

Review Article

A Systematic Review of Stakeholder Perspectives of Dignity and Assisted Dying

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Abstract

Introduction. The debate on assisted dying and its components, euthanasia and physician-assisted suicide has evolved with the emergence of the right to dignity and the wish to hasten death (WTHD). Whilst shaped by local legal and sociocultural considerations, appreciation of how patients, healthcare professionals and lawmakers relate notions of dignity to self-concepts of personhood and the desire for assisted dying will better inform and direct support of patients.

Methods. Guided by the Systematic Evidence Based Approach, a systematic scoping review (SSR in SEBA) on perspectives of dignity, WTHD and personhood featured in PubMed, Embase, PsycINFO, Cochrane Database of Systematic Reviews, CINAHL, Scopus databases and four key Palliative Care journals was conducted. The review hinged on the following questions: “*what is the relationship between dignity and the wish to hasten death (WTHD) in the assisted dying debate?*”, “*how is dignity conceptualised by patients with WTHD?*” and “*what are prevailing perspectives on the role of assisted dying in maintaining a dying patient’s dignity?*”

Results. 6947 abstracts were identified, 663 full text articles reviewed, and 88 articles included. The four domains identified include 1) concepts of dignity through the lens of the Ring Theory of Personhood (RToP) including their various definitions and descriptions; 2) the relationship between dignity, WTHD and assisted dying with loss of dignity and autonomy foregrounded; 3) stakeholder perspectives for and against assisted dying including those of patient, healthcare provider and lawmaker; and 4) other dignity-conserving measures as alternatives to assisted dying.

Conclusion. Concepts of dignity constantly evolve throughout the patient’s end of life journey. Understanding when and how these concepts of personhood change and trigger the fear of a loss of dignity or intractable suffering could direct timely, individualised and appropriate person-centred dignity conserving measures. We believe an RToP-based tool could fulfil this role and further study into the design of this tool is planned. *J Pain Symptom Manage 2022;000:e1–e14. © 2022 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>)*

Key Words

Assisted dying, Palliative care, Dignity, End of life, Euthanasia, Hasten death, Personhood, Physician assisted suicide, The ring theory of personhood

Introduction

Until recently, the debate on assisted dying and its components, euthanasia, and physician-assisted suicide, has been largely influenced by local legal,

practical, social and cultural considerations.^{1,2} It has also been largely confined to patients with limited prognoses. Here, euthanasia refers to the intentional administration of lethal drugs by a physician

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to end a patient's life.^{3–7} Physician-assisted suicide refers to the act of providing a patient with lethal medication and/or the means to end their lives.^{4,8,9}

However, the introduction of the right to die and the maintenance of dignity for the terminally ill has seen views and requests for assisted dying change. Hendry et al,¹⁰ Monteforte-Royo et al¹¹ and Rodriguez-Prat et al¹² found that the highly individualised requests by patients and their families for assisted dying were increasingly triggered by fears or the presence of a loss of dignity.^{10–12} These include irreversible physical deterioration, immobility, incontinence; failure to manage daily activities; limitations to or a loss of independence and autonomy; and/or compromises to one's personal, familial, professional, and societal roles.^{10–12} Determinations of intractable and/or 'unbearable physical or mental suffering' associated with an irretrievable loss of dignity are especially pertinent in the Netherlands, Belgium, Luxembourg, Switzerland, Canada, New Zealand and states such as Oregon, California, Colorado, District of Columbia, Hawaii, Maine, New Jersey, New Mexico, Vermont and Washington where it could lead to legally sanctioned access to assisted dying.⁵

Rodriguez-Prat and van Leeuwen¹³ revealed that concepts of dignity within the assisted dying debate are not static but dynamic, complex, highly personalised, socially informed, and context dependent suggesting that these concepts evolve over the course of a disease and in different care, health, social, relational and personal circumstances. In turn, these postulations demand holistic, longitudinal, and personalised study of dignity. However, such studies have been limited.

To help this process of understanding changing self-concepts of dignity, the research team built on links between self-concepts of dignity and notions of personhood or how patients conceive "what makes you, you" to posit that the Ring Theory of Personhood (RToP) could proffer a better appreciation of ties between self-concepts of personhood, dignity, WTHD and support or opposition to assisted dying.^{10,14–17} Perhaps more significantly, these authors suggest that the RToP could map changes in self-concepts of personhood as patients progress along their illness trajectories, providing physicians with a unique opportunity to address changing notions of dignity and direct timely, appropriate and personalised support to stakeholders confronting concerns over losses of dignity. This could prove invaluable in the care of patients in the Netherlands, Belgium and in states like Oregon and Washington where over 60% of requests for assisted dying relate to a loss of dignity.⁵

The Ring Theory of Personhood

The RToP posits that concepts of personhood may be represented by the Innate, Individual, Relational and

Societal Rings. Each ring contains specific values, beliefs and principles that inform their corresponding identities.

The Innate Identity is derived from the patient's Innate Ring which informs their thoughts, feelings, personality, narratives, conduct, values, beliefs, principles, biases, experiences, and decision-making processes in relation to their spiritual, religious and/or theist values, moral ideals, and ethical principles. The Individual Identity draws on the values, beliefs and principles surrounding the patient's conscious function contained within the Individual Ring. The Individual Identity is informed and informs the patient's narratives, experiences, and personality. The patient's Relational Identity is born of values, principles and beliefs governing their important personal relationships within their Relational Ring. The Societal Identity is shaped by the values, principles and beliefs informing their interactions with those people whom the patient deems do not share personal nor important relationships with them. The Societal Identity is also shaped by regnant societal, religious, professional, and legal expectations.

Need for this Review

Whilst it would be naïve to assume that all requests for assisted dying can be addressed through better appreciation and appropriate responses to distressing changes to self-concepts of personhood, these new insights do suggest that they may be helpful to some patients in this category, thus warranting closer attention. In the absence of studies into concepts of personhood, dignity, WTHD and assisted dying, we propose to study current arguments in the assisted dying debate through the lens of the RToP.

Theoretical Lens

The RToP's Innate, Individual, Relational and Societal elements embodies the notion of dignity as "an individual's intrinsic and inalienable right to respect, and a measure of self-worth and honour".¹⁴ Chua, Quah¹⁴'s recent review on concepts of dignity amongst patients suggests that the RToP accounts for the influence of the patient's personal history, experiences and narratives "generated in the interactions between and amongst individuals, collectives and societies".¹⁸ Importantly, Chua, Quah¹⁴ postulate that the four rings of the RToP are sufficiently sensitive and adaptable to detect and map changes in concepts of personhood and thus guide support of evolving concepts of dignity.

Methodology

Krishna's Systematic Evidence Based Approach (SEBA) is adopted to guide this systematic scoping review (SSR) (henceforth SSR in SEBA).^{19–26} SEBA's

constructivist approach^{27–31} and relativist lens^{32,33} acknowledges dignity as a sociocultural construct “which considers both social and cultural constructs and the interrelationships between them”³⁴ enabling this SSR in SEBA to map current concepts of dignity across diverse settings, cultures, healthcare systems and legal mechanisms. Critically, this approach incorporates data from traditional peer-reviewed research-based publications and information from position, perspective, conference, reflective and opinion papers, editorials, commentaries, letters, posters, oral presentations, forum discussions, interviews, blogs, governmental reports, policy statements and surveys (grey literature).

To provide a balanced review, an expert team comprised of a librarian from the National University of Singapore’s (NUS) Yong Loo Lin School of Medicine (YLLSoM) and local educational experts and clinicians at YLLSoM, National Cancer Centre Singapore, Palliative Care Institute Liverpool, and Duke-NUS Medical School helped to oversee SEBA’s 1) Systematic Approach, 2) Split Approach, 3) Jigsaw Perspective, 4) Funnelling Process 5) Analysis of data and non-data driven literature, and 6) Discussion Synthesis (Fig. 1).

Here we provide a brief description of SEBA’s six-stages but include a more detailed description in the appendix ([Supplementary File 1](#)).

Stage 1 of SEBA: Systematic Approach

The SEBA methodology begins with the research and expert teams agreeing upon the research

questions, the search terms, and the databases to be scrutinised. In this case, the primary research question was “*what is the relationship between dignity and the wish to hasten death (WTHD) in the assisted dying debate?*” The secondary research questions were: “*how is dignity conceptualised by patients with WTHD?*” and “*what are prevailing perspectives on the role of assisted dying in maintaining a dying patient’s dignity?*”

In keeping with SEBA, a PICO’s (Population, Intervention, Comparison, Outcome, study design) format was adopted to guide the research process (Table 1). There was no comparison group.

Independent searches of PubMed, Embase, PsycINFO, Cochrane Database of Systematic Reviews, CINAHL, Scopus databases were accompanied by hand searches of the Journal of Pain and Symptom Management, BMC Palliative Medicine, Death Studies, and Palliative Medicine. In keeping with Pham, Rajic³⁵’s recommendations, the searches were restricted to articles published between January 1st 2001 and December 31st 2021 to accommodate existing manpower and time constraints. Quantitative, mixed and qualitative research methodologies meeting the inclusion criteria were included. With many current survey and assessment tools unable to capture the intricate connections and personalised nature of wider concepts of dignity, assisted dying, WTHD, personhood and identity, grey literature was included as a rich source of information. These resources capture wider patient, HCP and lawmaker perspectives and offer information on ethical, existential, and societal considerations often excluded by traditional systematic reviews as evidenced

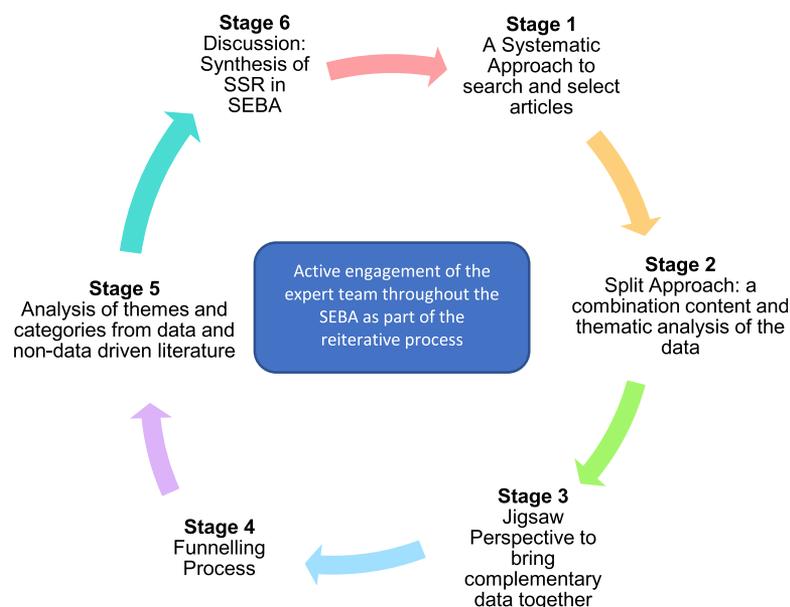


Fig. 1. The SEBA Process.

Table 1
PICOS, Inclusion and Exclusion Criteria Applied to the Database Search

PICOS	Inclusion Criteria	Exclusion Criteria
Population	Patients receiving end-of-life care (i.e. palliative care patients) Patients with terminal illnesses or life-limiting conditions Healthcare professionals, defined by and limited to: doctors, nurses, medical social workers, physiotherapists and occupational therapists Caregivers	Patients of non-medical specialties such as Veterinary, Dentistry, Alternative and Traditional Medicine Patients with non-terminal illnesses or non-life-limiting conditions
Intervention	Provision of avenues to perform euthanasia (active or passive), physician assisted suicide, mercy killing	Practices such as palliative sedation Papers not mentioning euthanasia (active or passive), physician assisted suicide, or any interventions intended to prematurely end a patient's life
Comparison	Comparisons of patient, healthcare providers and lawmaker views on the effect dignity has on the want for assisted death Comparisons of patient, healthcare providers and lawmaker views on how the act of assisted dying affects dignity.	N/A
Outcome	How the preservation of dignity affects patient views on assisted death How assisted death preserves dignity	Outcomes not relevant to assisted death or dignity
Study Design	Articles in English or translated to English All study designs including: mixed methods research, meta-analyses, systematic reviews, randomised controlled trials, cohort studies, case-control studies, cross-sectional studies, descriptive papers, guidelines, position, perspective, conference, reflective and opinion papers, editorials, commentaries, letters, posters, oral presentations, forum discussions, interviews, blogs, governmental reports, policy statements and surveys. Year of Publication: 2000-2021 Databases: PubMed, Embase, PsycINFO, Cochrane Database of Systematic Reviews, Scopus, CINAHL Journals: Journal of Pain and Symptom Management, BMC Palliative Medicine, Death Studies, Palliative Medicine	Articles in languages other than English Publications before 1 st January 2001 or after 31 st December 2021

by recent reviews into how physicians and patients deal with death and dying and moral distress.^{14,36–42}

Stage 2 of SEBA: Split Approach

Krishna's 'Split Approach'^{35,43–47} was employed to minimise oversight of key details, enhance the reliability of the analyses and provide a holistic picture of the included articles.^{43–45} This saw three groups of researchers independently analysing the included articles.

The first team summarised and tabulated the included full-text articles to ensure that key aspects of the included articles were not lost (*Supplementary File 2*).

Concurrently, the second team analysed the included articles using Braun and Clarke⁴⁸'s approach to thematic analysis.

A third team employed Hsieh and Shannon⁴⁹'s approach to directed content analysis using *a priori* coding categories from Rodriguez-Prat's¹² 'Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography' and Chua, Quah¹⁴ 'A

systematic scoping review on patients' perceptions of dignity'.

Directed content analysis reduces omissions of negative findings seen with thematic analysis and draws to the fore key points of discussion in regnant literature.^{43–45}

Stage 3 of SEBA: Jigsaw Perspective

Guided by Phases 4 to 6 of France, Uny⁵⁰'s adaptation of Noblit, Hare⁵¹'s seven phases of meta-ethnography the themes and categories identified in the Split Approach were combined to create themes/categories.

Stage 4 of SEBA: Funnelling Process

The Funnelling Process employs Phases three to five of the seven phases to juxtapose the themes/categories with key messages identified in the tabulated summaries to create domains. These domains form the basis for 'the line of argument' in the discussion.

Results

6947 abstracts were identified from the six databases and hand searches of the four selected journals. 663 articles were reviewed, and 88 articles were included (Fig. 2). 34 articles were primary studies^{7,9,52–84} which were articles with original data, such as case studies, cross sectional studies and phenomenological studies. 14 articles were secondary studies^{4,10–13,85–93} which includes reviews and articles that discuss material originally presented elsewhere. 39 articles were tertiary articles^{3,5,6,8,94–128} which include guidelines, position, perspective, conference, reflective and

opinion papers, editorials, commentaries, letters, posters, oral presentations, forum discussions, interviews, blogs, governmental reports, policy statements and surveys.

The included articles' setting, and legality of euthanasia and physician assisted suicide are summarised in Table 2.

The four domains identified include concepts of dignity through the lens of the RToP; the relationship between dignity, WTHD and assisted dying; patient, healthcare providers and lawmaker perspectives of dignity; and dignity-conserving measures.

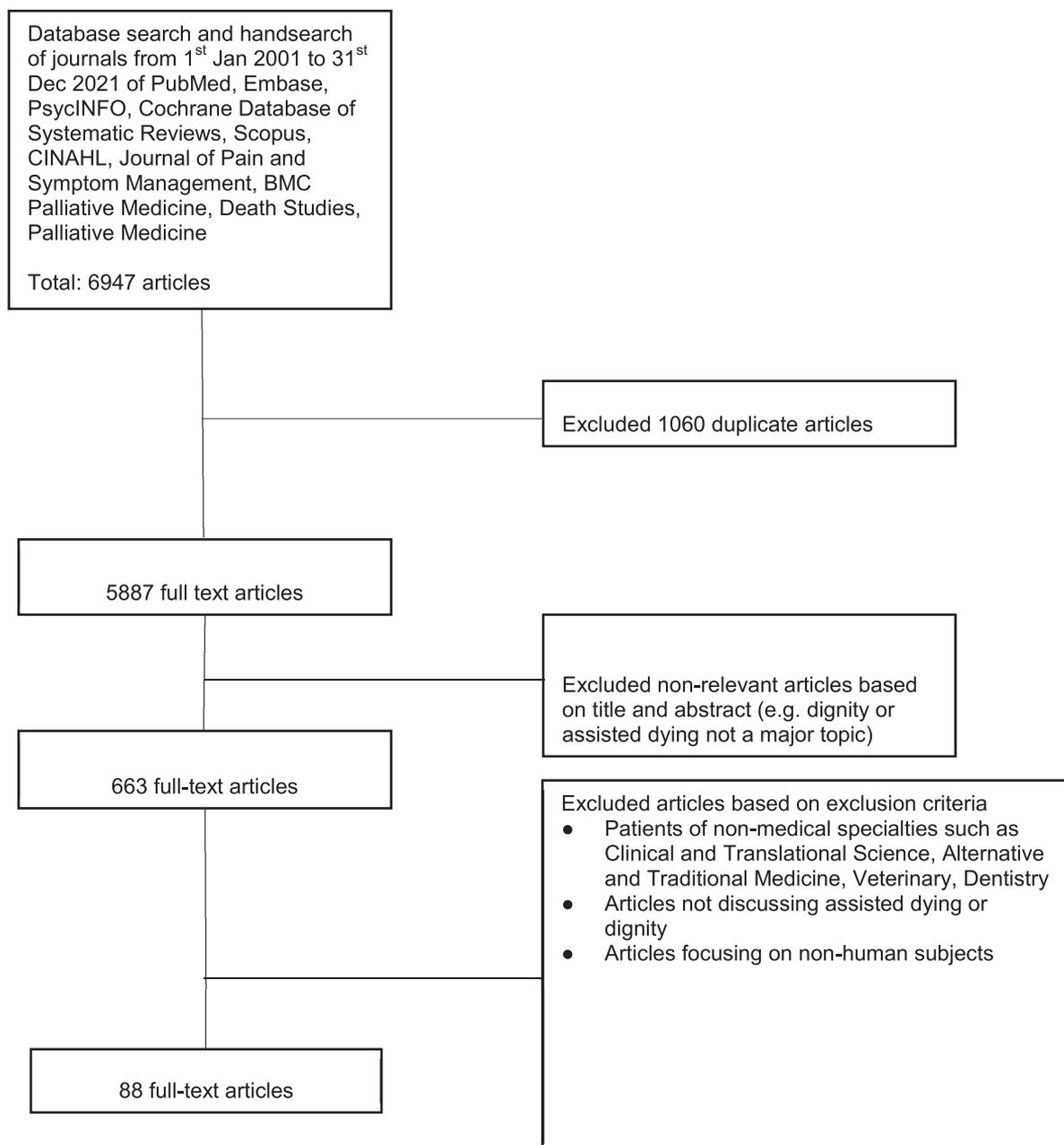


Fig. 2. PRISMA Flowchart.

Table 2
Setting of Included Articles

Country		Number of Articles	
Australia		6	
Belgium		3	
Canada		6	
Chile		1	
France		2	
Germany		2	
Greece		1	
India		1	
Japan		1	
Netherlands		11	
New Zealand		2	
South Africa		1	
Spain		1	
Sweden		1	
Switzerland		4	
United Kingdom		11	
United States	Massachusetts	1	
	Oregon	6	
	Columbia	1	
	New York	1	
	Washington	1	
	Unstated	6	
	Mixed	4	
Mixed		14	
Unmentioned		3	
PAS	Euthanasia		
Legal	42	Legal	25
Illegal	26	Illegal	49
Mixed	21	Mixed	15
Unmentioned	3	Unmentioned	3

Our primary research question – “*what is the relationship between dignity and the wish to hasten death (WTHD) in the assisted dying debate?*” – was addressed in Domains one, two and three.

Our secondary research questions – “*how is dignity conceptualised by patients with WTHD?*” and “*what are prevailing perspectives on the role of assisted dying in maintaining a dying patient’s dignity?*” were addressed in Domains two and four.

Domain 1: Concepts of Dignity

Twenty-three of the 88 included articles provided a description of dignity.^{3,8,12,13,53,56,61,64,72,76,80,85,89,97,103,109–112,116,119,120,126} When analysed individually through the lens of the RToP, some regnant definitions of dignity straddled more than one ring of the RToP.^{12,13,64,97,126}

Eight of the 23 definitions of dignity involved the Innate Ring^{12,13,76,97,103,111,116,126} and touched upon the patient’s intrinsic worth,^{12,13,97,103,111,126} self-image^{13,97,116} and spirituality.^{12,13,76,97,126}

Seventeen definitions contained aspects in the Individual Ring^{3,8,12,13,53,64,72,85,89,97,109–112,116,119,120,126} and involved autonomous function. These included loss of control,^{8,12,13,89,97,110,111,119,120,126} compromises to physical and cognitive capacity^{13,120} and increased dependence on others.^{8,12,13,85,111,119,120} These

considerations are exacerbated by symptoms,^{8,85,111,116} futility of treatment,^{3,13} treatment side-effects,⁸ the dying process^{13,53,72,109,111,112,119,120} and limitations to the desired place of death.⁷²

Six definitions involved the Relational ring,^{8,64,80,97,120,126} acknowledging the import of close social connections,^{8,126} familial roles, responsibilities and respect.^{64,97,120} Being a burden on family also negatively impacted the Relational Ring and exacerbated a loss of dignity.^{80,120}

Five aspects of current definitions considered maintenance of societal roles and responsibilities within the Societal ring.^{12,13,56,61,111} Dignity was developed through life via interpersonal relationships,^{56,111} and having value to society.¹³ A sense of self-burden was not just felt as an impact on those close to the patient, but also on the wider society.^{12,61}

Four elements impacted more than one ring. These were self-image,^{13,97,116} a developing sense of respect through interpersonal interactions,^{56,111} being a valuable member of society,¹³ and not being a burden to family and the wider society.^{12,61}

Domain 2: Relationship between Dignity, WTHD and Assisted Dying

A loss of or the fear of a loss of dignity and/or autonomy are amongst the biggest sources of WTHD.⁴
–13,52,53,58,60,62,66,67,69,71,73–75,78,79,83–88,91,93,94,96–98,100,

101,104,106,109,114–116,121–123 Unsurprisingly, attenuating these fears reduced WTHD.^{8,74} Gentzler¹¹⁹ argued that this can be accomplished simply by ensuring patients have the option to request for assisted dying.^{10,71,107,108,120,124,125} Here, the option offers an ‘escape route’.

Eight articles argued that access to assisted dying helped preserve patient’s dignity^{3,10,71,96,107,108,120,125} whilst three articles argued that the lack of such access exacerbated a loss of dignity.^{8,94,129}

Domain 3: Patient, Healthcare Provider (HCP) and Lawmaker Perspectives for and against Assisted Dying

Fifty-three articles reported on the position of patients, healthcare provider (HCP)s and lawmakers in support of and in opposition to assisted dying.

Patient Perspectives. Of the thirteen articles discussing patient perspectives, nine were in favour of assisted dying^{53,58,59,70,102,106,110,128} while eight opposed it.^{6,8,53,58,70,110} Three discussed its regulation.^{8,10,53} Proponents of assisted dying focused firstly upon the patient’s freedom of choice and their right to cease futile interventions,^{58,106} end suffering^{53,58} and determine their own death.^{53,58,70,102,110,128}

Patients opposed to assisted dying focused on ideological, moral, ethical, and religious positions.^{6,53,58,70}

Yet perhaps the most cited opposition to assisted dying revolved around practical concerns. These include concerns over the validity of consent,¹⁰ subjective judgement of a patient's quality of life,⁸ fears that legalisation of assisted dying would undermine patient-doctor trust^{6,110} and pressure vulnerable patients to accept assisted dying.^{53,58,70}

Healthcare Provider Perspectives. Thirty-six articles reported the views of healthcare providers (HCP)s. Sixteen articles were supportive of assisted dying.^{3-6,8,9,52,60,65,66,73,88,91,96,97,101,102,109,110,116,118}

They focused on facilitating a good death for the patient,^{4,8,9,60,66,73,88,91,96,97,101,102,109,110} respecting and fulfilling their autonomous desire for control^{8,60,65,66,73,88,97,110} and ending their suffering.^{4,9,66,91,101,102,109} Rodriguez³ suggested that physicians may also see assisted dying as a means of circumventing the notion of abandonment by continuing to 'journey with their patients', as well as a means of reducing the burden upon caregivers and family.

Twenty-three articles presented HCPs' opposition to assisted dying.^{3,4,6,8,52,55,56,72,96,97,99,101,104-106,110,112,117,118,121,125,126,130} These include guilt,^{112,125} grief⁷² and emotional and moral distress^{4,8,56,72,96,99,105,110,112,125,126} for transgressing regnant ethical and medical principles.^{4,56,96,105,110,126} Others believed that assisted dying diminished the role of palliative care⁸ and advocated instead for better palliative care^{3,6,101,104,105,118} and improved quality of life.^{6,105} Opposition amongst HCPs also revolved around the slippery slope argument that posits an eventual loosening of regulations^{3,72,83,99,102} and the application of assisted dying upon the vulnerable.^{106,121} HCPs point to inconsistencies in the understanding of many of the terms involved in current legislation to back these posits,^{72,102} along with vagaries surrounding prognostication,⁹⁹ the subjectivity of quality of life determinations³ and concerns over the influence and impact upon the family^{72,83} to counter evidence that no evidence of slippery slopes have been reported.

Lawmaker Perspectives. The seven papers containing perspectives of lawmakers focus on societal rights, and the protection of vulnerable groups. Those in favour of assisted dying^{94,106,114} tended to be from countries where it was legal. Dutch proponents posited that assisted dying provided a compassionate end of suffering^{106,114} whilst commentators in New Mexico, West Australia, South Australia, Switzerland, and Canada supported patients' constitutional rights to obtain aid in dying.⁹⁴ Swiss lawmakers also espoused respect for the patients' right to end their lives and their right to govern their private lives.⁹⁴

Conversely, the European Court of Human Rights declined to extend the Human Right Act of 1998 to

include the right to death in the case of Diane Pretty,¹³¹ maintaining that it would undermine the protection of life and lead to abuse of Assisted Dying.^{94,114,117} In *Haas v Switzerland*, the European Court of Human Rights maintained that a person wishing to commit suicide should not be allowed to do so hastily and that the government of Switzerland was correct in maintaining stringent requirements before patients were provided access to sodium pentobarbital for the purposes of hastening their demise. This would be consistent with governmental responsibilities to ensure that such decisions are neither hasty nor coerced particularly when Kishore⁹⁴ reports of lawmakers in the USA advocating for assisted dying to protect healthcare resources.

Domain 4: Dignity-Conserving Care

Forty-four articles made reference to alternatives to assisted dying. Twenty-two proposed palliative care interventions,^{3,5,6,8,52,55,58,63,74,79,85,88,95-97,102-105,124,125,127} better access to expert palliative care.^{58,103,104,121} Seven articles espoused that improved social support would reduce WTHD.^{52,71,73,88,101,112,123}

Twenty-one articles propose the use of dignity-conserving measures to control physical,^{10,52,55,65,85,119,126} psychological,^{52,70} and existential issues,^{52,54,58,70} enhance pain control^{10,52,55,65,85,119,126} and improve a patient's quality of life.^{83,101,103,105,112,113,118} Involving physical, psychological, social and spiritual support, compassionate personalised care^{57,118} and sensitive communication^{73,88,112,123} dignity-conserving measures are anticipated to attenuate WTHD.^{10,52,55,65,70,71,73,83,85,88,101,103,105,108,112,118,119,121,123,124,126} Concurrently, personalised and timely palliative care education will empower patients to make decisions about their end-of-life care and act to preserve their dignity and autonomy.^{73,88,101,103,108,112,123,124}

Five articles acknowledge the limitations of dignity-conserving and palliative measures,^{3,8,91,102,105} in extinguishing all forms of suffering,^{3,91} pain,⁸ and shortness of breath,¹⁰² and attend to losses in independence and autonomy.¹⁰² In such circumstances, four articles suggest use of palliative sedation^{88,96,119,125} and two the withdrawal of clinically-assisted nutrition and hydration (CANH-withdrawal)^{52,69,99} as an alternative.

Stage 5 of SEBA: Analysis of Data and Non-data Driven Literature

A novel aspect of the SEBA methodology has been its inclusion of non-data driven grey literature from PubMed, Embase, PsycINFO, Cochrane Database of Systematic Reviews, CINAHL, Scopus databases and the Journal of Pain and Symptom Management, BMC Palliative Medicine, Death Studies, and Palliative Medicine.

These papers were differentiated from data driven, evidence-based, and peer-reviewed papers, and separately compiled and thematically analysed. The themes identified from primary data sources and non-evidence based and/or tertiary data sources were then compared to enhance further the accountability and reproducibility. With themes from the two groups found to be similar, the expert and research teams were satisfied that their inclusion did not bias the overall data.

Stage 6 of SEBA: Synthesis of the Discussion

The Best Evidence Medical Education (BEME) Collaboration Guide¹³² and the Structured approach to the Reporting In healthcare education of Evidence Synthesis (STORIES)¹³³ were used to guide the discussion.

Discussion

This SSR in SEBA confirms the relationship between dignity and the wish to hasten death (WTHD) in the assisted dying debate. In so doing and in answering its primary research question, this review also reveals several considerations that build on earlier reviews by Hendry et al,¹⁰ Monteforte-Royo et al,¹¹ Rodriguez-Prat et al¹² and Rodriguez-Prat and van Leeuwen.¹³

One, the relationship between dignity and WTHD is patient, HCP, or lawmaker dependent. From the patient's perspective, concepts of dignity in current reports on assisted dying are informed by the values, beliefs and principles that underpin their self-concept of personhood, captured within the four rings of the RTOP. Building on these earlier reviews on dignity, WTHD and assisted dying which highlight that concepts of dignity conceived by patients revolve around exercising control, self-determination as well as autonomous and independent function^{8,12,13,89,97,110,111,119,120,126}, this SSR in SEBA reports that current notions of dignity are also shaped by fear. Fear may take the form of the fear of suffering physical, emotional and/or existential distress,^{8,12,13,85,111,119,120} fear of a loss of social and relational roles^{12,13,56,61,111} and respect,^{64,97,120} and a fear of being a physical, financial and/or emotional burden to family^{80,120} and others.^{12,61} Fears stemming from Individual, Relational and Societal elements of dignity appear to also precipitate requests for assisted dying.

For HCPs, the link between dignity and WTHD in assisted dying is context dependent and largely informed by whether such interventions are legal in the patient's setting. Echoing earlier reports, assisted dying is not generally supported by HCPs for existential, emotional, personal, professional, legal and/or sociocultural reasons.^{3,4,6,8,52,55,56,72,96,97,99,101,104-106,110,112,117,118,121,125,126,130} When they do support

assisted dying, HCPs see it as part of their obligation to respect a patient's autonomous desire to exert control,^{8,60,65,66,73,88,97,110} continue to 'journey with their patients', and end suffering.^{4,9,66,91,101,102,109} This respect for patient autonomy might fluctuate based on culture and changing circumstances in the care of the patient suggesting a contextual and largely individualised support for assisted dying.

The context-dependent nature of dignity and its ties to WTHD and assisted dying is especially evident amongst lawmakers, whose positions tend to be guided by whether assisted dying is available legally in their setting and if the patient satisfies the relevant requirements for assisted dying. Unlike in the Netherlands, New Mexico, West Australia, South Australia, Switzerland, and Canada, lawmakers from nations in which assisted dying has not been legalised often take a cautious view on this matter. Focus for these lawmakers is often on the potential for 'the slippery slope' and an 'inevitable erosion' of safety requirements, standards and laws that would lead to the abuse of assisted dying amongst the most vulnerable in society. Whilst fears surrounding the 'the slippery slope' argument and an 'inevitable erosion' of safety requirements, standards and laws have not been substantiated in current studies,¹³⁴⁻¹³⁶ fear that social pressure may still take its toll on vulnerable populations has not been lost in Kishore's⁹⁴ reporting of calls by some lawmakers in the USA that assisted dying may benefit decreasing resources. Here, too, circumstances and context appear to shape views on death with dignity and assisted dying.

The next few considerations tackle notions of an individualised and evolving concept of dignity and its ties with WTHD.

Two, concepts of dignity are highly individualised. Current data suggests that prioritising the importance of each aspect of dignity and determining the threshold and circumstances for what would amount to a breach in self-concepts of dignity leading to WTHD pivots on personal choices and interpretations of evolving contextual considerations. Changing priorities with regards to values, beliefs and principles within the Innate, Individual, Relational and Societal elements of personhood direct decisions as to when dignity is irreversibly compromised and when one's rights are exercised to determine the nature and timing of one's death.^{53,58,70,102,110,128}

Three, concepts of dignity evolve. This SSR in SEBA suggests that when viewed longitudinally through the lens of the RTOP, the impact of shifting contextual, practical, clinical, emotional, psychosocial, spiritual, relational, familial, and societal considerations changes individual concepts of dignity. Understanding these changes help appreciation of 'threshold events' that trigger WTHD. For example, deteriorating physical ability and mobility that compromises self-care,

independent action, autonomous functioning, increasing physical reliance on family members, healthcare professionals and caregivers, and personal failure and/or unwillingness to adapt to these realities cause change in the Individual Ring. These changes along with the patient's existential distress, emotional state, sociocultural circumstances, increasing financial and/or physical burdens on the caregivers and social isolation alter concepts of dignity and trigger WTHD and requests for assisted dying. This is supported by data that shows that WTHD often fluctuates throughout patients' end of life journey and underlines the need for a longitudinal perspective.^{8,97,105,137}

Four, self-concepts of dignity appear to be a proxy for sustaining self-concepts of personhood. Evolving concepts of dignity, reflect changes in self-concepts of personhood and identity and how patients want to be regarded by others. For example, changing social and familial roles, circumstances, and care settings in the Societal Ring shape how patients perceive themselves and see them adapt their concepts of dignity accordingly. Another implication is that it lends support for consent for treatments such as assisted dying as an effort to maintain the dignity and respect of the patient's personhood. Links between WTHD and a loss of dignity also suggest that the former may be seen as a means of relaying concerns regarding breaches in self-concepts of dignity. Rodriguez-Prat et al¹² suggest that WTHD may be a 'cry for help' or indeed a call to attention with regards to changing circumstances that the patient is unable to contend with.

A longitudinal perspective and an individual tolerance for breaches in dignity is seldom afforded to patients. The import of addressing patient distress using person-centred dignity conserving measures in a timely manner has also been neglected. Here, a RToP-based tool may be useful. Indeed, it has been proposed in recent reviews to support HCPs dealing with moral distress and those caring for the dying. It is also posited that such a tool could play a critical role in guiding decisions for palliative sedation, as a last resort in the event of a failure of specialist palliative care interventions.

An RToP-based tool offers unique potential benefits. Unlike well-established tools such as the Patient Dignity Inventory or the Dignity Care Intervention,^{64,138–140} a dignity-assessing questionnaire based on the RToP may be simpler to use and could be applied longitudinally to capture changing concepts of personhood, identity and dignity that shape WTHD and requests for assisted dying. Such a tool could identify violations to personal concepts of dignity and direct prompt, accessible, individualised, ongoing, and comprehensive support and dignity-conserving palliative care to patients, their families and their families. It is conceivable that this could

attenuate the potential for losses of dignity and possible spirals to WTHD.^{8,13,57,97,105,118,137,141}

Such a tool could temper HCPs' own biases, balance decision-making and, when applied with personalised palliative care measures, guide decisions for palliative sedation and CANH withdrawal as a viable alternative to assisted dying in the face of intractable suffering.^{92,142} It also raises the notion that a specialist palliative care consultation should be mandatory before assisted dying is considered. Guided by the RToP-based tool, holistic specialist psycho-existential support could ameliorate WTHD. This would also attenuate fears that use of assisted dying hampers palliative care development. More time for patients to cogitate on their perspectives of dignity and how it evolves in the face of various personal, clinical, contextual, sociocultural, and legal considerations may also allow deeper reflection on what defines who they are and 'what makes you, you'.

However, the RToP-based tool is not a naïve offering to circumvent needful discussions on the rights of patients nor an attempt to subvert the right to choose assisted dying where available. Rather, it serves to realise the goals of palliative care – to journey with patients and their family, guide holistic and person-centred dignity conserving care and ensure timely palliation of suffering.

We note several limitations to this SSR in SEBA. A critical consideration is its focus on articles published in English. This identified largely Western concepts of dignity within the assisted dying debate. Of the 73 articles, two publications involved Asian perspectives and only one covered perspectives from South Africa. In turn, 20 articles were set in the USA, 11 in UK and 11 in the Netherlands. These limitations are compounded by our focus upon articles published after 2000.

We also note that grey literature included in the final list of articles reviewed are opinion-based and neither evidence-based nor peer-reviewed. Whilst we have sought to evaluate and compare the themes drawn from grey literature and those from conventional data driven sources, it is still conceivable that grey literature may inadvertently give rise to partisan point of views particularly due the delicacy of this subject matter.

Conclusions

Concepts of dignity constantly evolve along individual contextual, practical, clinical, emotional, psychosocial, spiritual, relational, familial, sociocultural and legal considerations and continue to fluctuate throughout the patient's end of life journey. These self-concepts of dignity appear to be a proxy for sustaining self-concepts of personhood and how patients wish to be

perceived by others. A loss of or the fear of a loss of dignity or autonomy are amongst the more prominent sources resulting in the patient's wish to hasten death and their request for assisted dying. However, the import of addressing patient distress using person-centred dignity conserving measures in a timely manner has been neglected. We believe a tool based on the Ring Theory of Personhood may be helpful in identifying violations to personal concepts of dignity and allow for prompt, accessible, individualised, ongoing and comprehensive dignity-conserving support to be directed to patients and their families. Guided by this tool, holistic psycho-existential support provided by specialist palliative care teams could help to attenuate their distress. As we continue to extend our understanding of suffering, dignity and the wider role of palliative care, we will direct our attention to the design and evaluation of this tool.

Consent for Publication

NA.

Availability of Data and Materials

All data generated or analysed during this review are included in this published article and its supplementary files.

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Supplementary materials

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