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Control measures for continuous deep sedation until death: a framing analysis of the views of physicians

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Abstract

Physicians have been subject to increasing external control to improve their medical practice and scholars have theorized extensively about their opposition to such control. However, little empirical attention has been paid to the views and reasoning which lie behind this opposition. An in-depth understanding is necessary for enhancing the effectiveness and efficiency of external controls and continuous deep sedation until death (CDS) is an interesting case in this regard. This study aims to explore how physicians frame control measures for CDS. We conducted 47 semi-structured interviews with Belgian physicians in 2019. A qualitative framing analysis was performed to analyze their views and reasoning. This study reveals that physicians approach CDS practice and control measures with different emphases. Controlling by mechanisms of professional self-regulation and state governance are put forward as appropriate means to improve CDS practice. Policymakers should take into consideration physicians' frames in order to develop sound control measures.

1. Introduction

Medical practice in Western countries has been subject to increasing professional regulation in recent decades, for instance auditing, medical guidelines, protocols, medical standards and quality indicators, and incident report systems have emerged as improvement initiatives from inquiries into medical practice and health care systems (Numerato et al., 2012). Medical professionals, particularly physicians, have often not welcomed the idea of controlling medical practice and often claim that professional control undermines professional autonomy and medical expertise (Chamberlain, 2009; Pont, 2000). However, it remains unclear so far how physicians themselves perceive the contemporary challenges to medical autonomy and professional control (Chamberlain, 2009).

The practice of continuous deep sedation until death (CDS), might provide an interesting example in this area. CDS is a form of palliative sedation that intentionally maintains a deep state of unconsciousness until death in patients at the end of life, using sedative drugs to alleviate unbearable suffering from refractory symptoms (Morita, Tsuneto, & Shima, 2002). These symptoms are extremely difficult or impossible to manage, and they can be physical or psychoexistential (Claessens et al., 2008). To take away the patient's experience of refractory symptoms, the state of unconsciousness is intended as an option of last resort (Morita et al., 2002). More specifically, the state of unconsciousness is achieved and maintained through dose titration of the sedative drugs, for example via an infusion pump, and may last for several days as there is no intention of causing or hastening death (Cherny et al., 2009). Nationwide studies have indicated that CDS is prevalent in care settings where patients die, with prevalence estimations ranging from 3% to 19% of all deaths in Europe and 10% in the United States . Additionally, several national and international guidelines about CDS have been published (Abarshi et al., 2017; Schildmann &

Schildmann, 2014). These guidelines have several conceptual similarities (Abarshi et al., 2017). Similarities include that CDS should be indicated for patients close to death, with a life expectancy of two weeks or less, who suffer unbearably from refractory symptoms; that sedative drugs should be administered proportionally to the refractoriness of symptoms; and that the administration and monitoring of CDS should be performed by medical professionals, preferably physicians (Abarshi et al., 2017; Schildmann et al., 2014; Schildmann & Schildmann, 2014). In practice, however, nurses occasionally carry out the administration and monitoring of CDS in the absence of physicians (Abarshi et al., 2014; Anquinet et al., 2015). Moreover, most guidelines also state that physicians should conduct the decision-making of CDS based on an overall medical assessment of the patient's situation, involving patients and their families (Abarshi et al., 2017). Hence, according to the strict sense of guidelines, CDS cannot be carried out without prior medical assessment.

The tension between calls to reform medical practice through professional control and opposition from physicians has extended to the practice of CDS, which is seen as having potential for multiple hazards e.g. CDS might shorten survival (Maltoni et al., 2009); physicians use CDS to terminate or shorten a patient's life (Claessens et al., 2011); CDS distresses the carers and relatives involved; physicians use suboptimal drugs for the administration of CDS (Reuzel et al., 2008); CDS is not carried out in accordance with guidelines e.g. using disproportionate or inadequate assessment (Rietjens et al., 2009). It has therefore been suggested that CDS should be professionally regulated by control measures in order to reform and improve its practice.

Control measures, also referred to as preventive and/or protective measures, involve non-medical interventions, actions and solutions to prevent, mitigate and eliminate the occurrence of and/or the exposure to an identified hazard (World Health Organization, 2019). Expert consultation, for example, is regarded by the European Association for Palliative Care and various guidelines as a

proper control measure to prevent patients with inappropriate indications from being sedated (Cherny et al., 2009; Schildmann & Schildmann, 2014). Yet, there seems to be little compliance with and support for such recommendations among physicians. (Hoek et al., 2015; Koper et al., 2014). Koper et al. (2014) showed that physicians show little support for mandatory expert consultation within the context of CDS for practical and theoretical reasons, holding that CDS is a normal medical practice. This study also touched on another interesting element, namely the beliefs and reasoning that underlie physicians' views on control measures for CDS, an in-depth understanding of which is lacking within palliative care literature to date.

With this study we aim to contribute to medical literature in general and palliative care literature in particular by exploring in depth these views and attitudes. Elaborating upon Chamberlain's (2009) recommendation that research should focus on professional control from the viewpoint of physicians themselves, we argue that identifying and understanding physicians' views might provide valuable insights into better implementation of control measures for CDS practice as physicians are important actors in the medical decision-making process, and are often the only medical professionals who may indicate and administer CDS (Schildmann & Schildmann, 2014). Secondly, we aim to provide information for policymakers who want to issue evidence-based and participatory control measures for CDS; the perspective of physicians should indicate which specific measures would be effective and which ones they would put into practice.

The main research question is: how do physicians frame control measures for CDS? To answer this we conducted a qualitative framing analysis on in-depth interviews with Belgian physicians, drawing upon Entman's definition of framing (1993).

1.1. CDS practice in Belgium

At present, there is a lack of recent findings on the prevalence of CDS in Belgium. Nevertheless, previous studies have estimated that CDS is carried out in 1 out of 8 deaths in Belgium, and is more prevalent in hospital settings than in home settings (Robijn et al., 2016; Van Den Block et al., 2009). In these settings in Belgium, the care including CDS, can be provided by physicians working either individually e.g. general practitioners (GPs) in home settings, or in a team e.g. disease-specific specialists in hospital settings.

In 2012, the Federation for Palliative Care Flanders (FCPF) updated its guideline about palliative sedation including CDS (Broeckaert et al., 2012). This guideline states that CDS is a normal medical practice, namely a form of intensified symptom management, that can only be used to alleviate refractory symptoms in patients with a life expectancy of several days and exceptionally of more than one week (Broeckaert et al., 2012). To determine the refractoriness of symptoms, the guideline recommends using an interdisciplinary approach and seeking a palliative expert consultation, but puts the decision to initiate CDS under the authority of the treating physician (Broeckaert et al., 2012). Furthermore, it underlines that CDS differs from euthanasia, which is a legal practice in Belgium, in that it may never be intended to terminate a patient's life (Broeckaert et al., 2012).

2. Methods

2.1. Research design, sampling and data collection

We conducted an in-depth interview study with Belgian physicians using semi-structured interviews elaborating on social constructionism in order to explore the social phenomenon of the practice of CDS in all its richness. This approach allows us to grasp comprehensively multiple

understandings and diverse realities about how physicians define and experience the specific context of the practice and of potential control measures (Burr, 2003).

Eligibility criteria for this study were: (1) being employed as a medical doctor at the moment of study inclusion, (2) residency in Belgium, (3) fluency in Dutch and/or French, (4) having given informed consent to participate in the study and, (5) having administered CDS at least three times in the last five years. Concerning the latter criterion, we reasoned that physicians experienced in or knowledgeable about initiating CDS would have more profound insight and a better understanding of the ongoing dynamics of the practice, and consequently, have more reasoned views about appropriate and feasible control measures than those who do not have experience. Participants were recruited between January and March 2019. Purposive sampling was used to ensure sample variability in relation to our primary sampling criteria, obtaining a wide range of views and experiences: age, gender, setting, and medical specialism. This involved a multistage strategy in order to maximize validity (Palinkas et al., 2015):

- (1) The first strategy involved a random selection of 40 hospitals across Belgium, sending a letter of invitation by e-mail with the request to physicians from oncology, palliative care, ICU, and geriatric departments to participate in the study, while clarifying the specific context, aim, and eligibility criteria. We chose these settings because the prevalence of CDS could be expected to be higher in comparison with others. Subsequently, we followed the same procedure for GPs in which we randomly selected 30 GP practices across Belgium. Interested physicians were able to register for participation on a specially designed website.
- (2) With regard to the second strategy, we asked several national and regional medical organizations for GPs and palliative care physicians to send out a letter of invitation to

participate to its members. Interested physicians were also able to register on the website.

- (3) The third strategy used the snowball method. We asked participants sampled with the aid of the first two strategies to identify other potential physicians who could be eligible to participate. More specifically, participants were asked to provide the professional email addresses of these physicians. Thereafter, these potential participants were sent a letter of invitation by e-mail with the request to participate in the study. Interested physicians were also able to register on the website.

Face-to-face interviews were conducted with Dutch-speaking and French-speaking physicians. These interviews took place at the location chosen by the participants. We used a topic guide (see Supplementary Table 1) for in-depth exploration of their views on and their understanding of the reasoning behind control measures for CDS. The topic guide was structured in three themes: (1) definition of CDS and their general experience with CDS practice; (2) personal views on control measures for CDS practice; and (3) personal opinions about the implementation of mandatory registration and/or expert consultation for CDS. Significant changes were made to the third theme of the interview format after eight interviews had been conducted. Preliminary results of these interviews indicated that physicians also favoured and suggested other control measures and/or monitoring methods for CDS. Drawing upon the open-ended attitude (Patton, 2015), this theme was therefore modified into ‘feasible control measures, solutions, and actions for improving CDS practice’. All interviews were audio-taped and transcribed verbatim.

2.2. Ethical considerations

Ethics approval for this study (B.U.N. 143201938601) was granted from the Medical Ethics Commission of the Brussels University Hospital (2019/011). Participants provided written consent

to be interviewed. Furthermore, we assigned pseudonyms to participants in the interview transcripts.

2.3. Data analysis

We conducted a qualitative framing analysis in order to map and analyze physicians' views towards control measures for CDS. Our qualitative framing analysis aimed at identifying frames inductively by constructing them from the empirical data (Foley et al., 2019; Koenig, 2006). Frames are organized patterns of thought schemata used by people to make sense of their social environment and to organize their experiences (Fiske & Taylor, 2017).

The physicians' frames were identified drawing upon Entman's (1993) framework which states that frames or framing entails four interactive components, sometimes referred to as framing functions. Framing is (1) defining problems, that is determining what causal agents are doing with what costs and benefits; (2) diagnosing causes, that is identifying the forces creating the problem; (3) making moral judgments, that is evaluating causal agents and their effects; and (4) suggesting remedies, that is offering and justifying treatments for the problems and predicting their likely effects (Entman, 1993). The purpose of our analysis was more specifically to identify how physicians frame the problem of CDS practice and its cause, make moral and/or value judgments about this problem and/or CDS practice in general, and suggest solutions and actions, for example control measures, in order to tackle these problems and improve CDS practice.

Our qualitative framing analysis entailed four phases conducted inductively in parallel (Van Gorp & Vercruysse, 2012). Throughout all phases of the analysis, we discussed and reached consensus on outcomes from each phase. The first phase entailed an open coding system (Corbin & Strauss, 2008), identifying topic categories within Entman's four framing functions. Initially, transcripts and interview notes were read and re-read. Line-by-line open coding was conducted by means of

the qualitative data analysis software NVivo 12, organizing segments of text. The aim of this phase was to stay close to the data elaborating upon participants' words and phrases in order to provide codes. Saturation was reached with regard to the collected data, since no new topic categories emerged after 80% of the transcripts had been analyzed. The other 20% of the transcripts were used to verify whether the generated codes also applied to those. The second phase consisted of axial codification (Corbin & Strauss, 2008), in which codes were reduced to a smaller number of codes converting into several topic categories for each frame function. During the third phase, the frames were created through interconnecting the topic categories with each other as a logical chain of frame functions. Categories and frames were compared and discrepancies were modified until consensus was reached. Finally, the fourth phase involved the discussion and revision of the found frames in group analysis meetings.

Throughout the whole research process, we chose to structure the data collection and analysis by means of the iterative cycle of qualitative research (Srivastava & Hopwood, 2009). During systematic meetings with all authors every six weeks, there was a constant reflexive process of revisiting the data connecting them with new insights with the intention of sharpening our understanding of physicians' views. Simultaneously, this reflexivity enabled us to better comprehend our own research role in order to restrain personal conceptions and ideas concerning control measures for CDS.

3. Results

3.1. Sample characterization

In total 53 physicians registered on the website for study participation. We screened 51 physicians eligible for participation and excluded two who had not performed at least three cases of CDS

during the last five years. Of the 51 screened eligible, 49 were contacted successfully to schedule an appointment for an in-depth interview. One interview never took place, since the participant cancelled at the last-minute due to time constraints. In total 48 interviews were conducted. The in-depth interviews lasted 13 to 90 minutes (average = 44 minutes). There was an observed difference between interviews with Dutch- and French-speaking physicians in terms of length, those with French-speaking physicians on the whole being shorter with physicians having less time to be interviewed or being called away due to unforeseen medical incidents. Nevertheless, we argue that the length of these interviews did not influence the overall quality of the content. Finally, we excluded one interview from analysis because other health professionals from the palliative care team were present answering questions on behalf of the participant. In total, 47 participants were included in the analysis (see Supplementary Table 2 for an overview of the characteristics of participants): 13 oncologists, 13 GPs, 12 intensive care physicians, 8 geriatricians, and 1 anaesthetist. Of these participants, 25 completed a training in palliative medicine.

Throughout the interviews, it is apparent that most participants emphasize two aspects repeatedly in an explicit or implicit way, namely, (1) that they are competent in administering CDS and, (2) it is ‘time to act’ to improve CDS practice. Regarding the first, all participants identify themselves as being qualified for performing CDS. Most of them link this competence to their frequent experience with CDS practice itself, ‘palliative culture’ as a whole, and/or thorough knowledge of guidelines about palliative sedation and CDS. In addition, all participants assert that they only administer CDS with good intentions, acting in the best interests of patients and/or their relatives. Most participants say that providing the best possible medical care for patients and/or relatives is their underlying ‘main motive’ for carrying out CDS. Participants moreover describe the administration of CDS as fulfilling their ‘medical moral duty’ towards patients and/or relatives,

since they consider that no other medical treatment can be performed as an adequate response to the patient's refractory symptoms. Also, they believe that the majority of physicians who administer CDS share the same intentions. Apart from these intentions, most however argue that CDS is in general practiced sub-optimally and some even speak of 'malpractice'. Malpractice in this particular context refers to the intentional use of CDS by physicians to terminate or shorten a patient's life; all participants were united to a certain degree by the conviction that it is 'time to act' in order to improve CDS practice as a whole. Implementing actions and/or solutions is perceived as a necessary vehicle for improvement, since these problems do not tend to resolve themselves.

3.2. Frames that construe participants' views towards control measures for CDS

Despite overall agreement among participants that certain action is needed, their views differ with regard to the types of problems arising within CDS practice, the reasons and causes underlying these problems, and the possible solutions and actions, i.e. control measures and monitoring methods, for addressing them. Different explanatory models and reasoning are thus employed in order to give meaning to these control measures for CDS, i.e. frames. We identified five frames among participants: 'control through expertise' frame, 'strict due care' frame, 'safeguarding patient choice' frame, 'facilitating dignity' frame, and 'improving communication' frame. It is important to note that we as researchers have given these names to the frames based on our interpretation of the most salient features of participants' views.

In the following sections, we present the five different frames in more detail and describe the inherent four frame functions of each frame (Entman, 1993): (1) defining the problem(s), (2) the underlying reasons for or causes of these problems, (3) inherent value judgements and (4) possible solutions and actions (control measures) in order to tackle them. Table 1 shows a summary of each

frame and its frame functions. Although we describe each frame separately for analytical reasons, participants use various frames and frame functions simultaneously.

Control through expertise frame

According to the control through expertise frame, the problem of CDS practice stems from participants' belief that other physicians lack the knowledge and experience to perform CDS well as they only do it rarely. This belief is grounded in the participants' experience that the majority of their fellow physicians who carry out CDS make multiple errors in terms of both indications i.e. whether or not symptoms are actually refractory, and technique, i.e. not utilizing the recommended drugs or appropriate dosage. In this regard, participants particularly incidence GPs and physicians of an older generation who do not have the right competences for initiating CDS.

Participants who use this frame locate the source of the problem in the nature of CDS, which is considered to be a complex practice which requires specialized skills due mainly to its unforeseen side-effects, for example, sedated patients may awaken at any time during the sedation or die unexpectedly. Furthermore, it is particularly difficult to determine and adjust the accurate doses and type of medication necessary and sufficient to maintain the patient in a tranquil and tolerable condition because every patient responds differently. Secondly, participants claim that education and training programs for physicians have not paid comprehensive attention to palliative care, end-of-life practices and CDS practice in particular, which has led to significant ignorance about CDS among physicians.

The inherent value judgement in this frame focuses on the assumption that CDS is an exceptional but normal medical practice that should be performed by physicians with full knowledge of the criteria for CDS. Some participants further posit that CDS should be embedded only in secondary

or tertiary care services highlighting both the suboptimal practice occurring in primary care and the specialized character of the practice.

“Physicians do not have the skills, which are very important in order to initiate CDS correctly. Also, the chance of success might be higher. Initiating sedation is always difficult, because one never knows what will happen. Even if one has chosen the proper moment, it might turn out differently.” (Oncologist)

This frame encompasses two solutions which are grounded in mechanisms that concentrate on acquiring the proper competences to perform CDS. The first stresses the importance of consulting an expert before the administration of CDS. Expert consultation is more specifically described as a reciprocal communication process between the treating physicians and an expert specialized in CDS practice, preferably from secondary or tertiary care services, preceding the initiation of CDS, that focuses on addressing issues with regard to CDS, preventing and resolving situations rapidly to minimize risks and creating better patient outcomes. The underlying idea is the principle of ‘teach one, learn one’ so that physicians’ misconceptions and concerns about indication and performance of CDS could lead to good clinical practice due to the expert’s guidance and input during the consultation. The second solution is education and training which targets a physician’s knowledge and skills about CDS; intervision sessions among peers, peer coaching and bedside teaching are seen as effective training methods to reinforce and strengthen competences. In addition, most participants using this frame criticize heavily the use of registration as a possible solution, referring to the ‘ineffective’ registration procedure in euthanasia practice. The latter is

Table 1: Five frames that construe participants' views on control measures for CDS

	Problem definition	Problem source	Value judgment	Solutions and actions
Control through expertise	Physicians lack knowledge and experience to perform CDS	CDS is a complex and specialized practice	CDS is a normal medical practice that should be performed by experts	Expert consultation; training and education
Strict due care	Physicians employ CDS with the wrong intention	Physicians' paternalistic attitudes	CDS can only be used for relieving intolerable suffering from refractory symptoms	Registration of CDS; shared decision-making
Safeguarding patient choice	Patients wish to die in their sleep	Seeking a good death	Self-determination and patient autonomy/choice are inviolable	The legal option of initiating CDS to accompany the dying process of patients
Facilitating dignity	Some patients with severe loss of mental capacity die in a context lack of dignity, according to their relatives	The lack of legal framework that facilitates all end-of-life decisions	Every human being deserves a dignified death	Legal protection of physicians who initiate CDS to facilitate a dignified process of dying for patients with a severe loss of mental capacity
Improving communication frame	Patients' relatives have misconceptions about CDS	A lack of physician communication	Information sharing is key	Refining and improving the communication skills of physicians; raising public awareness

merely perceived as a ‘list of check boxes’ without any educational effect and thus as not doing anything to improve the competence of the physician.

Strict due care frame

This stems from the perception that physicians do not use CDS solely with the intention of reducing the patient’s level of consciousness in response to unbearable suffering from refractory symptoms.

The perception is that, firstly, the majority of physicians use CDS with the intention of providing comfort and/or relieving pain from non-refractory symptoms while there is still scope for other treatments and interventions to reduce the pain and secondly that some initiate CDS with the intention of shortening or terminating a patient’s life, sometimes without the consent of the patient.

According to this frame, this is because some physicians are not inclined to question their own intentions and exhibit a lack of self-reflection while identifying strongly with a paternalistic professional identity, leading them to the belief that they are best-positioned to decide, and act on, what is in the best interests of the patient. Their opinions are thus impossible to argue with and the patient and/or their relatives have to comply silently. This, according to some participants, is the consequence of the societal prestige and status inherent to the profession of medicine.

The value judgement underlying this frame is that CDS can only be used to mitigate intolerable suffering from refractory symptoms that cannot be alleviated otherwise. Participants strongly condemn the practice of administering it for other reasons and emphasize that CDS and euthanasia are two distinctive end-of-life practices with different intentions. If a patient clearly requests medical aid to end his or her life, it is the physician’s role to explore with them the option of euthanasia which is legal in Belgium but CDS should only be performed in strict accordance with the indications.

The main solution in this frame involves challenging a physician's intentions by breaking down their paternalistic attitudes; two solutions are suggested. One involves implementing mandatory registration of CDS involving filling in a registration document in which intention of administering CDS must be indicated, which would require self-reflection leading to awareness of underlying intentions and have a deterrent effect on the use of CDS to shorten a patient's life, as all registered information could be checked. The other is a mandatory requirement for shared decision-making among multiple professionals which could counter any unilateral paternalistic intentions on the part of the physician.

"Physicians are messing around with sedations without paying attention to indications. They try to avert euthanasia through CDS. [...] Like the old model, physicians decide everything and nurses have to comply with it. As a palliative care team, we have stepped in to stop this practice. We felt that we had to take up our role, because we as doctors have more influence on our colleagues." (Oncologist)

Safeguarding patient choice frame

In this frame the problem is that many patients express the wish to die in their sleep or to be unconscious during the process of dying, thus explicitly demanding CDS. Some participants explain that these requests mainly come from religious patients who are strongly opposed to euthanasia. This leads to a certain moral tension between meeting the patient's wish and the principle of fulfilling all the required indications for CDS. Regardless of this dilemma, participants declare that they prefer meeting the patient's wish, and thus performing CDS to accompany the process of dying on the condition that the majority of indications are met, namely (1) the presence of severe physical symptoms, (2) unbearable suffering, and (3) nearing death.

"Sedation is a choice that patients can make. We have had a few cases where people say they wanted to sleep. They do not want to experience it anymore. We explain that this is only possible with a life expectancy of two weeks. [...] I really see it (CDS) as a stopgap solution, especially when people are not open to euthanasia." (General practitioner)

According to participants using this frame, the source of the problem is based on patients seeking a 'good' or 'peaceful' death. Patients mainly identify a good death with a painless death or a minimum of suffering at the end of life and have a strong fear of suffering which causes even more distress. This frame furthermore argues that this anxiety is partially the consequence of a public stigma and taboo surrounding death and the fear that they might not be able to cope with the dying process.

Participants using this frame highly value both self-determination and patient autonomy; the patient's choice is given priority over the principle of meeting all indications for CDS. According to these participants, patients have the right to 'orchestrate' or determine the dying process on their terms, not those of the treating physician. In other words, one must respect the patient's choice, even if this entails terminating or shortening life by means of CDS. This belief is partially enhanced by the view that it is a physician's moral obligation to cover a patient's needs in terms of being responsive to and respectful of their preferences and wishes regarding care.

The solution focuses on drafting legislation establishing the right to perform CDS at the request of patients who are nearing death. As such, many of the physicians in this frame praise the spirit of the enacted Claeys-Leonetti law in France which provides a legal framework for CDS.

Facilitating dignity frame

The problem in this frame is associated with the fact that participants regularly experience pressure from relatives to shorten or terminate a patient's life by means of CDS. Relatives request this for patients with a major or total loss of mental capacity, primarily those with advanced dementia or a minimally consciousness state due to irreversible brain damage in ICUs. These relatives see themselves as the patient's 'spokesperson' since the patient can no longer speak for him or herself. Their role involves advocating for the patient's care and end-of-life preferences, emphasizing the patient should die in dignity.

"And the family are asking me: 'So Doctor? And now? What are you going to do now? He is lying there. You are going to give him something, right? You are going to do something, aren't you?'. These people are furious. Furious! And then 'the dog', the story of the dog. Over and over again. [...] So ultimately, I administer CDS." (Intensive care specialist)

The frame attributes the problem to the fact that relatives and/or the patient's legal representative are hardly heard when it comes to end-of-life care and/or medical end-of-life decisions, and the lack of a comprehensive legal framework regarding all end-of-life decisions for patients, especially for those with a major or total loss of mental capacity. Participants say they often feel frustrated about this legislative 'gap' that needs to be tackled with 'great urgency'.

The value judgment in this frame is that CDS may be initiated as a means to shorten or terminate the life of someone with severe loss of mental capacity at the explicit request of relatives. In fact, these participants declare that they or colleagues have already executed CDS with this intention. They view the medical practice of CDS not as an end in itself but rather as a means to facilitate a death in 'human dignity', a dignified dying process. This is partially embedded in the view that they cannot imagine experiencing their own end-of-life in the same 'inhumane' circumstances.

As a solution, participants suggest legal protection for physicians who deploy CDS in order to facilitate a dignified death for patients with severe loss of capacity at the request of the patient's relatives.

Improving communication frame

Participants believe that physicians perform CDS particularly well, especially in technical terms, though there is a 'rather minor' problem in that, according to them, relatives do not always have a clear idea of what CDS exactly entails and hold multiple misconceptions and beliefs about it, for example that it shortens the patient's life. Therefore, most relatives are relatively upset when they have to wait too long for death to come after the initiation of sedation which often leads to incomprehension and frustration which can escalate into a conflict between the treating physician and the relatives.

Participants note that the problem of misunderstanding about CDS is the result of a lack of appropriate communication between the physician and the relatives. Whereas physicians have the skills in diagnosing and treating a patient, they can be less than 'tactful' in their communication. Also, they have less time to explain fully all the specific details and consequences of their medical actions to their patients, due to work overload. Participants explain that this is particularly grounded in an education that had not paid sufficient attention to the development of soft skills, but was solely focused on clinical skills. Nevertheless, they believe that physicians from a 'younger generation' have fewer difficulties with communication skills.

These participants say they greatly value 'communication' and 'information sharing'. This is described as the process by which someone explains in a clear, concise and well-organized way their medical actions and decisions and the consequences and risks to the patient and their relatives. In the case of CDS, they see this as providing all background information in terms of intention and

potentially unforeseen outcomes, such as sudden death, awakening during sedation, and the unpredictability of the time of death.

“When we initiate CDS, the family knows what our palliative treatments are. We are very clear on that. We give all the information, so the patient knows from the very beginning what CDS and euthanasia include. [...] That is the package we offer.” (Geriatrician)

The frame encompasses two solutions. One is training in good communication skills, for example during peer intervision; they consider current training should pay more attention to physician-patient communication. Another is a public awareness-raising campaign addressed directly to the general public, for example distributing information brochures across all general practices, describing in detail all medical end-of-life decisions in ‘plain language’ with a particular focus on CDS.

4. Discussion

4.1. Summary of main findings

Participants make sense of control measures for CDS by using five different frames. The ‘control through expertise’ frame suggests that control measures should focus on providing the proper expertise to physicians who carry out CDS, since CDS is a normal, if exceptional, medical practice that requires unique competences. The ‘strict due care’ frame postulates that control measures should change physicians’ paternalistic attitudes, which often lead to unilateral medical decision-making in which the initiation of CDS is discordant with the recommended due care criteria. The ‘safeguarding patient choice’ frame posits that control measures for CDS should establish the right to perform CDS at a patient’s request because many patients wish to die in their sleep, even when not all criteria for CDS are met. The ‘facilitating dignity’ frame stresses that control measures

should legally protect physicians who perform CDS in order to facilitate a dignified death for patients with a severe loss of mental capacity. The ‘improving communication’ frame emphasizes that control measures should enhance the communication skills of physicians, since the relatives of sedated patients are not fully informed about the consequences of sedation.

4.2. Strengths and limitations

To the best of our knowledge, this is one of the first studies to provide qualitative in-depth accounts of how physicians frame control measures for CDS. We have sought to expand current knowledge by concentrating on multiple control measures suggested by physicians themselves. The main strength of this study concerns deploying a framing analysis based on Entman’s notion of framing (1993) in order to explore how physicians make sense of control measures for CDS by identifying specific frames. Our methodological approach of analytically assessing single frame elements tends to have a higher reliability and validity (Matthes & Kohring, 2008), reducing researchers’ bias in the data analysis process (Van Gorp, 2005) and enhancing transparency and trustworthiness (David et al., 2011), than does the approach of identifying holistic frames without framing functions. This framing analysis allowed us to elucidate latent and layered meanings behind the words and narratives offered by physicians commenting on the social phenomenon of control measures for CDS. A simple thematic analysis would have merely provided a description of problems and solutions (Lloyd & Hawe, 2003).

With regard to limitations, the interviews were carried out at a time when public debate in Belgium was questioning whether stringent control measures for CDS should be implemented by public authorities. It is therefore possible that this focus has convinced certain physicians to participate in this study, for example those who firmly support or oppose such implementation or those who are very confident of their own CDS practice. We sought to reduce bias of this sort by incorporating a

wide range of participants with a variety of different views and experiences in order to strive for a maximal theoretical generalizability of the findings. In addition, our findings might not necessarily be theoretically generalizable to contexts outside Belgium. Participants are rooted in Belgian society, a sociocultural context in which physicians generally hold relatively permissive attitudes towards end-of-life decisions and actual end-of-life decision-making (Cohen et al., 2008), and apply a broader conceptualization of CDS in practice than in other countries (Seymour et al., 2015). Therefore, it should be remembered that different frames may exist in other countries or contexts.

4.3. Interpretation of the findings

This study contributes to literature in multiple ways: it expands the general finding that different physicians perceive the practice of CDS - and inherent control measures - quite differently; it provides nuance about the common premise that physicians prefer the idea of professional self-regulation in medical practice and it illustrates that physicians consider it important that several aspects of end-of-life decision-making should be safeguarded.

Palliative care research has paid much attention to the question of how physicians and health professionals as a whole approach CDS practice; health professionals and physicians may differ in terms of attitudes, perceptions, experiences and reasoning towards it (Anquinet et al., 2012; Maeda et al., 2019; Morita et al., 2017; Raus et al., 2014). Our findings expand on this by suggesting the existence of various frames among physicians. Participants in our study take different stances in terms of problems and their causes that arise in CDS practice, and the value judgements related to them. Our findings not only demonstrate there is interpersonal variation between participants as regards framing of control measures for CDS, but also intrapersonal variation. Participants often switch from one frame to another, employing up to three frames, sometimes being conscious of probable contradictions. Throughout their narratives, the ‘control through expertise’ frame is used

interchangeably with the ‘improving communication’ frame, while the ‘safeguarding patient choice’ frame especially interacts with the ‘facilitating dignity’ frame. Although the ‘strict due care’ frame shows fewer defined patterns of intertwining with other frames, participants who adopt this frame occasionally use arguments from both the ‘control through expertise’ and ‘safeguarding patient choice’ frames. These combinations of frames indicate that certain frames are more compatible to each other than to others. This might explain why the public debate in Belgium about implementing stringent control measures for CDS, in which important stakeholders such as the Chairs of the Belgian Federal Control Commission for Euthanasia and the Federation of Palliative Care Flanders take opposite positions, has been considerably polarized. Therefore, our frame analysis might help these stakeholders to find common ground.

Secondly, our findings put into doubt the premise common in the vast literature on the subject that physicians are more inclined to favour the idea of professional self-regulation or self-governance rather than state governance or even ‘interference’ (Chamberlain, 2009). The frames point in different directions when it comes to determining who should issue control measures for CDS. The ‘facilitating dignity’, ‘safeguarding patient choice’, and ‘control through expertise’ frames point in the direction of government interference, for example in the form of registration of CDS cases performed, or of developing a legal framework for CDS. Viewpoints within these frames might be attributed to a spillover effect of participants’ positive attitudes towards the control measures for the practice of euthanasia (Cohen et al., 2012), which are regulated in Belgium by means of a legal framework of mandatory registration (Smets et al., 2009). This may also explain why these frames often include concepts used in discussion of euthanasia practice, such as dignity, patient choice and self-determination (Jacobson, 2007). The ‘control through expertise’ and ‘the improving communication’ frames, however, show preference for professional self-regulation over external

control for example in the form of expert consultation or training. This seems to stem from participants' perception that CDS is a normal medical practice (Koper et al., 2014), as explicitly indicated within the 'control through expertise' frame. Another plausible explanation may be that these participants view professional self-regulation as a supportive measure giving them more confidence in terms of sound medical decision-making (Onwuteaka-Philipsen et al., 2000).

Thirdly, our findings show that participants believe that a range of issues should be focused on when safeguarding end-of-life care and decision-making. The 'control through expertise' and 'improving communication' frames highlight control measures that improve physicians' expertise and communication. These views might be driven by a rather paternalistic model of medical decision-making or of CDS practice in particular as central to the model is a basically one-way flow of information from the physician to the patient with a minimum of participation from the latter, with medical deliberations and decisions made by the treating physician alone or in consultation with other physicians (Charles et al., 1999). Physicians appear to adopt such attitudes towards medical decision-making in order to preserve their professional authority and autonomy (Greenfield et al., 2012) and although recent models of decision-making consider them undesirable, some authors suggest 'palliative paternalism' is the right way to make difficult medical decisions at the end of life (Roeland et al., 2014). However, participants using these frames seem to be rather more 'modern' than 'classical' paternalists. They tend to decide for the patient, but simultaneously underline the importance of knowledge of and understanding by the patient, persuading him/her that the medical decision to initiate CDS is right (Falkum & Førde, 2001). Analogously, the 'facilitating dignity' and 'safeguarding patient choice' frames seem to safeguard the decisions and values of patients and relatives and those deploying these frames appear to be driven by models of shared decision-making. Compared with the paternalistic model, these models

take the values, preferences, and needs of the patient into consideration more and make room for more patient participation in the decision-making process (Wirtz et al., 2006). This could be viewed as the manifestation of a more patient-centered orientation on health care (Street et al., 2007). Lastly, the ‘strict due care’ frame insists that all clinical indications should be met in order to initiate CDS, particularly stressing refractory symptoms and intolerable suffering. These participants privilege strict compliance with CDS guidelines which may indicate that they have strongly internalized them. A plausible explanation for this might be that more attention has been given in the last decade to the development and use of such guidelines for CDS in order to steer medical practice (Schildmann & Schildmann, 2014).

4.4. Recommendations and implications

Answering the question of whether policymakers should implement control measures for CDS is beyond the scope of this study. Nonetheless, we do argue that a key question for policymakers is how to hold physicians accountable for achieving good-quality care in cases of CDS. In this respect, our findings indicate that policymakers who seek to implement control measures should first clarify the core issues they want to tackle in light of the ethical and public debate. This study may help them in deciding which measures are necessary, feasible and effective. Our findings could contribute to such evidence-informed policy-making by establishing physicians’ frames and patterns of reasoning through linking problem definitions with measures to counter them. Moreover, the identified frames may support policymakers in predicting the effectiveness of certain control measures within the medical field, since frames are not merely cognitive structures but also represent cultural elements (Van Gorp, 2007). Control measures that do not align to a certain extent with physicians’ frames seem highly unlikely to be adopted and applied by physicians. Moreover, policymakers should also consider the effect of implementing control measures on the public and

on medical framing of CDS practice itself and to what extent this is desirable. In this respect, it seems not unlikely that if CDS practice becomes subject to a post-hoc review, medical professionals might have difficulty in distinguishing it from euthanasia (Cohen-Almagor & Wesley Ely, 2018).

A future research direction might explore how the implementation of control measures might impact the practice of CDS. Also, participants in our study have suggested that control measures could take various forms, governed by different organizational structures. Therefore, future research may examine whether either the state or the medical field would be the most efficient and effective structure in which to monitor these control measures.

Although most national and international guidelines and medical decision-making models for CDS and palliative sedation have solely incorporated the recommendation of deploying expert consultation as a proper control measure (Schildmann et al., 2014), our participants suggest that they could be expanded with other control measures in order to improve CDS practice significantly. Furthermore, it seems important that education and training programmes for physicians should not solely focus on clinical technicalities and indications when it comes to the initiation of CDS, but should pay equal attention to the surrounding decision-making and communication processes involving all actors concerned.

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