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# "An indelible mark" The response to participation in euthanasia and physician-assisted suicide among doctors: a review of research findings.

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#### **Abstract**

#### Introduction

The debate regarding euthanasia and physician assisted suicide (E/PAS) raises key issues about the role of the doctor, and the professional, ethical and clinical dimensions of the doctor-patient relationship. This review aimed to examine the published evidence regarding the response of doctors who have participated in E/PAS.

#### **Methods**

Original research papers were identified reporting either qualitative or qualitative data published in peer-reviewed literature between 1980 and March 2018, with a specific focus on the impact on, or response from physicians, to their participation in E/PAS. PRISMA and CASP guidelines were followed.

#### **Results**

Nine relevant papers met selection criteria. Given the limited published data, a descriptive synthesis of quantitative and qualitative findings was performed. Quantitative surveys were limited in scope but identified a mixed set of responses. Where measured 30-50% described emotional burden or discomfort about the participation, while findings also identified a comfort or satisfaction in believing the request of the patient was met. 15-20% reported significant ongoing adverse personal impact. A minority of doctors sought personal support, generally from family or friends, rather than colleagues. The themes identified from the qualitative studies were summarised as: 1) Coping with a request; 2) Understanding the patient; 3) The doctor's role and agency in the death of a patient; 4) The personal impact on the doctor and 5) Professional guidance and support

### **Significance of Results**

Participation in E/PAS can have a significant emotional impact on participating clinicians. For some doctors, participation can contrast with perception of professional roles, responsibilities and personal expectations. Depsite the importance of this issue to medical practice, this is a largely neglected area of empirical research. The limited studies to date highlight the need to address the responses and impact on clinicians, and the support for clinicians as they navigate this challenging area.

Keywords: euthanasia; physician-assisted suicide; review

#### INTRODUCTION

Internationally, the debate concerning medically assisted dying, whether euthanasia or physician-assisted suicide (E/PAS), has focused attention on the complex issues faced in the medical care of the seriously ill and dying. Intrinsic to this debate is the place of assisted suicide in medical practice, the role of the doctor, and the professional, ethical and clinical dimensions of the doctor-patient relationship. However, research among doctors to date regarding their perspectives on assisted suicide have chiefly focused on general attitudes towards assisted suicide (Van der Heide et al., 2007). When actual clinical practices are surveyed, studies have been chiefly large scale studies of prevalence of self-reported interventions and intentions to hasten death.

Why might clinician perspectives matter? Firstly, considerable debate focusses on the role of E/PAS as a "medical treatment", constructing chosing to die as a medical decision (Chochinov, 2016). Secondly, previous research has identified the potential link between clinician attributes and the wish to hasten death among terminally ill cancer patients (Kelly et al., 2004). It is established that factors such as "non-conscious bias" can influence a clinician's assessment and choice of treatment offered to patients (Stone & Moscowitz, 2011). This can manifest in potential "collusion" between patients and clinicians that may lead to a failure to explore potential concerns, carefully assess decision-making capacity (Kissane, 2004) or challenge the patient's perspective, such as feelings of futility of living in the face of incurable disease (Robinson et al., 2015; Robinson et al., 2016), or the perceived indignity of loss of independence that accompanies severe illness (De Vries et al., 2018). Research has also highlighted the complexity for clinicians of meaning and intention attached to clinical decisions made in the care of dying patients: the misperceptions regarding the consequences of actions such as potential beneficial or hazardous effects of treatments such as analgesia (e.g. the complexity of "double effect"; White et al., 2011); and the different

meanings and impacts for clinicians between withholding or withdrawing treatment (Chung et al., 2016).

Furthermore, the psychological impact on clinicians of adverse patient outcomes in many fields of clinical practice is well established (Guest et al., 2011 a; Guest et al., 2011 b). This includes the impact of the death of a patient on the clinician, even when this occurs as a direct consequence of natural cancer progression (Granek et al., 2015). Clinical observations suggest that these reactions are likely to be more intense when involving a degree of real or perceived personal responsibility for poor outcomes or death of a patient (Tan & Gallagher, 2017). Finally, the death of a patient through suicide is known to have a profound effect on treating clinicians (Draper et al., 2014).

These lines of evidence demonstrate a range of challenges faced by doctors in the care of dying patients. These complexities may be accentuated in the care of the dying patient requesting assisted suicide (Muskin, 1998; Hudson et al., 2015) and may lead to a degree of "moral distress", compounded by the often diverse and divided opinions regarding such complex treatment decisions and their consequences. This has direct implications for the practice of assisted suicide in which clinicians will have a direct or indirect role in the deliberate hastening of the death of a patient. Furthermore, research from other fields (e.g. veterinary practice) suggest that such actions leading to death, or actions that may be experienced as "killing", can have long term adverse psychological effects, that have been described as "perpetrator-induced" traumatic stress (Rholf & Bennett, 2005).

Linking these lines of enquiry and observations from previous research, this study aimed to examine the existing evidence regarding the experiences and reported impact on doctors as a result of participation in euthanasia/physician-assisted suicide (E/PAS). The specific focus for this review was on those studies that examined the impact and experiences

of doctors who had undertaken Euthanasia, defined as "the deliberate administration of medications with the explicit intention of ending a patient's life (with or without an explicit request)", and/or Physician Assisted Suicide, defined as "the prescribing or supplying drugs with the explicit intention of enabling the patient to end his or her life" (Haverkaate et al, 2001).

# **METHODS**

#### Inclusion criteria

The search comprised original research papers published in peer-reviewed English language literature between 1980 and October 2018. This included both studies reporting quantitative and qualitative data, with a specific focus on the impact on, or response from physicians, to their participation in PAS/E. The quantitative review was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009). The qualitative review used the Critical Appraisal Skills Programme (CASP, 2013) to assess whether studies were valid, reliable and trustworthy. The results from the qualitative and quantitative studies were summarised using a "best evidence" synthesis (Slavin, 1995). This entailed a systematic approach to selection of papers and a descriptive approach to synthesis of findings as detailed below.

#### **Exclusion criteria**

As this review focussed on original research evidence regarding the impact of participation in E/PAS, reports of findings from surveys soley focussing on physician views about E/PAS (rather then experiences of) were excluded, as were studies of physicians experiences of end-of-life care in general. Where not identified by the initial search terms, conference abstracts or editorial papers were manually excluded.

# **Search Strategy**

The following MeSH terms were used for the search: "euthanasia" or "assisted suicide" or "hastened death" or "desire to die" or "suicide" or "end of life". In order to ensure a sufficiently comprehensive search of published data, broad terms were needed that reflected the relevant terminology in this field. Three databases were searched: Medline, Embase, and PsychINFO. A broad initial search was necessary given the varying terminology used in this field to describe medical involvement in end-of-life decisions. As indicated above, the specific focus for this review was on those studies that examined the impact and experiences of doctors who had undertaken E/PAS in accordance with the definition (Haverkaate et al, 2001). As a result, our review aimed to identify those studies from a sufficiently encompassing initial set of search terms with this specific focus, rather than responses to a range of the many other aspects of end-of-life care. A step-wise process was undertaken with review of title, abstract, and then full paper where relevant.

# **Data collection**

Potential papers were screened by two authors (TH and BK). As required by PRISMA and CASP guidelines, the following details were extracted from each relevant paper: Study population, locality, outcome measures and data analytic methods. Quality criteria were applied using accepted metrics for evaluation of qualitative research publications (Hannes et al Cochrane Collaboration)<sup>22</sup> (indicated by asterix in Table 1). Within a "best evidence" synthesis, a descriptive approach to summarising key findings was necessary derived from the systematic selection of published research findings.

#### **RESULTS**

In total the search resulted in 13,684 papers being identified. Of these, 3,385 were duplicates, leaving 10,299 results to be screened. The predominant reasons for excluding results were that they were conference abstracts or papers (n = 2,956), editorials, commentaries or ethical/legal perspectives (n = 1,838), review articles (n = 770), or were written by an anonymous source (n = 188). The majority of the remaining studies (n = 4,317) were research on opinions (general population surveys, surveys of health professionals' views, vignettes), or had a focus on end-of-life care in general rather than euthanasia/assisted suicide. Flow chart 1 depicts this process of study selection. Following the screening, ten relevant papers were identified. One paper was excluded as it did not meet quality criteria (Obstein et al., 2004), hence nine papers were reviewed. In keeping with the small number of studies, the diversity of methods and published data, it was not possible to pool data for statistical analysis.

#### **Quantitative studies**

The four key studies identified were surveys of clinician practices and experiences with PAS/E, in which questions related to the impact on the clinician were included. In the majority of these studies, this impact was not the key focus of the study. The most specific published report on this topic concerned a study of 405 physicians in the Netherlands (89% response rate), in a nationwide survey of physicians regarding their emotional responses to E/PAS and medical decisions at the end of life undertaken between 1995-96 (Haverkaate et al., 2001). While E/PAS remained illegal, doctors were considered exempt from liability "if they report their actions and show that they have satisfied the requirements for prudent practice" (p519). Of the 159 physicians who reported having performed euthanasia, feelings of "discomfort" were reported by 52% of the sample (described as "emotional" in 28% and "burdensome" in 25%). Forty three percent (43%) had sought any form of support following

these actions, chiefly non-professional in nature (83% of those seeking support, doing so from family or friends). Greater discomfort was reported in those cases of euthanasia (75% reporting discomfort), where it was conducted without explicit patient request, where there was a perceived greater shortening of life as a result; when the patient was a male, and the patient had a cancer diagnosis. It is important to note that alongside the discomfort, feelings of "comfort" (e.g. relief, satisfaction) were also reported by 63% of instances of PAS and 52% of Euthanasia cases, and despite the other findings only 5% reported having doubts about conducting euthanasia.

Ganzini and colleagues (2000) reported on findings from a survey of 2649 physicians (65% response rate) in the US State of Oregon conducted in 1999 following legalisation of PAS in 1997. One hundred and forty four participants reported having received a total of 221 requests for PAS via prescription. The findings reported here concern the findings among the 29 respondents (18% of the sample) who had provided prescriptions in response to such a request. The reported reason given for the request was predominantly a desire for control over death (83% of cases). In only nine of these cases (31%) was the physician present at the death. The problems reported by those physicians included unwanted publicity (n=3), difficulty understanding the law (n=3), difficulty with hospice providers (n=1), not knowing the patient (n=1), and absence of somebody to discuss the case with (n=1). A majority expressed concerns about reporting the cases (n=18). Four participants reported ambivalence about having provided assistance, and one indicated that they would not provide assistance again. Reasons were not provided.

In 2015 Riou et al. reported findings from the 2009 'End of Life in France' Survey, a jurisdiction in which E/PAS is prohibited. This survey included questionnaires relating to 4891 deaths (response rate 35%), completed by the physicians who had certified the death.

The report presented findings from physicians who had indicated utilizing "medical drugs to deliberately end a patient's life" (Riou et al., 2015). Thirty six physicians (majority general practitioners) indicated having undertaken such actions. The report highlighted "ambivalence regarding actions," a degree of "confusion" regarding the clinicians' intention, and actions especially relating to the dual effect of interventions (e.g. "terminal sedation"). Four cases involved discussion with a "fully competent" patient, but findings also indicated decisions were often made on the patient's behalf, with the report indicating that in 23 cases, the actions were not discussed with the patient and no advance directive was available. Other interesting observations included the frequent delegation of the actions to a nurse, and the limited interprofessional communication around such cases at the time.

In 1998, Emmanuel and colleagues reported on a US study of a random selection of 355 US based oncologists (72.6% response rate), undertaken in 1994 (prior to legislation of PAS). Fifty three indicated that they had been physicians who participated in PAS or Euthanasia. Although 50% reported "comfort" with their actions, 30% described an emotional burden resulting from these actions, including an impact on future practice, with 15% reporting significant adverse effects (e.g. feeling "burned out", and "avoidant"). Twenty five percent regretted their actions, reporting feeling some conflict about their role in the patient's death, and some ongoing doubts e.g. "the patient might have benefited from living to the end"). Forty percent described a fear of prosecution.

#### **Qualitative studies**

Five qualitative studies met accepted qualitative research assessment criteria (Hannes et al Cochrane Collaboration, 2011). The following six themes arose from the synthesis of qualitative studies: 1) Experience of the request; 2) Understanding the patient; 3) The

doctor's role and agency in the death of a patient; 4) The personal impact on the doctor; and 5) Professional guidance and support.

# **Experience of the request**

A diversity of responses occurred to the experience of the request for assisted suicide from a patient. It appeared that for those more experienced in the care of dying patients, the managing of such requests was perceived as being in "parallel with other end-of-life decisions" (Dobscha et al., 2004). In one report (Kohlwes et al., 2001), clinicians reported that many requests were "exploratory", reflecting fears regarding the uncertain process of dying. Reflecting on requests occurring in the last stages of life, this report highlighted the importance to clinicians of exploring the "why" rather than "when" of the request. A recent study among a sample of Dutch clinicians indicated a sense of their role being "overlooked" in the public debate about E/PAS, particularly in those experiencing requests not based on a medical condition (Snijdewind et al., 2016). This study reported statements from clinicians such as "people have no idea what it entails for a GP" and "I felt (then) that the family were putting an incredible amount of pressure on me". A notable perspective reported in one study was the sense of failure as a clinician when confronted by a patient's request for assisted suicide: "whatever you are doing isn't good enough", and "it's not meeting my (patient's) needs" (Dobshca et al., 2004).

#### **Understanding the patient**

The studies identified a range of experiences and reflections from clinicians concerning their consideration, in retrospect, of the patient's motivations and the extent to which they were satisfied with their understanding of their patient at the time. This was clearly seen as a distinct task for the clinician by participants in at least two of the studies (Kohlwes et al.,

2001; Dobshca et al., 2004). Issues noted included the dominance of the patient's desire for assertion of autonomy and control (Kohlwes et al., 2001; Dobshca et al., 2004) and also "existential concerns" such as coping with "a world undone" (Kohlwes et al., 2001). Others expressed a concern at having, on later reflection, "not full understanding" or not agreeing with the patient's perspective or choices, and having "not communicated enough" (Dobscha et al., 2004). One participant summed up the dilemma as needing to understand "why to die, not when to die" (Kohlwes et al., 2001). Others reflected on "insufficient knowledge of alternatives"; or in retrospect, the perceived influence of others (e.g. family; Riou et al., 2015). The experience of the perceived extension of E/PAS to "address non-medical reasons", provoked the comment that "we are getting into a situation where people are chosing to die because of loneliness" (Snijdewind et al., 2016).

# "Being a Doctor": Role and agency in the death of a patient

A dominant theme that was identified across these studies could best be described as "Being a Doctor: Role and agency in the death of a patient". As expressed by one participant, "to have to decide the moment of death has created enormous unrest around the deathbed" and that the role was "at odds with myself and my role" (Emanuel et al., 1998). Others reported experiencing tension with what was perceived as the societal expectations of the "modern doctor" (i.e. to hasten death) despite personal or professional misgivings (Dobscha et al., 2004; van Marwijk et al., 2007). Similarly, this was encompassed in the view that even if it was considered legal, "I felt uncomfortable doing it myself" (Dobscha et al., 2004).

This perception related to the ongoing emotional ambivalence about the act, reflecting the experience of a tension between "duty to patient" vs "unacceptable act" (Emanuel et al., 1998; van Marwijk et al., 2007). Independent of the clinician's desire to deliver patient-centered care, doubt and uncertainly persisted for some clinicians as to whether they had

optimally assisted the patient. This particular theme is perhaps best exemplified in the experience of one participant:

"(Not about right or wrong..) but my thoughts are about the fact that I know that it is a very difficult thing as a physician . . . I wonder if I have the necessary emotional peace to continue to participate" (Dobscha et al., 2004).

A related element of this theme was one that concerned "understanding the patient" including a sense of "duty", "obligation" to patient and "relief of suffering". Findings included perceived conflict between patient wishes, patient self-determination and professional roles, responsibilities and the concept of "duty".

# **Personal repercussions**

In regards to adverse effects, these were often expressed in terms of reflecting on the responsibility inherent in the taking of a life: e.g. "I no longer know whether it is good for me"; "we are appointed to take someone's life" (van Marwijk et al., 2007).

Across a number of the studies, similar enduring adverse impacts were noted "I felt very lonely. I couldn't share that with anyone...I felt powerless and alone." (van Marwijk et al., 2007).

This adverse impact was expressed poignantly in one study in terms of a sense of enduring "damage" from the experience: "you've got an indelible mark on your soul" (Dobscha et al., 2004). Furthermore another participant remarked that "Despite doing something for the patient"... "I still always have a sense of guilt. I feel as if I'm an executioner. Who am I to have the right to do this?" (van Marwijk et al., 2007).

Another element of this impact appeared to be the significance of later reflection itself, reactions that may not have been anticipated at the time of undertaking the PAS. A perceived gap between the "thought" or concept of E/PAS and active participation was noted: a "large gap between idealistic agreement with a thought and being actively involved in it…an immeasurable gap I hadn't anticipated" (Dobscha et al., 2004). In some instances, discomfort was related to enduring perception by participants that, on reflection, perhaps not everything had been done to address the patient's suffering.

Examples of being "moved" by the experience, experiencing positive professional learning and growth through the experience were noted by some. These consequences included the capacity to understand and respond to the needs of dying patients, a perception of providing better care to future patients or a sense of satisfaction in having fulfilled the patient's wishes and relieved suffering. Such growth included the approach to needs of future patients along with growth in "oneself" as a clinician (Dobscha et al., 2004), including a greater appreciation for palliative care for future patients. In some instances this was expressed in terms of a sense of "doing the right thing"... "comfort in helping a patient end his or her life the way the patient wished" and being more aware of future patients' needs (Emanuel et al., 1998).

#### Professional guidance and support

A consistent theme across these studies was the limited perceived availability and use of professional advice and support by the participating clinicians, in dealing emotionally with requests or coping with the impacts. It is notable that discussions with colleagues were rare, and reference was made to a professional "code of silence" (Kohlwes et al., 2001). Instead of these complex clinical scenarios being assessed by a multidisciplinary team providing diverse impressions before consensus about the optimal treatment is determined, PAS/E practice

appears individually governed. This is particularly significant when bearing in mind that studies included those in jurisdictions in which assisted suicide was legal at the time. When support was sought, this was chiefly from non-professional sources (e.g. family).

#### **DISCUSSION**

#### Main findings/results of the study

This review examines research regarding the impact of participation by clinicians in E/PAS on clinicians. A small number of reports were identified including both survey based quantitative studies and qualitative research Despite the relevance of the clinician's role (both in practice and in legislation where it exists), it is notable that few studies have examined the responses, experiences and impact on clinicians of participation in assisted suicide.

Where measured, 30-50% described emotional burden or discomfort about the participation (moreso in cases of euthanasia than PAS), while findings also identified a comfort or satisfaction in believing the request of the patient was met. A smaller number (15-20%) reported significant ongoing adverse personal impact. A minority of doctors sought personal support, and when they did so it was generally from family or friends, rather than colleagues. The themes identified from the qualitative studies indicate the diverse and often complex responses among doctors, reflecting personal and professional impacts, reflections on their role and the care of dying patients, and their approach to seeking advice or support.

In regards to the challenges faced in clinical assessment of a request for E/PAS, the findings point to the clinician self-reported limitations in understanding the forces influencing the patient's request. In one Dutch study, depressed patients were 4 times more likely to request euthanasia than the non-depressed (van der Lee at al., 2005). Ganzini reported unrecognized depression in patients seeking PAS in Oregon, with 26% of initial inquiries

coming from depressed subjects, and 33% of those completing PAS having had unrecognized and untreated depression (Ganzini et al., 2008). Another major study of 21,000 Scottish oncology outpatients revealed that 73% of those found to be depressed were not in receipt of any treatment for this (Walker et al., 2014). An additional factor driving the request for E/PAS is demoralization, a state distinguishable from depression, that is associated with feelings of greater dependency on others or the perception of being a burden, along with existential distress, and a loss of meaning (Kissane et al., 2001; Robinson et al., 2017) and experienced by up to 15% of palliative care patients (Robinson et al., 2015).

These factors highlight the barriers that can exist to clinical assessment of patients and comprehensive appraisal of decision-making capacity. Furthermore, some clinicians, in retrospect, acknowledged limitations in the care provided, and in some cases, reported a belief that they had gained a better understanding of the needs of dying patients after reflecting on these difficulties. The findings also accord with the evidence regarding the frequent reasons for request for E/PAS (Hendry et al., 2013; Emanuel et al., 2017), reflecting prominent existential concerns (e.g. concerns of loss of dignity or independence and control), contrasting with lesser prominence of uncontrollable physical symptoms (such as pain). Furthermore, the findings point to the level of "moral" discomfort experienced when such "existential" aspects of suffering underpin requests, or perceived extension of E/PAS to nonterminal conditions (Quill, 2018; Snijdewind et al, 2018). While this review focussed on studies in which participants had participated in provision of E/PAS, the emotional demands and burden for clinicians in responding to requests identified in this group were noteworthy and have been highlighted in other studies (Georges et al, 2008). Taken together, the findings from this review support evidence citing the unique difficulties clinicians face in addressing such suffering and existential issues for patients (Emanuel et al., 2016).

It is also acknowledged that some clinicians reported a perception of positive aspects of their participation. Where positive aspects were identified these included a perception of having "learnt" or "grown" through the experience in reflecting on the care provided, sometimes identifying gaps in care (e.g. in ability to understand patient's motivations) and its impact on the care of future patients. For others, there was a wish to avoid participation in E/PAS in the future. Nevertheless, it is important to appreciate the complexity of the impact, even in settings in which the practice was sanctioned, given the findings in the limited research to date.

# What this study adds

Within the limited available literature, noteworthy findings emerge from this review. They suggest a substantial short and long term emotional impact for a significant proportion of clinicians who have participated in E/PAS. Personal and professional support needs are often unaddressed, with only a minority of those reporting adverse impacts seeking support from colleagues, and when support was sought, respondents relied chiefly on family or friends.

#### Limitations of the study and this field of research

All studies carry the important caveat of retrospectivity and varying time frames since participation in the E/PAS. There are varying definitions for E/PAS, this problem reflecting some of the ambiguity in clinical practice that is reported by clinicians. Bias is also relevant in a topic that has been polarizing in both professional and public debate. Recruitment and participation bias need to be considered, as it is possible that those most affected by their experience will be most motivated to participate in the studies. Nevertheless, representativeness of a sample is of less concern when undertaking the exploratory nature of qualitative research. In addition, such a review is open to a critique of author bias in the

evaluation of the findings. The selected papers were reviewed in detail by two of the authors (BK, TH) and the authorship team comprises diverse clinical and discipline expertise and perspectives: general medicine, epidemiology, and research methods (JA), psychiatry and palliative care (BK, DK, MV).

Although it is noteworthy that the gender of the patient appeared to influence response to E/PAS among clinicians, factors such as gender or socio-cultural backgrounds among clinicians and patients were generally not reported. Quantitative findings are very limited, being based on limited items within larger surveys of clinical practice. Ambiguity in definitions regarding end-of-life decisions and euthanasia/physician assisted suicide is also a key limitation. In some respects this reflects the same theme that emerged in the review, i.e. the impact of the uncertainty by clinicians of the intention and outcome of their actions, especially as they pertain to practices such as opioid use among the dying. Even in the most specific study addressing the emotional impact of E/PAS on clinicians<sup>21</sup> the focus of the study included responses to "euthanasia, assisted suicide, the ending of life without an explicit request from the patient, and alleviation of pain and other symptoms with high doses of opioids", thereby potentially conflating what might be considered standard clinical practice (i.e. use of opioid analgesics for relief of pain) with the more specific intentional actions aimed at ending the patient's life. In other reports (e.g. the Dutch study by Obstein et al., 2004), the term 'active euthanasia' is used, no specific definition is detailed, and interview questions refer to assisting patients "in their pursuit (sic) of dying with dignity" and "carrying out "death with dignity" acts". In the French study (in a setting where such actions are not legal), the phrase "using medical drugs to intentionally end the patient's life" was used. In others, the term "assisted suicide" is used (e.g. Dobscha et al., 2004) without more specific definition. Emmanuel et al. (1998) used two screening questions: "have you ever actually injected drugs with the intention of ending a patient's life?" and "have you ever

actually prescribed drugs to a patient knowing the patient intended to use them to end his or her life?". The study by Ganzini et al. (2000) referred to implementation in response to explicit requests for prescription for a lethal medication (in accordance with the Oregon Death with Dignity Act).

Consideration needs to be given to the broader societal, cultural, ethical and legal frameworks. Most of the studies have been conducted in Europe and USA, and for the most part in settings in which the practice has been legalized (e.g. Netherlands and Oregon, USA). Such factors influence the participation in research and the context of these practices – in those settings where it is not legal or where studies were conducted prior to legalization, these legal and cultural influences are likely to significantly influence research participation and the nature of clinician responses.

### **CONCLUSIONS**

Participation in E/PAS can have a significant emotional impact on participating clinicians. For a number this can include significant adverse long term personal and professional consequences. For some this experience has been a focus to reflect on ways to improve care of dying patients, and for some, a sense of having respected a patient's requested form a death. Nevertheless, the role of implemented E/PAS can contrast with perception of professional roles, responsibilities and personal expectations. Clinicians often acknowledge the difficulty in understanding the basis for a patient's wishes for E/PAS and assessing the needs of patients in this setting. For some this can be a source of ongoing discomfort with the process, with a perceived lack of expertise in responding to existential concerns. This suggests the complexity of E/PAS for participating clinicians. The impact on clinicians is a largely neglected area of research, as evidenced by the limited research data available.

Among the issues future research needs to explore include how we can best understand the

meaning of patients' requests for E/PAS; ways to strengthen clinician expertise in responding to exploring and responding to existential concerns and non-physical forms of suffering; how might we understand why some doctors (or any other participating health professionals) are negatively emotionally affected by involvement in E/PAS, yet others can feel fulfilled by similar actions; and how can we adequately support clinicians as they navigate this challenging area?

#### References

Chochinov, H.M. (2016). Physician-assisted death in Canada. *Journal of the American Medical Association*, 315, 253-254.

Chung, G.S., Yoon, J.D., Rasinski, K.A., & Curlin, F.A. (2016). US physicians' opinions about distinctions between withdrawing and withholding life-sustaining treatment. *Journal of Religious Health*, 55, 1596-1606.

Critical Appraisal Skills Programme (CASP). *Qualitative research checklist*. Oxford 2013: CASP.

De Vries, A.M.M., Gholamrezaee, M.M., Verdonck-de Leeuw, I.M., de Roten, Y., Despland, J.N., Stiefel, F., & Passchier, J. (2018). Physicians' emotion regulation during communication with advanced cancer patients. *Psychooncology*, 27, 929-936.

Dobscha, S.K., Heintz, R.T., Press, N., & Ganzini, L. (2004). Oregon physicians' response to requests for assisted suicide: A qualitative study. *Journal of Palliatiave Medicine*, 7, 451-461.

Draper, B., Kõlves, K., De Leo, D., & Snowdon, J. (2014). The impact of patient suicide and sudden death on health care professionals. *General Hospital Psychiatry*, 36, 721-725.

Emanuel, E.J., Daniels, E.R., Fairclough, D.L., & Clarridge, B.R. (1998). The practice of euthanasia and physician-assisted suicide in the United States: Adherence to proposed safeguards and effects on physicians. *Journal of the American Medical Association*, 280, 507-513.

- Emanuel, E.J., Onwuteaka-Philipsen, B.D., Urwin, J.W., & Cohen, J. (2016). Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *Journal of the American Medical Association*, 316, 79-90.
- Ganzini, L., Nelson, H.D., Schmidt, T.A., Kraemer, D.F., Delorit, M.A., & Lee, M.A. (2000). Physicians' experiences with the Oregon Death with Dignity Act. *New England Journal of Medicine*, 342, 557-563.
- Ganzini, L., Goy, E.R., & Dobscha, S.K. (2008). Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey. *British Medical Journal*, 337, a1682.
- Georges, A.A. The, A.M., Onwuteaka-Philipsen, B.D., & van der Wal, G. (2008). Dealing with requests for euthanasia: a qualitative study investigating the experience of general practitioners. *Journal of Medical Ethics*, 34, 150-155.
- Guest, R., Baser, R., Li, Y., Brown, A.E., Scardino, P., & Kissane, D.W. (2011). Cancer surgeons' distress and well-being, I: the tension between a culture of productivity and the need for self-care. *Annals of Surgical Oncology*, 18, 1229-1235.
- Guest, R., Baser, R., Li, Y., Brown, A.E., Scardino, P., & Kissane, D.W. (2011). Cancer surgeons' distress and well-being, II: Modifiable factors and the potential for organizational interventions. *Annals of Surgical Oncology*, 18, 1236-1242.
- Granek, L., Bartels, U., Scheinmann, K., Labrecque, M., & Barrera, M. (2015). Grief reactions and impact of patient death on pediatric oncologists. *Pediatric Blood Cancer*, 62, 134-142.
- Hannes K. Cochrane Collaboration Qualitative Methods Group. Chapter 4: critical appraisal of qualitative research. In Noyes, J., Booth, A., Hannes, K., Harden, A., Harris, J., Lewin, S., & Lockwood, C. (eds.)(2011). Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions Version 1. Available from URL http://cqrmg.cochrane.org/supplemental-handbook-guidance. Updated August 2011.
- Haverkaate, I., van der Heide, A., Onwuteaka-Philipsen, B.D., van der Maas, P.J., & van der Wal, G. (2001). The emotional impact on physicians of hastening the death of a patient. *Medical Journal of Australia*, 175, 519-522.
- Hendry, M., Pasterfield, D., Lewis, R., Carter, B., Hodgson, D., & Wilkinson, C. (2013). Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying. *Palliative Medicine*, 27, 13-26.
- Hudson, P., Hudson, R., Philip, J., Boughey, M., Kelly, B., & Hertogh, C. (2015). Physician-assisted suicide and/or euthanasia: Pragmatic implications for palliative care [corrected]. *Palliatiave & Supportive Care*, 13, 1399-1409.
- Kelly, B.J., Burnett, P.C., Pelusi, D., Badger, S.J., Varghese, F.T., & Robertson, M.M. (2004). Association between clinician factors and a patient's wish to hasten death: Terminally ill cancer patients and their doctors. *Psychosomatics*, 45, 311-318.

- Kissane, D.W., Clarke, D.M., & Street, A.F. (2001). Demoralization syndrome A relevant psychiatric diagnosis for palliative care. *Journal of Palliative Care*, 17, 12-21.
- Kissane, D.W. (2004). The contribution of demoralization to end-of-life decision making. *The Hastings Center Report*, 34, 21-31.
- Kohlwes, R.J., Koepsell, T.D., Rhodes, L.A., & Pearlman, R.A. (2001). Physicians' responses to patients' requests for physician-assisted suicide. *Archives of Internal Medicine*, 161, 657-663.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Medicine*, 6, e1000097.
- Muskin, P.R. (1998). The request to die: Role for psychodynamic perspective on physician-assisted suicide. *Journal of the American Medical Association*, 279, 323-328.
- Obstein, K.L., Kimsma, G., & Chambers T. (2004). Practicing euthanasia: The perspective of physicians. *Journal of Clinical Ethics*, 15, 223-231.
- Quill, T.E. (2018). Dutch practice of euthanasia and assisted suicide: a glimpse at the edges of the practice. *Journal of Medical Ethics*, 44, 297-298.
- Rholf, V. & Bennett, P. (2005). Perpetration-induced traumatic stress in persons who euthanize nonhuman animals in surgeries, animal shelters, and laboratories. *Society & Animals*, 13, 201-219.
- Riou, F., Aubry, R., Pontone, S., & Pennec, S. (2015). When physicians report having used medical drugs to deliberately end a patient's life: Findings of the "End of Life in France" survey. *Journal of Pain & Symptom Management*, 50, 208-215.
- Robinson, S., Kissane, D.W., Brooker, J., & Burney S. (2015). A systematic review of the Demoralization Syndrome in individuals with progressive disease and cancer: A decade of research. *Journal of Pain and Symptom Management*, 49, 595-610.
- Robinson, S., Kissane, D.W., Brooker, J., & Burney, S. (2016). A review of the construct of demoralization: history, definitions, and future directions for palliative care. *American Journal of Hospice and Palliative Medicine*, 33, 93-101.
- Robinson, S., Kissane, D.W., Brooker, J., Hempton, C., & Burney, S. (2017). The relationship between poor quality of life and desire to hasten death: A multiple mediation model examining the contributions of depression, demoralization, loss of control, and low self-worth. *Journal of Pain & Symptom Management*, 53, 243-249.
- Slavin, R.E. (1995). Best evidence synthesis: An intelligent alternative to meta-analysis. *Journal of Clinical Epidemiology*, 48, 9-18.
- Snijdewind, M.C., van Tol, D.G., Onwuteaka-Philipsen, B.D., & Willems, D.L. (2016). Developments in the practice of physician-assisted dying: perceptions of physicians who had experience with complex cases. *Journal of Medical Ethics*, 44, 292-296.

Stone, J., & Moskowitz, G.B. (2011). Non-conscious bias in medical decision making: what can be done to reduce it? *Medical Education*, 45, 768-776.

Tan, A.S.L. & Gallagher, T.H. (2017). Discussing adverse outcomes with patients. In: Kissane, D.W., Bultz, B.D., Butow, P.N., Bylund, C.L., Noble, S. & Wilkinson, S. (Eds.) *Oxford Textbook of Communication in Oncology and Palliative Care*. Second Edition. Pp. 249-256. Oxford: Oxford University Press.

Van der Heide, A., Onwuteaka-Philipsen, B.D., Rurup, M.L, et al. (2007). End-of-life practices in the Netherlands under the Euthanasia Act. *New England Journal of Medicine*, 356, 1957-1965.

van der Lee, M.L., van der Bom, J.G., Swarte, N.B., Heintz, A.P., de Graeff, A., & van den Bout, J. (2005). Euthanasia and depression: A prospective cohort study among terminally ill cancer patients. *Journal of Clinical Oncology*, 20, 6607-6612.

van Marwijk, H., Haverkate, I., van Royen, P., & The A.M. (2007). Impact of euthanasia on primary care physicians in the Netherlands. *Palliative Medicine*, 21, 609-614.

Walker, J., Hansen, C.H., Martin, P., Symeonides, S., Ramessur, R., Murray, G., & Sharpe, M. (2014). Prevalence, associations, and adequacy of treatment of major depression in patients with cancer: a cross-sectional analysis of routinely collected clinical data. *Lancet Psychiatry*, 1, 343-350.

White, B.P., Willmott, L., & Ashby, M. (2011). Palliative care, double effect and the law in Australia. *Internal Medicine Journal*, 41, 485-492.

Figure 1. Process of study selection

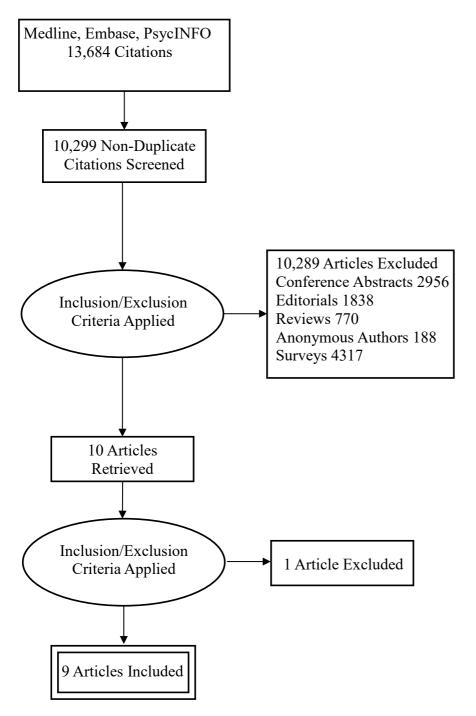


Table 1. Key studies of physician coping after involvement in euthanasia or physician-assisted suicide

Study	Year	Country	N	Method	Sample
Quantitative studie	es		•	•	
Emanuel et al.	1998	USA	53	Interview	Oncologists
Ganzini et al.	2000	USA	144	Survey	Physicians
Haverkate et al.	2001	Netherlands	405	Interview	Physicians
Riou et al.	2015	France	36	Survey	Physicians
<b>Qualitative studies</b>	•	<u>.</u>			
Kohlwes et al.	2001	USA	20	Interview	Oncologists/HIV clinicians
Dobscha et al.	2004	Netherlands	30 35	Interview	Family physicians
van Marwijk et al.	2007	Netherlands	22	Focus group	Primary care physicians
Galushko et al.	2016	Germany	19	Interview	Palliative care specialists
Snijdewind et al.	2016	Netherlands	28	Interview	Physicians