitative and quantitative studies collecting and analysing primary data (original research), but we excluded purely theoretical papers, reviews, opinions, research letters, notes, and editorials.

We considered 'surrogate terms' (Granda-Cameron and Houldin, 2012, p. 634) for good dying, including but not limited to the 'good' or the 'peaceful' death, 'dying well', 'dying with dignity', or 'quality of life at the end of life'. In presenting our results here, we used the term 'good dying' as an inclusive term for these different notions to emphasise the processual nature of the phenomenon.

We were interested in studies that empirically investigated good dying as a multifaceted social phenomenon. Thus, we included studies that dealt with various conditions and elements of good dying concurrently but excluded studies that only dealt with the positive or negative impact of isolated, single aspects of dying, such as place of death, advance directives, or physician-assisted suicide. In line with this, we excluded studies that aimed at evaluating or testing processes, therapies, or interventions to improve care at the end of life, because these only considered particular elements or conditions of good dying. Furthermore, we included studies that described the professional caregivers' assessment of dying processes (e.g., as good or bad), but excluded studies that only dealt descriptively with care practices, without an explicit assessment of their positive or negative influences on dying.

With regards to the participants of the studies, we defined professional caregivers broadly by including medical and non-medical professionals: nurses, physicians, paramedics, social and community workers, clergy members, undertaker, morticians, and other staff conducting care activities in end-of-life situations. We only considered articles dealing with professional caregivers not working in specialised palliative or hospice care; thus, we excluded articles on the perspective of specialised palliative care providers and informal caregivers. Several papers concurrently described the perspective of different actor groups on good dying within and outside the scope of this review, for example the perspective of professional caregivers (inside our scope) as well as family members of dying persons (outside our scope). We included them if they distinguished the different groups' perspectives but excluded studies that conflated them.

2.2. *Search and retrieval strategy*

We used the databases Scopus, MEDLINE, and CINAHL for our literature search; we searched MEDLINE and CINAHL via EBSCOHOST service. In combination, these databases covered a wide range of peer-reviewed journals from different disciplines potentially concerned with our research topic including, but not limited to, medical and nursing sciences (especially MEDLINE and CINAHL), as well as sociology, psychology, or anthropology (especially Scopus).

In line with our research focus and inclusion criteria, the search string combined different terms for professional caregivers (nurse, provider, staff, professional, physician, doctor, paramedic, chaplain, pastor, social worker, community worker, undertaker, mortician, aide, practitioner) and their perspective (perception, attitude, perspective, opinion, experience, view, meaning, image, concept) towards good dying (good, better, quality, or dignity combined with dying, death, or end-of-life). Wildcards accounted for minor variations (e.g., 'nurs*' for 'nurses' or 'nursing') and proximity operators narrowed searches ('W/15' defining a maximum of 15 words in between the search terms for 'good' and 'dying').

Table 1 shows our search strings including filters; we modified the search string in accordance with the requirements of the different databases. Results were exported and duplicates removed. The publications' metadata, including titles and abstracts, were further processed with Microsoft Excel (see Table 2).

2.3. *Selection and analysis*

[Author 1] and [Author 2] screened titles and abstracts independently and in line with the predefined criteria; there was a 97,4% agreement between [Author 1] and [Author 2]. In cases of

Table 1
Search strategy and string.

Search in	Title, abstract, keywords
Search string	(nurs* OR care* OR provider OR staff* OR professional OR physician OR doctor OR paramedic* OR chaplain OR pastor OR "social worker" OR "community worker" OR undertaker OR mortician OR aide OR practitioner) AND (perception OR attitude OR perspective OR opinion OR experience OR view OR meaning OR image OR concept) AND ((good OR better OR quality OR dignity OR dignified) W/15 ("end of life" OR dying OR death))
Filter: limit to	Type: journal articles Date: years 2000–2020 (April) Language: English, German

disagreement, [Author 3] decided on the inclusion or exclusion of articles. Then, the full texts of articles selected were screened again independently by the two reviewers, yielding a high proportion of agreement for inclusion or exclusion in 91% of cases. In cases of disagreement, the third reviewer decided.

We used Microsoft Excel to systematise study characteristics and calculate descriptive statistics. For the analysis of the full texts, we used ATLAS. ti 8.0 (ATLAS.ti Scientific Software Development GmbH, 2019). We did not aim to quantify the occurrence of certain aspects of good dying across our data, but rather aimed to qualitatively identify different aspects of good dying. We searched for similarities and differences across the different publications/studies. We conducted a thematic analysis (Braun and Clarke, 2006). Based upon close reading of the publications, we developed and applied thematic codes inductively, which we then used to code all articles in our sample. In this process, codes could be thematically enhanced, split into separate codes, or merged. Later on, we categorised various codes in overarching themes.

2.4. Quality control

Given the diversity of research approaches in the reviewed papers, we refrained from operationalising and applying a quantitative score to grade the quality of studies. As Whittemore and Knafl (2005) argue, such a rigid approach may not be suitable for a review that includes different types of empirical studies. Nonetheless, we implemented several measures to ensure the quality of the studies included in our review. We only searched for and included peer-reviewed studies published in journals listed in renowned scientific databases. In reviewing papers, we considered the presentation of the methodological approach and data. The reviewed studies used a variety of empirical approaches based upon different methodological concepts. We did not want to assess (and question) these concepts per se or initiate a fundamental discussion about advantages and disadvantages of certain methodologies. However, we excluded articles if they insufficiently described and outlined the studies' methodological approaches because in these cases it would have been difficult to reproduce key aspects of these studies as part of our review.

To prevent error and bias in selecting papers, at least two researchers screened every paper independently. Furthermore, in the process of analysing the selected full texts, a sample of ten papers was analysed independently by two reviewers to monitor and check consistency in retrieving information from the studies.

3. Results

Database searches were conducted on 24 April 2020. This resulted in 4.959 articles after removal of duplicates. Through title and abstract screening, we selected 103 publications for full text examination. Out of these, we evaluated 48 articles as relevant for in-depth review. In analysing them, four articles were removed because of quality issues or because they did not meet our review criteria after all (see Fig. 1). Furthermore, one paper (Adesina et al., 2014) was removed because it reported on the same study and findings with regards to good dying as another one (Adesina et al., 2016), but in less detail. Two other papers were based on the same study (Díaz-Cortés et al., 2018; Fernández-Sola et al., 2017), but focused on different aspects of good dying. We included both papers in the review, but in analysing the study characteristics (see 3.1), we only counted them as one study. In the end, the review included 43 papers dealing with 42 empirical studies.

3.1. Study characteristics: research design, participants, and concepts

33 studies had a qualitative design, eight had a quantitative design, and only one had a mixed-methods approach. Most studies used interviews (n = 18) or surveys (n = 16), others also used focus groups (n = 3) or combined focus groups and individual interviews (n = 5) to investigate the perspective of professional caregivers on good dying. 55% (n = 18) of the qualitative studies used interviews and all quantitative studies used surveys to collect data.

The majority of studies collected data in the USA (n = 11), the UK (n = 8), or Australia (n = 5). Furthermore, two studies each were concerned with Canada, Italy and Sweden, and one study each with China, Ethiopia, Finland, India, Ireland, Israel, Japan, Kenya, The Netherlands, South Africa, South Korea, Spain, Thailand and Turkey. Two studies used and compared empirical evidence from several different national contexts including Ethiopia, India, Kenya, and the USA (Coenen et al., 2007) and England and Israel (Endacott et al., 2016). While we also translated our search string and searched for studies in German, no study in German met our inclusion criteria.

In the qualitative studies, the number of participants ranged from five in an exploratory interview-based study (McCallum and McConigley, 2013) to 707 participants in a survey-based study (Cagle et al., 2017) (median: 25, average: 81). Qualitative survey-based studies used written responses to a limited number of open-ended questions for their analysis and thus could include a higher number of participants than usual in qualitative research (Beckstrand et al., 2006; Cagle et al., 2017; Coenen et al., 2007; Dillon et al., 2018). Quantitative studies had between 76 (Gibson et al., 2008) and 856 participants (Demir et al., 2017) (median: 368, average: 426). Studies investigated professional caregivers working foremost in hospitals (n = 24) (emergency departments, intensive care units, oncology units, progressive care units, surgical units, paediatric (oncology) units), nursing homes (n = 10), and private homes (n = 6); in several cases, caregivers working in different contexts were included (n = 7) or no place of care was indicated (n = 7). Nurses, including registered nurses, nurse practitioners, acute or critical care nurses, were the most prevalent participants and addressed by 35 studies. Nine studies analysed data from physicians, five from managers, four from social workers, two from psychologists, two from clergy, two from other staff, and one from nursing students. One study empirically investigated the perspective of traditional healers (Graham et al., 2013). Studies sometimes focused on different professional groups concurrently. While not all studies indicated their samples' gender distribution, study participants in those who reported it were predominantly female, ranging from 53% female participants (Kim, 2019) to 100% female participants in several studies (Karlsson and Berggren, 2011; Kongsuwan et al., 2010; McCallum and McConigley, 2013; Volker and Limerick, 2007). Some studies had an explicit focus on care for specific groups including children (Bennett and Proudfoot, 2016; Nagoya et al., 2016; Souza et al., 2013), people with advanced dementia (Kupeli et al., 2016), intellectual disabilities (McNamara et al., 2019; Todd, 2013), or a particular illness such as heart-failure (Borbasi et al., 2005).

The studies employed different concepts for 'good dying'. Most studies conceptualised a 'good death' (n = 20) and others used concepts of 'dignity' of dying, death, or end-of-life care (n = 9). A few studies framed their research in terms of 'quality' of dying and death or of life at the end of life (n = 3). In some instances, the phenomenon was labelled in more processual terms such as 'dying well' (n = 3) or 'good dying' (n = 1). Several studies focused on experiences in end-of-life care (n = 4) or

Table 2
Overview of reviewed studies.

Reference	Country	Concept/ terminology	Design	Sample (gender) and participants	Place of care
Adesina et al. (2016)	Australia	Good/bad death	Qualitative: survey	N = 87 (85% female, 13% male, 2% unspecified) Nursing students with clinical experience	No information available
Albers et al. (2013)	The Netherlands	Patient dignity inventory	Quantitative: survey	N = 653 (not available) Support and Consultation on Euthanasia Physicians (n = 427) and trained volunteers (n = 226)	Home, hospice
Becker et al. (2017)	USA	Dying well	Qualitative: survey	N = 49 (86% female, 14% male) Registered nurses	Community hospital
Beckstrand et al. (2006)	USA	Good death	Qualitative: survey	N = 485 (93% female, 7% male): 53% staff nurses, 36% charge nurses, 4% clinical nurse specialists, 6% other	Hospitals: intensive care units (ICU)
Bennett and Proudfoot (2016)	USA	Quality of dying and death	Quantitative: survey	N = 309 (not available): Registered nurses (44,6%), chaplains (13%), social workers (8,8%), respiratory therapists (8,8%), physicians (7,5%), nurse practitioners (3,3%), child life specialists (2,9%), supportive care team members (1,6%), other (9,4%)	Tertiary paediatric hospital
Borbasi et al. (2005)	Australia	Good/bad death	Qualitative: interviews	N = 17 (70,6% female, 29,4% male) Registered nurses	Hospital, home, hospice
Bovero et al. (2019)	Italy	Patient dignity inventory	Quantitative: survey	N = 306 (75,5% female, 24,5% male) Nurses (46,1%), physicians (29,1%), nurse assistants (14,4%), psychologists (10,5%)	Hospital
Bratcher (2010)	USA	Good death	Qualitative: interviews	N = 15 (66,6% female, 33,3% male) Critical care nurses	Hospital: ICU
Cagle et al. (2017)	USA	Positive/negative experiences	Qualitative: survey	N = 707 (93,4% female, 4,7% male, 2% missing) Nursing assistants (39,9%), practical nurses (29,8%), registered nurses (15,1%), social workers (3,8%), other (8,9%), missing (2,7%)	Nursing home
Casey et al. (2011)	Ireland	Dying well	Qualitative: interviews	N = 33 (88% female, 12% male) General nurses (60,6%), health care assistants (27,3%), general practitioners (6,0%), occupational therapist assistant (3,0%), physiotherapist assistant (3,0%)	Hospital, public extended care units, nursing homes, long-stay unit attached to palliative care centre
Cipolletta and Oprandi (2014)	Italy	Good death	Qualitative: focus groups	N = 37 (67,6% female, 32,4% male) Nurses (48,6%), physicians (35,1%), health workers (13,5%), psychologist (2,7%)	General medical organisations, hospitals, home service
Coenen et al. (2007)	Ethiopia, India, Kenya, USA	Dignified dying, Dignity-Conserving Care Model	Qualitative: survey	N = 560 (not available) Nurses	No information available
Costello (2006)	United Kingdom	Dying well	Qualitative: interviews	N = 29 (not available) Registered nurses	Hospital
Decker et al. (2015)	Australia	Good death	Qualitative: focus groups	N = 25 (100% female) Registered nurses	Hospital: emergency department
Demir et al. (2017)	Turkey	Dying with dignity, good death	Quantitative: survey	N = 856 (92,3% female, 7,7% male) Nurses	Hospital: intensive care and oncology
Díaz-Cortés et al. (2018) and Fernández-Sola et al. (2017)	Spain	Dignified end-of-life care	Qualitative: focus groups and interviews	N = 26 (65,38% female, 34,6% male) Nurses (61,5%), physicians (38,5%)	Hospital: emergency department
Dillon et al. (2018)	USA	Good death	Qualitative: survey	N = 117 (not available) Physicians and surgeons	Hospital: colon and rectal surgery
Dwyer et al. (2009)	Sweden	Dignity in end-of-life care	Qualitative: interviews	N = 21 (80,95% female, 19,5% male) Nurse assistants (57,1%), registered nurses (23,8%), managers (19,0%)	Nursing homes
Endacott et al. (2016)	England, Israel	Good death	Qualitative: focus groups and interviews	N = 55 (not available) Registered nurses	Hospital: ICU
Gibson et al. (2008)	Canada	Good death	Quantitative: survey	N = 76 (82,9% female, 9,2% male, 7,9% missing) Nurses	Nursing homes: long-term care programme for war veterans
Graham et al. (2013)	South Africa	Good death	Qualitative: focus groups and interviews	N = 21 (61,9% female, 38.1% male) Traditional healers	No information available
Griggs (2010)	England	Good death	Qualitative: interviews	N = 17 (not available) Community nurses	No information available
Hanson et al. (2002)	USA	Good death	Qualitative: focus groups	N = 77 (not available) Nursing assistants, nurses, physicians	Nursing homes
Hopkinson and Hallett (2002)	United Kingdom	Good death	Qualitative: interviews	N = 28 (not available) Nurses	Hospital: acute hospitals
Karlsson and Berggren (2011)	Sweden	Good end-of-life care	Qualitative: interviews	N = 10 (100% female) Nurses	Home
Kim (2019)	South Korea	Good/bad death	Qualitative: interviews	N = 15 (53% female, 47% male) Social workers	Long-term care: institutional settings, nursing homes, home care
Kongsuwan et al. (2010)	Thailand	Peaceful death		N = 10 (100% female)	Hospital: ICU

(*continued on next page*)

Table 2 (*continued*)

Reference	Country	Concept/ terminology	Design	Sample (gender) and participants	Place of care
			Qualitative: interviews	Nurses	
Kupeli et al. (2016)	United Kingdom	Good qualitative end-of-life care	Qualitative: interviews	N = 14 (78,6% female, 21,4% male) Care home managers, nursing managers, nurses, therapists, other health care professionals	Nursing homes, hospitals, nursing services
LeBaron et al. (2015)	USA	Good/poor death	Qualitative: focus groups and interviews	N = 35 (91,4% male, 8,6% female) Clergy: ministers and pastors	No information available
McCallum and McConigley (2013)	Australia	Experience	Qualitative: interviews	N = 5 (100% female) Critical care nurses	Hospitals: high-dependency units
McNamara et al. (2019)	Australia	Person-centred care, good end-of-life care	Qualitative: focus groups and interviews	N = 26 (not available) Nurses (34,6%), disability residential accommodation managers (23,1%), social workers (15,4%), occupational therapists (11,5%), disability support workers (7,7%), counsellors/psychiatrists (7,7%)	Nursing homes, homes
Nagoya et al. (2016)	Japan	Quality in dying and death	Quantitative: survey	N = 427 (71,4% female, 28,6% male) Nurses (63,2%), paediatricians (36,8%)	Hospital: paediatric oncology
Oliver and O'Connor (2015)	England	Good death	Qualitative: interviews	N = 13 (92% female, 8% male) General nurses	Hospital: acute hospital
Souza et al. (2013)	Brazil	Dignified death	Qualitative: interviews	N = 8 (87,5% female, 12,5% male) Nurses	Hospital: paediatric oncology
Srinonprasert et al. (2019)	Thailand	Good death	Quantitative: survey	N = 656 (96,7% female, 3,3% male) Nurses	Hospital: various departments
Stokes et al. (2019)	Canada	Meaningful experiences	Qualitative: interviews	N = 6 (not available) Nurses	Hospital: ICU
Terkamo-Moisio et al. (2016)	Finland	Good death	Qualitative: survey	N = 81 (93,9% female, 6,1% male) Nurses	No information available
Todd (2013)	United Kingdom	Experiences	Qualitative: interviews	N = 22 (not available) Staff	Care homes for people with disabilities
Volker and Limerick (2007)	USA	Dignified dying	Qualitative: interviews	N = 19 (100% female) Oncology advanced practice nurses	Hospital: oncology
Wilson et al. (2006)	USA	Dignified dying	Mixed-methods: survey	N = 281 (not available) Nurses	No information available
Yang et al. (2019)	China	Good death	Quantitative: survey	N = 122 (98,4% female, 1,6% male) Nurse's aides (50,8%), nurse practitioners (37,7%), nurse-in-charge (10,7%), associate professor of nursing (0,8%)	Hospital: cancer hospital
Young et al. (2017)	United Kingdom	Good dying	Qualitative: interviews	N = 16 (94% female, 6% male)	Nursing homes

on the quality of end-of-life care (n = 2), but thereby analysed normative assessments of these too. In a single instance the focus was on a 'peaceful' death. Sometimes, concepts to frame good dying in general reappeared as single attributes of other notions of good dying, especially dignity as one attribute of good death amongst others (Becker et al., 2017; Beckstrand et al., 2006; Bratcher, 2010; Cagle et al., 2017; Cipolletta and Oprandi, 2014; Costello, 2006; Demir et al., 2017; Griggs, 2010; Hopkinson and Hallett, 2002; LeBaron et al., 2015; Stokes et al., 2019).

The majority of qualitative studies conducted their empirical work in an exploratory and descriptive manner and with no reference to an explicit and detailed theoretical framework. However, two qualitative studies used the Dignity-Conserving Care Model (Chochinov, 2002) as conceptual framework (Coenen et al., 2007; Díaz-Cortés et al., 2018). A few other studies located themselves in a symbolic interactionist (Decker et al., 2015; Todd, 2013) or phenomenological tradition (Hopkinson and Hallett, 2002; Karlsson and Berggren, 2011; Oliver and O'Connor, 2015; Volker and Limerick, 2007); one identified as 'Phenomenographic Study' (Terkamo-Moisio et al., 2016).

Most quantitative studies were based upon existing survey instruments, including two studies adapting the 'Patient Dignity Inventory' by Chochinov et al. (2008) (Albers et al., 2013; Bovero et al., 2019). Other studies developed their instruments based on different concepts and instruments (Srinonprasert et al., 2019; Wilson et al., 2006) or on the basis of their own qualitative studies (Nagoya et al., 2016).

3.2. Good dying from the perspective of professional caregivers

Overall, although in different countries and locations of care, with different patient groups, or by different professional groups, we observed rather similar descriptions of good dying across the studies. The same holds true for conceptual differences; key requirements and characteristics of a positively assessed dying process were similar across studies. However, some studies nonetheless considered different aspects related to good dying that brought forward specific insights not thematised by other studies (see 3.3).

3.2.1. Expected, accepted, and prepared good dying

In several studies, professional caregivers assessed that the dying and death of a person needed to be *expected* in order for good dying to be possible. Death should not occur suddenly, but the actors involved had to predict and know about the approaching death, for example, by having a valid diagnosis of an illness. This was interlinked with the issue of *awareness*. Professional caregivers had to adequately inform the dying, the family, and the relatives (open awareness) about a terminal illness and expected death. These persons needed realistic expectations about the development of an illness and dying processes (Adesina et al., 2016; Becker et al., 2017; Beckstrand et al., 2006; Borbasi et al., 2005; Bratcher, 2010; Cagle et al., 2017; Cipolletta and Oprandi, 2014; Costello, 2006; Dillon et al., 2018; Endacott et al., 2016; Griggs, 2010; Hopkinson and Hallett, 2002; Karlsson and Berggren, 2011; LeBaron et al., 2015; Oliver and O'Connor, 2015; Srinonprasert et al., 2019; Todd, 2013). In turn, several quantitative studies found that professional caregivers associated unexpected deaths with negative impacts on dying

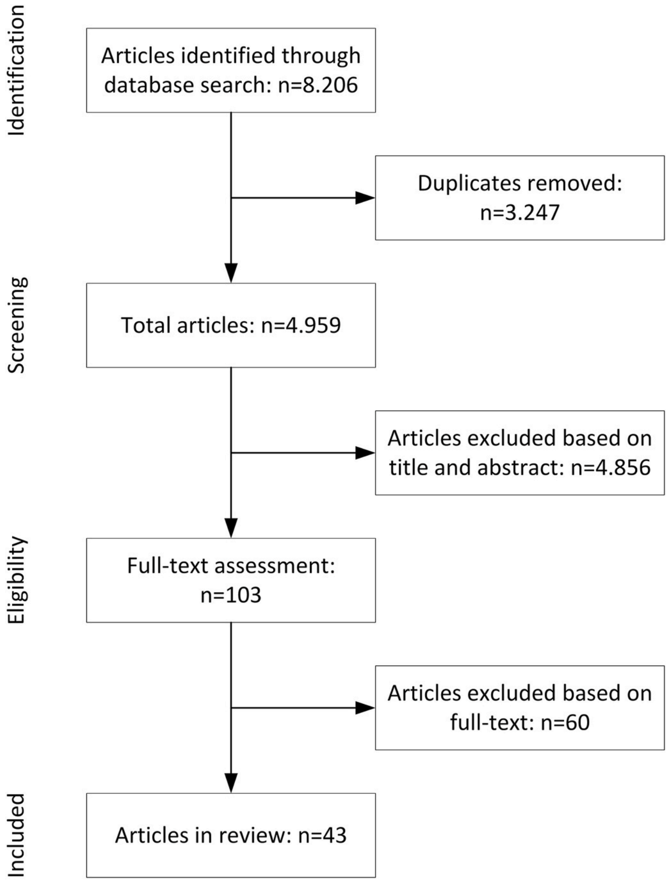

Fig. 1. Systematic screening and selection process (adapted from Moher et al. (2009).

or bad dying (Bennett and Proudfoot, 2016; Gibson et al., 2008), and highly valued full knowledge about one's own illness (Srinonprasert et al., 2019). In contrast, some quantitative studies analysing the prioritisation of elements of good dying showed that professional caregivers prioritised the expectation of death or having awareness lower than other aspects (Albers et al., 2013; Demir et al., 2017; Nagoya et al., 2016). However, even in these studies, expecting death, that is knowing about the terminal nature of a patient's condition, seemed to be essential in order to facilitate a range of other activities prioritised higher as necessary for good dying, for example, 'to have access to hospice care' (Demir et al., 2017, p. 120) or 'dying in the presence of family' (Nagoya et al., 2016, p. 489).

With respect to awareness, single studies described how some professional caregivers favoured closed awareness, i.e., that patients were not (fully) informed about the lethality of their disease (for the concept of 'awareness contexts' see Stacey et al., 2019). For example, in a study on the dying of people with intellectual disabilities, '"being there" involved masking dying from the person with intellectual disability' (Todd, 2013, p. 223). Another study described both staff working in long-term care advocating for open awareness as well as others opting for closed awareness, because they felt that 'discussion of death was unsettling for residents' (Casey et al., 2011, p. 1828). In a study on professionals working in paediatric cancer care, the awareness of the child and family was also rated as less important than other aspects, especially by nurses, while paediatricians rated this aspect significantly higher (Nagoya et al., 2016).

In addition to being aware of death, according to professional caregivers, death also needed to be *accepted* by all actors involved, including patients, family and relatives, as well as caregivers. Acceptance appeared as a prerequisite for further preparation activities, for example, for saying goodbye to family and friends, as well as necessary for good dying (Borbasi et al., 2005; Bratcher, 2010; Hanson et al., 2002; Kongsuwan et al., 2010; LeBaron et al., 2015; McNamara et al., 2019). LeBaron et al. (2015, p. 1002) described how acceptance was a pre-requirement of other elements of good dying, that '[w]ithout acceptance, preparation within any domain was impeded, rendering dying more difficult'.

Thus, expectation, awareness, and the acceptance of death were important for the professional caregivers because it was only then that *preparation* to achieve good dying was possible. One study summarised the relationship between expectation and preparation as follows:

> 'The nurses saw expected deaths as good because everyone had been given an opportunity to prepare for the death and had been afforded the opportunity to say goodbye' (Hopkinson and Hallett, 2002, p. 536).

Preparation encompassed various activities in different domains with regards to the organisation of end-of-life care, social and personal arrangements, and medical interventions including pain and symptom management (Adesina et al., 2016; Borbasi et al., 2005; Cagle et al., 2017; Costello, 2006; Dillon et al., 2018; Griggs, 2010; Hanson et al., 2002; Hopkinson and Hallett, 2002; Kongsuwan et al., 2010; Kupeli et al., 2016; LeBaron et al., 2015; Terkamo-Moisio et al., 2016). For example, Borbasi et al. (2005, p. 106) analysed preparation on the level of the individual and family (saying goodbye), but also on a professional level (palliative measures) and that a.

'"good" death was one where patients and family had "planned ahead" […] so the individual had "their affairs in order" and "said goodbye" to their relatives and were provided adequate palliative measures.'

On behalf of the professional caregivers, preparation was also connected to the aspect of having control over the situation (Becker et al., 2017; Costello, 2006; Decker et al., 2015). Costello (2006, p. 598) described how professional caregivers perceived absence of preparation as responsible for a bad death because organisational procedures were disturbed:

> 'Bad death was characterised by limited control over the events leading up to and including the "death event". Lack of preparation and time to get to know the family and make an accurate assessment of patients' needs constituted a risk to the smooth running of the ward.'

In line with the issue of preparation and control, one study described how suicides, as well as accidents or other sudden deaths, were assessed as bad deaths by clergy, because they inhibited preparations on different levels (LeBaron et al., 2015).

3.2.2. *Free from pain and suffering*

In most studies, good dying was related to the absence of pain and symptoms, an issue which appeared in connection to health conditions at the end of life, terminal illnesses, or the dying process. Professional caregivers identified distressing pain and bodily symptoms (especially breathlessness) as problematic, and the management, alleviation, and inhibition of pain and symptoms as key for good dying (Adesina et al., 2016; Albers et al., 2013; Becker et al., 2017; Beckstrand et al., 2006; Bennett and Proudfoot, 2016; Borbasi et al., 2005; Bovero et al., 2019; Bratcher, 2010; Cagle et al., 2017; Casey et al., 2011; Coenen et al., 2007; Costello, 2006; Decker et al., 2015; Demir et al., 2017; Dillon et al., 2018; Endacott et al., 2016; Gibson et al., 2008; Griggs, 2010; Karlsson and Berggren, 2011; Kim, 2019; Kupeli et al., 2016; LeBaron et al., 2015; McCallum and McConigley, 2013; Nagoya et al., 2016; Oliver and O'Connor, 2015; Souza et al., 2013; Srinonprasert et al., 2019; Stokes et al., 2019; Terkamo-Moisio et al., 2016; Volker and Limerick, 2007; Wilson et al., 2006; Young et al., 2017). In quantitative studies which prioritised elements of good dying, absence of or minimal pain and symptoms, were often rated higher than other aspects. In one study, 99,3% of participants rated 'having no pain and suffering in the body' as important or very important (Nagoya et al., 2016, p. 489) and in another one 100% of participants rated 'that it be painless or largely pain-free' as essential or important (Gibson et al., 2008, p. 377).

Professional caregivers framed pain and symptom management in terms of reducing stress and improving the comfort of patients (Becker et al., 2017; Beckstrand et al., 2006; Bratcher, 2010; Oliver and O'Connor, 2015; Souza et al., 2013). Sometimes, professional caregivers assessed a 'brief' dying process as good dying because it reduced suffering (Dillon et al., 2018; Kim, 2019). In other instances, death was assessed as relieving the dying person from suffering (Costello, 2006; Souza et al., 2013; Todd, 2013), but also for the family (Costello, 2006). Another study found that pain management measures 'allow the family to be close to the patient' (Endacott et al., 2016, p. 13) and thus benefited families too. In one study, reduction of 'distressing signs and symptoms' (Cagle et al., 2017, p. 202) of the dying person was described as also comforting the care staff. Thus, pain and symptom management, while having positive effects on the patients, also had positive impacts on caregivers and families.

A number of studies drew attention to prevention and cessation of futile treatments, for example, artificial nutrition, resuscitation, artificial ventilation, or surgery. From the perspective of professional caregivers, such futile treatments caused more misery than benefits for the patients, and consequently their cessation was found as a means of reducing pain and suffering (Adesina et al., 2016; Becker et al., 2017; Beckstrand et al., 2006; Bennett and Proudfoot, 2016; Bratcher, 2010; Cagle et al., 2017; Cipolletta and Oprandi, 2014; Costello, 2006; Demir et al., 2017; Díaz-Cortés et al., 2018; Dillon et al., 2018; Endacott et al., 2016; Fernández-Sola et al., 2017; Kongsuwan et al., 2010; Kupeli et al., 2016; McCallum and McConigley, 2013; Nagoya et al., 2016; Srinonprasert et al., 2019). However, professional caregivers described how this ideal may be counteracted by strong expectations of physicians or the patients' families in medicine, a lack of acceptance of death (Beckstrand et al., 2006; Cipolletta and Oprandi, 2014; Decker et al., 2015; Demir et al., 2017; Díaz-Cortés et al., 2018), or by the 'logic' of certain care contexts that focus on saving lives (McCallum and McConigley, 2013). These may lead to futile treatments from the perspective of professional caregivers.

3.2.3. *Not alone: socially embedded good dying*

The reviewed studies found that professional caregivers assessed the presence of family, relatives, or friends of the dying as vital for good dying. In line with this, being alone was most often related to bad dying. The professional caregivers described the presence of others as important for its own sake and because it created a comfortable atmosphere and reduced stress as well as anxiety (Adesina et al., 2016; Becker et al., 2017; Bennett and Proudfoot, 2016; Bovero et al., 2019; Bratcher, 2010; Cagle et al., 2017; Cipolletta and Oprandi, 2014; Endacott et al., 2016; Fernández-Sola et al., 2017; Gibson et al., 2008; Graham et al., 2013; Hopkinson and Hallett, 2002; Karlsson and Berggren, 2011; Kim, 2019; Kongsuwan et al., 2010; LeBaron et al., 2015; McCallum and McConigley, 2013; Nagoya et al., 2016; Srinonprasert et al., 2019; Stokes et al., 2019; Terkamo-Moisio et al., 2016; Todd, 2013). Furthermore, social presence was identified as a prerequisite for saying goodbye or for creating closure (Borbasi et al., 2005; Cagle et al., 2017; Dillon et al., 2018; Fernández-Sola et al., 2017; Graham et al., 2013; Volker and Limerick, 2007). Graham et al. (2013, p. 389) described the various opportunities and benefits social presence entailed in their study:

> 'Their family gathering at the deathbed is not only for the comfort of the dying person but also for the chance to restore relationships, express wishes for the family, and give a verbal will.'

Sometimes, professional caregivers even assessed the involvement of family in care activities positively (Coenen et al., 2007; Wilson et al., 2006). And one study identifies the possibility for people to see their pets as important (Coenen et al., 2007).

Several studies found that from the professionals' perspective, the social accompaniment of the dying person should also involve the professional caregivers, especially in cases where no family or relatives could be present (Becker et al., 2017; Coenen et al., 2007; Hanson et al., 2002; Hopkinson and Hallett, 2002; LeBaron et al., 2015; McCallum and McConigley, 2013; Stokes et al., 2019; Todd, 2013; Wilson et al., 2006). Hanson et al. (2002, p. 121) outlined this finding in long term care as follows:

> 'Nursing staff felt they had to be surrogate family, chaplain, or friend to a dying resident who did not have these sources of support […] They knew when a resident was afraid to die alone, and would work to find extra time or come in after their shift to be with her.'

One study described how the professional caregivers' personal presence was important for their relationship to the patients and for their quest for meaning in their work (Todd, 2013).

In contrast to the above, one study reported on some research participants who 'stated that a good death is faced alone, without the presence of mourning relatives' (Terkamo-Moisio et al., 2016, p. 456, p. 456). In other studies, professional caregivers also described how family presence could have negative impacts on the end of life in cases of conflicts in the family that disturb the dying process (Bennett and Proudfoot, 2016; Cagle et al., 2017; Dillon et al., 2018; LeBaron et al., 2015; Terkamo-Moisio et al., 2016). Professional caregivers brought up the feeling that the dying person had of being a burden for their families. Having this feeling was assessed as adverse to good dying (Albers et al., 2013; Bovero et al., 2019; Díaz-Cortés et al., 2018; Kim, 2019; Srinonprasert et al., 2019). In one study, caregivers related suicides of patients to a lack of social support and assessed these deaths as bad deaths (Kim, 2019).

3.2.4. *Being at peace and preserving personhood*

Socially embedded dying opens an opportunity to deal with unresolved issues and the necessity to say goodbye to family and friends. This seemed to be connected to a broader biographical aspect of good dying. Professional caregivers in several studies emphasised the importance of being at peace with one's own life and situation. This included settling lingering conflicts (e.g., within the family) and managing unresolved issues and businesses (e.g., burial or legacy) (Adesina et al., 2016; Bennett and Proudfoot, 2016; Borbasi et al., 2005; Bovero et al., 2019; Bratcher, 2010; Dillon et al., 2018; Endacott et al., 2016; Gibson et al., 2008; Graham et al., 2013; Griggs, 2010; Kongsuwan et al., 2010; LeBaron et al., 2015; Srinonprasert et al., 2019; Terkamo-Moisio et al., 2016; Volker and Limerick, 2007). Professional caregivers related this to the issue of acceptance too, which we have already discussed as a precondition for preparing for good dying (see 3.2.1). They associated acceptance with the state of being at peace with the situation and with death, which promoted calmness and reduced stress (Adesina et al., 2016; Cagle et al., 2017; Coenen et al., 2007; Fernández-Sola et al., 2017; Gibson et al., 2008; Kongsuwan et al., 2010; Terkamo-Moisio et al., 2016).

Some studies linked good dying to the broader biographical background: Professional caregivers identified having lived a fulfilled or good life as a factor for good dying (Adesina et al., 2016; Kim, 2019; Terkamo-Moisio et al., 2016). In some studies, this was connected to the prerequisite of dying at old age while dying young was assessed as bad (Adesina et al., 2016; Terkamo-Moisio et al., 2016). However, studies concerned with good dying of children showed that also dying at a young age was rated in a differentiated manner, and also for younger people and children, good dying was deemed possible (Bennett and Proudfoot, 2016; Nagoya et al., 2016; Souza et al., 2013).

With regards to the biographical context of dying, professional caregivers described the preservation of the dying person's identity and personhood as important for good dying. This aspect was foremost identified with respect to the dignity of the dying person and included the subjective feeling of being oneself despite declining health, illnesses, or impairments (Albers et al., 2013; Bovero et al., 2019; Nagoya et al., 2016), as well as being recognised and treated as an individual with an individual identity (Dwyer et al., 2009; LeBaron et al., 2015; Srinonprasert et al., 2019; Todd, 2013). One study described how professional caregivers evaluated dying processes against the biographical background and personality of the dying person. Thereby, good dying reflected the way of life of the dying person and meant 'dying with integrity' (Borbasi et al., 2005, p. 108).

3.2.5. Individualised and holistic care

Professional caregivers identified the need for care and medical treatment to respect the individual's autonomy, needs, demands, and values. In the reviewed studies, this was often interlinked with the necessity to continuously communicate with the dying persons and their families in order to get to know their wishes (e.g., regarding medical treatments) and needs (Adesina et al., 2016; Albers et al., 2013; Becker et al., 2017; Beckstrand et al., 2006; Bennett and Proudfoot, 2016; Borbasi et al., 2005; Bratcher, 2010; Cagle et al., 2017; Casey et al., 2011; Coenen et al., 2007; Decker et al., 2015; Demir et al., 2017; Dillon et al., 2018; Dwyer et al., 2009; Fernández-Sola et al., 2017; Gibson et al., 2008; Graham et al., 2013; Griggs, 2010; Karlsson and Berggren, 2011; Kongsuwan et al., 2010; LeBaron et al., 2015; McCallum and McConigley, 2013; Nagoya et al., 2016; Souza et al., 2013; Srinonprasert et al., 2019; Stokes et al., 2019; Terkamo-Moisio et al., 2016; Volker and Limerick, 2007; Young et al., 2017). Professional caregivers identified different areas of personal autonomy; LeBaron et al. (2015, p. 1002) described the range as follows:

> 'Autonomy was exercised when the wishes of patients were honored in terms of preferences related to treatment options, location of care, appointment of a health care proxy, and desires regarding interventions such as cardiopulmonary resuscitation or intubation. Autonomy extended not only to medical choices at the end of life, but also to the extent of spiritual support desired by the patient.'

In some studies, professional caregivers identified advance directives as organisational means to better know about the wishes of patients (Beckstrand et al., 2006; Demir et al., 2017). In other cases, challenges related to preserving autonomy and decision making were described, for example, with regards to persons with intellectual disabilities at the end of life, especially in hospital environments (McNamara et al., 2019). Professional caregivers not only saw the necessity to adapt their care to the specific situation and personal needs of people at the end of life, but in some studies they also identified the preservation of a normal daily life as important for good dying (Albers et al., 2013; Bovero et al., 2019; Nagoya et al., 2016; Terkamo-Moisio et al., 2016).

In one study, professional caregivers discussed euthanasia as the 'ability to decide about one's own death' (Terkamo-Moisio et al., 2016, p. 454) and related to good dying, whilst others in the same study indicated that one's autonomy should not be expanded to this kind of decision making. Otherwise, euthanasia or physician-assisted suicide were not discussed by professional caregivers in the reviewed studies.

Studies showed that professional caregivers identified individualised care not only considering medical and physical aspects of the dying persons, but also their social, emotional, spiritual, religious, and cultural needs (Becker et al., 2017; Bennett and Proudfoot, 2016; Bratcher, 2010; Coenen et al., 2007; Costello, 2006; Demir et al., 2017; Gibson et al., 2008; Griggs, 2010; Hanson et al., 2002; Hopkinson and Hallett, 2002; Kongsuwan et al., 2010; Kupeli et al., 2016; LeBaron et al., 2015; McCallum and McConigley, 2013; Souza et al., 2013; Srinonprasert et al., 2019; Terkamo-Moisio et al., 2016; Wilson et al., 2006). Some studies explicitly described how, according to professional caregivers, different goals in different domains of care needed to be achieved concurrently in order to enable good dying (Borbasi et al., 2005; Casey et al., 2011; Coenen et al., 2007). Studies also described the necessity of compassion for the patient and family (Coenen et al., 2007; Díaz-Cortés et al., 2018; Fernández-Sola et al., 2017; Souza et al., 2013; Stokes et al., 2019). One study on traditional healers also showed how rituals and ceremonies after death were deemed important for the spirit of the deceased and the well-being of the family (Graham et al., 2013). Another study emphasised the importance of activities such as cleaning the dead body for the family (Griggs, 2010; Kongsuwan et al., 2010).

In several studies, professional caregivers identified having enough time and resources as necessary for such forms of individualised and comprehensive care (Beckstrand et al., 2006; Borbasi et al., 2005; Casey et al., 2011; Cipolletta and Oprandi, 2014; Decker et al., 2015; Díaz-Cortés et al., 2018; Dwyer et al., 2009; Hopkinson and Hallett, 2002; McCallum and McConigley, 2013; Oliver and O'Connor, 2015).

3.2.6. Good (inter)professional cooperation and communication

Studies found that professional caregivers emphasised good communication and cooperation within care staff and between different disciplines, which included information exchange, requesting professional support from other disciplines, and shared decision making (Adesina et al., 2016; Becker et al., 2017; Beckstrand et al., 2006; Bennett and Proudfoot, 2016; Borbasi et al., 2005; Casey et al., 2011; Cipolletta and Oprandi, 2014; Dillon et al., 2018; Griggs, 2010; Hanson et al., 2002; Karlsson and Berggren, 2011; Kupeli et al., 2016; Souza et al., 2013; Stokes et al., 2019; Young et al., 2017). As an example, Young et al. (2017, p. 856) described the importance of communication as follows:

> 'Communicating with those internally and external to the nursing home was visible across all practice elements and seen as fundamental for the staff to achieve their value of "good dying".'

Several studies highlighted the importance of good cooperation and communication, especially between nurses and physicians (Griggs, 2010; Hanson et al., 2002; McCallum and McConigley, 2013). For example, Hanson et al. (2002, p. 122) outlined:

> 'Physicians and nurses felt a need for shared communication to facilitate treatment decisions when a resident was dying.'

Professional caregivers also emphasised the importance of good communication and cooperation in order to be 'on the same page' (Stokes et al., 2019, p. 4) and to have an agreement within and between different professional groups on the care and treatment of a dying person (Adesina et al., 2016; Dillon et al., 2018; Griggs, 2010).

Furthermore, professional caregivers indicated the need for appropriate (palliative care) education and training to provide care for patients at the end of life in order to be able and confident enough to provide good care in these situations (Casey et al., 2011; Cipolletta and Oprandi, 2014; Díaz-Cortés et al., 2018; Hanson et al., 2002; Kupeli et al., 2016; Oliver and O'Connor, 2015; Souza et al., 2013).

3.2.7. Peaceful and private environments: at home and elsewhere

In several studies, home was identified as a preferred place of dying; however, under specific conditions (e.g., need for specific therapies) hospitals or other places of care were seen as better for the well-being of the dying person and the family (Dillon et al., 2018; LeBaron et al., 2015; McNamara et al., 2019; Terkamo-Moisio et al., 2016; Todd, 2013). The emergency department was assessed as altogether not optimal for good dying in two studies investigating the views of professionals working in emergency departments (Decker et al., 2015; Díaz-Cortés et al., 2018), but also in another study (McNamara et al., 2019).

Palliative and hospice care, both stationary or mobile teams, were most often assessed positively by professional caregivers if they thematised them (Adesina et al., 2016; Borbasi et al., 2005; Cagle et al., 2017; Demir et al., 2017; Oliver and O'Connor, 2015). However, in two studies, some professional caregivers from nursing homes described their experiences with hospice care rather negatively because they felt excluded by hospice providers from caring for their residents (Cagle et al., 2017) or they identified hospice as not the home of the dying person (Todd, 2013).

Apart from the care context, professional caregivers identified several key requirements regarding the environmental conditions that were important for good dying. These included having, in the best case, a private single room or at least a room situation that allowed for some privacy, sufficient space for the patient and their family to be present, a low noise level and an overall calm environment. Sometimes, professional caregivers described how they created special spatial arrangements (e.g., privacy screens) or moved patients to specific rooms to die (Becker et al., 2017; Beckstrand et al., 2006; Borbasi et al., 2005; Bratcher, 2010; Cagle et al., 2017; Casey et al., 2011; Cipolletta and Oprandi, 2014; Coenen et al., 2007; Díaz-Cortés et al., 2018; Dillon et al., 2018; Dwyer et al., 2009; Endacott et al., 2016; Fernández-Sola et al., 2017; Kim, 2019; McCallum and McConigley, 2013; Stokes et al., 2019; Terkamo-Moisio et al., 2016; Wilson et al., 2006). Several of these studies also highlighted creating a sense and atmosphere of 'home' in institutional contexts as desirable, for example, Cipolletta and Oprandi (2014, p. 22):

> 'Participants pointed out that a good death is comforted by loved ones in a quiet and comfortable environment, which recreated the home atmosphere, where the patient might die away from prying eyes, and where families might express their grief without feeling embarrassed.'

In this, a second sense of 'peaceful' dying is tangible: On the one hand, good dying was related to being at peace (accepting, having closure) with the situation and one's life (see 3.2.4), on the other hand, peaceful as described here is related to characteristics of the care environment as being calm, quiet, private, and not public, hectic, or stressful. The studies described how an appropriate environment benefitted the patients, but also the family and relatives. In contrast, one study described the emergency department as an inappropriate environment because it lacked these characteristics (for another example see McNamara et al., 2019, p. 9):

> 'participants believed that the ED was not an appropriate environment for death to occur because it created an environment that was busy, noisy and lacking in privacy' (Decker et al., 2015, p. 71, p. 71)

In line with the overall emphasis on individualised care, the assessment of a place of death was also interlinked to the preferences of the dying person (see 3.2.5). Given the overall descriptions of good dying in the various studies, the social, emotional, and care aspects seemed to be more important than (but sometimes related to) specific places of death. One study summarised this as follows:

> 'In general, the quality of the microenvironment—access to loving, competent caregivers and feeling secure—and the spiritual status of the dying person, were reported as more important than the location of dying.' (LeBaron et al., 2015, p. 1004, p. 1004)

3.3. *Approaching good dying: opening different perspectives*

Besides identifying the meaning of good dying from the perspective of professional caregivers, our review aimed to identify differences in the studies' approaches towards good dying through a comparative examination of the included studies. Through this comparison, peculiarities in how different studies analysed good dying became apparent. We detected three issues that single studies in our review addressed, and thus are not in principle out of scope of such empirical investigations, but which were not considered by most other studies. These three perspectives widen and differentiate our view on good dying. First, in making explicit who benefits from certain practices related to good dying, but not only focusing on the patient's well-being, some studies highlighted the wider implications of care and social practices supporting good dying (section 3.3.1). Second, some studies comprehended the dying process beyond a strict dichotomous relationship of good versus bad dying, thus offering the opportunity to account for differentiated views on this matter (section 3.3.2). Third, studies opened up a space for critically reflecting and weighting specific practices and ideals of care against one another by thematising the practical compatibility of different elements of good dying (section 3.3.3). In addition to these issues derived from our comparative analysis, we identified other 'blind spots' in research on good dying by drawing on and discussing further studies that were not part of our review (section 4).

3.3.1. *Good dying for whom?*

The first issue we identified concerns the analytical focus on, or the omission of, specific social actors involved in the dying process. It is about the question of who benefits from specific requirements and practices that promote good dying as identified by the research participants: Good dying for whom?

In most studies, the beneficiaries of certain practices or norms were often not made explicit. Rather, they had a focus on the well-being of the dying person as a default (and sometimes implicit) assumption. They described the well-being of others parenthetically amongst a bundle of practices targeting the well-being of the dying person, especially considering the acceptance of and preparation for death, the resolution of family issues, as well as saying goodbye. Professional caregivers indicated that families need to be supported in these matters for their own, and ultimately for the patient's well-being (Adesina et al., 2016; Becker et al., 2017; Beckstrand et al., 2006; Bennett and Proudfoot, 2016; Borbasi et al., 2005; Bratcher, 2010; Cagle et al., 2017; Casey et al., 2011; Coenen et al., 2007; Graham et al., 2013; Griggs, 2010; Kim, 2019; Kupeli et al., 2016; McCallum and McConigley, 2013; Souza et al., 2013; Terkamo-Moisio et al., 2016). Studies also described elements of good dying pertaining to families alone, for example, when caregivers supported families in grief after the death of their beloved ones (Adesina et al., 2016; Becker et al., 2017; Cipolletta and Oprandi, 2014; Coenen et al., 2007; Griggs, 2010; McNamara et al., 2019; Terkamo-Moisio et al., 2016). Some studies also discussed the well-being of the professional caregivers. Costello (2006, p. 598) stated that '[g]ood death benefited nurses as much as patients and relatives'. He described how nurses assessed those deaths good that involved minimal stress for the patients and for themselves and had minimal impact on their ward's routine. Furthermore, good end of life care appeared as a source of meaning and satisfaction with their own work (Borbasi et al., 2005; Hopkinson and Hallett, 2002; Stokes et al., 2019; Todd, 2013; Young et al., 2017).

However, there were only some studies explicitly differentiating and systematising the perspectives of the actor involved and affected. Griggs et al. (2010, p. 142) distinguished the 'focus' of 'contributory factors' to a good death for the patients, the nurses, or the professionals' team, and Dwyer et al. (2009) analysed the dignity of patients and staff members separately. Professional caregivers in the study by Borbasi et al. (2005) reflected on the possibility of imposing their own values on the dying person and their families, thus having a negative effect. Similar, McNamara et al. (2019, p. 8) stated that 'it is important that the person's wishes are not conflated with those of the family' but that also their needs and the needs of professional caregivers are considered. And Cagle et al. (2017, p. 200) made explicit that the assessment of good dying always constituted an indirect account of the well-being and desire of someone else. Therefore, they categorised the experiences of the professional caregivers in end-of-life care as 'first-hand', and those experiences of residents and families reported by the professional caregivers as 'observed in others'.

3.3.2. *Good or bad dying: beyond a dichotomous relationship?*

Our review, and many studies therein, in terms of terminology imply a dichotomous relation of good dying and bad dying on opposite ends of a scale. While some studies only dealt with good dying and just implicitly with bad dying as the absence of specific conditions (e.g., Bratcher, 2010; Casey et al., 2011; Demir et al., 2017; Hopkinson and Hallett, 2002; Terkamo-Moisio et al., 2016; Yang et al., 2019), others identified negatively and positively assessed dying processes explicitly (Adesina et al., 2016; Borbasi et al., 2005; Cagle et al., 2017; Costello, 2006; Kim, 2019; LeBaron et al., 2015).

However, single studies scrutinised the seemingly dichotomous nature of good and bad dying: One study in its results analysed a 'middle death' as 'more nuanced experiences' that 'cannot be easily dichotomized' (LeBaron et al., 2015, p. 1004) from the perspective of their research participants. The authors of this study interpreted this notion of middle deaths as having a 'pervasive sense of conditionality' (LeBaron et al., 2015, p. 1006) considering the subjectivity of dying processes. Another study highlighted the challenge of finding a conclusion on what constitutes good dying; their 'focus groups participants could not identify clear components of a good death' linked to a 'discomfort that many participants expressed when dealing with death and dying' (Cipolletta and Oprandi, 2014, p. 25).

In the topic of care approaches that consider the individual needs, demands, and values of those dying (and their relatives), the subjectivity of good dying is reflected to some extent (see 3.2.5). However, in these cases good dying was also identified as attainable through personalised care approaches, often in contrast to the identification of bad dying as a non-personalised or uniform way of caring for a dying person, and thus a (unproblematic) dichotomous relationship is implied.

3.3.3. *Compatibility of elements of good dying*

Above, we presented several elements of good dying that were identified by the reviewed studies. In line with their publications and findings, good dying emerged as a comprehensive phenomenon. And, as some studies explicitly conclude, the concurrent realisation of different elements of good dying was deemed important for achieving an ideal good dying.

However, some studies scrutinise the possibility of realising this in practice. Cipolletta and Oprandi (2014, p. 24) outlined how professional caregivers were ambivalent in their assessment of analgesics since 'removing awareness becomes a problem for many because it prevents the dying persons from being present and sharing their last wishes and thoughts with their loved ones'. In some studies, professional caregivers also raised the problematic issue of correct identification and evaluation of pain and suffering from symptoms with regards to patients with 'cognitive impairments' (Hanson et al., 2002, p. 119) or 'intellectual disabilities' (McNamara et al., 2019, p. 6). As described above, some other studies also showed ambivalent views of caregivers with regards to the awareness of patients about their impending death: Caregivers favoured closed awareness of patients in support of a peaceful situation with less suffering and fear (Casey et al., 2011; Todd, 2013). In these studies, these different ideals seem to be (partially) irreconcilable to the professional caregivers.

In total, the compatibility of specific conditions with requirements of good dying (e.g., certain mental capabilities) and the compatibility of elements of good dying amongst each other (such as pain management and awareness) were rarely discussed. Rather, many different elements were listed and described, often without critically discussing their relationship to one another.

4. Discussion

We analysed 43 peer-reviewed articles dealing empirically with the perspectives of professional caregivers not working in specialised palliative or hospice care on good dying. We found common elements of good dying across different countries, locations of care, and professional groups. They were related to the social anticipation of dying, the management and relief of pain and symptoms, the social embedding of dying, the consolidation and completion of one's life, the provision of individualised and comprehensive care, good professional cooperation, as well as environmental conditions.

4.1. *Good dying in generalist palliative care: commonalities and non-topics*

Comparing the main elements of good dying we identified in our review with that of other reviews on the meaning of good dying, we found many commonalities. With some variation, many of the above outlined elements of good dying were also identified by reviews focusing, for example, on professionals, patients, and families altogether (Meier et al., 2016), on specific patient groups such as patients with dementia (Takahashi et al., 2021) or heart failure (Asano et al., 2019), or only on specific concepts such as dignity (Guo and Jacelon, 2014). Elements of good dying identified in the reviewed studies also largely mirror palliative and hospice care concepts and discourses. Awareness and acceptance of death, pain and symptom management, personalised and holistic care approaches, communication, interdisciplinarity, and so on were not only described by professional caregivers in generalist palliative care, but are at the core of palliative and hospice care concepts and discourses too – as studies analysing the palliative care literature showed (Pastrana et al., 2008; Zimmermann, 2012). Thus, we may hypothesize that principles of palliative care have permeated non-specialised care at the end of life. Furthermore, we found that many studies shared elements with broader societal discourses around good dying. Studies have shown that media frame dying alone as bad death (Nelson-Becker and Victor, 2020; Seale, 2004) or that awareness, control, and autonomy are key elements of the 'subject position of the dying person' in the dominant 'medical-revivalist discourse' (Van Brussel and Carpentier, 2012, p. 491) on death in late modernity.

However, other topics around good dying, often at stake in social or expert discourses, were rarely or not at all raised in the studies. For example, given the often-controversial public debates around good dying that often revolve around the issues of euthanasia and physician-assisted suicide (Lang, 2020; McInerney, 2006; Van Brussel and Carpentier, 2012), it was interesting that this had hardly been an issue in our reviewed studies. Exceptions occurred in one study in which euthanasia was discussed with regards to autonomy (Terkamo-Moisio et al., 2016) and one in which suicide in general was identified as the outcome of a lack of support and inappropriate social conditions (Kim, 2019). In quantitative studies with predefined items and closed questions, this could be attributed to the conceptual omission of these topics; they were simply not part of a questionnaire. However, in qualitative studies the non-thematisation of topics such as physician-assisted suicide was not simply explainable. The reason could have related to the questions posed, conversational dynamics, the perspective and attitude of the professional caregivers, or the analytical focus on specific topics; however, we cannot provide a conclusive finding on this not being a topic of most reviewed studies. Other studies have shown that professional caregivers in countries with legalised medical assistance in dying sometimes relate this option to a good death because it alleviates the patient's pain and suffering and is seen as part of a patient's right to make end-of-life decisions (Beuthin et al., 2018). At the same time, professional caregivers also report ambiguous and negative effects of such practices on their work and well-being (Beuthin et al., 2018; Mathews et al., 2021).

Furthermore, while individualised care respecting the cultural or religious specifics of the dying persons was identified as important, gender, ethnic, or other social differences regarding good dying were not found to be issues from the perspective of the professional caregivers. As studies outside the scope of our review emphasised, there are differences in how women and men spend the evening of their lives when faced with dying due to differences in life expectancy and marriage patterns (Seale, 2000), as well as differences in their expectations, wishes, and patterns of medical treatments at the end of life (Carmel, 2001; Sharma et al., 2015), and in terminal care communication (Skulason et al., 2014). Similarly, the studies did not discuss how gendered roles and expectations in care (Sutherland et al., 2018) and gendered care labour distribution might affect the professional caregivers' perspective on good dying. And although other studies have shown that there are variations in how different social groups understand good death (Cain and McCleskey, 2019; Volker, 2005), ethnicity or social class as factors of social inequality at the end of life were not discussed by the studies or the professional caregivers therein. As broader social determinants of good dying, the reviewed studies foremost identified structural issues in the healthcare organisations, such as scarcity of resources or lack of palliative care education. Beyond that, for future studies, it might be worthwhile to raise issues around social inequity in dying and how socio-structural conditions related to gender, class, or ethnicity are perceived and understood by actors involved in the care of dying, and how they are related to their ideas and practices of good dying.

In our review, most studies dealt with the perspective of health professionals (nurses, physicians), whereas other professions included in our search were less prevalent (e.g., clergy members) or not present at all (e.g., morticians or undertakers). In the reviewed studies, the role of clergy and other actors outside of the medical professions was described to some extent (e.g., regarding the spiritual dimension of good dying) but their own views were explored only in single instances (LeBaron et al., 2015). The same holds true for other non-health professionals, including social workers or personal assistants. Investigating the understanding of good dying of further actors could contribute to a more complete picture of this phenomenon in our societies.

Since the beginning of 2020, the COVID-19 pandemic has posed a major challenge to society and the health care system. In our review, we could not consider its impact on professional perspectives on good dying. However, it appears as if central elements of good dying have been rather consistent. Research and commentaries have repeatedly highlighted that the social embedding of dying patients and also the adequate management of their pain and symptoms are threatened by the pandemic and related preventive measures. Thus, care practices have been adapted in order to fulfil these requirements of good dying including the use of information and communication technologies to enable social connectedness at a distance (Crispo et al., 2021; Wang et al., 2020). Actors from the field of palliative care have also emphasised this discipline's 'key role' in dealing with the pandemic (Radbruch et al., 2020). Further research is needed to determine how new care practices will be maintained and how these practices in particular, and the COVID-19 pandemic in general, may transform ideas around good dying.

4.2. Analytical approaches to good dying: extending the perspective

The second aim of our review was to explore how to better grasp the social complexity of good dying in empirical research based upon our comparative analysis of the included studies.

We found that the studies infrequently identified whose good dying was described by the caregivers, or who benefitted from certain elements of good dying. While studies in passing identified ramifications for family, relatives, and the professionals themselves, the few studies that did raise such issues more systematically, yielded interesting findings related to the dynamics and effects of specific ideals of good dying within care organisations. In line with this, we propose to explore the interwoven nature of the well-being of different relevant social groups in palliative care as well as discuss the well-being of others, apart from the dying person. Dying as process and situation involves the patient, those providing care and social support, and others affected including family, relatives, friends, or workmates. Given the close relationship of the well-being of the different involved actors, good dying could be more adequately understood as an ideal process that concurrently affects and is implemented by various social actors. Researching good dying then means analysing the interrelated state and well-being of those dying, their caregivers, their families and relatives, and others affected, as well as how ideas and practices of good dying emerge in these social contexts. This conclusion is in line with other critical inquiry and discussion around concepts of good dying. Many scholars have highlighted the importance of scrutinising who benefits from specific ideals and ways of good dying (Hart et al., 1998; Zimmermann, 2012) or that good dying means different things depending on the social perspective (Kearl, 1996). Thereby, conflicting definitions and practices related to good dying need to be considered; for example, in a German study, the necessity to reach acceptance before dying is seen critically from the patients' view (Ohnsorge et al., 2017) in contrast to our findings.

Furthermore, the reviewed studies rarely dealt with the interplay and congruence of different elements of good dying. In supporting and implementing specific characteristics of good dying, tensions might arise because of the incompatibility of different aims, as Sandman (2005) argues. In addition, some studies discussed the feasibility of categorising dying processes or certain elements of them as good or bad, and highlighted the possible inadequacy of such dichotomous categories for understanding a highly subjective and contingent matter such as good dying. Research on the assessment of practices and goals could aim for more nuanced data and analysis by considering what one study in our review (LeBaron et al., 2015) coined 'middle deaths'. This is an aspect that other scholars have raised with regards to palliative care and the practical ambivalence of good death through the notion of 'good enough death', both, on behalf of professionals (McNamara, 2004), but also patients and relatives (Masson, 2002). These investigations showed how social actors in practice dealt with tensions between different elements of good death and the inability to reach a good death. In empirical research, such aspects could be addressed more openly, probably without introducing a dichotomous category of good versus bad dying in the first place. Narrative approaches (Mueller, 2019; Thomas et al., 2009) to data collection using broader open-ended questions, for example, eliciting memorable experiences of professional caregivers, could be useful in this regard. Furthermore, research could search for and interpret cases that defy easy categorisation and illustrate the practical tensions between different goals. However, our own strategy of searching papers that deal with 'good dying' and similar concepts might have limited our results in this regard in the first place.

4.3. Limitations

A majority of studies in our review were conducted in anglophone countries (USA, UK, Australia). Amongst others, this could be linked to the language restriction inherent in our search and review strategy focusing on English and German publications. Further studies on this topic may be published in the respective national language of the country of data collection, but it was beyond our language competencies to consider them appropriately.

In addition, we focused on peer-reviewed journal articles, thus excluding study results published in monographs, edited volumes, as reports, or conference papers. Although we covered a wide range of academic journals searching Scopus, MEDLINE, and CINAHL, using additional databases could have expanded our review and findings.

While we used a broad variety of search terms to grasp different concepts related to good dying, we cannot rule out that we have missed studies using different terminology. The same holds true for our definition of professional caregivers. We searched studies on different professional groups, not only considering nurses or physicians, but also social workers or clergy. However, other professional actors might also be relevant for promoting good dying. Furthermore, by searching for papers dealing with 'good', 'dignified', or 'better' dying, our review to some extent remained within a conceptual frame of categorising dying processes and experiences in dichotomous categories. Although we still found papers going beyond these categories, we cannot rule out that we missed empirical research approaching our topic in other ways.

In addition, our review synthesised study findings in an a-historic way: We did not consider differences over the course of these two decades. Thus, differences presented here could not only be related to the variations in empirical approaches and contextual factors of data collection, but also to social change. Although we found rather uniform definitions of good dying across different national contexts, we cannot rule out more fine-grained differences depending on the cultural context of the studies.

Declaration of competing interest

None.

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