

Addressing the Concerns Surrounding Continuous Deep Sedation in Singapore and Southeast Asia: A Palliative Care Approach

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Abstract The application of continuous deep sedation (CDS) in the treatment of intractable suffering at the end of life continues to be tied to a number of concerns that have negated its use in palliative care. Part of the resistance towards use of this treatment option of last resort has been the continued association of CDS with physician-associated suicide and/or euthanasia (PAS/E), which is compounded by a lack clinical guidelines and a failure to cite this treatment under the aegis of a palliative care approach. I argue that reinstating a palliative care-inspired approach that includes a holistic review of the patient’s situation and the engagement of a multidisciplinary team (MDT) guided by clearly defined practice requirements that have been lacking amongst many prevailing guidelines will overcome prevailing objections to this practice and allow for the legitimization of this process.

Keywords Palliative care · Continuous deep sedation · End of life · Palliative sedation · Terminal sedation · Ring Theory of Personhood

Introduction

The practice of continuous deep sedation (CDS), which Rys et al. define as “the act of reducing or removing the

consciousness of an incurably ill patient until death” (2012, 171), continues to be drawn into debates regarding physician-assisted suicide or physician-assisted death (PAS) and euthanasia (E). This has limited its acceptability and its justified application in the treatment of intractable suffering at the end of life (Rys et al. 2012; *Washington v. Glucksberg*, 521 U.S. 702 [1997]; Raus, Sterkx, and Mortier 2012). Underpinning the persistent association between the practices of PAS/E and CDS are two significant factors: (1) the continued application of CDS within the “argument of preferable alternative” (APA) as a legally and clinically acceptable treatment substitute for PAS/E and (2) the inherent inconsistencies and lack of guidelines within the practice of CDS that occasion concern of abuse and slippery slopes to PAS/E (Rys et al. 2012; *Washington v. Glucksberg* 1997; Raus, Sterkx, and Mortier 2012). The unfortunate repercussion of such concerns has been the injudicious withholding and/or the suboptimal application of this treatment (Rys et al. 2012; Cherny and Radbruch 2009; Rousseau 2005).

The purpose of the paper is to provide additional information and a potential way forward in efforts to overcome the resistance and misapplication of this treatment of last resort. This discussion describes the reintegration of this practice into a palliative care approach that has been thus far been largely ill-defined within most clinical guidelines (Davies and Ford 2005; Rousseau 2007; Cherny 2006; Krakauer and Quinn 2010; Committee on National Guideline for Palliative Sedation, Royal Dutch Medical Association 2009; Cherny and Portenoy 1994; Morita et al. 2000, 2005a, b). This palliative care approach is implemented by a

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multidisciplinary team (MDT) that is guided by a holistic case-specific review and clear practice definitions and clinical guidelines. It better addresses prevailing concerns and meets patient-specific needs in this complex care situation (Rys et al. 2012). This discussion is divided into four sections. In the first two sections, I begin with a study of the APA, followed by an overview of prevailing concerns associated with it as set out by Rys et al. (2012). The positions of a number of detractors to this practice are also considered. The third part of this paper evokes the key elements of palliative care practice, the MDT approach and the use of a holistic case-specific review process, and addresses how combining these elements can stratify practice in an accountable, transparent, and evidence-based manner. The final part of this paper will address the importance of practice definitions drawn from Singapore's forthcoming continuous deep palliative sedation (CDPS) framework in aiding the adaptation of prevailing practice guidelines. I maintain that clarity of case-specific practice definitions that explicate care determinants within the Singaporean care setting, in tandem with the delineating of the other key facets of a palliative care approach, will allow for the appropriate adaptation of prevailing CDS guidelines. This is particularly pertinent when many prevailing definitions fail to consider patients who are sedated to mitigate the discomfort arising directly as a result of the cessation of active therapies or "treatments not oriented toward meeting the comfort goals of care such as vasopressors, pacemakers, intraaortic balloon pumps" and that are deemed to serve "no role other than delaying death and prolonging the patient's potential discomfort" (Rubinfeld 2004, 442). It is in this context that three critical considerations arise. First, patient candidates for CDS include both patients being sedated for their intractable symptomology at the end of life and patients who have their active therapies ceased following determinations as to their futility. Second, it is within this latter patient population that the doctrine of double effect (DDE), which has for so long guided the application of CDS, makes way for the clinically relevant principle of proportionality (PoP). The PoP, unlike the DDE, does not seek to discern the intentions of the multidisciplinary team but pivots instead upon patient-specific, clinically relevant, evidence-based considerations practised within the remit of prevailing clinical, professional, social, and legal standards. Finally, it is also within this context of dissonance in care and treatment settings that the goals of treatments such as CDS are

distanced from PAS/E. For while CDS seeks to ensure the preservation of life and dignity without hastening death, PAS/E seeks to preserve dignity and ameliorate suffering through actively seeking to abbreviate life.

The Argument of Preferable Alternative (APA)

Underpinning U.S. Supreme Court Justice Sandra Day O'Connor's application of CDS in the pivotal case *Washington v. Glucksberg* (1997) as that of a preferred alternative to PAS/E is the belief that CDS is an effective, legally acceptable, clinically appropriate means of treatment of terminally ill patients in "severe pain" that does not rely upon the hastening of death amongst patients in the terminal phase to alleviate suffering (Raus, Sterkx, and Mortier 2012). Further, siting this procedure within the armamentarium of palliative treatments of last resort and thus under the oversight of a professionally trained healthcare team appears to reduce cause for concern with regards to the potential abuse of this therapy (*Washington v. Glucksberg* 1997; Raus, Sterkx, and Mortier 2012). The combination of these considerations is then held to negate the need for the legalization of PAS (*Washington v. Glucksberg* 1997; Raus, Sterkx, and Mortier 2012).

Whilst Justice O'Connor is not explicit in the form and manner that this treatment of last resort ought to take, her statement that "a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death," appears to point to the practice of sedation at the end of life (*Washington v. Glucksberg* 1997, ¶2/¶3 in Justice O'Connor's concurring opinion). Justice O'Connor uses flexible descriptors to delineate the practice she avers, and this underpins a desire to remain relevant in the face of evolving conceptions to the practice of sedation at the end of life (Ventafriidda et al. 1990; Green and Davies 1991; Enck 1991; *Washington v. Glucksberg* 1997; Raus, Sterkx, and Mortier 2012). The practice of CDS must be seen as an evolving process that continues to inculcate into its guidelines improvements in prognostication methods, advances in symptom management, and improvements in medical training. Such evolution to guidelines must be carried out under the aegis of palliative care and according to the tenets of evidence-based medicine. This will not only ensure accountability

and transparency of this process but also allow it to effectively guide clinical practice and steer clinicians away from life-abbreviating options (*Washington v. Glucksberg* 1997).

As developments in the practice of sedation at the end of life progressed from terminal sedation (TS) to palliative sedation (PS) to the present concept of CDS, so too have practice guidelines and definitions. These include: (1) the substitution of the term “severe” symptoms for the more clearly defined terms “refractory” or “intractable”; (2) the application of the term “suffering” instead of “pain” in keeping with growing acceptance of the interrelatedness of physical and psycho-existential experiences; (3) tighter safeguards and monitoring procedures to reduce concerns with regard to the side effects of this treatment of last resort; and (4) the requirement that all “safer” treatment options have been exhausted, e.g., the requirement that this treatment be subject to the determination by a multidisciplinary team guided by prevailing clinical guidelines that the application of this treatment is appropriate for the specific patient. All serve to highlight efforts to ensure the accountability, justifiability, and transparency in the use of CDS (Davies and Ford 2005; Rousseau 2007; Cherny 2006; Krakauer and Quinn 2010; Committee on National Guideline for Palliative Sedation, Royal Dutch Medical Association 2009; Cherny and Portenoy 1994; Morita et al. 2000, 2005b; Krishna 2010, 2011a, 2011b, 2012; Krishna and Chin 2011; Cassell 1983, 1999; Boston, Bruce, and Schreiber 2011; Schuman-Olivier et al. 2008). These newer evidence-based definitions demand that the employment of CDS is proportional to the demands of the situation and act to protect the particular patient’s holistically appraised best interests (Davies and Ford 2005; Rousseau 2007; Cherny 2006; Krakauer and Quinn 2010; Committee on National Guideline for Palliative Sedation, Royal Dutch Medical Association 2009; Cherny and Portenoy 1994; Morita et al. 2000; Morita 2005b; Krishna 2010, 2011a, 2011b, 2012; Krishna and Chin 2011; Cassell 1983, 1999; Boston, Bruce, and Schreiber 2011; Schuman-Olivier et al. 2008).

Prerequisites for the consideration of CDS have also been tightened, especially in light of tacit acceptance that these treatments might in fact endanger the very lives of those they are meant to help (Davies and Ford 2005; Rousseau 2007; Cherny 2006; Krakauer and Quinn 2010; Committee on National Guideline for Palliative Sedation, Royal Dutch Medical Association 2009; Cherny and Portenoy 1994; Morita et al. 2000). A diagnosis of intractability implies the exhaustion of all

other viable treatment alternatives, and a limited prognosis of days to up to two weeks ensures that any clinically indicated cessation of hydration and/or nutrition does not impact upon the life expectancy of the patient. This ensures an overarching goal of care focused upon maximizing comfort and the exhaustion of disease-modifying treatments (Morita et al. 2005a, b; De Graeff and Dean 2007; Committee on National Guideline for Palliative Sedation, Royal Dutch Medical Association 2009; Krishna 2010, 2012; Juth et al. 2010; Krishna and Chin 2011; Materstvedt 2012; Raus, Sterckx, and Mortier 2012). Central to these prerequisites is the fact that death must not be intended, even when CDS is applied in the face of the inevitable distress that follows the cessation of treatments that have been determined to be futile, such as intubation or ionotropes (Rubenfeld 2004).

These advances in the practice of sedation at the end of life have overturned Justice O’Connor’s own preconditions for CDS to be applied only upon the request of the patient (*Washington v. Glucksberg* 1997). In light of increasing evidence that the presence of intractable suffering, the influence of strong medication, and the concomitant effects of co-morbid conditions can compromise valid informed consent, Justice O’Connor’s stipulation for CDS to be applied only upon the request of a competent patient has been replaced in favour of a holistically appraised best interests determination (Battin 2008; Krishna 2010, 2011a, 2011b, 2012, 2014; Krishna and Chin 2011). This highlights the fact that an evolution in practice of CDS is led by advances in clinically based data practice and remains under the oversight of careful, transparent, and accountable palliative care case-specific review that lies within the confines of prevailing clinical guidelines and legal statutes (Krishna and Chin 2011; Krishna 2014).

Despite these adaptations in practice, there is inherent ambiguity surrounding the oft-unaddressed practice of cessation of active treatments that Rubenfeld describes as “treatments not oriented toward meeting the comfort goals of care” (2004, 442). These include vasopressors, pacemakers, and intra-aortic balloon pumps that serve merely to delay death and prolong potential discomfort (Rys et al. 2012; Davies and Ford 2005; Raus, Sterckx, and Mortier 2012). The second part of this paper will scrutinize the persistent concerns of commentators such as Rys et al. (2012); LiPuma (2013); Raus, Sterckx, and Mortier (2012); Quill (1991, 1997, 2012), and Battin (2008).

Prevailing Concerns Associated With the APA

Rys et al.'s Position With Relation to Continuous Deep Sedation (CDS)

Rys et al. carried out a “qualitative design based [study] on a thematic content analysis of English-language editorials, comments, and letters that discuss CDS and are indexed in MEDLINE/PubMed or CINAHL (1966 to November 2009)” (2012, 172). This allowed the identification of a number of recurrent themes in relation to the “the act of reducing or removing the consciousness of an incurably ill patient until death” (Rys et al. 2012, 172). These themes include clarification of the intention behind employing CDS, the withholding of artificial nutrition and hydration (ANH), and evaluation of the proportionality of this response and its effects (Rys et al. 2012). Rys et al. conclude that in light of a lack of universally accepted practice guidelines, “discussion about the relation between CDS and PAS is first and foremost a semantic rather than a factual dispute” (2012, 179). Rys et al. further suggest that, based upon their review, it is this prevailing dearth of clear understanding in the practice that prevents practical progress being made in differentiating PAS/E from CDS.

LiPuma's Concerns With Respect to CDS

A further pervading concern surrounding CDS raised by Davies and Ford (2005); Materstvedt and Bosshard (2009); Juth et al. (2010); Materstvedt (2012); Rys et al. (2012), and Raus, Sterckx, and Mortier (2012) has been the issue of the effects of sedation upon the personhood of the individual. LiPuma (2013) crystallizes these concerns by stating that neglect in appropriately acknowledging the effects of iatrogenic unconsciousness until death “does not do justice to being human and the significance that consciousness and all other human awareness abilities have to human life” (2013, 12). LiPuma concludes that a terminally ill patient in a deeply sedated state with little chance of recovery of consciousness ought to be considered “dead” (2013, 12). Central to LiPuma's (2013) position is the belief that human life is only of value when conscious function is preserved and social function is maintained. According to LiPuma (2013), a loss of social function that follows irreversible unconsciousness renders a patient treated with CDS effectively in a state un-differentiable to death. LiPuma's new

classification of death then places the employment of CDS both firmly within the realms of PAS/E and outside the applicability of the APA (LiPuma 2013).

Battin's Concerns With CDS

Battin (2008) also questions the position of CDS on the issue of preserving the sanctity of life. Battin suggests that the application of CDS is coercive, poorly regulated, and open to abuse and believes that in the face of “patients suffering from severe pain, for whom pain management has failed ... reflective, unimpaired consent may no longer be possible” (Battin 2008, 27). She suggests that “[a]utonomy is therefore undercut” and “various familial, institutional, or social pressures will maneuver the patient into death when that would have been neither her choice nor in accord with her interests” (Battin 2008, 29). These coercive effects, compounded by the practice of routine cessation of ANH, leads Battin to dismiss the “airy, rather romantic notion of ‘natural’ death” and to conclude that “in terminal sedation death typically results from or is accelerated by dehydration” (Battin 2008, 28).

Accompanied by the well-documented vagaries surrounding surrogate decision-making and in the almost inevitable presence of competing interests amongst decision-makers (particularly within the Singaporean setting), Battin's fear of the inappropriate applications of this treatment option is further heightened (Battin 2008; Tan et al. 1993; Goh 2008a, 2008b; Toh 2011; Krishna 2010, 2011a, 2011b, 2014).

Quill et al.'s Position on CDS

A further concern highlighted in Battin's review is the lack of universally accepted practice definitions for the employment of CDS (Battin 2008). Here I focus particularly upon the lack of clear definitions for Quill's principle of proportionality (PoP) that is employed in *Glucksberg v. Washington* and in ensuing formulations of TS, PS, and CDS (Quill 1991, 1995, 1997, 2012; Quill, Cassell, and Meier 1992; Quill, Coombs Lee, and Nunn 2000; Quill et al. 2009; Quill and Kimsma 1997; Quill and Bycock 2000). Although it provides arguably more transparent and accountable oversight of the application of CDS, relegation of the DDE in favour of the PoP in CDS guidelines could be seen to provide an avenue for the acceptance of PAS as the treatment of choice in the event of a failure of CDS (Davies and Ford

2005; Rousseau 2007; Cherny 2006; Krakauer and Quinn 2010; Committee on National Guideline for Palliative Sedation, Royal Dutch Medical Association 2009; Cherny and Portenoy 1994; Morita et al. 2000; Quill 1991, 1995, 1997, 2000, 2009, 2012; Quill, Cassell, and Meier 1992; Quill and Kimsma 1997; Quill and Bycock 2000; Quill, Coombs Lee, and Nunn 2000; Quill et al. 2009). This controversial interpretation of Quill's use of the PoP draws upon Quill's 1991 article entitled "Death and Dignity: A Case of Individualized Decision Making," where Quill justifies his part in the suicide of his patient by suggesting that such action was a "proportional response" to the threat of "increasing discomfort, dependence and hard choices" (Quill 1991, 693). Quill re-employs a more organized formulation of the PoP in his and his colleagues' "Care of the Hopelessly Ill: Proposed Clinical Criteria for Physician-Assisted Suicide" that is later translocated to CDS guidelines (Quill, Cassell, and Meier 1992). Such reapplication of the PoP incites fears that the PoP could be employed to authorize the application of PAS in the event of a failure of CDS (Quill 1991, 1995, 1997, 2000, 2012; Quill, Cassell, and Meier 1992; Quill and Kimsma 1997; Quill, Coombs Lee, and Nunn 2000; Quill and Bycock 2000; Quill et al. 2009).

There are two situations that would allow for this possible acceptance of PAS as a treatment of last resort within the specific confines of an exhaustion of treatment options that would include CDS: the likelihood of the patient's continued suffering until death and an overarching goal of care focused upon ameliorating suffering and maximizing comfort. The first seizes upon the differing definitions of the practice of sedation at the end of life that have precipitated varying reports as to the efficacy of CDS (Chater et al. 1998; Cowan and Walsh 2001; Morita et al. 2005a; Claessens et al. 2008). Morita et al. (2005a) reported the failure rate of CDS to be 17 per cent, while Chater et al. (1998); Cowan and Walsh (2001), and Claessens et al. (2008) report the efficacy of CDS in ameliorating awareness to be 90 per cent. Assuming a 5 per cent to 15 per cent failure rate of CDS, PAS/E could be portrayed as the only option left to preventing further suffering amongst patients with intractable suffering at the end of life (Chater et al. 1998; Cowan and Walsh 2001; Morita et al. 2005a; Claessens et al. 2008).

The second scenario that could allow the PoP to be used to justify the employment of PAS relies upon the physician's duty of non-abandonment and obligation to respect the choice of the patient and to provide

"compassionate care" (Quill 1995). Quill holds that the duty of non-abandonment trumps all other considerations, particularly "when suffering becomes intolerable in spite of excellent palliative care" (Quill 1995, 189). Thus, when CDS does not lie in a patient's goals of care and when CDS cannot contain his or her suffering, the wish for PAS/E should be respected (Quill 1995, 1997) rather than abandoning the patient. PAS/E would therefore become "the treatment of last resort" in place of CDS for those unfortunate patients who experience failures of CDS and face the prospect of continued suffering for the remainder of their lives.

Addressing Concerns With Regard to CDS

With concerns that CDS may be seen to usher in the practice of PAS/E, it is unsurprising that authors such as Rys et al. (2012); Raus, Sterkx, and Mortier (2012); LiPuma (2013); Battin (2008), and Quill (1995, 1997, 2012) acknowledge significant physician resistance in applying this treatment option. Yet overcoming these concerns may lie simply in the reapplication of the tenets of a palliative care approach that require a set of clearly delineated practice definitions and guidelines (Krishna and Chin 2011).

The adaptation to the Singaporean context of prevailing practice guidelines such as those forwarded by the European Association of Palliative Care (EAPC) and the Royal Dutch Medical Association (KNMG), or those presented within the major textbooks such as the *Oxford Textbook of Palliative Medicine* and the *Textbook of Palliative Medicine*, provides the basis for an evolutionary and clinically relevant, socioculturally appropriate, ethically sensitive formulation for CDS (Davies and Ford 2005; Rousseau 2007; Cherny 2006; Krakauer and Quinn 2010; Committee on National Guideline for Palliative Sedation, Royal Dutch Medical Association 2009; Cherny and Portenoy 1994; Morita et al. 2000). However, such modifications are complex, particularly in light of constraints in the provision of specialist palliative care, access to palliative care services and palliative treatment options, variations in safety profiles and sensitivities of the drugs within the local Singaporean population, and the inherent limitations in monitoring capabilities (Krishna 2011a, 2011b, 2012, 2014; Krishna and Chin 2011). Furthermore, the influence of local sociocultural factors must also be duly considered, particularly when their impact within the Singapore context upon the consent process and upon

the issue of clinically assisted nutrition and hydration (CANH) at the end of life is not insignificant (Tan et al. 1993; Goh 2008a, 2008b; Low et al. 2000, 2009; Ho, Krishna, and Yee 2010; Tan and Chin 2011; Toh 2011; Krishna and Chin 2011; Krishna 2010, 2011a, 2011b, 2012).

The Key Elements of Palliative Care Practice

Continuous Deep Palliative Sedation

With this in mind, Singapore's forthcoming continuous deep palliative sedation (CDPS) guidelines define CDPS as the proportional and monitored induction of deep continuous sedation for the amelioration of all forms of intractable physical, psychological, and existential suffering. The guidelines state that this must follow holistic, multi-professional assessment of the patient's condition to affirm that suffering is in fact intractable, that the anticipated prognosis is less than two weeks, and that the application of such an intervention is in the patient's best interests. The intent of this procedure is to circumnavigate awareness of suffering through the maintenance of deep levels of sedation in a manner that is consistent with prevailing guidelines and clinical, professional, and legal standards. This procedure is monitored and overseen by a multidisciplinary team (MDT) to ensure accountability, transparency, and justifiability of actions and to make certain that life is not intentionally abbreviated.

CANH is routinely provided unless clinically contraindicated. This is in part as a result of an inconclusive finding in Good et al.'s (2008, 2014) Cochrane review of "Medically Assisted Hydration for Adult Palliative Care Patients" and in light of prevailing sociocultural views on feeding and hydration at the end of life in Singapore (Good et al. 2014; Krishna 2011a, 2011b; Ho, Krishna, and Yee 2010; Chai, Krishna, and Wong 2014). The prevailing sociocultural view of maintaining hydration and nutrition even in the terminal stages of life amongst local patients and families has directly influenced Singapore's *Advanced Medical Directive Act 2010* and underpins the position adopted within these new guidelines.

The position adopted in the forwarding of CDPS is supported by clinical reports and data on a number of other facets of this practice. This includes: (1) evidence that the proportional employment of sedation and

opioids and the cessation of CANH at the end of life have little impact on prognosis, particularly when applied in the last two weeks of life; (2) evidence that patients do not consider the preservation of conscious function all-important in care considerations nor does it trump all other goals of care; (3) the incorporation of an evidence-based, multidimensional concept of personhood; (4) the improvement in prognostication tools; (5) the employment of evidence-based safety protocols in monitoring; and, finally, (6) the inculcation of newer clinical palliative care practices into the new formulation (Good et al. 2008; Ho, Krishna, and Yee 2010; Chai, Krishna, and Wong 2014; Krishna 2010, 2011a, 2011b, 2012; Committee on National Guideline for Palliative Sedation, Royal Dutch Medical Association 2009; Boston, Bruce, and Schreiber 2011; Schuman-Olivier et al. 2008; Krakauer and Quinn 2010). As a result, the prerequisites for implementing CDPS in terminally ill patients as determined by a palliative care MDT are:

1. A diagnosis of intractability, where there is an exhaustion of treatment options to palliate the distressing symptoms experienced to a tolerable level within an acceptable time frame.
2. A diagnosis of "terminality" of the illness, where a prognosis of less than two weeks is anticipated.
3. A diagnosis of "futility," when it is determined that illness progression is no longer responsive to disease-altering treatments.
4. A determination that application of this procedure is in keeping with the holistically determined best interests of the patient.

I will argue later that applying the CDPS framework, replete with clear practice definitions and a MDT-led palliative care approach, allows for better accommodation of prevailing CDS guidelines and also serves to overcome the concerns raised earlier.

Holistic Review

Key to this process of reconfiguring guidelines to the Singaporean context is the adoption of a holistic review of the specific case. The definition of a holistic review or holistic common assessment draws upon the U.K.'s National Health Service's National End of Life Care Programme's guidance on holistic common assessment. This "covers the full range of physical, psychological, social, spiritual, cultural and, where appropriate,

environmental needs” (Department of Health 2008, 53). This process must necessarily encapsulate the patient’s background information; physical, psychological, spiritual, sociocultural, and occupational needs; and preferences, values, beliefs, and goals that allow for a fluid and multidimensional, multi-professional appraisal of the patient’s best interests (Department of Health 2008; Krishna 2012).

Multidisciplinary Team Approach

According to the United Kingdom’s Manual of Cancer Services, the MDT is defined as a

group of people of different health care disciplines, which meets together at a given time (whether physically in one place, or by video or tele-conferencing) to discuss a given patient and who are each able to contribute independently to the diagnostic and treatment decisions about the patient (Department of Health 2004, 3 under “Topic 2A”).

In this collaborative, which is widely accepted as a quintessential part of a palliative care approach, various professionals maintain their “disciplinary specific orientations” yet come together to integrate their expertise and traverse the many complex and evolving social, psychological, ethical, and practical considerations involved in any decision-making process where CDS is being considered (Crawford and Price 2003; Hermsen and ten Have 2005; Vissers et al. 2012; Onyeka 2013). The CDPS framework thus requires that the MDT include the primary physician, the specialist palliative care physician, palliative care nurse, and medical social workers as well as consider the input of the patient’s family and carers (Payne and Oliviere 2009).

The United Kingdom’s National Cancer Action Team’s (2010) report entitled the “Characteristics of an Effective Multidisciplinary Team (MDT)” adds that:

- 1.4.1. Each MDT member has clearly defined roles and responsibilities within the team which they have signed up to and which are included in their job plans.
- 1.4.2. The team has agreed what is acceptable team behaviour/etiquette including:

- mutual respect & trust between team members;

- an equal voice for all members—different opinions valued;
- resolution of conflict between team members;
- encouragement of constructive discussion/debate;
- absence of personal agendas;
- ability to request and provide clarification if anything is unclear (National Cancer Action Team 2010, 10).

This approach engenders better teamwork and holistic reviews and facilitates the decision-making process within the confines of a specific case review (Yang, Kwee, and Krishna 2012; Foo, Lee, and Soh 2012; Ching et al. 2013).

To ensure accountability and balance within MDT determinations, evaluation by an independent palliative care specialist, social worker, and specialist in the patient’s primary condition is required to determine if the various preconditions for CDPS have been met. This highlights the critical need to define key practice definitions such as intractability, appropriateness, justification, necessity, best interests, futility, and proportionality.

Intractability

The importance of clarity in the definitions of intractability or refractoriness is highlighted in Juth et al.’s comment that

the presence of refractory symptoms is a necessary condition for an ethically defensible initiation of sedation at the end of life, in particular when there is no intention of discontinuing sedation before the patient dies (Juth et al. 2010, 3).

Within the present context, the practice definitions for intractability or refractoriness combine Cherny and Portenoy’s (1994) determination with that of Morita et al. (2000). Cherny and Portenoy assert that a symptom is refractory if “all other possible treatments have failed, or it is estimated by team consensus, based on repeated and careful assessments by skilled experts, that no methods are available for alleviation within the time frame and risk–benefit ratio that the patient can tolerate” (1994, 35). Morita et al. stipulate that “systematic assessments based on the physical-psychological-social-existential model, survival predictions, competency evaluations and holistic understanding as a whole patient” that encapsulates

“supportive psychotherapy and patient orientated compassionate care” must be met to circumnavigate concerns of a solely clinically driven process (2000, 192).

These determinations are to be objectively assessed and determined by the MDT, guided by prevailing clinical guidelines and care standards (Krishna 2010, 2011a, 2011b, 2012; Krishna and Chin 2011). This last point reaffirms that whilst much of the diagnosis of intractability is subjective, a determination of intractability must nevertheless be objective but nonetheless not a diagnosis that can be arrived solely as a result of refusal of less-sedating treatment options.

As a result, the MDT is tasked to ensure that there is a balance within this process and that refusal and/or the circumvention of certain treatment alternatives are justified and appropriate.

Appropriateness

Practice definitions for appropriateness of an intervention move beyond patient- and family-centred considerations to include due considerations of the care providers and what they can realistically provide within the confines of current legal and clinical standards (Braun et al. 2007). This should include, but is not limited to, the competency and experience of physicians, their training and expertise in end-of-life care, the relationship that they share with the patient and the patient’s family, their communication skills, and their ability to appropriately understand, weigh, and balance the various and sometimes competing obligations and the cultural, religious, ethical, psychosocial, and clinical factors involved within a specific situation.

Additionally, careful consideration must be given to the

adequacy of disease and symptom diagnosis, on estimation of the patient’s stage in the trajectory of the disease, on calculation of the benefits to burdens/risks calculus of both investigations and treatments, on the patient’s goals and values, on the family or significant others’ goals and values where appropriate, and, to a lesser extent, on the cost of investigations and treatments (Taube and Bruera 1999, 69).

Fuchs adds to this wider consideration of appropriateness by requiring careful scrutiny of “the heterogeneity of patient populations and uncertainty about the response of individual patients to an intervention” and

underscores “that it is often difficult or impossible to determine in advance which ones [i.e., interventions] will prove to help particular patients and which will turn out to have been unnecessary” (Fuchs 2011, 356).

Fuchs argues further that in fact appropriateness revolves around “the primacy of patient welfare” and represents a commitment to provide “appropriate health care” that is based on “wise and cost-effective management of limited clinical resources” (Fuchs 2011, 356).

Such wide considerations reaffirm the position adopted here for the employment of an independent review process.

Justification

Central to any justificatory action is the requirement that variances in care practices and provision must lie within the confines of clinical standards and the institutionally and professionally determined minimum care. Care must be documented and clearly explained, particularly in the presence of a majority decision within the MDT. Rationale for the discounting of alternative options must also be clearly explained. This would include the means, manner, and route of applications, provisions for monitoring, and the necessity underpinning the action.

Necessity

The application of CDPS is not a decision that is taken lightly. It is one that must be seen as a “choice of evils” brought on at a moment when urgent action is required in order to preserve the overarching goals of care that involve a choice between attenuating the patient’s agency and breaching his or her interests (Moore 1972; Bickenbach 1983; Brudner 1987; Kahan et al. 1994; Sabin et al. 1994; Charles et al. 1997; Jacobson 1997). Whilst this process is guided by the principle of necessity, there is significant dissonance in the manner in which this concept is conceived, the form that any medical response ought to take, and who should determine the when, where, and nature of this care (Menon 2009).

Further, the principle of necessity is contextually dependent. For example, in the United States, Medicare defines “medical necessity” in terms of the provision of necessary services for the delivery of care to standards stipulated by the Department of Health and Human Services (2014) and who should qualify for reimbursement for care. This contrasts significantly from the concept of “force majeure” evident within the

English and Welsh *Mental Capacity Act 2005* (see <http://www.legislation.gov.uk/ukpga/2005/9/contents>) and the *Mental Health Act 2007* (see http://www.legislation.gov.uk/ukpga/2007/12/pdfs/ukpga_20070012_en.pdf).

Variances in defining, interpreting, and applying the principle of necessity create significant concern about the practice that *Mosby's Medical Dictionary* describes as empowering a physician to “assume a person’s consent to medical treatment when he or she is in imminent danger and is unable to give informed consent to treatment” (Mosby, Inc., 2009; Sulmasy et al. 1998).

Necessity as it is interpreted here also has to contend with changing clinical context and goals, for example being compelled to immediate action to address continuing and intractable suffering at end-of-life events in the same manner that life-threatening situations are met in the accident and emergency care setting (Krishna and Chin 2011).

I believe a holistic review met by the MDT would lend validity and justifiability of the actions of the physician in charge in breaching the rights of the patient in order to realize this demand for immediate care. It would also meet the stipulations set out by the *Mental Capacity Act 2005* and section 118(2) of the *Mental Health Act 2007* to fair, just, accountable, transparent, and evidence-based care based upon holistic appreciation of the patient and his or her context.

Best Interests Determinations

It is not uncommon for patients being considered for treatments such as CDS to be incapable of providing informed consent (Krishna 2010, 2012). For those who still maintain capacity to consent and CDS is being considered, their choices are to be respected, as should the wishes of patients who have instituted an advance medical directive (AMD). However, for those patients who lack capacity to consent appropriately, the duty of determining the appropriate course of action falls upon the MDT.

Within the Singaporean context, the employment of an MDT determination advocated here has been in direct response to growing data on the prevalence of the practice of familial-led collusion in end-of-life care. Such collusion not only compromises patient autonomy but also circumnavigates direct patient involvement in care determinations within the Singaporean setting (Low et al. 2000, 2009; Tan and Chin 2011; Krishna 2010, 2011a, 2011b, 2014; Foo, Lee, and Soh 2012; Ching

et al. 2013; Foo et al. 2013). Supported by the local credo that a harmonious and calm lifestyle, free of distress and consternations, enhances life expectancy, families often practise collusion and non-disclosure, adjudging it acceptable partly on the belief that discussions about death or indeed the breaking of dire news would be inauspicious and even taboo (Tan et al. 1993; Goh 2008a, 2008b; Toh 2011; Krishna 2010, 2011a, 2011b, 2014). These beliefs are coupled with the continued dominance of the concept of filial piety amongst most South East Asian populations. Filial piety requires the younger generation to care and protect the interests of their elders, often in a manner that the family, and not necessarily the patient, holds (Tan et al. 1993; Black 2001; Htut, Shahrul, and Hua Poi 2007; Goh 2008a, 2008b; Sittisombut and Inthong 2009; Toh 2011; Krishna 2014). Meeting these obligations to support and protect frail and dependent family members in a manner that is consistent with the views of the family unit and the wider community is critical for the family, given the great store placed upon the maintenance of “face” or familial and individual honour by Singaporean and indeed many South East Asian societies (Tan et al. 1993; Black 2001; Htut, Shahrul, and Hua Poi 2007; Goh 2008a, 2008b; Sittisombut and Inthong 2009; Toh 2011; Krishna 2014). Data would suggest that in Singaporean society a “loss of face” is a fate fearfully avoided (Tan et al. 1993; Goh 2008a, 2008b; Black 2001; Ho, Krishna, and Yee 2010; Toh 2011; Krishna 2014).

“A loss of face” is also incurred for the family should the patient choose to employ alternative means other than reliance upon family members to protect his or her interests (Foo et al. 2013; Krishna 2014). This may explain the relatively low use of AMDs within the Singaporean context, despite clear evidence that patients are keen to participate in their own care determinations and protect their enduring interests (Tan et al. 1993; Low et al. 2000, 2009; Foo et al. 2013; Krishna 2014). This fear of causing familial “loss of face” may also explain the continued deference to familial determinations (Chan, Peart, and Chin 2013; Krishna 2014). This is particularly pertinent in a Singaporean society that adopts a shared financing approach to healthcare, where the costs of care are shared between the patient and the family and the government. This in turn creates competing interests amongst familial decision-makers faced with shouldering the care costs and their responsibility to their vulnerable family members (Chan, Peart, and Chin 2013; Ministry of Health Singapore 2013). It is the

combination of these considerations that underlies the position taken here to employ a holistic, accountable, transparent, and evidence-based MDT-led approach to best interests and care determinations. This approach sits quite apart from the practices of many Western societies that seek instead to include and sometimes be led by the determinations of surrogate decision-makers (Krishna 2010; Krishna and Chin 2011).

Within this context, the MDT plays three key roles. First, the MDT plays a key role in determining if the patient is capable of providing valid consent in the atmosphere of collusion and significant psychophysical and existential distress that accompanies a clinical situation requiring CDS. Second, the MDT must still facilitate patient involvement in this decision-making process through continued attempts to reduce the burden upon the patient's deliberative abilities and must facilitate communication even if it is reduced to interpreting the patient's gestures or simple answers as a means of considering his or her inputs in the MDT determinations of best interests. Third, the MDT must ascertain, based upon a holistic review of the patient's condition and available treatment options, that the patient's continued suffering can only be alleviated by CDS. This process must include the independent reviews of a palliative care physician, a specialist in the patient's primary illness, and a social worker, in addition to a psychiatrist to ensure that the circumstances do demand immediate action and that treatment options to protect the patient's interests are indeed limited to CDS.

Determinations of Futility

A determination that treatments are limited to CDS pivots upon the determination of the futility of all other treatments. However, such a judgement is subjective. Within the context of CDS, this is a determination that there are no more treatment options available both to alter the course of the patient's illness and to ameliorate his or her symptoms. Yet such determinations are dependent upon statistical probabilities. Not infrequently within the clinical context, however, a one per cent chance of response may be considered better than none for many patients at the end of life, particularly when their overall goals of care are not focused upon maximizing comfort. As a result, determination of futility is frequently a process of agreeing that there are no viable treatment options available that would likely provide an appreciable improvement without resulting in unacceptable effects within a tolerable time frame.

Determinations of futility are case specific, context dependent, clinically related, and determined by patient and familial goals, cultural and religious views, and socio-economic realities. Therefore, the decision to apply CDS can be difficult to reach. While such determinations ought to include the patient, the presence of intractable symptomatology may impede and even prohibit the patient's ability to participate fully in these determinations—as a result of the impact of these symptoms, their treatments, and the effects of coexisting co-morbidities upon the competence of the patient (Schuman-Olivier et al. 2008; Krishna 2011a, 2011b, 2012; Krishna and Chin 2011). Further restrictions to patient participation and increased reliance upon surrogate decision-makers become increasingly clear in the face of the continued practice of collusion, circumnavigation of patient involvement in his or her own end-of-life care determinations, and familial determinations that may place the interests of the family over those of the patient (Ho, Krishna, and Yee 2010; Tan and Chin 2011; Krishna 2011a, 2011b, 2012; Krishna and Chin 2011; Foo, Lee, and Soh 2012; Yang, Kwee, and Krishna 2012; Chan, Peart, and Chin 2013; Foo et al. 2013; Ching et al. 2013).

With potential conflicts of interests on the part of the families who are key participants in care determinations and the tendency of local families to attempt to override the previously stated wishes of the patient, there is propensity for situations where accommodation cannot be attained without compromise to the patient's condition (Krishna 2010, 2011a, 2011b; Tan and Chin 2011; Ching et al. 2013).

Here it falls upon the primary physician in tandem with the palliative care team to determine how best to protect the interests of the patient in an accountable, balanced, holistic, and evidence-based manner. In rare cases where compromise cannot be attained between families and the palliative care team—particularly where the integrity of the family unit is at risk, when concerns are raised as to the ability of the family unit as a whole or individual members of the family to cope, or when bereavement care may be significantly compromised—the institutional ethics committee may be called upon to determine the course of treatment.

Proportionality

Determining if a response is proportional to the needs of the patient and his or her particular situation is key. Such decisions move beyond simply maintaining that any

therapeutic response must be commensurate with the severity of the symptoms as determined by a multidimensional appraisal of the situation, an appreciation of “force majeure” that demands appropriate treatment, the overall goals of care, and appropriate balancing of the risks and benefits of the treatment within the confines of prevailing practice guidelines and clinical standards, including contextual considerations (Quill, Lo, and Brock 1997; Quill and Bycock 2000; Quill 2012).

Within the breadth of clinical considerations, ranging from active cessation of futile treatments such as cardio-respiratory support to the employment of deep sedation to circumnavigate awareness of intractable suffering at the end of life, the rationale for the principle of proportionality over the DDE is re-emphasized. In the treatment of intractable suffering at the end of life, lighter forms of sedation are not sought, given that it is anticipated to provoke awareness of the patient to the ill effects of this action (Rubenfeld 2004). Titration is not aimed at preserving consciousness but rather to induce deep unconsciousness, emphasizing a significant variance from the intent of sedation in the treatment of intractable suffering and the use of CDS at the end of life. Such differences may have been seen to breach the provisions of discerning intention in the DDE but do not do so under the principle of proportionality so long as the other provisions for the application of CDS are met.

Intention

In situations where balance and sometimes compromise is called for, particularly where adaptations of the prevailing guidelines are required, the intention of the physician in employing CDS is often questioned. This is especially so when there is data to suggest that physicians may apply CDS to acquiesce to the demands of the family or as a result of being no longer able to cope with the situation (Rietjens et al. 2004, 2006, 2008, 2009a, 2009b, 2012).

The presence of the MDT can circumvent concerns surrounding the intentions of a sole practitioner tasked with adjudging the appropriateness of employing CDS and ensure that the various prerequisites for its application have been met through transparent, accountable, and inclusive joint decision-making, particularly within the context of ceasing active life support. A further attribute that stems from this well-circumscribed procedural approach is the application of this multidimensional assessment process that, when applied to the patient's,

the family's, and the carers' views, aids in addressing concerns around the implication of iatrogenic induction of unconsciousness upon the personhood of the patient.

Holistic Review Within the Context of Personhood

In this final segment of this paper, I focus on the manner that personhood or “what makes you who you are” is conceived. I also address concerns regarding the negation of all experience and the concepts of “social death” and biological death as a result of the application of CDS (Davies and Ford 2005; Juth et al. 2010; LiPuma 2013; Matersvedt 2012; Krishna 2013; Krishna et al. 2014). Krishna posits that the manner in which personhood is conceived is an evolving, multidimensional concept that is particular to a patient (Krishna 2013; Krishna et al. 2014; Krishna and Alsuwaigh 2014). The “Ring Theory of Personhood” proposed by Krishna et al. is seen to encapsulate four key dimensions, refuting prevailing views that personhood is not determined solely by the presence of one element. The four elements are the familial, social, relational, and innate elements of personhood (Krishna 2013; Krishna et al. 2014; Krishna and Alsuwaigh 2014).

The lack of primacy afforded to consciousness in conceptions of personhood allays fears that amongst many patients at least, the rendition of unconsciousness is seen either as a negation of their personhood or as an abbreviation of their social existence. This contradicts LiPuma's position on the primacy of consciousness in conceptions of personhood and indeed life (Krishna 2013; Krishna et al. 2014; Krishna and Alsuwaigh 2014).

Autonomy

Under the Ring Theory of Personhood, personhood and an individual's unique personal identity is maintained by those who share close personal ties that the patient him- or herself deem important (Krishna 2013; Krishna et al. 2014; Krishna and Alsuwaigh 2014). Such a perspective might be taken to explain the relative rare employment of an AMD or a living will in the Asian setting. Personal exercise of self-determination has been documented, particularly within the Singaporean setting, to be neither pivotal to the concerns of patients nor central to individual conceptions of personhood (Krishna 2013; Krishna et al. 2014; Krishna and Alsuwaigh 2014). Pertinent to the present discussion,

many Singaporean palliative care patients do not see efforts to preserve their autonomy to be the overriding consideration in determining their care provisions. Significantly, preservation of personal autonomy is not evidenced to trump efforts to maximize comfort (Krishna 2013, 2014; Krishna et al. 2014; Krishna and Alsuaigh 2014). This sits quite apart from the positions taken by patients in the West, although even here where the use of living wills and AMDs are more common, the application of CDS is not necessarily seen to inhibit the employment of deep continuous sedation until death.

Redressing Rys et al.'s Position

The reintegration of this practice under the auspices of a holistic palliative care MDT approach both is sensitive to the sociocultural sensitivities and clinical realities and allows for accountable, justified, transparent, and evidence-based implementation of CDS, displacing the concerns raised by Rys et al.'s review (2012).

Employment of a palliative care-influenced approach also allows for the acceptable adaptation of prevailing practices in light of the dearth in guidelines and also succeeds in both distancing CDS from the practice of PAS/E and establishing it as a legitimate and acceptable treatment option of last resort within the aegis of end-of-life palliative care.

CDS should be seen as an appropriate, valid, and effective means of treating intractable suffering at the end of life when the key prerequisites for its application are met.

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