Continuous Deep Palliative Sedation:  
An Ethical Analysis

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Declaration

I hereby declare that this thesis is my original work and it has been written by me in its entirety. I have duly acknowledged all the sources of information which have been used in the thesis.

This thesis has also not been submitted for any degree in any university previously.

Dr Laksh Kumar Radha Krishna
23 February 2013
Acknowledgements

For those who have inspired me, guided me, stood with me and supported me

For my parents who made me the man I am

&

For my wife and son who inspire me to be more

~ words fail
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Summary

The practice of employing sedation to unconsciousness at the end of life is reserved for those patients with intractable suffering. However, whilst the need for symptom relief for these patients is recognized, employment of this intervention has been subject to significant controversy. In recognition of this, the palliative care community upon which care of these patients have been entrusted have made great strides to disperse these concerns both through the employment of evidence-based measures and standardization of this practice through the production of clinical guidelines.

Clinical data and careful specification of care approaches have appeared to assuage some of these concerns but careful study of the ethical and practical elements of this treatment of last resort raises yet more questions.

Practically, once this treatment has been employed, issues such as variances in access to care facilities and palliative care, differences in the manner that the overall goals of care when addressing care of these patients are determined, and how monitoring requirements and support of these patients and their families are met remain a cause for concern. Ethical issues such as the decision-making processes behind the application of these treatments, the consent process involved in applying the treatment, the guiding principles with regards to the oversight of this procedure and its wider effects upon the personhood of the patient are also frequently overlooked. These issues have increasingly been seen as the new face of controversy with regards the employment of these treatments.
This thesis will scrutinize the prevailing practices of terminal sedation (TS) and palliative sedation (PS) from a clinical and ethical perspective, highlighting five areas of concern that have and will be a cause for concern for these practices. Through careful ethical and clinical study of these areas of concern, this thesis will offer a new, clinically relevant, ethically sensitive, culturally appropriate practice called “continuous deep palliative sedation” (CDPS) that addresses many of the procedural and ethical worries that have plagued its predecessors.

This thesis will argue for the continued application of clinically assisted nutrition and hydration (CANH) as a matter of routine unless medically contraindicated, and the proportional and monitored titration of sedatives and opioids that is consistent with prevailing clinical guidelines, for this very specific form of sedation at the end of life. To further distance this practice from prevailing clinical controversies, this thesis will also argue for oversight of a multidisciplinary specialist palliative care team on all aspects of care and decision-making to ensure that this practice is holistically considered, balanced, transparent, accountable and evidenced-based. Additionally, in adopting a homogeneous view to suffering, the CDPS framework will extend its boundaries of care to include all forms of suffering inclusive of existential suffering in keeping with the ethos of palliative care.

This framework will also argue in favour of the overall goals of care to be firmly focused upon the palliation of intractable suffering as determined by a holistic review by a multiprofessional team. Where patient involvement in this deliberative process is limited by compromises to their cognition and competence as well as a result of their susceptibility to the undue influence of their underlying clinical condition and/or their prevailing psychosocial context, the CDPS
framework invokes the application of a multidisciplinary-team-determined best interest assessments to inform and guide the decision-making process.

Furthermore, in light of concerns about the effects of CDPS that have shifted from potential life abbreviation to the apparent negation of personhood, this thesis will proffer an evidence-based approach to viewing personhood that will dispel fears that this procedure induces “social death” and is thus not dissimilar to euthanasia.

The prerequisites to applying this intervention of last resort include:

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. “terminality” of the illness where a prognosis of less than two weeks is anticipated;
3. a diagnosis of “futility” when it is determined that the cancer progression is no longer responsive to disease altering treatments; and
4. a determination that application of this procedure is in keeping with the holistically determined best interests of the patient.

In giving an ethical defence of this position, this thesis addresses a number of key considerations: the professional obligation to relieve suffering and the ethical justification for holistic palliative treatment of intractable suffering including existential suffering; the issues surrounding treatment without consent when many patients being considered for sedation at the end of life lack the capacity to authorize such treatments; justifying best interests decision-making that extends beyond the physician-patient dyad; the ethics of appropriateness and proportionality of response given its centrality to the employment of this treatment, and its related monitoring and safety precautions; and the need for an
account of personhood to distance this treatment from euthanasia. Clarification of these facets will serve to set CDPS as a distinct and acceptable practice of last resort within the armamentarium of palliative care.
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<tbody>
<tr>
<td>AAHPM</td>
<td>American Academy of Hospice and Palliative Medicine</td>
</tr>
<tr>
<td>ACP</td>
<td>American College of Physicians</td>
</tr>
<tr>
<td>ALS</td>
<td>amyotrophic lateral sclerosis</td>
</tr>
<tr>
<td>AMA</td>
<td>American Medical Association</td>
</tr>
<tr>
<td>AMD</td>
<td>advanced medical directive</td>
</tr>
<tr>
<td>APA</td>
<td>American Psychiatric Association</td>
</tr>
<tr>
<td>ASIM</td>
<td>American Society of Internal Medicine</td>
</tr>
<tr>
<td>BIP</td>
<td>Best Interest Principle</td>
</tr>
<tr>
<td>BIS</td>
<td>Bispectral Index</td>
</tr>
<tr>
<td>CANH</td>
<td>clinically assisted artificial nutrition and hydration</td>
</tr>
<tr>
<td>CDPS</td>
<td>continuous deep palliative sedation</td>
</tr>
<tr>
<td>CDS</td>
<td>continuous deep sedation</td>
</tr>
<tr>
<td>CEJA</td>
<td>Council on Ethical and Judicial Affairs (of the AMA)</td>
</tr>
<tr>
<td>DDE</td>
<td>Doctrine of Double Effect</td>
</tr>
<tr>
<td>DNR</td>
<td>Do Not Resuscitate (order/protocol)</td>
</tr>
<tr>
<td>DoPC</td>
<td>Duty of Palliative Care</td>
</tr>
<tr>
<td>EAPC</td>
<td>European Association of Palliative Care</td>
</tr>
<tr>
<td>EEG</td>
<td>electroencephalogram</td>
</tr>
<tr>
<td>ES</td>
<td>existential suffering</td>
</tr>
<tr>
<td>GP(s)</td>
<td>general practitioner(s)</td>
</tr>
<tr>
<td>HCP(s)</td>
<td>healthcare professional(s)</td>
</tr>
<tr>
<td>HPNA</td>
<td>Hospice and Palliative Nurse Association</td>
</tr>
<tr>
<td>ICESCR</td>
<td>International Covenant to Economic Social and Cultural Rights</td>
</tr>
<tr>
<td>IEC</td>
<td>Institutional Ethics Committees</td>
</tr>
<tr>
<td>JAMA</td>
<td>Journal of the American Medical Association</td>
</tr>
<tr>
<td>KNMG</td>
<td>Royal Dutch Medical Association</td>
</tr>
<tr>
<td>MCA</td>
<td>Mental Capacity Act 2008</td>
</tr>
<tr>
<td>MCS</td>
<td>minimally conscious state</td>
</tr>
<tr>
<td>MDT(s)</td>
<td>multidisciplinary team(s)</td>
</tr>
<tr>
<td>NANDA</td>
<td>North American Nursing Diagnosis Association</td>
</tr>
<tr>
<td>NH</td>
<td>nursing home</td>
</tr>
<tr>
<td>NHPCO</td>
<td>National Hospice and Palliative Care Organization</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Description</td>
</tr>
<tr>
<td>--------------</td>
<td>------------------------------------</td>
</tr>
<tr>
<td>NMA</td>
<td>Norwegian Medical Association</td>
</tr>
<tr>
<td>PAD</td>
<td>physician assisted death</td>
</tr>
<tr>
<td>PAS</td>
<td>physician assisted suicide</td>
</tr>
<tr>
<td>PCC</td>
<td>patient-centred care</td>
</tr>
<tr>
<td>PPS</td>
<td>proportionate palliative sedation</td>
</tr>
<tr>
<td>PS</td>
<td>palliative sedation</td>
</tr>
<tr>
<td>PSU</td>
<td>palliative sedation to unconsciousness</td>
</tr>
<tr>
<td>PVS</td>
<td>persistent vegetative state</td>
</tr>
<tr>
<td>QoL</td>
<td>quality of life</td>
</tr>
<tr>
<td>RLWDs</td>
<td>residents living with dementia</td>
</tr>
<tr>
<td>SEL</td>
<td>sedation at the end of life</td>
</tr>
<tr>
<td>SDM</td>
<td>shared decision-making</td>
</tr>
<tr>
<td>TS</td>
<td>terminal sedation</td>
</tr>
<tr>
<td>VAE</td>
<td>voluntary active euthanasia</td>
</tr>
<tr>
<td>VHA</td>
<td>Veterans Health Administration</td>
</tr>
<tr>
<td>VSED</td>
<td>voluntary stopping eating and drinking</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
INTRODUCTION

The practice of palliative medicine has evolved a great deal over the last decade. The research, education and symptom management in this area of practice have expanded rapidly whereas other areas have struggled to match this growth (1,2). This can be seen in the stuttering growth of palliative medical services amongst non-cancer patients and in end-of-life care for those suffering from poorly controlled symptoms (1,2). This uneven development owes much to the struggles of palliative medicine in overcoming long held misconceptions about the end of life, fears regarding the medications used and particular societal beliefs and misconceptions about the role and goals of palliative medicine (1,2). Slow progress in expanding end-of-life care is also due to unfortunate associations with life attenuating measures, a lack of clarity in its goals of care, a dearth of universally accepted clinical approaches and monitoring techniques as well as the extent of care that can be afforded these patients (1,2).

A plethora of issues remain unresolved within end-of-life care for those with poorly controlled symptoms (3,4). This thesis focuses on patients whose symptoms do not respond to conventional means of treatment and amongst whom the perceived risks of hastening death are very great. I will consider the subgroup of patients who despite maximal palliative care interventions remain in a state of distress at the end of life.

For these patients, it is the practices of palliative sedation (PS) or terminal sedation (TS) that represent the best serviceable means of ensuring that their final
stages of life are comfortable and indeed free of distress [Appendix 1-6]. However such practices continue to be fraught with controversy (3,4).

**Controversies surrounding the application of palliative sedation and terminal sedation**

Controversy regarding the application of treatments such as PS or TS which entail the application of sedatives and sometimes opioids to induce unconsciousness as a means of circumnavigating awareness of suffering has raised concerns that this medication may potentially hasten death in frail patients (3-8). These forms of sedation stand apart from lighter forms of sedation described by Morita that include mild sedation where “patients can communicate with caregivers”, and intermittent sedation which “provide some periods when patients are alert”; continuous sedation like PS and TS, on the other hand, continue to alter a patient’s consciousness until they die (29). For the relatively small subset of palliative care patients (estimated to be about 1-3% of cases locally) the type of sedation being applied is primarily deep continuous sedation where light, light intermittent, deep intermittent sedation have been tried and found to be ineffective and there is confirmation of an exhaustion of treatment options, continued suffering and a prognosis of two weeks or less. I describe just such a case in section 3.3 on page 141 to provide a background of care for these patients with increasingly difficult to treat suffering that culminates in the need for continuous sedation.
Prevailing concepts of TS and PS, however, are fraught with inconsistencies, as I will highlight in Chapter 1, though a brief summary is enclosed here in the form of Table I.1. In the light of these concerns, an alternative to prevailing practices – continuous deep palliative sedation (CDPS) – is proposed.

<table>
<thead>
<tr>
<th>Facets</th>
<th>CDPS</th>
<th>TS (refer to extant guidelines in Appendix 3)</th>
<th>PS (refer to guidelines in Appendices 5 and 6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goals</td>
<td>Relief of all forms of suffering</td>
<td>Not clear whether the focus is treating symptoms or suffering, or whether existential suffering is a valid indication – see Appendix 1,2,3,5 and 6.</td>
<td></td>
</tr>
<tr>
<td>Prognosis</td>
<td>&lt; 2/52</td>
<td>Not strictly defined for example Morita et al had suggested a prognosis of three weeks whilst the ACP-ASIM guidelines suggest that it may be used in patients with burns.</td>
<td></td>
</tr>
<tr>
<td>Intractable</td>
<td>Defined</td>
<td>Not clearly defined; various undefined terms used – see Appendix 4.</td>
<td></td>
</tr>
<tr>
<td>MDT review</td>
<td>Required</td>
<td>Not strictly required. Second opinions and palliative care inputs not required.</td>
<td></td>
</tr>
<tr>
<td>Consent</td>
<td>Required where possible; and when not, best interests determinations</td>
<td>Some require informed consent; others rely on surrogate decision makers.</td>
<td></td>
</tr>
<tr>
<td>CANH</td>
<td>Continued unless medically contraindicated</td>
<td>Vary from routine cessation of CANH to case-by-case review.</td>
<td></td>
</tr>
<tr>
<td>Proportional titration</td>
<td>Required</td>
<td>Means, manner and guidance – variably defined.</td>
<td></td>
</tr>
<tr>
<td>Depth of sedation</td>
<td>Deep continuous</td>
<td>Includes light intermittent, light continuous, deep intermittent and deep continuous.</td>
<td></td>
</tr>
<tr>
<td>Monitoring and professional oversight</td>
<td>Required</td>
<td>Means and frequency of monitoring are not specified; requirement of professional oversight is not discussed.</td>
<td></td>
</tr>
</tbody>
</table>

Table I.1 Fundamental differences between TS, PS and CDPS

It is in these settings where the application of sedatives such as benzodiazepines and/or opioids to achieve these goals, that concerns arise over fears precipitating respiratory depression (3-8). The situation is made more complicated by the frail
state of these patients, which leaves them particularly predisposed to such ill
effects (3-8).

This situation is further complicated by the practice of the routine cessation of
clinically assisted artificial nutrition and hydration (CANH), which has been held
to predispose patients to yet further side effects as a result of a reduction in the
excretion of opioid metabolites (6). The issue of CANH provision is also a key
consideration for some authors who suggest that sedating a patient to
unconsciousness, leaving them incapable of eating and drinking and not
providing them with CANH was tantamount to intentionally seeking their demise
(6). This in turn has led to the term “slow euthanasia” being applied to the
practice of sedation at the end of life (7,8).

A further concern regarding the application of these treatments centres on the lack
of clear practice guidelines and monitoring protocols [Appendix 1-6]. Clear
inclusion criteria, transparency and justification for attempting these treatments
and clear objective and reproducible endpoints are needed. Furthermore,
variances in the types of drugs used, the manner that they are applied, the
duration of application and the variations in pharmacodynamics and
pharmacokinetics as a result of genetic differences have meant that there remain
significant gaps in knowledge (9-13).

Concerns also arise as to how decisions to employ PS or TS come about and
whether patients plagued with apparent unremitting symptoms, frail with their
progressive illness and on maximal treatment doses of various medications could
participate in a deliberative process (14). The consent process for these treatments
has thus been under increasing scrutiny (14).
Monitoring the state of patients under TS and PS has offered some evidence that patients do still retain some awareness of suffering and pain (15-17). Questions then arise as to whether the monitoring processes that are carried out during the applications of sedation at the end of life are appropriate for the tasks for which they are applied. Ensuring that an appropriate level of sedation is provided and that present monitoring techniques are effective has now become a concern (16,17). This is particularly important given that the current practice of applying the lowest possible doses of medication to achieve the stated goals of care may be benchmarked upon inaccurate information and compromised by ineffective monitoring techniques (16,17). This in turn compromises the ethos of proportional response.

The goals of care of TS and PS have also come under scrutiny over their approach to managing the needs of terminally ill patients (18-20). Also under the spotlight has been the manner that intractable existential suffering is viewed under the auspices of these goals of care (18-20).

The personhood of sedated patients is a further area of concern (21-23). Some philosophers and neurobiologists hold that the seat for personhood lies within the realms of consciousness, which would be lost in the event of sedation (21-26). The importance of this issue becomes clear and returns TS and PS full circle to the vexed practices of euthanasia when it is suggested that if personhood replete with its social functions and features that endow a patient with their individuality can be sacrificed for comfort, could life itself not be sacrificed, when there is only a limited prognosis at stake and the potential for further suffering (21,22)?
Would intractable existential suffering be warranting of such a “drastic” intervention? Clearly the response is dependent upon the prevailing sociocultural views of suffering and perceptions as to the “severity” and extent of damage and distress a patient suffers (19,20,27,28). Whilst studies into the effects of suffering upon an individual’s personhood are seen to provide healthcare professionals (HCPs) with just such insight, these reviews have yet to bridge the gulf between the two dominant and opposing views on the viability of treating intractable existential suffering with sedation at the end of life (SEL) (19,20,27,28) [Appendix 3,5 and 6].

![Diagram showing Areas of concern of this thesis](Image)

**Figure I.1** Areas of concern of this thesis

Consideration of this spectrum of concerns reveals significant overlap between the various issues making it possible to categorize present concerns into the seven
key areas featured in Figure I.1, which in turn form the focus of this thesis in its efforts to address prevailing concerns with regards to the practice of SEL.

**Objectives of this thesis**

The CDPS framework begins by addressing the prevailing concerns with respect to the practice of SEL that have left it poorly understood and open to conjecture with respect to its treatment goals, prerequisites and extent of care [Appendix 1-6]. Chapter 1 highlights these inconsistencies in the practice of TS and PS and reviews the clinical, bio-psychosocial, ethical and practical issues that affect these practices [Appendix 1-6]. Clarification of the manner that the practices of TS and PS are conceived and utilized will aid in overcoming some of the practical concerns with respect to SEL. The proposed alternative to prevailing practices of SEL is inspired by Morita et al’s description of continuous deep sedation (CDS) and Quill’s description of proportionate palliative sedation (PPS) (29,30). CDPS represents an evolution of both these concepts (29,30). Unlike Morita et al’s described practice, neither physical nor psychological distress is seen as the only indication for CDPS (29). Furthermore vital organ failure is not a primary requirement for its application (29). CDPS, like Quill’s PPS formulation, applies sedation in progressive titrations to ameliorate suffering but CDPS is clear in the manner and route that this sedation is applied (30).

In CDPS, medications with the primary function of inducing sedation are applied to complement the effects of other medications used to alleviate symptoms that are resistant to all practical and viable standard treatment modalities. The intent is
the induction of deep and continuous sedation until death as a form of circumnavigating awareness of the suffering when the cause cannot be reversed and the effects of suffering cannot be ameliorated by any other manner. In these patients who have short estimated life expectancies and who are expected to continue to suffer unabated until death without CDPS, the induction of unconsciousness is seen as a treatment of last resort. This controlled and monitored application of sedation in combination with increasing data on the safety of sedatives and opioids when applied in keeping with increasingly available guidelines and care standards lays to rest many of the concerns regarding the death hastening effects that have plagued the practices of TS and PS [Appendix 1-3, 5 and 6].

Implemented under the aegis of palliative care, the practice of CDPS is defined as the proportional and monitored induction of deep continuous sedation for the amelioration of all forms of intractable physical, psychological and existential suffering in a cancer patient with a prognosis of less than two weeks following a holistic multiprofessional assessment of the patient’s condition to affirm that suffering is in fact intractable and 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 current guidelines and clinical, professional and legal standards after other forms of light and deep intermittent sedation have been employed and have failed to reduce the severity of the suffering. This procedure is monitored and overseen by a MDT to ensure accountability, transparency and justifiability of actions and to make certain that life is not intentionally abbreviated. CANH is provided as a matter of routine in the application of CDPS
unless clinically contraindicated. The prerequisites for implementing CDPS in cancer patients 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 the cancer progression is no longer responsive to disease altering treatments; and
(4) a determination that application of this procedure is in keeping with the holistically determined best interests of the patient.

Including CDPS under the aegis of palliative care ensures the provision of effective multiprofessional, multidimensional, transparent and accountable care. It has been this failure to fully comprehend the ethos of a palliative-care-led approach and observe recognized palliative care standards and guidelines that have hindered the appropriate use of PS and TS. I submit that when overseen by prevailing ethical, social, cultural, spiritual, professional and legal standards, many of the practical and sociocultural concerns that have arisen around this practice of sedation at the end of life can be allayed.

Concerns, however, remain with regard to the determinations of the goals of care and the deliberative process that underpins it, the consent process that authorizes the implementation of these treatments, how it is monitored and the safeguards that are taken. There is also an increasing fear that the personhood of the patient is sacrificed as a result of this treatment. I review these issues as they are seen
under the aegis of the three prevailing approaches of sedation at the end of life, highlighting the key areas of discussion in the chapters to follow.

In Chapter 2, I discuss the manner in which the goals of care determine the course and means that care is approached and delineated. I argue that the goals of care must remain firmly focused upon a palliative intent given an exhaustion of treatment options, a limited prognosis of two weeks or less and the continued presence of intractable suffering. These goals focus upon the relief of all forms of suffering, even at the cost of hastening the patient’s demise (19,20). The limits as to what manner and what indications steer these determinations are discussed. Of specific interest is the position afforded to existential suffering in the CDPS framework.

Chapter 3 considers the decision-making process that underpins the application of CDPS. There are no clearly specified guidelines on how decisions are made and most decision-making approaches remain focused upon the patient-physician dyad seen in clinic settings rather that the realities of end-of-life care where there are many parties involved (31-33). I argue that addressing the complexities of decision-making in the presence of so many interested parties and within the emotionally charged arena of end-of-life care requires a multidisciplinary-team-led holistic review of the case (34-41). I will consider the process that should be adopted in the deliberative process, which will better engage the patient and their family within the deliberative process without compromising the best interests of the patient (14,35,41). This is addressed in particular to societies that favour a family centric approach to care determinations (35-37).
The presence of intimate involvement of the family in the decision-making process also raises the question about the viability of consent in TS, PS and CDPS applications (35-37). Chapter 4 considers this question in the light of the effects of intractable symptoms, treatments and clinical conditions amongst these patients and shows that they negatively impact the ability to consent. Chapter 4 argues for the application of best interest determinations, ascertained by the MDT as an alternative form of authorization when all attempts to obtain informed consent from the patient have failed (35,41,42). Further, in keeping with the patient centred care determination that is applied, I argue that best interests determinations of a particular patient cannot be based upon a priori judgement but must consider the specific wishes, values and goals of the patient, including their views and consent at all stages of treatment (34,35,41). This process must be overseen by the prevailing professional and legal standards.

Chapter 5 considers the increasing concerns regarding the implementation and monitoring of CDPS, particularly whether reliance upon the traditionally conceived ideas of proportional response to symptom management that continue to steer the employment of sedation at the end of life, are accurate and indeed effective (16,17,43-47). Underpinning this is the fact that there is increasing data to suggest that even in an unconscious state, patients may still be aware of their suffering, suggesting that other endpoints to assess the efficacy of the treatment applied should be employed (43-47). I provide alternative means to realizing these goals.

However, in realizing this goal of rendering a patient unconscious in order to negate their awareness of their suffering, concerns with regards to the personhood
of the patient are raised (21,22). Chapter 6 considers the most recent concern regarding the application of sedation at the end of life. I review concerns by some commentators on the practice of PS that the application of sedation to unconsciousness is akin to negating a patient’s personhood which in turn appears to be ethically indistinct from the practice of euthanasia (21,22). Central to this belief is the primacy accorded to consciousness as the definitive property to personhood (23-25). A human life without personhood is held to be lacking value and is comparable to non-existence, making comparisons with biological death possible (21,22). I present a critique of this position based on ethical considerations and a clinically derived, empirically validated account of personhood within the palliative care patient population that overcome these concerns (48,49).

This concept of personhood, referred to as the Ring Theory of Personhood also serves to aid in the study of the impact of suffering upon the person (48,49). This is the central feature of Chapter 7 where I show that irrespective of the manner that intractable existential suffering is conceived, its effects upon personhood are significant and multidimensional. This analysis serves to justify the inclusive and holistic view of suffering adopted within this thesis and the applicability of CDPS for the treatment of all forms of intractable suffering so long as all the prerequisites are met.

Through study of the issues featured in the chapters to come, this thesis will address the main prevailing and the prime anticipated concerns relating to the practice of CDPS to pave the way towards appropriate, accountable and justified
treatment of patients suffering from intractable symptoms at the end of life

(Fig I.1)
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Chapter 1

THE PRACTICE OF SEDATION AT THE END OF LIFE

1.1 INTRODUCTION

The practice of sedating patients at the last stages of life has been increasingly applied internationally, yet its prevalence outside Europe, Japan and North America remains unstudied [Appendix 1,2,3,5 and 6]. While many studies show an increasing trend in its application amongst terminally ill cancer patients within the hospital setting in countries where palliative care practice is more established, a study by Krishna et al within a similar setting in Singapore revealed no cases meeting prevailing definitions of this practice (1-3) [Appendix 1,2,3,5 and 6]. This omission is instructive if only to highlight the complexities inherent in this practice that have yet to be acknowledged in the extant literature on this subject.

I argue that existing definitions in this sphere of practice, such as terminal sedation (TS) and palliative sedation (PS), do not adequately capture key meanings of the act of sedating patients nearing death for healthcare professionals (HCPs) who practice within specific ethical, legal, social and policy contexts [Appendix 1,2,3,5 and 6].

To be clear, this thesis concerns itself with a very specific and small subset of terminally ill patients. These are patients who experience intractable suffering, have a prognosis of less than two weeks to live, and have exhausted all curative measures; palliation of their continuing suffering through medical, psychological, spiritual and social support, either on their own or in combination, has failed and
despite all forms of alternative and holistic care continue to suffer. This subgroup of patients also represent those who have not responded to other forms of sedation be it light intermittent, light continuous or deep intermittent sedation.

With deep continuous sedation as the only alternative after stepwise increments of sedation and palliative options, these patients require specialist palliative care review within an institutional setting where a multiprofessional, multidimensional review of their psychosocial, spiritual, clinical and existential concerns can be addressed. It is also in this setting that a review is undertaken with regards to these patients’ understanding of their condition, their views, values, beliefs and goals of care, as well as their opinions concerning treatments attempted and those proposed. Informed consent is desirable wherever possible and for those patients who cannot consent, a best interests determination is made by the multidisciplinary team (MDT) in conjunction with independent specialists and input from family and indeed the patient themselves.

To begin, this thesis describes a cluster of practices around sedating patients at the final stages of a patient’s life, observed in clinical settings within Singapore. I shall examine them from a clinical, bio-psychosocial, ethical and practical standpoint in order to describe and defend in ethical terms an observed practice, which I shall denote by the term “continuous deep palliative sedation” (CDPS).

CDPS is defined as the proportional and monitored induction of deep continuous sedation for the amelioration of all forms of intractable physical, psychological and existential suffering in a cancer patient with a prognosis of less than two weeks following holistic multiprofessional assessment of the patient’s condition to affirm that suffering is indeed intractable and 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 current guidelines and clinical standards after other forms of light and deep intermittent sedation have been employed and have failed to reduce the severity of the suffering. This procedure is monitored and overseen by a MDT to ensure accountability, transparency and justifiability of this intervention and that life is not intentionally abbreviated. CANH is provided as a matter of routine in the application of CDPS unless clinically contraindicated.

The prerequisites for implementing CDPS in cancer patients 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. “terminality” of the illness where a prognosis of less than two weeks is anticipated;
3. a diagnosis of “futility” when it is determined that the cancer progression is no longer responsive to disease altering treatments; and
4. a determination that application of this procedure is in keeping with the holistically determined best interests of the patient.

I argue that CDPS is a practice of last resort whose goal is to alleviate intractable symptoms of terminally ill patients for whom all curative and palliative treatments of their underlying disease condition have been exhausted. I argue that there is sufficient ethical and clinical evidence to allow the application of CDPS for the treatment of all forms of intractable symptoms that cause unremitting suffering in the terminal phase of life. This includes unremitting existential suffering experienced by patients, though at present it is generally not applied for
the treatment of these forms of intractable suffering (4-13) [Appendix 3 and 5]. My position on the use of CDPS for the treatment of intractable existential suffering does not rely solely upon the positions taken by all the major European guidelines on palliative sedation nor the positions taken by the major textbooks of palliative medicine [Appendix 5 and 6]. It rests primarily on the arguments presented in Chapters 2 to 7 and on the safeguards elaborated throughout the thesis. While I believe this position is ethically defensible, acceptance of the position in practice must depend on further social debate and consensus.

The focus of this chapter is to highlight the complexities of the practice of CDPS and the ethical issues facing prevailing practices of terminal sedation (TS) and palliative sedation (PS). CDPS raises questions in a number of areas. Through careful, practical and ethical analysis of these practices, key points of interest will be highlighted and become the focus of coming chapters. These include sedating patients with intractable suffering at the end of their life, the goals of care and the extent to which relief of suffering is a goal of medicine, the means and ethics of shared decision-making, the place of consent under these specific conditions, the analysis of proportionality of response within this application, and the potential effects of this treatment as well as the effects of suffering upon a patient’s personhood.

To begin, I offer a descriptive account of a localized practice of sedating cancer patients near death in a hospital setting. This practice is influenced by the guidelines set out by the following textbooks: the Oxford Textbook of Palliative Medicine, Saunders’ Palliative Medicine and Textbook of Palliative Medicine (14-16).
1.2 CONTINUOUS DEEP PALLIATIVE SEDATION (CDPS)

1.2.1 Goals of CDPS

1.2.1.1 Distinctive option of last resort

CDPS is focused upon the goal of alleviating intractable symptoms of terminally ill patients for whom all curative and palliative treatments of their underlying cancer have been exhausted (14-16).

CDPS as an “option of last resort” is restricted to terminally ill adult cancer patients with a prognosis of less than two weeks (16). Typically it is applied for the treatment of fits, delirium, agitation, pain and dyspnea, which appear remedial to standard palliative interventions (14-16).

In all cases the level of sedation that is desired is a function of symptom response to the treatment applied (14-16). For those cases where CDPS is required, it is as a result of a failure of lighter levels of sedation or indeed deep intermittent sedation therapy (14). It is only when “lesser” options prove ineffective that stronger doses of treatment or indeed more substantial interventions are employed (14). Increasing doses of sedatives are proportionally titrated according to response and need, and CDPS is applied to render the patient unaware of their intractable symptoms (14-16).

 Attempts to engage the patient in the consent process for this intervention are carried out at all stages of the deliberative process, as are efforts to involve the family in the decision-making process. In situations where patient consent is not possible, their previous wishes and views along with their stated goals, values and beliefs are considered by the multidisciplinary team in determining care options.
Significantly, their opinions and consent for lesser levels of sedation are of great
importance in the deliberative process leading up to the application of CDPS.

This process must be overseen by a specialist palliative care physician and carried
out within the setting of a hospital or hospice. Close monitoring of the patient is
normally carried out, with clear guidelines to the staff on the manner that they
ought to respond both to recurrences of symptoms and ill effects both of this
treatment or progressive disease (14). In all cases, unless clinically
contraindicated, artificial hydration and nutrition is maintained (14-16).

Concurrently for all patients and their families, psychosocial, pastoral and
counselling support are provided in tandem with regular updates of assessments
of the situation and appraisals of treatment response (14-16). It is integral for care
to be provided for family members caring for patients in these situations in order
to allow for better assessments of the patient and for bereavement support of the
family upon the patient’s demise (14,15).

1.2.1.2 Relief of physical symptoms

The applying of CDPS within the Singaporean context for example reveals a
number of considerations. CDPS would not be applied for the treatment of
existential suffering at present (14). This is partly due to the difficulty in
identifying, diagnosing, treating and monitoring these symptoms (8-12). The
subjective nature of symptoms of existential suffering, the difficulty in agreeing
upon objective criteria for its clinical assessment, a lack of understanding and
recognition of existential complaints, inadequate training and an inability to treat
the person beyond simply the illness and their immediate effects amongst dying patients obfuscates diagnosis of existential suffering (8-13,17-20). I will discuss this issue in more depth in Chapter 2.

Although psychological symptoms are not taken to be part of existential suffering, their presence can confound diagnoses of existential suffering (12). Differentiating symptoms such as depression and anxiety from existential presentations within the end-of-life setting is confounded by the fact that many of the behavioural manifestations of existential suffering and symptoms of depression and anxiety described in the Diagnostic and Statistical Manual of Mental Disorders (Text Revision) IV (DSM IV –TR) are commonly present in terminally ill patients (12,21-25). Treatment options, too, are affected by patients’ brief prognosis (12). Many non-pharmacological adjuvants such as psychotherapy, pastoral interventions, meditation, massage and hypnosis to alleviate these symptoms are unlikely to be effective in this “limited” time (11,12). Similarly, Schuman-Olivier et al’s proposal of applying concurrent psychopharmacological interventions may be limited given the poor prognosis of these patients (12).

Schuman-Olivier et al suggest the consideration of timeframes does not only consider the “proximity to death” and the time available for effects of an intervention to be experienced by a patient but also the patient’s “functional capacity to engage in the logistics of a therapeutic relationship” (12). Many patients in these situations are liable to be suffering from altered levels of consciousness, reduced levels of concentration, reduced mental alertness and exhaustion, limiting their participation in these interventions and attenuating this treatment window. Similarly, treatments with concurrent psychopharmacological
Interventions that Schuman-Olivier et al propose may be of limited use given the duration they require to take effect may outstrip the patient’s prognosis or may begin to take effect much too late to provide the patient with any meaningful relief (12,26-28). These conventional measures may also cause harm to some patients due to their propensity for inducing sedation, interactions with other medications and for side effects amongst these frail patients (26). Alternative treatment options such as electroconvulsive therapy and psycho-stimulant interventions are also not without risks (26-28).

Not infrequently if conventional medications are applied, intermittent sedation to allow rest and relief for the patient is also applied. Here the sedation is intermittent and may take the form of light or deep sedation to ameliorate the patient’s suffering while the pharmacological agents begin to take effect or even to allow respite overnight. The situation is closely monitored and if it is felt to be effective, the sedatives are tapered and stopped as early as possible. The views of the patients of their experience of lesser levels of sedation are also noted and duly considered when CDPS is being contemplated and formal consent may not be possible. This process is overseen and monitored by the primary physician, the palliative care physician and the psychiatrist in tandem with the psychologist, counsellor and the nursing teams.

Notably, whilst sedatives are applied in this manner with due consideration of the wishes of the patient, this procedure cannot be requested for by the patient and remains a treatment of last resort when all other means of treatment have failed to ameliorate symptoms. Similarly, even if a patient wishes to remain sedated after the application of intermittent sedation, that request in itself cannot be the reason...
for circumventing trials of alternative pharmacological measures if these alternative options are felt to be potentially helpful. This point raises issues about the manner that authorization for treatment is granted and how the deliberative process that underpins it is carried out. I will discuss this issue in further depth in Chapter 4.

1.2.2 Prerequisites for applying CDPS

A key consideration with regards to the application of CDPS is the prerequisite of a cancer diagnosis. There are a number of reasons for this and they are outlined below.

A prime consideration for this limitation to patients with cancer is the variability in the pathologies encountered and the effects they have upon the process of prognostication, the determination of intractability and the diagnosis of futility, which represent three of the four prerequisites for valid application of CDPS. A general lack of practical guidance, experience and access to specialized palliative care to contend with the complexities of non-oncological end of life conditions compounded by pharmacodynamics and pharmacokinetics worries in the face of polypharmacy and complex comorbidities ultimately serve to limit considerations of extending the application of CDPS to the non-cancer setting.

This is not to denigrate the needs of non-cancer palliative care patients nor to suggest that their symptoms are any less severe that those experienced by cancer patients. However, variances in access to general medical care and specialist palliative care, variability of clinical practice, differences in monitoring and care
provision and the assorted views on the overarching goals of care for these patients create a significant amount of ambiguity that cannot be deemed acceptable for a practice that is encumbered with concerns of being a form of “slow euthanasia” or of being on a slippery slope towards this vexed practice.

These considerations re-emphasize the importance of the four prerequisites for the application of CDPS, which are themselves influenced by prevailing guidelines set out by the Oxford Textbook of Palliative Medicine, Saunders’ Palliative Medicine and Textbook of Palliative Medicine:

1. a diagnosis of intractability in which it is ascertained that there is an exhaustion of treatment options available to palliate the distressing symptoms experienced by the patient to a tolerable level within an acceptable time frame (14-16);
2. a diagnosis of “terminality” of the illness where a prognosis of less than two weeks is anticipated (14-16);
3. a diagnosis of “futility” when it is determined that the cancer progression is no longer responsive to disease altering treatments (15); and
4. a determination that application of this procedure is in keeping with the holistically determined best interests of the patient (14-16).

I will briefly describe the various aspects of these criteria in sections 1.2.2.1, 1.2.2.2, 1.2.2.3 and 1.2.4 and provide a more detailed account of them in Chapters 3 and 4.

1.2.2.1 Intractability

The context in which symptoms experienced are determined to be intractable is dependent upon the persistence or worsening of symptoms despite the application
of maximally tolerated doses of medications and the exhaustion of non-pharmacological interventions either individually or in combination with one another. Here neither light levels of sedation, applied intermittently or continuously, nor deep intermittent sedation have been found to relieve suffering to a tolerable level.

Determination of such a diagnosis is complex and is in part dependent upon access to specialist care, medication and palliative input. This makes the deliberative process underlying any determination variable and highly dependent upon the views of those who assess the symptoms and their estimations of the benefits accrued from ongoing and previous interventions. Applications of treatment options are also situationally dependent and can only be considered if deemed acceptable for the case at hand. The use of the term “acceptable” here reiterates the subjectivity of this determination and reinforces the need for any determination as to whether CDPS is applied as one that is primarily a negotiated statement agreed upon within the multidisciplinary team (MDT). The participants of a MDT and the manner in which such a determination is arrived at will be discussed in Chapter 3.

![Figure 1.1 Key elements for determining intractability](image)
1.2.2.2 Terminality

The MDT will also determine the “terminality” of the patient’s condition. Terminality is a clinical judgment of a prognosis of less than two weeks. Whilst this estimation can be difficult, accuracy in such estimations does improve with the proximity to death and with clinical experience complemented by the presence of a spectrum of experience and skill in end-of-life care contained within the MDT and also with the application of better prognostic indicators (29-34).

1.2.2.3 Futility

The MDT is also tasked, upon due consideration of the holistic situation, with determining if available treatment options are futile. This is primarily to confirm that all treatment options have been exhausted and CDPS is the treatment of last resort as well as to corroborate diagnoses of intractability and terminality (Fig 1.1). In this context, a futile intervention is one where “there is a low (e.g., less than 1%) likelihood that it will achieve its physiological objective” or one where there is “no benefit to a patient and therefore should not be prescribed” (35). In keeping with the holistic approach adopted in palliative care, opinions are sought from patients and their carers and family to ensure that the determination of the burdens and benefits concerning “value-laden quality-of-life decisions” are appropriately assessed and considered within what has traditionally been a purely clinical determination (36). Whilst a consensus building process between HCPs and the patient and family is desirable, it is also clear that the final decision lies
with the clinical team, given the concerns about viability of surrogate decision-making, in particular by the family, within the local context (37-41). I will discuss the decision-making process for CDPS in Chapter 3.

1.2.3 Treatment decision-making in CDPS

From clinical observations and practice influenced by guidelines forwarded by the Oxford Textbook of Palliative Medicine, Saunders’ Palliative Medicine and Textbook of Palliative Medicine, there is little in the way of explicating how decisions are arrived at for the application of sedation at the end of life (14-16). For the most part the decisions for CDPS appear to vary from a medical paternalism approach to a familial centric decision-making process (14-16,37-41). More consistent and transparent are the decisions made on treatment options and the manner that sedation ought to be applied.

The decision to apply sedation is usually applied by the MDT with agreement by the primary decision makers and is viewed as a form of basic medical care to control intractable symptoms such as those previously mentioned. To begin, the application of intermittent sedation usually takes the form of subcutaneous or intravenous injections of the benzodiazepine, midazolam for the treatment of agitation or fits, or the antipsychotic, haloperidol for hallucinations or agitation (14-16). Administration of these drugs in this manner allows some insight into the responsiveness of the symptoms to these interventions and further titration of this medication according to response (14-16). The objective of this intervention would be to induce the desired effect through the application of the lowest
possible doses of the sedative whilst minimizing any ill effect to the patient’s condition.

These drugs may be used in tandem with ongoing treatments such as morphine or other opioids for the treatment of other coexistent symptoms such as pain and dyspnea (14-16). The midazolam for agitation will be used to supplement the morphine for exacerbations of pain or shortness of breath, whilst haloperidol may supplement exacerbations of agitation and confusion (14-16). However it may be that frequent doses of midazolam or haloperidol are required and usually when more than four doses are required within a 24 hour period, a continuous infusion of these drugs are sought to provide better control and to dampen down the frequency of symptom exacerbations.

Further indications for the need for a continuous infusion include rapidly recurring symptoms and frequent use of extra doses of medications, symptoms that require repeated dose escalations and symptoms that only partially respond to medications and for variable durations despite consistent dosings. Frequently patients and families become more distressed as doses of medications wear off and symptoms recur. In some cases these symptoms may revert to their original state even before the next dose can be administered. Once again the doses applied are titrated gently under the supervision of a senior palliative care physician based upon the effect these doses have upon the symptoms and upon the patient as a whole. All increments are closely monitored, as are the patient’s vital parameters and symptoms.

In Chapter 2, I shall discuss the goals of care that oversee such applications and the desired endpoints of an application of CDPS. In Chapter 6, I will discuss the
ethical questions that arise from relieving suffering by means of extinguishing consciousness or awareness in patients. In Chapter 7, I will highlight the effects of intractable existential suffering has on a patient’s personhood and thus their quality of life and comfort and consider whether it as a valid indication for CDPS.

1.2.4 Patient consent to CDPS

Seeking patient consent is not simply a means of ensuring that patients and family have an informed understanding of proposed plans but it also respects patient autonomy and maintains a patient-centred care process (42,43). Beauchamp and Childress define informed consent as consisting of preconditions which contain elements of competence and voluntariness, informational elements which include disclosure, recommendations of a plan and understanding, and consent elements which are composed of decisions in favour of the plan and authorization of the chosen plan (44). With a potentially dangerous treatment option such as CDPS, gaining the patient’s consent also serves as a protective measure that wards off criminal liability (43). Skegg suggests that the presence of legally effective consent mitigates criminal liability by allowing physicians to report that they had warned the patient of the risks, discussed their options and respected their exercise of autonomous choice to proceed with them after deliberation (42,43).

Within the present context, medical and psychosocial considerations conspire to compromise a patient’s capacity to consent. By most legal definitions a patient lacks capacity if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the
functioning of, the mind or brain that is irrespective of its temporality, the patient’s age, appearance, behaviour or condition and is derived following a “balancing of probabilities” (45). This inability to make decisions in turn arises if the patient is unable

a) to understand the information relevant to the decision;

b) to retain that information;

c) to use or weigh that information as part of the process of making the decision;

d) to communicate his decision (whether by talking, using sign language or any other means)” (45).

In light of the high incidence of delirium, loss of consciousness, confusion, hallucinations, various states of sedation and coma, it is not uncommon for patients to be unable to receive information in any meaningful sense (40,41,46,51-53). At the same time, the information itself needs to be conveyed in a manner that may be understood by the patient (46,52).

The idea of complete and thorough disclosure is thus impractical in many situations where CDPS is being considered, particularly given the effects of intractable symptoms, comorbid conditions and the presence of a cocktail of medications (46). Furthermore disclosure of information tends to be biased and incomplete in such circumstances (40). To begin with, determinations of what information is relevant is decided upon by the physician based their own assessment of the capacity of the patient, the psychosocial situation, the patient’s clinical context and prognosis, the physician’s own beliefs and values as well as biases and the influences that they are under to formulate “bite size chunks” of information that they envisage the patient may be able to “deal” with. Blanket
disclosures as much as inadequate information provision can be damaging to the deliberative process of the patient. Reliance on the professional’s ability to gauge what will be necessary for meaningful consent pivots on the trust between the MDT and the patient and their family (54).

Onara O’Neill proposes that the consent process be viewed within the wider context of the communications of HCPs and patients spanning their whole relationship rather than a sentinel moment in the deliberative process (42,54). There are good reasons for such a review. The first may be that the patient is unlikely to be able to consent in the presence of intractable symptoms that are liable to affect their decision-making capabilities or serve as coercive factors in their deliberative processes (46,55). A second factor to consider might be the presence of mood and cognitive disturbances such as delirium, depression and anxiety amongst many dying patients that further cloud their ability to deliberate upon these important considerations (42,46). In both these cases, a review of past conversations and statements may throw light on a patient’s wishes as would discussions with the patient’s carers, loved ones and healthcare providers (25,51).

When a patient’s consent cannot be obtained for CDPS, who should authorize such a course of treatment? I discuss this problem in Chapter 4 where a description of the process of involving different relevant stakeholders in the decision is given. First the family’s concerns and goals are considered.

The influence of the family cannot be discounted. Within the local setting family members frequently occupy the position of proxy decision makers even when they may neither be best placed or authorized to do so (3,51-56). Despite cultural expectations that may be seen to require families to act as primary decision
makers, their ability to meet the demands of this role has come under increasing scrutiny (3,51-56). Evidence suggests that families are ill equipped to meet the demands of these roles with studies showing that only 13% of family members are aware of a patient’s treatment preferences (44,56-58). This is unsurprising as discussions about death are considered taboo in many societies and cultures (37-41,59-71). Additionally, efforts to minister to a patient’s psychological and spiritual needs and to maintain hope, adherence to filial roles and observance of the duty of non-abandonment may complicate the manner that family members meet their obligations as prime decision makers in affairs of the patient’s health (37-41,46,59-74).

The family’s role in the deliberative process is also based on recognition that without their support and involvement many of the care provisions suggested by HCPs will fail. Relevantly, local families do provide the main source of physical care, psychosocial support and financial subsidy for many of these patients (39-41,53). In many cases these provisions come at a great cost to the family as a whole. Additionally, local sociocultural expectations place great expectations on the family to maintain hope and continue to care for the patient irrespective of the financial, psychological and physical costs (3-41,53,70,71). Tied in to these expectations are beliefs in family honour and filial piety that compel many local families, irrespective of culture, religion or ethnicity, to act to maintain hope of cure despite dire outlook and press for extreme and sometimes futile treatment options (40,41,70,71).

Additionally, the role of the family that has become etched in social and cultural traditions finds apparent backing in law and policy (75-85). The local health care
financing framework requires partial self-funding of care and this inevitably involves the family (37,83-85). Furthermore, by the Maintenance of Parent Act 2010 and Singapore’s Shared Values Initiative, Singaporeans are socioculturally and legally required to support their parents (85-87). These are but a few examples of how the role of the family within the deliberative process has been misconstrued by some local healthcare professionals to validate the apparent right of the family to shape decision-making on care and treatment (37,39-41,83).

Where patients are unable to function autonomously either as a result of informational limitations, ongoing disease processes, treatment side effects or as a result of coercive or influencing factors that may limit their ability to deliberate on matters clearly and unhindered, it falls upon HCPs to protect the rights and opportunities of the vulnerable patient (52). Legal, professional and societal expectations obligate HCPs to protect and further the patient’s best interest guided by a MDT whenever possible, seeking the advice of proxies and surrogates, particularly in considering CDPS (45,86-93). This is in line with the Mental Capacity Act (45,86-93).

The best interests of the patient are a means of considering the “value of the life for the person who must live it” and are discerned from a multidimensional review of the patient’s case derived from the patient’s own appraisals and views, those of their family and a multi-professional assessment (44). The various parties come together in keeping with the tenets of shared decision-making models to deliberate and attempt a consensus decision. If consensus cannot be gained or when the minimum standard of care to the patient is threatened, the responsibility for the final decision falls upon the primary decision makers based on their
estimations of the patient’s best interests (44,45,88-93). Singapore’s Mental Capacity Act 2008 (MCA) does not utilize the term “best interest”; however, its amended version in 2010 does, as does its advisory notes for deputies produced in 2010 (45,90-93). It states that deputies must “act in the best interests of the person who lacks capacity” and defines “best interest” as “a duty to consider many factors on what is best for the person lacking capacity before making a decision on his behalf” (93). Part II Section 6 paragraphs 5-8 of the 2010 Amendment of the MCA itself covers a number of areas including ensuring that the person making the determination is well intended and acting in the best interests of the patient (45). It also considers

1. the patient’s past and present wishes and feelings;
2. the patient’s beliefs and values;
3. the patient’s psychosocial considerations;
4. [the views of] carers and family members and those engaged in the patient’s care, any donee of a lasting power of attorney and any court appointed person (45).

Family involvement is neither set aside nor negated, but is not conferred the authoritative position it has sometimes enjoyed (39-41,59-74,94-99).

1.2.5 Treatment procedure in CDPS

Once the need for sedation is established and assuming that the problems of valid consent have been overcome, sedation is applied through the administering of either midazolam or haloperidol (40). The selection of these drugs is dependent upon their efficacy when administered in an intermittent manner for the control of symptom exacerbations (14-16). Other measures that were being used that are
deemed useful are maintained and for the most part the sedative is simply added to those interventions that have been found to be necessary and effective for the patient’s care thus far. Medications with purely sedative characteristics are ceased to avoid overlap wherever possible. If extra doses or breakthrough doses are required then they will be administered at doses and in a manner that is in keeping with strict guidelines and monitoring protocol. For the most part midazolam breakthrough doses used to treat additional symptoms that manifest themselves over and above the level of symptom intensity and frequency that the infusion is tasked with managing is usually identical to the hourly rate of the midazolam infusion (100). The same proportions are applied for haloperidol breakthrough doses with respect to its maintenance dosing within the infusion (100). The maximal dose of midazolam applied is 240mg per day and the maximal dose of haloperidol is 30mg per day (14,15). This process is closely monitored and changes in care patterns and drug provisions are carried out according to clear guidelines not unlike those presented by the European Association of Palliative Care (EAPC) or within the Oxford Textbook of Palliative Medicine, given the lack of local guidelines (14,15,100) In keeping with these guidelines, nursing staff monitor the patient at least once an hour for the presence of the target symptoms as well as side effects (14). Should either be present, steps are taken to remedy the situation according to guidelines set out.

Response to the breakthrough dose is then noted after a 24-hour period as are the total doses administered over this duration. This total dose is added up and the overall infusion rate is increased accordingly (14,16,101). If the baseline dose is insufficient in that the patient remains very symptomatic or if the rescue doses are inadequate, then the review of the baseline dose may be brought forward and the
corresponding dose of the breakthrough dose, increased proportionate to the overall increase in the infusional dose. Side effects, should they become present, usually call for a change in drug or a reduction in the overall dose provided. The baseline dose refers to the total amount of drug being administered whilst breakthrough dose refers to the extra doses of medication that are required over and above that of the baseline to control any exacerbations of symptoms (2).

Family and carers of the patient are regularly briefed and supported during this period with updates of the patient’s condition and counselled for any concerns that they may have (14-16).

Morphine or fentanyl, the only two opioids available locally in intravenous formulations is only applied if there is a clear indication for the treatment of pain or dyspnea (2,3). Combinations of these classes of drugs are rare and are only carried out when there are specific indications (2). Opioids are however frequently applied in tandem with sedatives (2,3). The indications for combinations of opioids and sedatives include the treatment of pain, dyspnea or cough (2). Whilst opioids do have secondary sedative properties, these effects are taken into account and the primary sedative dose is lowered in keeping with the goal of sedating the patient as lightly as possible with as little drug as possible for the purpose of reducing their awareness just sufficiently to reduce their awareness of their intractable symptoms. Thus far, all patients that have been sedated in this manner have been for physical symptoms and not solely for existential symptoms though an overlap of symptoms does occur.

A further pertinent consideration is the relatively low prescription of opioids and other constituents of sedation in the end stages of life (1,2,102,103). Whilst
unpacking the reasons for this fact lie outside the remit of this thesis, it may be said that a significant factor in this rather low employment of opioids at the end of life when compared with other nations ranked amongst the top 20 nations in “The Quality of Death” survey is societal fear of the use of these drugs (2,102). This can present problems, which I take up in Chapter 5 in a discussion of what appropriate and proportional treatment requires in the context of CDPS.

1.2.6 CDPS and clinically assisted artificial nutrition and hydration (CANH)

In describing the approach toward CANH within the practice of CDPS, it is societal fear and expectations that underpin key considerations in the provision of hydration and nutrition even amongst the terminally ill (3,94-99,104-107). Prevailing cultural attitudes toward the meaning of food and hydration among families consider these to be a “symbolic personal intervention” that is part of a carer’s duty of care and non-abandonment, and a minimum standard of care within the “traditional medical model of care” (1,70,71,74,108-119). Such views are also held in Japanese, Taiwanese, Korean and even Israeli, Canadian, European, US and Latin American care settings (108-119). In Singapore, the Advance Medical Directive (AMD) Act, which calls for the reasonable provision of nutrition and hydration unless clear contraindications exist, serves to encourage this practice (69,70,104).

Whilst data reported on the effects of CANH upon prognosis remains largely unclear, growing evidence does appear to be veering towards the belief that the
non-provision of hydration at the end of life is unlikely to hasten death (1,120-123). However it appears some HCPs state that if there is a possibility that such a prognostication could be inaccurate and that life may be potentially abbreviated as a result of the concurrent application of CDPS, not applying a means to reduce the chances of this may be construed as willing the patient’s demise. They, like those who state that they would prefer to err on the side of caution, opt for continued application of hydration even in the terminal phase.

With data still ambiguous as to the benefits and indeed risks of CANH amongst the terminally ill, there may be just consideration to employ this intervention, if only to reduce or even negate the reported side effects such as confusion, sedation and delirium that Ellershaw et al, Bruera et al and Fainsinger et al assert occur as a result of ceasing hydration amongst the terminally ill (119,124-129).

### 1.2.7 Intentions in CDPS

The application of sedatives is primarily to alleviate intractable symptoms through the induction of unconsciousness of the patient following the failure of other conventional treatment options and the applications of light sedation and intermittent deep sedation. The primary premise here is that by rendering the patient unconscious, the patient will not be aware of their intractable physical symptoms and thus no longer be afflicted by the effects of these symptoms (12). Yet there is also an acceptance that the provision of such an intervention is not taken lightly but seen to be part of the greater goal of palliative care as delineated by the World Health Organization (WHO) to relieve suffering (130).
However, Juth et al and Matersveldt and Bosshard suggest that any practice where consciousness and thus the personhood of the patient is effectively extinguished lies closely related to the practice of euthanasia (131,132). It appears that underpinning this position is the belief that the suppression of consciousness simply reduces a patient to a basic biological entity dispossessed of all that is significant and particular about the individual in question. Importantly, the ensuing “social inertness” that follows sequesters the patient from their social interactions, and this is said to leave them “socially dead” (131,132). For Juth et al and Matersveldt and Bosshard, “social death” is not so dissimilar to biological death particularly as this level of sedation is continued ostensibly till the patient’s biological demise (131-133).

This situation is made all the more complex given the practice of routine cessation of all life-prolonging measures and the withholding of resuscitation should the need arise, even if this deterioration is an immediate result of the application of CDPS. The authors observe that the patient, no longer able to communicate, has said their good byes to loved ones and is sedated with no real intention of “bringing them back” (132). The combination of this can be described to be a state not dissimilar to that of the “living dead” and not too far from the practice of euthanasia (132). The difference between the two practices is more than simply about the fact that CDPS is reversible. CDPS is less likely to be open to conjecture and the slippery-slope argument due to its denial of psychological and existential suffering as an indication for use and the continuation of CANH ostensibly till death (132,133). Furthermore, the objectives of these two procedures as well as the intentions behind their applications, the presence of patient consent for these procedures, compliance
with prevailing ethical practice in applying these interventions and a circumstantial review of the clinical situation also set the two practices apart (43). These elements become prime considerations within this study of the practices of CDPS, terminal sedation (TS) and palliative sedation (PS) (43).

This extinguishing of personhood and the provision of CANH as a means of maintaining life even in the face of ceasing all other life-prolonging measures need some clarification of the intentions that drive them. Personhood may be taken to be “the individual substance of a rational nature” that highlights the uniqueness of a person (134). This neuroscientific view of the concept of personhood revolves around the presence of consciousness as the primary determinant of personhood and holds that it is the capacity to think, decide, choose, understand, act, exercise autonomy, have intentions, rights, duties, moral responsibility and have ongoing relationships that confers personhood upon an individual (134). Yet within the CDPS scenario, many if not all these elements that confer personhood are extinguished, leaving stubborn protection of personhood thus conceived largely superfluous. Similarly, as Cassell argues, many of the integral “needs” and functioning of the person are unlikely to be met without “sentience” or consciousness, thus attempting to protect the potential for these facets when they are unlikely to be attained is also misplaced (20,134).

The idea of personhood within the palliative care setting is essential and reiterates Dame Cicely Saunders’ aspirations of individual and holistic care of patients, where physical, psychological, social and spiritual care are provided specific to the needs of the patient. The neuroscientific idea of personhood described earlier fails to capture the true essence of how personhood is viewed by many thinkers.
(135-137). Rather, the palliative care ideal of personhood transcends these rather limited views and refers to a wider conception replete with relational connections and enduring interests that persist even after the patient is unconscious. The importance of a good death, the maintenance of dignity and preservation and improvement of quality of life of the patient and family persist, requiring that personhood be respected even when many of those elements that Cassell suggests have been extinguished (138,139). This wider ideal of personhood is seen to persist and warrants respect and dignity even when the person may not be fully functioning. In Chapter 6 I propose a wider view of personhood that is more culturally appropriate, ethically relevant and clinically sensitive and counters many of these concerns.

The process of employing CDPS presented here describes local practice that has evolved in accordance to current clinical practice, sociocultural expectations and regnant professional and legal standards. Much of this practice is still based upon the frameworks of prevailing practices of sedation at the end of life such as TS and PS set out in palliative care texts such as the Oxford Textbook of Palliative Medicine, Saunders’ Palliative Medicine and the Textbook of Palliative Medicine, though with important differences (14-16). It is these differences that are of concern here both in distancing CDPS from the concerns of euthanasia that continue to plague both TS and PS but also in highlighting the various issues that have been neglected in current TS and PS practices. To begin with, a review of terminal sedation (TS) is called for.
1.3 TERMINAL SEDATION (TS)

Coined in 1991 by Enck in the US, the term “terminal sedation” was seen shortly after in a review article on the practice of sedation at the end of life by Williams in 1992 (140,141). On both occasions the term “terminal sedation” (TS) was not fully defined. At its inception, Enck was commenting on the use of sedatives and opioids at the end of life by Ventafridda et al and Greene and Davis (141-143). In the first study of its kind, Ventafridda reported on the incidence of patients reporting “unendurable” physical symptoms amongst 120 terminally ill Italian cancer patients within a home care setting. He reported that in 52.5% of reported cases, “sedation-inducing sleep” was required to ameliorate these symptoms (142). This report, along with Greene and Davis’ retrospective case reports of 17 imminently dying urological cancer patients managed in the community in South Carolina who required the same manner of treatment for a “constellation of desperate symptoms”, appears to have provided Enck with the inspiration for the term “terminal sedation” (141,143).

In all these cases the patients attained good symptom amelioration of their previously poorly controlled complaints (141-143). Greene and Davis also described the basic “prerequisites” for such a treatment modality, which became the standard adopted by many frameworks that followed (141-143). These conditions included a diagnosis of terminal disease, the exhaustion of all other treatment options for the amelioration of these symptoms, the presence of a “Do Not Resuscitate” (DNR) order, imminent death, consent of patient and family and the presence of the family at all times (143).
Despite being conceived at least initially as the administration of sedatives to imminently dying patients with intractable symptoms, many definitions of TS exist [Appendix 1]. To some extent, it is due to these variances in conceiving this practice that ambiguities surrounding the practice of TS remain (55,120,144).

1.3.1 The term TS

The definitions in Appendix 1 reveal the various conceptions of TS over the years and highlight the differences of opinion regarding this treatment option and controversy that this treatment option has courted. These variances include the actual goals of TS, the manner that they may be met and their indications for use [Appendix 2 and 3].

Enck’s original introduction of the term “terminal sedation” made only one reference to this term that was to become synonymous with the practice of sedation at the end of life (141). Given there was little direct definition nor explication of this term within his editorial, Cowan and Walsh and Chater et al reported that there was a lack of consensus “amongst experts” on Enck’s conception, though Chater et al did note the presence “a general understanding among palliative medicine practitioners today that it is sedation for intractable symptoms near the end of life” (120,141,145).

Little has changed from Chater’s 1998 report in Palliative Medicine and the Cowan and Walsh review in Support Care Cancer in 2001 (120,145). When Simon et al opted to carry out a questionnaire survey of the 477 members of the German Academy for Ethics in Medicine on the most common term used to
describe the use of “sedation in the imminently dying patient”, these authors found that TS was known to 92% of the 281 respondents but a clear lack of consistency in their perceptions of this procedure prevailed (146). However, in a study on the attitudes of members of the German Association for Palliative Medicine by Muller-Busch et al in 2003, nearly 95% of palliative care physicians supported the use of the term TS leading the authors to conclude that “doctors clearly considers TS a medically adequate and ethically justified means to overcome suffering in that phase” (147). Rietjens et al also showed that in the Netherlands, the term TS is the most popular term to describe sedation at the end of life with 211 out of 410 surveyed physicians reporting that they had employed TS in the past (148).

Simon et al’s study revealed that whilst there was wide acceptance of the term TS, there was variation in understanding the substance of this intervention (146). In a survey of 697 Japanese oncologists and palliative care physicians on their attitudes towards TS, Morita et al found that nearly 95% of respondents felt that TS was a necessary end of life treatment option within the armamentarium of palliative care (149). However 17% of clinicians in this survey reported feeling that this practice was indistinguishable from euthanasia (149). Whilst reiterating the importance of TS, the scope and boundaries of its goals, depth of sedation, inclusion criteria, the practice of cessation of CANH and ethical acceptance of this intervention had come under scrutiny (146).
1.3.2 Goals of TS

1.3.2.1 Distinctive option of last resort

The goals of TS are unclear on a number of areas as highlighted in Appendix 2 and 3. Whilst it does seem focused upon the rendering of unconsciousness to patients with intolerable, intractable, unendurable, uncontrolled, unbearable, severe symptoms or “extreme exacerbations of conditions”, significant variations exist as to the prognostic requirements for TS, the depth of sedation, the underlying pathology of the illness, the manner that it is applied and the drugs that are utilized [Appendix 3 and 4].

1.3.2.2 Relief of physical and psychological symptoms

There is significant variation in whether TS is indicated for solely physical symptoms or should also be taken to include psychological concerns as well [Appendix 3].

1.3.3 Prerequisites

The prerequisites for TS also appear variable. Firstly, the diagnosis of intractability or refractory symptoms do not appear universally accepted, with wider, more subjective and less vigorously ascertained inclusion criteria such as intolerable, intractable, unendurable, uncontrolled, unbearable, severe symptoms or “extreme exacerbations of conditions” being suggested [Appendix 4]. Secondly, terminality does not appear to be a universally specified consideration
with Quill et al in the American College of Physicians-American Society of Internal Medicine (ACP-ASIM) Position Paper, suggesting that it may be considered for potentially curative conditions such as burns, whilst Morita et al suggests that a prognosis of three weeks is applied (150,151). Thirdly, given the ACP-ASIM position, there is also variance over the issue of futility of remaining treatment options ranging from the variability of access to the “acceptability” of alternative treatment option (150). Fourthly, the applicability to non-cancer diagnosis also appears to be not uniformly adopted [Appendix 3]. Fifthly, the application of TS for existential and psychiatric indications is also a source of divergence [Appendix 3].

### 1.3.4 Treatment decisions

Many guidelines advocate the application of a MDT-led holistic appraisal as a precursor to this deliberative process and the application of second opinions but this approach is not unanimously adopted [Appendix 3]. Such a wide ranging review is useful given the inherent variability of access to treatment, the societal, cultural and practical differences within the individual determinations, and the subjective nature of largely patient-determined terms such as acceptability, intolerability and unendurability of symptoms [Appendix 4].

Similarly variances exist with respect to the decision to cease all life-prolonging treatments or having a DNR order enforced [Appendix 2 and 3].
1.3.5 Consent

Whilst considered important in all the guidelines, the process of getting consent is not easy [Appendix 3]. This is unsurprising given that Rietjens et al found that patient consent for TS only occurs in 61% of cases in the Netherlands, largely due to the patient being incompetent or “subcomatose” (152,153).

There are a number of alternative means to obtain consent. Cherny and Portenoy, Morita et al and Greene and Davis suggest that the consent process must necessarily involve the family (141,143,144,154). Quill et al and Hawryluck et al approach this issue from a multidimensional appraisal of best interests (55,155). Rietjens et al report that in the Netherlands consent for TS usually involves familial involvement and proxy decision-making in 94% of cases but make no mention of the remaining 6% of cases where it would seem TS was applied based solely on the physician’s orders (152,153).

1.3.6 Treatment procedure

There is disagreement regarding the treatment procedure in TS and there is minimal consensus on the manner and depth of sedation that would be employed [Appendix 3]. Dose ranging is also variable as are the type of drugs that are employed (2,3,59,60,103,120,121,145). There is no agreement as to the constituents of this procedure and a dearth of clear guidelines as to how, when and where it could be applied and to whom it is applicable. There is also no clear delineation as to what, how and by whom this procedure will be monitored, how constituents of TS will be titrated, and for how long TS would be applied.
1.3.7 Clinically assisted artificial nutrition and hydration (CANH)

The issue of the continued application of CANH is divisive within TS deliberations. Muller Busch et al, Lanuke et al, Gillick, Quill et al, Hawryluck et al, Sykes and Thorns, Jansen and Sulmasy, Tannsjo, and Rietjens et al maintain that CANH ought to be ceased as a matter of a wider decision of stopping all life-sustaining treatments or as a matter of routine practice of end-of-life care or even as routine practice upon the application of TS [Appendix 3].

On the other hand, Materstvedt et al, the EAPC guidelines, Yamagishi et al and Morita et al suggest that hydration be continued as a matter of routine, whilst the ACP-ASIM Position Paper, Morita et al and Hallenbeck suggest a case by case review [Appendix 3]. Frequently, this act is seen as a “symbolic personal intervention” that would allude to a duty of care and non-abandonment, a part of the “traditional medical model of care”, or as a minimum standard of care or in keeping with cultural and societal beliefs, expectations and values (1,39-41,53,54,74,92-99,110,122,158-161) For clinicians such as Quill, Bruera, Billings, Ripamonti, Stiener, Orentlicher, Lanuke, Valko, Troug and Loewy routine cessation of CANH was viewed as having negative connotation upon a patient’s care and life expectancy (55,150,162-167).

1.3.8 Intentions

Intentions are believed to separate TS from euthanasia. Kaldjian et al’s reports attest to this when they reported that whilst many internists place great value in ameliorating symptoms and maximizing comfort, they draw a clear distinction in
intending death as part of achieving this goal from merely intending comfort and risk death (168). Compliance with guidelines and accepted clinical practice will also serve to focus review of actions upon the true intentions behind actions (46). Battin suggests that discerning the intentions of the physician in the light of such variability of practice, the lack of consensus based guidelines, the presence of sociocultural and practical variances, the dearth of treatment algorithms and monitoring procedures make adjudging intentions through compliance of guidelines difficult and leaves the process open to conjecture (169).

1.3.9 Evaluating TS

Fatal flaws exist within the prevailing understanding of TS in its efforts to remain overly inclusive, pragmatic and open to adaptations in care provisions [Appendix 1, 2 and 3]. The lack of a clear definition and understanding of the pivotal terms and practice not only negates much of the positives that clinical research on the subjects of hydration, opioid use and sedative use amongst the terminally ill has brought to bear upon the discernment of TS, but allow many ongoing concerns such as its possible overlap with euthanasia to simmer (120,170-179).

Connotations about the term “terminality” and the indeterminateness of purpose particularly with the inclusion of non-cancer diagnoses and psychiatric and existential distress as indications for TS have clouded understanding of this procedure and have seen an abortive attempt to reclassify TS as part of the practice of euthanasia in the Netherlands (120,123,146,149,150,162-166,181).
The proportionality of this procedure and the appropriateness and manner of its responses have also been open to conjecture (153).

“Unfortunate” connotations with “terminating” life are also highlighted in the variable practice of CANH, particularly given the strong public and professional sentiment in favour of its continued use (92-99,158-161,182-186). Even amongst signatories of the EAPC who have adopted the guidelines set out on TS, persistent differences in basic end-of-life practices continue (119,187-192).

Among Dutch and Danish patients, 64% were reported to not have hydration in their last phase of life, which contrasts starkly with the practice in Italy where only about 35% of patients in a similar condition did not receive this intervention (119,147,188-192). Such variability in practice have only served to heighten concerns about the real intentions behind the practice, particularly when data does reveal that many of the feared contraindications to its provision are largely overstated and negatively impact public sentiment and patient trust of palliative care teams and of the hospice movement within the local setting (1,74).

Concerns of abuse of this practice are also widespread. Battin and Krishna raise doubts as to whether consent for the application of TS can actually be valid particularly when one considers the presence of the cognitive impairments that are associated with the dying process such as deterioration in concentration and alertness, the high prevalence of mood disorders such as depression and anxiety that would affect the cogitative ability of patients, the ubiquity of delirium at the end of life and the coercive influences that range from familial considerations to the presence of intractable symptomology (46,169). Reliance on surrogates, proxies and familial determinations are also suspect, particularly where the
interests of the patient succumb to those of the wider family in the face of conflicts of interests (37-41,46).

Proportionality of response and the manner that patients are monitored have also been a source of disquiet. Tannsjo suggests that central to the practice of TS is the requirement that the “risks of causing harm must bear a direct relationship to the danger and immediacy of the patient’s clinical situation and the expected benefit of the intervention” (193). As a result, in clinical cases, proportionality can be highlighted through clearly showing that treatment options adopted are commensurate with the exigencies of the medical situation, medications are titrated according to symptoms and doses revised when side effects are present or as a result of changes in the patient’s condition. Similarly supportive measures such as the provision of CANH are provided dependent upon the actual clinical needs of the case rather than in compliance of a general rule.

Clay Jackson, Lanuke et al, Koh et al, Chin and Woods argue that estimations of commensurability of interventions must necessarily include holistic appreciation of the bio-psychosocial and cultural elements of the individual case if care needs are to be appropriately met and abuses negated (70,71,99,177,194,195) This is a particular concern within the practice of TS where there is little if any monitoring of the process despite the acknowledged ill effects of this procedure and even when present clinical observations remain focused upon monitoring for side effects rather than the success of the process. The concern here is that there is growing data that suggests variability in conscious levels under sedation and without close monitoring patients may not be appropriately sedated and thus may be aware of their suffering.
The absence of a clear set of practice guidelines especially upon the frequency and manner that monitoring of these patients ought to take further highlights the inconsistencies in the prevailing practice of TS (4,144,145,163,182,183). Exemplifying this dissonance in current TS practice is the debate surrounding the prerequisite for a DNR order. Any such prerequisite fails to meld the overall goals of care with the clinical data on the outcome of measures of resuscitation, the overarching duty of care, and a holistic appreciation of the patient’s condition. Furthermore, it emphasizes the lack of coherence amongst prevailing TS guidelines and variability in perception amongst health care professionals as to the implications of an application of TS (196).

This position, though adopted by some guidelines, is not universally accepted and such variability of practice highlights the fatal flaw in the practice of TS [Appendix 3]. Seen as a natural evolution to the practice of TS in light of increasing concerns regarding its apparent associations with the practice of euthanasia, the phrase and concept of palliative sedation (PS) was forwarded.

1.4 PALLIATIVE SEDATION (PS)

1.4.1 Goals

1.4.1.1 Distinctive option of last resort

The basic goal of PS is alleviating refractory suffering of imminently dying patients through the application of medications that lower their consciousness. Whilst differences between the various guidelines appear to revolve around their boundaries with some choosing to dispense with distinctions as to the applicability of PS to cancer and non-cancer diagnoses, the pivotal difference for
some of these treatment guidelines lie in their treatment of “suffering” and in particular in addressing existential suffering [Appendix 5 and 6].

1.4.1.2 Relief of physical, existential and psychological suffering

This more inclusive approach to care appears to take root in the more expansive role of palliative care, which sees existential suffering (ES) as being “within the scope of the approach to palliative care” and thus dispensing with attempts to delineate applicability of treatment along etiological lines of suffering upon the belief that this would safeguard the personhood of the patient and meet the primary goals of palliative care [Appendix 5 and 6].

1.4.2 Prerequisites

A primary prerequisite for PS remains the diagnosis of intractable symptoms, though the means of diagnosing this entity varies. Vague when considering physical symptoms, present PS guidelines do not contain any means of diagnosing existential suffering much less determining its refractoriness [Appendix 5 and 6].

Terminality appears to be a key requisite but there is no firm definition of this within many of the guidelines [Appendix 5 and 6]. The KNMG, NHPCO and the EAPC guidelines do describe the “dying phase”, which does shed light on patients entering this phase (100,121,197,198).
Futility of life-prolonging treatments and an emphasis on comfort driven goals of care are delineated by some of the guidelines; however, there is little in the way of delineating when and how treatments of existential symptoms are to be deemed futile [Appendix 5 and 6].

1.4.3 Treatment decisions

The means by which treatment decisions are arrived at with respect to the application of PS are also variable. Only the KNMG, Alberta, HPNA, VNA and Massachusetts guidelines, the Sedation Guideline Task Force in Japan and the guidelines set out by the palliative care textbooks employ a MDT-led approach and use second opinions in the deliberative process to ensure holistic appraisals, and balanced and accountable decision-making [Appendix 5 and 6]. Additionally the four guidelines set out by the respective palliative care textbooks also express a need to ensure that DNR protocols are in force [Appendix 6].

There is however no mention of whose input will be considered within this deliberation, what weight would be provided to the opinions of the various parties and how the decision-making process will take place, particularly when it involves so many different parties and views; nor is there any clear specification as to how an impasse or indeed a failure of consensus would be dealt with.
1.4.4 Consent

The ubiquitous requirement for consent is present in all the prevailing guidelines. However, a consistent stance on how this may be attained when the patient is clearly incapable of consenting is not viable [Appendix 5 and 6]. Even the guidelines set out in the palliative care textbooks do not agree [Appendix 6]. The Principles and Practice of Palliative Care and Supportive Oncology and Saunders’ Palliative Medicine, and the HPNA and Fast Facts guidelines appear unwavering in their requirement of informed consent, whilst the AMA-CEJA, AAHPM, VNA, NHPCO, EAPC, Massachusetts and Alberta guidelines and the guidelines set out in the Oxford Text Book of Palliative Medicine and the Textbook of Palliative Medicine allow for the input of surrogates in the event the patient is not competent [Appendix 5 and 6].

The NMA guidelines revert to best-interests determinations should the patient be unable to consent to this procedure whilst the KNMG guidelines allows for HCPs to overrule surrogate decisions if it is felt that they obstruct the best interests of the patient (121,188).

1.4.5 Treatment procedure

Procedural guidance for PS is largely inconsistent with only some guidelines providing procedural checklists, titration algorithms and monitoring protocols [Appendix 5 and 6]. However whilst guidelines such as those found in the KNMG and the EAPC guidelines form the basic standards of care expected of
HCPs upon applying PS, significant variances in practice and even in conception exist (96,121).

Indeed the term PS has been applied in relation to a number of treatment procedures at the end of life, most famously by Quill et al in their article entitled “Last Resort Options for Palliative Sedation” in Annals of Internal Medicine in 2009 (162). In this article Quill et al describe three forms of PS (162). They are “ordinary sedation”, proportionate palliative sedation (PPS) and palliative sedation to unconsciousness (PSU) (162). In “ordinary sedation”, sedation is used to treat symptoms without affecting the patient’s level of consciousness (162). In PSU, “unconsciousness is the intended goal of sedation rather than the side effect” as opposed to PPS where sedation is merely the foreseen but unintended effect of progressive titrations of sedatives to ameliorate suffering (162). Whilst most resembling the practice of CDPS, the term PPS has not been adopted here given that it does not specify either the route nor manner of the administration of sedation (162). The term PSU on the other hand misrepresents the manner and the intention behind CDPS and thus also found wanting (162).

1.4.6 Intentions

Elucidation of intention for the application of PS appears to be underpinned by the proportionality of response and the maintenance of appropriate and justifiable treatment in order to prevent a slippery slope slide to the abuse of PS as a means to euthanasia. Compliance with treatment algorithms such as those set out by the EAPC and KNMG guidelines then help delineate the intentions of HCPs in
applying this option as do observance of applicable care and professional standards.

1.4.7 Evaluating PS

There are two important considerations regarding the present PS guidelines. Firstly, it attempts to treat suffering rather than symptomology, and secondly, it extends the idea of suffering beyond the physical domain to include the consideration of existential suffering. At first blush, such an expansive accommodation of treatment objectives would be in line with a grander, more holistic view of the goals of palliative care as envisaged by the founder of the modern hospice movement, Dame Cicely Saunders, and a society that increasingly sees multi-professional, multi-dimensional palliative care as a basic right for all dying patients regardless of etiology (134,136,137,199-201).

However, concerns arise when little is made on what is to be understood from the term “suffering”, how suffering would be diagnosed and when it would be considered intractable. The underlying concern here is that such complex indications that are in turn largely dependent of highly subjective factors will lead to a loosening of practice standards and a precipitation of a slippery slope. In order to comprehend these concerns, a better appreciation of suffering ought to be delineated.
1.5 SUFFERING AND DISTRESS

1.5.1 Defining suffering and distress

The term “suffering” is not new to palliative care and is found within the definition of palliative care as set out by the WHO (130). Relevantly, the phrases “relief of suffering” and “the treatment of pain and other problems, physical, psychosocial and spiritual” allude to the idea that suffering as it is understood within the present definition is multidimensional (130). Cassell defines suffering as the state of severe distress associated with events that threaten the intactness of the person as a complex social and psychological entity (13,17-20). Suffering has also variously been described as a complex negative emotional response that may result from psychosocial and spiritual factors (202).

It is its close association with pain that has brought this phenomenon to the fore (202). The terms “suffering” and “pain” have been used interchangeably in the past, with suffering being seen as part of the secondary response to pain (11,202-209). Increasingly, however, pain and suffering are viewed as distinct entities albeit with significant overlap as the concept of suffering has evolved to include a wider spectrum of consideration, dependent on cultural and inter-individual variations that leave it difficult to clearly differentiate, particularly along physical and existential lines (11,202-209). This multidimensional view of suffering defined within the particularities of the individual contrasts starkly with the concepts of the regnant “Cartesian disconnect” which maintains the idea that physical and existential symptoms are separate and distinct and can be effectively disentangled and addressed individually (202-209).
This categorical approach appears to underpin Jansen and Sulmasy’s position that envisions suffering as two distinct entities, and underlies the AMA’s position on a tenable distinction between physical and existential suffering (10,101,210). This differentiation is said to underlie the AMA’s prerogative to address suffering on a physical plane and clearly demarcate existential distress as being outside the remit of palliative care (101,210). The first category taken by the authors credited with being the architects of the AMA’s present stance is referred to as “neurocognitive suffering” which is envisaged to bear a “direct causal relationship with the patient’s underlying condition” and is akin to physical suffering (10,101,210). This type of suffering would include pain, seizures, insomnia and psychiatric symptoms (10). The second category within Jansen and Sulmasy’s conception is “agent narrative” suffering. This appears to be understood in the same manner as existential suffering, which does not share a “direct link” with the ailment (10,13). This manner of suffering would include symptoms such as angst, fear, loneliness, sadness, disgust, anger and worthlessness (10,13). Jansen and Sulmasy deny that refusal of PS for intractable agent narrative suffering is a reflection that the severity or need for treatment of this form of suffering is in any way below that of physical suffering but maintain that as this second category of suffering is resistant to medical and supportive care, it lies outside the remit of medical care and thus beyond the applicability of PS (10). In her reply to Rich and Cassell some eight years later, Jansen appears to have softened this stance and states that there must be flexibility in determinations between her two categories and if the case is clear and the need dire enough, then PS may even be applied irrespective of its designation (211). This moderation of Jansen and Sulmasy’s approach appears to raise questions as
to the rationale of maintaining this categorization and appears to return conceptions of suffering to a holistic and individual view of suffering as suggested by Saunders in 1984 (135,211).

Cassell and Rich reject Jansen and Sulmasy’s approach to suffering, stating that there is no clear justifications for this symptom categorization and prefer to adopt a position akin to Dame Cicely Saunders’ posit of the multidimensional nature of suffering at the end of life or “total pain” (135,199,200). This approach remains a central theme of modern palliative care with most research on the subject supporting this premise (11-13). However, as Jansen and Sulmasy concede, diagnosis of these elements of suffering may not be easy given the wide range and frequently overlapping symptomology that include loss of personal meaning, dignity and purpose of life, fear of death, anguish, despair, hopelessness, being a burden to others, helplessness and betrayal (11-13,17-20). This has led Rich and Cassell to conclude that a cohesive approach is warranted (13,205).

1.5.2 Identifying suffering and distress

Dean and fellow palliative care physicians suggest that distress may be identified through conversations with the patient and/or their family, simple verbal descriptors, facial expressions, behavioural changes, postural changes and autonomic changes (212). These authors argue that in 80% of cases these symptoms and signs will be present, allowing the experienced clinician a chance to diagnose distress and act to overcome it (212). Failure to act appropriately is envisaged to predispose the onset of suffering (212-214).
In terms of recognizing suffering, Cassell and Cherny are clear in stating that “diagnosis is made by considering the person, not only the body” and at a highly interpersonal and experiential level (20,213). Cassell identifies five domains to suffering and posits that the presence of any element of these five domains “of special concern for the dying” suggests the presence of suffering (20). The five domains are inadequate pain and symptom control, loss of control, a prolonged dying process, being a burden to those around them, and straining personal relationships (20).

Tan et al corroborate these findings in their study amongst Malaysian palliative care patients (205). They found that there are 10 types of suffering that can be clinically identified through a multidisciplinary team approach, reiterating that despite its many personal and patient-specific manifestations, suffering can be both identified and potentially addressed at least in the “early stages of the dying process” (205).

1.5.3 Justifying an “inclusive” idea of suffering

For patients with intractable symptoms replete with their own ideas of suffering and a poor ability to communicate, as is the case for patients in this phase of life, an endeavour to uncover the specific meaning underlying their suffering may be difficult particularly in the face of a fast receding time frame and limited means available. A patient-specific review may reveal that in the face of such troubling symptoms and the unabated deterioration in clinical conditions, treatment options that are available are unlikely to be effective within a “tolerable” time frame.
Thus, as a corollary to a physician’s duty to alleviate suffering, standards of care and the right of the patient to adequate relief, all suffering must be treated in the speediest, most efficient manner which includes PS (213-219).

This position can be justified on three fronts. The first comes from the stance that all patients have a right to health care and with that a right to good palliation of their symptoms. This right arises from the legal obligations of nations being signatories to the International Covenant to Economic Social and Cultural Rights (ICESCR) which imposes obligations upon these governments to meet the goal that “everyone has the right to the enjoyment of the highest attainable standard of physical and mental health” (219). From these legal obligations and those enshrined with Articles 12, 24 and 25 of the Universal Declaration on Human Rights come binding legal obligations that in turn evince standards of care and pursuant obligations of the physician and the rights of the patient to such care. Brennan argues that the “foundations of a right to palliative care”, which are derived from local statutes and legislation either directly or indirectly from the stipulations of the UNHCR Declaration and the ICESCR statements, provide patients with rights to the “highest attainable standard of physical and mental health” (218-220). The argument then follows that this will necessarily include health at the end of life, which would include palliative care. As such it can be argued that this engages the right of terminally ill patients to relief of pain and suffering (201,218). This position is supported by the Korea Declaration, the Montreal Statement on Human Rights to Essential Medicines, the 2006 Papal Address and the Cape Town Declaration (221-226). Given that the goals of palliative care is the “relief of suffering” and the “improvement of quality of life”, it follows that there is an inherent right to effective management of suffering and
with the diagnosis of intractability as a result of an attenuation of alternative treatment options, the options for PS ought to be considered for “all avenues” of suffering (130). However, does this actually follow?

The Oxford Textbook of Palliative Medicine as do Quill and Bycock maintain that treatment of suffering is part of the “continuum of symptom management” that lies within the domain of palliative care (49,150). Such a wide and holistic aspiration thus determined, the rather discriminatory treating and non-treatment of “subtypes” of suffering along lines of diagnoses is set in conflict with these goals. Weight may be added to such a stance given that other more widely accepted goals of palliative care such as quality of life have also been found to be affected by suffering. A decrease in a patient’s quality of life, an increase in their suicidal ideations and their desires for death and an increase in their frequency of pain reporting have all been shown to be associated with suffering (6,11,14,150,227). More specifically Cherny and Blinderman noted that existential suffering increased morbidity amongst palliative care patients (228). Boston and Bruce in their systematic review of the suffering of palliative care patients found that the impact of existential suffering on patient quality of life and care was not insignificant and also noted that a lack of clear conceptualization has left diagnosis and management protocols floundering and as a whole appearing to be in dispute with the central ideals of palliative care (11).

Unsurprisingly Rich and Cassell, the EAPC guidelines and the KNMG guidelines appear to adopt a stance in favour of the application of PS for existential suffering particularly in light of Jansen’s concession that prevailing ambiguities between the types of suffering do make it possible for PS to be applied for complex cases.
where overlap between the various “types” of suffering may occur (11-13,100,121,211). It may be that in light of the attenuation of alternative treatment options and at the risk of continued suffering that will affect both the quality of life of the patient and that of their carers and family, the application of PS may be viewed as making the best out of a difficult situation despite unsubstantiated evidence of its efficacy in the treatment of “all” types of suffering. Importantly, within an amorphous concept of suffering that is clearly not easily delineated, the provision of PS may still be applied if only to treat the physical as a means of ameliorating the existential suffering in the face of overlapping symptomology. However, is such a practice acceptable?

The second justificatory argument arises from the stance taken by the EAPC and KNMG guidelines that it is a doctor’s duty to relieve suffering and pursues the idea that physicians have a duty to alleviate all suffering irrespective of cause through the use of efficient and safe means of maximizing comfort (96,211,213,229). This philosophy of care must be in line with established standards of care for such conditions, which in turn would necessarily include consideration of PS such as those, set out by the EAPC (96). Wider questions that also need to be addressed are, whether attempts to treat existential distress lie within the remit of palliative care, and even if the answer is “yes”, given the limited treatment options available even within its multidisciplinary set up, is palliative care adequately equipped to meet the challenges of treating existential distress?

Further, suffering in some settings and cultures is considered to be acceptable (70,71). Thus, there is a need for balance in considering the various facets within
the goals of care and it is suggested that within the evolving context of the disease process, the MDT, replete with their multi-professional and multidimensional appraisals, are best placed to review and realign care stances on an individual basis.

The third justification is founded upon the uncoupling of palliative care goals from the traditional goals of medicine and seeing them on a wider plane of practice that is no longer shackled to a monocular view of care (204). Dame Cicely Saunders oversaw a conception of palliative care that moves beyond a blinkered medical perspective to adopt an inclusive multidisciplinary, multi-professional, multidimensional approach to care (136). This wider view has since become the central theme of palliative care (130). Within the larger medical sphere, too, wider stances appear to be adopted with Cassell stating that without such a transformation, medicine as a whole would be failing in its basic goals by not catering to the needs of patients with existential distress, particularly when one of the pivotal goals of medicine identified by the Hastings Center Report relate to the promotion and maintenance of health (230-232). Here “health” is defined by the WHO as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”, sharply focusing considerations upon the mental aspects of care (230).

However questions still remain unanswered. Does it follow that “relief of suffering” necessarily suggests the application of PS? Does it follow that PS is appropriate for the treatment of “total” or all forms of suffering? Does the treatment of all suffering actually lie within the remit of medicine?
1.6 STANDARDS OF CARE

As part of its proposed standards of care, the EAPC guidelines delineate four “problem practices”; these are abuse of PS, injudicious use of PS, injudicious withholding of PS and substandard clinical practice of PS (96).

Abuse is described as being the application of PS with the intention to hasten death (96). Injudicious use of PS occurs when there is no intent to hasten death but PS is applied without adequate assessment or input from specialists, when reversible cause of symptoms are not appropriately evaluated and reversed or when PS is demanded by the patient or the family or is applied without appropriate consideration (96). Injudicious use of PS is also envisaged in situations where HCP, exhausted and frustrated by the complexities of a situation, may resort to the application of PS as a means to circumvent the complications of the situation (96).

Injudicious withholding of this treatment option is exhibited when PS is clearly warranted but physicians hesitate to provide it due to “counter phobic decisions to treat” or the physician’s own anxieties or self-serving interest (96). Inadequate consultations, monitoring, assessments, responses of the patient or indeed inadequate care and concern for the family would be deemed to be provisions of substandard care (139). These issues are taken up in Chapter 2.

1.7 TREATMENT DECISIONS

Despite the presence of treatment protocols for PS and TS, individual subjectivity still affects the deliberative process. One such example pertains to treatment
decisions regarding existential suffering. The AMA and the VHA in stating that existential and/or psychological symptoms ought not be treated by PS despite determinations of intractability and ought to be addressed by means other than PS simply to negate inter-HCP variability in application is but one of the responses to this concern (100,210,233).

However the “wisdom of taking a conservative stance with respect to palliative sedation for existential suffering” proposed by the VHA and the posit that existential suffering “is not an appropriate indication for treatment with palliative sedation” because “the causes of this type of suffering are better addressed by other interventions” set out by the AMA-CEJA report on PS, appear to be discordant with the statement that the duty of a physician is “to relieve pain and suffering” and the understanding that no viable alternative exists other than PS to ameliorate this suffering (9,101,210). Aside from contradicting statements, it fails to take into account a number of issues. The first is that it provides no means of discerning between psychiatric symptoms and those it would consider to be of existential origin; neither does it lay down any clear approach for determining the applicability of PS if there is in fact a mixture of psychological, physical and existential suffering present (9).

Secondly, as Rich argues, there is no justification for such categorization of suffering as the American College of Physicians-American Society of Internal Medicine’s (ACP-ASIM) position takes (9,150). Banja suggests that in the face of physicians’ fears of having their integrity and intentions questioned, categorizing those elements that a physician may find difficult to justify allows physicians to circumnavigate their conscience (234). Aside from these self-serving concerns,
categorization of suffering along lines of etiology make no recognition of the fact that treatments such as conventional antidepressants are liable to be ineffective and treatments such as methylphenidate, and semi-psychotherapeutic techniques remain relatively unproven in this phase of life, raising questions over the care of the patients (6,27,28,235). It is thus no surprise that such categorization also falls foul of the EAPC and the KNMG’s standards of care (96,121).

A further matter to consider is the manner in which a diagnosis of intractability or refractoriness is arrived at. Variances of access to specialist care and treatment may make for variable determinations of intractability and refractoriness of a symptom. This is particularly important within nations in South East Asia where there is a limitation to access to palliative care specialist centres and interventions. It is largely for this lack of expertise and depth of experience in such care that local practitioners for instance refrain from effecting PS for existential distress. This also highlights the need for contextual and practical considerations within any determination of this diagnosis.

Such variances call for flexibility of practice; however, such pliancy and individualistic approaches also open themselves for concerns regarding a potential slippery-slope situation where creeping “advancements” in practice take operational platforms beyond acceptable parameters and standards of care and inch closer to unacceptable interventions such as euthanasia.
1.8 CONCLUSION

Sedation at the end of life must evolve in order to meet the specific demands of the determinative social, cultural, legal and practice considerations. The dissonance in the goals of the treatments, the consent process when consent itself is suspect, the decision-making process particularly in the utilization of an inclusive MDT in the deliberative process, the consideration of the impact of the treatments upon personhood and in appreciating proportionality of their application are prime considerations as to the acceptability of such intervention.

Given these issues, this thesis will approach the five areas of interest beginning with the study of the goals of palliative care and the place of the treatment of suffering within them.
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Chapter 2

GOALS OF CARE

2.1 INTRODUCTION

The goals of care determine the manner and the extent of care that is provided by a treatment approach. This chapter considers the practice of continuous deep palliative sedation (CDPS) from the perspective of its goals and the extent that these are identified with the broader goals of the practice of medicine. CDPS is defined as the proportional and monitored induction of deep continuous sedation for the amelioration of all forms of intractable physical, psychological and existential suffering following holistic multiprofessional assessment of the patient’s condition. 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 regnant guidelines and clinical standards. This procedure is monitored and overseen by a MDT to ensure accountability, transparency and justifiability of actions and that life is not intentionally abbreviated. Clinically assisted artificial nutrition and hydration (CANH) is provided as a matter of routine in the application of CDPS unless clinically contraindicated. As already stated earlier, the prerequisites for implementing CDPS in cancer patients 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. “terminality” of the illness where a prognosis of less than two weeks is anticipated;
(3) a diagnosis of “futility” when it is determined that the cancer progression is no longer responsive to disease altering treatments; and
(4) a determination that application of this procedure is in keeping with the holistically determined best interests of the patient.

The discussion of this thesis and chapter centres on the application of forms of sedation at the end of life that involve the application of deep and continuous sedation for the treatment of intractable symptoms for patients with a prognosis of less than two weeks. Reference to palliative sedation (PS) will be included under this specific subtype of sedation.

Debates on the goals of CDPS are animated by disagreements over the care of patients with existential suffering, and whether CDPS should be offered as a treatment option should this condition become intractable at the end of life. There are two main groups of arguments shaping this debate. On one side are the positions adopted by the American Medical Association’s Council on Ethical and Judicial Affairs (AMA-CEJA) and the National Ethics Committee of the Veterans Health Administration (VHA), which oppose the application of PS for existential suffering (1, 2). The VHA and the AMA-CEJA positions, which were produced in 2007 and 2008 respectively, draw from arguments by Jansen and Sulmasy (1-7). On the other side sits the position taken by Cassell and Rich, which holds that as a result of the entwined nature of different aspects of suffering, discriminating between the various etiologies of suffering is untenable (8-20). This position is echoed by the European Association for Palliative Care (EAPC) and the Royal Dutch Medical Association (KNMG) in their guidelines on PS (21, 22). Both these guidelines were produced in 2009 (21, 22).
The disagreements in question reach into debates on the goals of medicine, medical and philosophical accounts of suffering, and proportionality and appropriateness in the treatment of suffering, including existential suffering (5,8). Jansen and Sulmasy see medicine focused upon a restorative function, which the authors maintain “persist until death, for even very sick terminally ill patients” (5). Jansen and Sulmasy believe that the role of the physician is

“not just to treat symptoms, but to care for their patients. A primary goal of medicine is not simply to relieve suffering, but also to restore the patient to a state of health. Serving this restorative goal requires physicians to attend to the psychosocial well-being as well as the physical well-being of their patients” (5).

Jansen and Sulmasy reiterate the need to consider treatment of psychosocial and physical suffering separately and with equal importance:

“Like other patients, terminally ill patients’ well-being consists of both physical and psychosocial aspects. If they are experiencing agent-narrative suffering, it may be possible to treat them in a manner that restores them to a state of psychosocial well-being.” (5).

Jansen and Sulmasy state that the extent of this restorative interest is “as much as their condition permits” (5).

The VHA and the AMA-CEJA guidelines, drawing from Jansen and Sulmasy’s position set out in 2002, maintain that there are two categories of suffering: neurocognitive suffering and agent narrative suffering (1-5). Jansen and Sulmasy maintain that there is a
“clinically and ethically significant difference between suffering that has a direct causal relationship to the patient’s underlying disturbance in physiological, neurochemical, or mechanical function or integrity (what we call neurocognitive suffering) and suffering that is belief-dependent, bearing, at most, an indirect relationship to the patient’s underlying medical condition (what we call agent narrative suffering)” (5).

The VHA and the AMA-CEJA guidelines maintain that agent narrative suffering or existential suffering lies outside the remit of medicine and ought not to be addressed by medical interventions (1-4). The VHA and the AMA-CEJA guidelines represent a general medical view, whilst Dame Cicely Saunders and the palliative medicine movement view this issue rather differently (1,2,23-32). Saunders, much like Cassell and Rich, holds that care should “remain the centre of a team who work together to relieve where they cannot heal, to keep the patient's own struggle within his compass and to bring hope and consolation to the end” (31).

Cassell and Rich maintain that the goals of care should be focused upon the relief of suffering rather than a continued focus upon a restorative goal (8). Cassell and Rich’s position is inspired by improvements in clinical capabilities and changes in the manner that suffering is viewed by society (8). They state that

“the relief of suffering has recently become a more pressing imperative because of the increasing dominance of chronic diseases resulting both from medicine's successes and demographic shifts; in addition, social changes in the last generation have removed suffering from the almost
exclusively private domain it occupied in the past to a more public view, where demands for its recognition and relief have become acceptable” (8).

On the issue of suffering, Cassell and Rich maintain that suffering is always of the whole person rather than of the mind, or the body in isolation (8). Nor is it meaningful to think about suffering in terms of causal relationships as Jansen and Sulmasy advocate (5-9). Cassell points out that suffering “cannot be whole in body alone. Nor should the threat to the whole person be understood as solely a quantitative matter – that persons subjected to more than x amount of pain or y amount of tissue destruction suffer (even if this amount of pain or tissue destruction may virtually always cause suffering) – since one individual may suffer from pain considered unimportant by another. They see suffering as a homogenous entity that is indivisible into discrete kinds” (11).

Important to this present discussion, given that CDPS is being employed under the aegis of a palliative care approach to end-of-life care, this perspective resonates with the views of Dame Cicely Saunders who maintains that “physical and mental suffering are seen almost dialectically: each capable of influencing and shaping the other” (31,25,32). It is therefore unsurprising that this multidimensional view of suffering that Saunders espoused when confronting “total pain” has in turn become one of the central tenets of the palliative care philosophy of holistic care (31,25,32). Clark, Dame Cicely Saunders’ biographer, adds that Saunders had maintained that “[s]uch an approach required attention to the meaning of pain, leading to a medicine capable of an orientation to suffering which allows the finest
human sentiments to shine through. In this way pain is seen as something indivisible from the body and the personality, but also as something caught up in wider social circumstances” (31).

Saunders accepts that as a result “a profound challenge had been issued to the Cartesian body-mind dualism of modern medical practice”(31).

Underpinning this departure from a wholly Cartesian approach is the advent of a more patient-centred care approach where the patient’s own goals become the “compass” for care provision (31). Here there is acknowledgement of the subjective nature of suffering with the views, wishes and beliefs of the patient influencing the manner that suffering is seen and addressed within each specific context.

<table>
<thead>
<tr>
<th>Goals of medicine</th>
<th>VHA and AMA-CEJA</th>
<th>Jansen and Sulmasy</th>
<th>Cicely Saunders</th>
<th>Cassell and Rich</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appearance to be consistent with the goals of medicine set out by the Hastings Center Report on the Goals of Medicine</td>
<td>Restorative duty</td>
<td>Amelioration of suffering guided by patient-determined goals of care</td>
<td>Amelioration of suffering</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Approach to suffering</th>
<th>VHA and AMA-CEJA</th>
<th>Jansen and Sulmasy</th>
<th>Cicely Saunders</th>
<th>Cassell and Rich</th>
</tr>
</thead>
<tbody>
<tr>
<td>Categorical – suffering viewed as physical and nonphysical</td>
<td>Categorical – causal relationship</td>
<td>Holistic but within a pragmatic categorical approach</td>
<td>Holistic</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Application of PS for existential suffering</th>
<th>VHA and AMA-CEJA</th>
<th>Jansen and Sulmasy</th>
<th>Cicely Saunders</th>
<th>Cassell and Rich</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No – for conditions that are not borne directly from the underlying disease</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
</tbody>
</table>

**Table 2.1 Analysis of positions held by various parties**

Table 2.1 represents a summary of the positions taken by the various parties featured in this chapter. In what follows,
I will consider these competing positions in critical perspective, beginning with Jansen and Sulmasy’s views.

2.2 THE JANSEN AND SULMASY POSITION

2.2.1 The physical-existential approach to the treatment of suffering

In their article entitled “Proportionality, terminal suffering and the restorative goals of medicine” published in 2002 in the Journal of Theoretical Medicine and Bioethics, Jansen and Sulmasy posited that there are two discrete types of suffering (5). They state that

“there is a clinically and ethically significant difference between suffering that has a direct causal relationship to the patient’s underlying disturbance in physiological, neurochemical, or mechanical function or integrity (what we call neurocognitive suffering) and suffering that is belief-dependent, bearing, at most, an indirect relationship to the patient’s underlying medical condition (what we call agent narrative suffering)” (5).

Jansen and Sulmasy maintain that this discriminative account of suffering enables appropriate clinical response based on causal relationships (5,33).

Agent narrative suffering is held not to have immediate associations with suffering (5,33). Jansen and Sulmasy describe this to mean

“it is not the medical condition as such that causes the patient to suffer. Nonetheless, it may arise from the patient’s beliefs about what the condition means or will mean to his or her life. So characterized, agent
narrative suffering depends on factors that are (largely) particular to the person experiencing the suffering” (5).

The authors add that when the roles and relationships of a suffering patient “are threatened or undermined, the narrative interests of the patient are adversely affected. Quite understandably, terminally ill patients often experience suffering as a result of reflection on the significance that their medical condition has or will have on their ability to be an agent in the world or to sustain valuable social relationships. Moreover, they often experience suffering as a result of reflecting on the fact that their condition causes suffering to family members or other loved ones. Suffering that results from this kind of belief-based reflection is agent narrative. Examples include, but are not limited to, various forms of psychosocial suffering that are not correlated with underlying pathologies of the brain such as despair, loneliness, perplexity and alienation” (5).

Jansen and Sulmasy adopt this interpretation of suffering in response to what they feel is an overcompensation of the medical fraternity for their previous neglect of the psychological aspects of care (5). For instance, they note that there was a tendency of clinicians to respond to suffering at the end of life with “aggressive pharmacological interventions” that they feel is harmful to the patient (5). Their discrimination of the two forms of suffering also serves a further purpose. The authors believe that each form of suffering can be treated independently of the other (5).

To highlight the importance of responding appropriately to the two forms of suffering, Jansen and Sulmasy discuss the cases of Patient A, who suffers from
severe phantom limb pain and agent narrative suffering, and Patient B, who
suffers solely from agent narrative or existential suffering (5). In the case of
Patient A, the authors assert the appropriate clinical response lies in “recognizing
the differences between the types of suffering” in order to treat them
proportionally (5). As a result medications are used to treat the neurocognitive
suffering whilst psychosocial and/or spiritual counselling are used to restore the
patient’s psychosocial well-being (5). Whilst on the surface application of opioids
and anticonvulsants may have treated both sets of symptoms, Jansen and Sulmasy
insist that such application of pharmacological interventions would not be in
keeping with the physician’s overarching restorative duties (5). Furthermore
pharmacological intervention would inhibit thorough assessment of the patient,
prevent direct patient involvement in care decisions, negate the potential to
strengthen the relationship between patient and physician and thus improve the
physician’s insight of the situation (5). A multidimensional and thorough review
of the patient’s overall situation will ensure that careful considerations have been
made before actions are taken (5).

Medical treatment for symptoms ostensibly resistant to conventional measures
would also run against the authors’ conception of proportionality (5). The
Principle of Therapeutic Responsiveness, which Jansen and Sulmasy propose,
emphasizes the concepts of (a) appropriateness of a response with respect to the
etiology of the patient’s suffering, and (b) proportionality of treatment in keeping
with the goals of care (5). The authors state “the measures implemented are
appropriate for the type of suffering the patient is experiencing and, therefore, are
properly responsive to the patient’s restorative interests” (5).
Accordingly, the application of alternative treatment options such as pastoral care, meditation, relaxation, imagery and/or psychotherapy would represent the best means of realizing the patient’s overriding interests to be restored to a state of psychosocial well-being despite being in a state of “irreversible physical deterioration” (5). The authors stress that the two states of well-being may exist independently, necessitating that physicians respond to the demands of these symptoms in a manner that best “fits the nature of their suffering” (5). When delineation between the two forms is not “clear cut or straightforward”, the authors maintain that efforts ought to be redoubled and more patient-centred (5).

Appropriateness of treatment is crucial both in ensuring that overall goals of care are preserved and also in treating suffering in a discriminative manner (5). It also requires that physicians recognize the limits of medicine and their own medical authority (5). In situations where medical interventions have reached the limit of their efficacy, physicians must be prepared to defer to the expertise of non-physicians (5).

At the limit of their capabilities, physicians must also resist attempting to treat suffering despite requests by patients or families to provide PS (5). Jansen and Sulmasy offer a further example to reinforce their opposition to the use of PS (5).

Patient B, a man with end stage amyotrophic lateral sclerosis (ALS) “suffers intensely from his profound dependence upon others” despite intensive efforts to restore his psychosocial well-being (5). Jansen and Sulmasy argue that sedation would not be appropriate for the amelioration of his existential suffering for a number of reasons (5). The first is that despite maintaining consistently that he has no interest in remaining conscious, Jansen and Sulmasy maintain that he does
in fact have an overriding interest in being restored (5). Jansen and Sulmasy stress that in the presence of a high degree of psychological and psychiatric complications, the ability of patients to act rationally is suspect (5). An appropriate response to these issues will reverse the patient’s wishes for disproportionate measures and reaffirm their need to realize their fundamental interests (5). Jansen and Sulmasy maintain that patients have “an important interest” in responding to psychosocial, spiritual and familial concerns and interests “in a manner that is consistent with their character and considered values” (5). These considerations engender an abiding interest in restoration “as much as their condition permits”, and underscores the importance of helping patients “find the appropriate means to satisfy this interest” (5). This is in keeping with their conception of proportionality and “even if past efforts to restore a patient have failed, it does not follow that the patient has no interest in restoration” (5). Jansen and Sulmasy’s Principle of Therapeutic Responsiveness holds that

“[a] physician’s therapeutic response to terminal suffering is justified, even if it imposes a high risk of hastening the patient’s death, if and only if (i) the measures implemented are directly proportionate to the intensity of the patient’s suffering; (ii) the measures implemented are appropriate for the type of suffering the patient is experiencing and, therefore, are properly responsive to the patient’s restorative interests; and (iii) the patient or the patient’s legal surrogate understands and accepts the risks associated with the measures” (5).
In a situation where a patient in similar circumstances to Patient B asks for PS, employing this intervention would be “inappropriate insofar as the restorative interests of patients are ignored or set back” (5). Furthermore, any such intervention would “violate a fundamental norm of medicine” in overstepping the boundaries of acceptable and proportional care (5). Furthermore, as agent narrative suffering may be tied with “psychological and psychiatric complications during the terminal stage of illness”, it is common and pervasive and open to treatment options that might still be able to restore a patient to a “condition of psychosocial well-being” (5). There is a need for physicians to evaluate conditions closely and discriminate between agent narrative suffering and neurocognitive suffering whilst being cognizant of the limits of pharmacological interventions for the treatment of agent narrative suffering (5). Physicians should also be aware of the limits of medical treatment and intervene appropriately and in keeping with the duty to “care for patients” (5). Importantly physician has to be aware that these interests do not “vanish simply because the medical team has been unsuccessful in advancing them” (5). To ignore this fact with the application of sedation in these circumstances would be incongruent with the patient’s “character and considered values” (5). In the case of Patient B, for example, this action would leave this fiercely independent and private professor of sociology in a position where he would be even more dependent upon “hired strangers” and merely compound his increasingly “unbearable” state of lost independence and “pride” (5).

Jansen and Sulmasy do accept that a patient may refuse all appraisals and interventions, as Patient B does, which would precipitate the need to consider PS as a last resort; however they maintain that such an intervention would still be ill
advised (5). This is because Jansen and Sulmasy hold that this treatment would not be medically appropriate as it does not attend to the problems at hand but merely circumnavigates them (5). Likewise sedating the patient would mean a failing on the part of the physician in developing the “skills that make it possible to diagnose, and appropriately attend to, the different types of suffering present at the end of life” (5). Therefore applying PS would appear to always be wrong since it renders impossible any attempt to meet the patient’s important interest in responding to their social, cultural, familial and spiritual needs, especially on the basis of an uncertain diagnosis of intractability (5).

Jansen states that dependence upon a diagnosis of intractability can be complex and leaves a potential for abuse of this treatment (33). Jansen states in her response to Cassell and Rich in 2010 that

“[c]ompared with neurocognitive suffering, it is exceedingly more difficult to establish that agent narrative suffering is truly refractory. It is all too easy to mischaracterize as refractory agent narrative suffering that is merely difficult to treat” (33).

However, in this same response, Jansen does appear to accept that under very specific conditions where intractability is established, PS may be considered (33):

“[S]uppose that in a given case it could be ‘proven’ that agent narrative suffering was indeed refractory. Does this possibility justify adopting guidelines that counsel physicians to treat end-of-life suffering with palliative sedation, irrespective of its nature and its origin? No. Guidelines speak to the general case” (33).
According to her modified position, patients must be diagnosed with intractability before attempts at PS are considered, and this would signal a clear failure of alternative options for the treatment of existential (i.e. agent narrative) suffering (33). Thus, Jansen has distanced herself from the stance of the AMA-CEJA framework, which consistently maintains that the application of sedation at the end of life for agent narrative suffering is never indicated (see Table 2.1), and now adopts a position that is more consistent with the position of Cassell and Rich (8,33).

Underpinning this shift in Jansen’s position is a development in her conceptions of proportionality and appropriateness of treatment and an evolution in the manner that she views suffering within her understanding of medicine as a restorative enterprise (33). In her later view, Jansen argues that the goals of medicine are not immutable (33). Neither the goal of “restoring the patient to a state of health” nor the premise that “even very sick terminally ill patients have an interest in confronting their death in a manner that is consistent with their character and considered values” are unchanging over time (5,6,33). A “proven” diagnosis of intractability of suffering and a limited prognosis should indicate a shift in the goals of care from attempting to restore physical and psychosocial function and addressing suffering in a manner that “fit[s] with the nature of terminal suffering” to one that is focused on relieving suffering (33). Emphasis here is on the term “proven” and the difficulty in precisely discriminating “causal relationships” (33).

Acceptance of the potential obstacles to correctly delineating the nature of suffering may potentially highlight the rationale for Jansen and Sulmasy’s
resistance in accepting a determination of intractability, particularly given the
great variability in access to specialist care (5). This situation is compounded
further by Jansen and Sulmasy’s insistence on maintaining mutual exclusivity
between physical suffering and existential suffering (5).

However, this uncompromising view highlights a number of inconsistencies with
Jansen and Sulmasy’s position on existential suffering (5). Jansen and Sulmasy
associate existential suffering with psychiatric and psychology presentations,
which show either an acceptance in the overlap in the presentations of these
elements of suffering, or a view that the presence of these elements compounds
the manifestations of existential suffering. Both these positions may make
discriminations between various presentations difficult particularly as
etiologically based treatments that do not consider wider repercussions of
suffering are likely to fail. Rich sees these difficulties in determination as merely
a symptom of a categorically inconsistent approach underpinned by an equally
flawed understanding of suffering and a misplaced reliance upon an inflexible
and ultimately untenable comprehension of the goals of care (5,6,19,33).

So what underpins this unwavering focus upon a restorative goal even in the
terminally ill? Evidence for the existence of such an overall duty for restorative
care may lie with a study that Sulmasy was involved in, on the preferences of
cancer patients for quality of life and length of life (34). This study validates
Jansen and Sulmasy’s position as cancer patients within this study reported a key
interest in the maintenance of their abilities, roles and lifestyle, suggesting that
restorative goals were a prime consideration (34). Validation for this position may
come from the findings of the 1996 Hastings Center report entitled “Specifying
the Goals of Medicine”, where the first of the four goals of medicine identified was the promotion and maintenance of health (35). Jansen and Sulmasy’s restorative duties supports this goal, though it does appear to be a rather focused view of this duty underpinned by the statement, “Healing is a very real possibility even when the body cannot be restored to a well-functioning state” (35).

However, whilst Jansen and Sulmasy’s position is validated by the Hastings report on Aging and the Goals of Medicine, Daniel Callahan the main author of this report, does not support the unwavering persistence in restoration that Jansen and Sulmasy maintain (36). Callahan stresses upon a more realistic view that

“[the] goals of medicine that lie behind life cycle traditionalism are those of helping people to remain in good health within the boundaries of a finite life span, and helping them to cope well with the poor health they may have. It is thus a more modest view of medicine's appropriate goals, aiming to restore and maintain health within a limited time frame rather than substantially improve the human condition” (36).

There is also little substantiation within present data to suggest that an uncompromising view of this restorative goal is held in such a manner by either patients or physicians (37). Jansen and Sulmasy’s position on this matter does open itself to temperance, given that they do state that the extent of this restorative interest is to be “as much as their condition permits” (5). However such concessions do not appear to extend to acknowledgement of the intractable nature of the patient’s suffering, their abbreviated life expectancy, nor what can realistically be carried out to restore function (5).
Jansen and Sulmasy’s reliance upon their concept of the Principle of Therapeutic Responsiveness to validate their rigid position on the application of PS, too, comes under increasing threat with the dispelling of two central parameters upon which it is constructed (5). The first is that the application of PS would abbreviate life (5). This point has since been disproved by prevailing clinical evidence which shows that in most cases the application of sedatives and opioids either on their own or in combination with one another does not abbreviate life when applied in a manner that is in keeping with clinical guidelines (38,39). Sykes suggests that survival may be improved for patients who are administered PS as compared to patients who are not provided this treatment (40).

The second disproved tenet underpinning the Principle of Therapeutic Responsiveness is the belief that care determinations still depend upon the determinations of a single healthcare professional (HCP) (5). The AMA-CEJA guidelines, for example adopts a multidisciplinary team (MDT) approach to care determinations since Jansen and Sulmasy first proposed this framework in 2002 (1). As a result Jansen and Sulmasy’s insistence on discovering alternative treatment options beyond medicine – when a MDT similar to what I have described in Chapter 1 ought to have considered all reasonably available alternative avenues of treatment – is no longer warranted.

Persisting with treatments that are medically futile and inflexibly adhering to a restorative duty over all other considerations, including intractable suffering and patient preferences that are legally allowed, also suggest a dogged paternalistic approach that defies both clinical evidence and an appropriate standard of medical practice under the law. Jansen and Sulmasy also use this position based on the
“working assumption … that all can be restored in some way and some degree” to insist that it will prevent “simply summing up all kinds of suffering” and as a result prevent the advent of a slippery slope down the path where symptoms are mischaracterized as intractable and treated as such (5). This position raises a number of substantial objections.

In considering both the clinical context of Patient A with his phantom limb pain and agent narrative suffering and Patient B with a diagnosis of ALS and agent narrative suffering, Jansen and Sulmasy fail to site their arguments within the true dimensions of where treatments such as PS would be applied (5). They do not consider the situation where in fact the prognosis of the patient is actually less than two weeks and where up to 86% of patients are not capable of participating in the “alternative treatment options” being advocated as treatment for their “agent narrative” suffering (5,41-45).

This rigid approach to determining if treatment is appropriate based upon whether or not it “fits with the nature of the terminal suffering experienced by the patient” is equally problematic particularly when the patient is diagnosed with “proven” intractable physical and existential suffering. Suggestions that efforts ought to be redoubled in delineating the root cause of the suffering ignores Jansen and Sulmasy’s own overarching goals of providing “care for patients” in keeping with the patient’s prognostic status and clinical needs (5).

These inconsistencies remain unaddressed by the Jansen and Sulmasy position and serve to highlight the true intentions and primary goal for Jansen and Sulmasy’s undertaking – the prevention of a slide towards the practice of euthanasia – which whilst laudable, do not translate well in clinical practice. As a
result there is a need to consider alternative approaches to this clinically troubling predicament of some patients who are very near the end of their lives (5,6).

Table 2.2 represents a summary of the evolving views on the goals of care and views on existential suffering taken by the various parties.

<table>
<thead>
<tr>
<th></th>
<th>Jansen and Sulmasy</th>
<th>AMA-CEJA</th>
<th>VHA</th>
<th>Jansen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year</td>
<td>2002</td>
<td>2006</td>
<td>2008</td>
<td>2010</td>
</tr>
<tr>
<td>Goals of care</td>
<td>Restorative</td>
<td>Relief of suffering</td>
<td>Maximizing quality of life</td>
<td>Restorative unless symptoms are &quot;proven&quot; to be refractory</td>
</tr>
<tr>
<td>View on existential suffering (ES)</td>
<td>No direct causal relationship</td>
<td>Response to conventional medical treatment requires the utilization of alternative treatment modalities</td>
<td>Accountability of process is suspect when symptoms cannot be defined by clinical criteria</td>
<td>There is interaction between the two types of suffering</td>
</tr>
<tr>
<td>Applying PS for treatment of ES</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes – if intractability in terminally ill patients is &quot;proven&quot;</td>
</tr>
<tr>
<td>Rationale</td>
<td>Does not meet the restorative interests of patients</td>
<td>ES does not fall within the clinical symptoms listed for PS and because ES symptoms are best treated with other means of treatment</td>
<td>ES cannot be defined with reference to clinical criteria and will erode public trust in the agency</td>
<td>Acceptance in a &quot;proven&quot; case of agent narrative suffering, PS/CDPS may be warranted</td>
</tr>
</tbody>
</table>

Table 2.2 Analysis of views held by various parties on goals of care and existential suffering
2.3 THE CASSELL AND RICH POSITION

Consider Patient C who shares an identical background, personality and set of circumstances to Jansen and Sulmasy’s Patient B, with one exception. Patient C is a Hindu, who in the face of a diagnosis of intractable existential suffering, does wish to have PS as he believes that it will help clear his mind of thoughts and “free” his soul from the chains of his present circumstances. Patient C subscribes to the belief that meditation has healing properties and also allows him to “concentrate on God and discover [his] inner self” (46-48). For Patient C, PS is “beneficial” if only as a means of moving to another plane of existence by silencing his tumultuous inner voices and removing all sensory distractions so as to enable him even in his weakened state to focus upon his meditative goals. Patient C has complied with and exhausted all treatment options, both physical and psycho-existential, and still continues to report persistent suffering. He does not demand for sedation but voices his wish to pursue this option as a result of the MDT’s confirmation that with a prognosis of less than two weeks of life and proven intractability of symptoms, there are no more viable treatment options available to ameliorate his symptoms.

Under both the AMA-CEJA and VHA guidelines, the intractability of Patient C’s existential suffering will be overlooked in favour of yet more attempts at “alternative” treatment options (1,2). PS would not be available to Patient C even though he chooses to have it after complying with and failing all other treatment options employed thus far (1,2). Patient C’s goals and wishes, short prognosis and failure thus far to respond to both conventional and alternative measures would be set aside in favour of the paternalistic leanings of a restorative goal of care (1,2).
Part of the reason underpinning this stipulation is the acknowledgement that the VHA guidelines still operate under the premise that evaluations and treatments are being carried out by a single physician or a small team of HCPs rather than a MDT (1,2). This inevitable lack of a holistic assessment and multidimensional expertise necessitates that these guidelines require second opinions be sought and “alternative” interventions be attempted to meet the requirements of a diagnosis of intractability. The situation within these guidelines is further complicated due to their requirement of careful elucidation of the etiology of the suffering and the limitations placed upon the treatment of existential suffering (1,2). In such circumstances Cassell and Rich offer an alternative means to addressing the goals of care based upon an alternate view of suffering (8).

Based on his article “Diagnosing Suffering: A Perspective”, Cassell explains that suffering is a multidimensional experience that affects every element of the person (10). Cassell believes that

“[s]uffering involves some symptom or process that threatens the patient because of fear, the meaning of the symptom, and concerns about the future. The meanings and the fear are personal and individual, so that even if two patients have the same symptoms, their suffering would be different” (10).

This position is not dissimilar to the position that Jansen and Sulmasy adopt that extend the implication of this subjective experience beyond the corporeal plane to involve temporal and wider psychosocial considerations such as cultural, social and personal beliefs (5,10). The two positions appear to diverge in the manner that they view treatment of this suffering (6,10). Jansen and Sulmasy hold that
suffering that does not have a direct relationship with the cause of the suffering is not best treated pharmacologically, Cassell holds that the patient’s suffering poses a threat to the integrity of the person which should be addressed by the physician through any means available so long as they are proportional to the demands of the situation and the patient’s particular contextual considerations (5,10). Cassell argues that suffering

“is a specific distress that occurs when an impending destruction of the person is perceived and continues until the threat is gone or the integrity of the person can be restored. A person is an embodied, purposeful, thinking, feeling, emotional, reflective, relational human individual existing through time in a narrative sense. Generally, all of these parts are consistent and are harmoniously accordant. Suffering, in which all of these parts are affected, variously destroys the coherence, cohesiveness, and consistency of the whole. It is in this sense that the integrity of the person is threatened or destroyed” (8).

Offering a biological basis for this claim, Cassell observes, firstly, that whilst pain and suffering are two different and distinct forms of distress, they are closely related (16). The human nociceptive apparatus or nervous system pathways involved in the transmission of noxious stimuli routinely enhances, diminishes or inhibits the messages or information transmitted to the central nervous system from the location of injury (16). Thus, the nociceptive apparatus modulates the perception and therefore the meaning of these pain messages. Chemical messengers and their receptors within the nervous system also influence the original message, for instance endorphins or drugs exert analgesic effects by
binding to specialized receptors, and neurotransmitters like serotonin and dopamine temper the transmission of the nociceptive message. Cassell argues that pain is a perception, and qua perception, it is a cognitive state involving judgment (16). The actions human beings take in response to pain, which “generally take account of location, severity, cause and anticipated course of the pain”, are indicative of the operations of cognitive knowledge and judgment (16).

Secondly, the concept of suffering that Cassell adheres to involves an inextricable link between the physical, existential, psychological and psychiatric planes making the “arbitrary discrimination of suffering” inherently misguided (8,12). Cassell maintains that “[w]hat is called existential distress arises from the impact of their sickness on their existence; helplessness, isolation, and loss of control that characterize severe illness, and which is brought on by symptoms as varied as pain or profound weakness. When these things are seen by the person as threatening their destruction as the persons they have known themselves to be, they start to suffer. Their suffering then becomes the problem. Their suffering, as suffering, is no different than the suffering that comes about because of pain” (8).

Cassell argues that the goal of care is “to maintain the intactness and integrity of the person in the face of severe or increasing sickness and a deteriorating body” (12). This goal of care cannot be limited by concern for only physical suffering (12). Cassell explains that at the centre of this endeavour is a goal of care, which is focused on the relief of suffering and that
“[w]hen a source of distress, like pain, produces suffering, it is the suffering that becomes the central distress not the pain. It is not valid to make a distinction between suffering whose source may be physical, such as pain, and suffering coming from the threat to the integrity of the person from the very nature of the person’s existence” (8).

Whilst Jansen and Sulmasy hold that suffering can be treated according to the “causal relationship to the patient’s underlying condition”, Cassell and Rich maintain that even if causal relationships were possible, the overlap between the various elements of the patient’s psychological, physical, existential and psychiatric dimensions would see such etiologically-focused treatments unlikely to be effective without an equally holistic response to the suffering (5,8).

Jansen in her article “Hastening Death and the Boundaries of Self” in 2006, accepts this more inclusive view (14). Jansen acknowledges in this article on the boundaries of personhood that

“the composition of the self cannot be determined simply by appealing to biological or genetic considerations. These considerations are relevant to fixing the boundaries of the self, but they do not settle the matter. We have also seen that the self cannot be defined by spatial boundaries” (14).

Cultural and temporal factors play their part in Jansen’s view that shares some similarities with Cassell’s idea of “topology of a person” (14). Rich explicated that

“Cassell offers a ‘topology of a person.’ On this account, the unique and essential characteristics of person are a body; personality and character;
behavioral patterns; a sense of both a past and a future (as well as awareness of existence in the present moment); life experiences; a cultural (social) background and family ties, as well as roles associated with those relationships; a political status (rights and obligations); a private life; and finally, a transcendent dimension or life of the spirit (distinguishable from religiosity or adherence to theological dogma). In this article Cassell goes on to critique reductionism in the domain of persons as antithetical to a full understanding and appreciation of their essential nature, instead emphasizing by means of the topology how complex, highly nuanced, and interrelated are the dimensions of human persons. He asserts, categorically and unequivocally, contrary to the received view of medical science heretofore, that the body, qua body, does not suffer; persons suffer” (19).

Cassell and Rich’s view of the “self sustaining” nature of suffering is diametrically opposite to Jansen and Sulmasy’s perspective (5,8). Cassell and Rich see suffering persisting even if the precipitating symptoms are ameliorated, quite unlike Jansen and Sulmasy’s view of existential suffering, which recedes upon amelioration of its underlying cause (5,8). Jansen and Sulmasy pursue focused, etiological-based care options where “agent narrative suffering” is addressed by treatment focused at ameliorating its source of suffering (8). However, little is made of the possibility of there being more than one such cause that threatens the disintegration of the person and more than one element within the topology of the person affected by the threat (5,8). Similarly, Jansen and Sulmasy ignore the possibility that there may be more than one underlying illness involved, a commixing of comorbidities, or even an effect that may not be as a
result of the primary complaint but indirectly as a result of a coexisting pathology or illness, or even as a result of the patient’s particular experiences and/or beliefs. Such complexity, particularly within increasingly frail patients, makes discernment of causal relationships more difficult to discern than Jansen and Sulmasy claim (5).

These difficulties also serve to polarize opinion on the goals and extent of care provision and serve to highlight the extent of the variance between the position of Jansen and Sulmasy, and Cassell on the issue of the goals of medicine (14). In an article in 1977 for the Hastings Center Report entitled “The function of medicine: Restoring autonomy to the patient”, Cassell began to set out his view of the function of medicine that formed the basis of his critique of Jansen and Sulmasy later (8). In this article, he envisaged the goals of medicine to be firmly focused upon “do[ing] everything possible to maintain the integrity of the person in the face of death” (5,14). To Cassell, this must involve a multidimensional review of the patient’s situation since

“[i]t appears that to know the suffering of others demands an exhaustive understanding of what makes them the individuals they are – an awareness of when they feel themselves whole, threatened, or disintegrated. This necessitates knowledge of their ideas about their identities, their views of the past, present, and future, their relationships to others and their environment, their aims and anticipated actions” (11).

Therefore from the outset, Cassell dispels the belief that identifying the cause of suffering is always possible and maintains that
“[s]uffering may occur when one does not expect it or is ignorant of its source, or pain and other physical symptoms may be so intrusive that they push aside consideration of suffering. (In such circumstances the sufferer may wrongly believe that if the pain were gone everything would again be well when, in fact, the injury to the person's self-identity now transcends the pain.)” (11).

Pursuant to this holistic view of suffering, Cassell and Rich, who build upon Cassell’s original position, hold that suffering must be an entwined concept that cannot be discriminated upon on the basis of etiology or apparent causal relationships (8). This clarifies their position of a holistic approach to the treatment of suffering (8). This position runs parallel to the stance taken by Callahan et al for the Hastings Center report entitled “Specifying the Goals of Medicine” on the “causal relationship to the patient’s underlying condition” (49). Rich states further that the “phenomenon of suffering in the advanced stages of terminal illness cannot be sliced, diced, compartmentalized, or otherwise relegated to such watertight compartments” (19). Together these positions and a lack of substantive evidence casts doubt on the viability Jansen and Sulmasy’s maintenance of a “causal relationship to the patient’s underlying condition” (5,8,19).

Reverting to the case of Patient C, Rich and Cassell view the severity of Patient C’s existential suffering as being

“no different than the suffering that comes about because of pain. To see such suffering as somehow not as real as (say) vomiting or as ‘just emotional’ is not true of severe illness as any clinician knows it to be” (5).
As “all other options failed” and as Patient C is in “the final stages of terminal illness”, Cassell and Rich would treat Patient C’s suffering with PS (8,19). This action would be justifiable upon clinical standards and regnant views of suffering (8,19). Rich states that

“[i]f medicine and society are to deprive even a distinct and insular minority of dying patients of sedation that would relieve their otherwise intractable distress, and to claim an ethical justification for doing so, our common understanding of the nature of suffering must be shown to be demonstrably false and thereby inadequate to support the palliative care approaches that have been developed consistent with that understanding” (19).

Rich’s position moves beyond simple diagnoses of intractability and reaches to the established goals of palliative care and indeed to the general goals of medicine (19). If the goals of care are indeed to relieve suffering, Cassell maintains that in light of intractable suffering at the end of life, such suffering may in fact be alleviated via the application of sedation given that he argues that suffering does not exist without sentience or consciousness (16).

So here is a treatment that Cassell feels is valid and effective and one Rich would argue would be in keeping with the “rights” of the patient in keeping with the positions taken by the US courts (11,16,18). Based on a review of US court judgments on the cases of James v Hillhaven Corp and Bergman v Wing Chin, where the judges in the respective cases found in favour of the complaint that care did not appropriately address their suffering, Rich draws the conclusion that the continued application of a discriminative treatment approach to the relief of
suffering would be legally and ethically unacceptable (18). Rich states that this would also be incongruent with a physician’s duty to

“ensure that dying patients did not suffer, because when all other options failed, palliative sedation could be provided consistent with clinical, ethical, and legal standards of professional conduct” (18).

Despite their multidimensional, evidenced-based view of suffering, Cassell and Rich still leave a number of issues unattended to. There is no clear means of tailoring this focus upon the relief of suffering to the needs of specific patients particularly when some patients hold that some suffering is actually desirable or acceptable in order to realise other goals. Consider Patient D, who like Patient B and Patient C, is identical in character and condition save for one point. Patient D unlike Patient C is a Buddhist and, in keeping with his beliefs, despite his existential suffering does not wish complete relief of his suffering. For him his suffering is seen as a means of “atoning for his past indiscretions” (50). For Patient D, “repaying karma” is the overarching goal of care, not relief of suffering (50).

It is unclear in light of a failure to site determinations of the overarching goals of care on a case by case basis, how Cassell and Rich balance the wishes and views of Patient D under a rigid overarching goal of care that they espouse nor how the concepts of proportionality and appropriateness would be conceived in these circumstances.
2.4 THE POSITION OF CDPS

Patient D’s scenario is not altogether uncommon amongst the terminally ill. Many patients do have goals of care that may not be entirely centred upon the alleviation of suffering much less a restorative goal. The modern palliative care framework upon which CDPS responds to the needs of Patient D, adopts a framework to end-of-life care that is guided by patient-determined goals of care. It also approaches care from a holistic perspective and adopts a multidisciplinary team (MDT) approach in keeping with the central palliative care approach advocated by Dame Cicely Saunders (3). Various members of the MDT address elements of the patient’s appraisal and care according to their area of expertise. Saunders sees this approach as the best means of delivering the holistic review (31).

However, Saunders, like Cassell and Rich, is vague on the manner that the MDT’s response would balance and respond to Patient D’s stance on suffering and how it would determine the appropriateness and proportionality of its response.

2.4.1 View on suffering

The position of CDPS on the issue of suffering represents an evolution of Saunders’ views and one that is congruent with Cassell’s views of suffering (8-17,23-32). This view of suffering also incorporates social and practical considerations and evidence-based medical considerations into its framework (Fig 2.1).
The CDPS view of suffering does not attempt discrimination between the “types” of suffering and is inspired by Saunders’ concept of “total pain” where “terminal pain can fill the whole consciousness of a patient and be a most complex and interwoven problem” (28,32). Drawing from her own experiences caring for the dying, Saunders held that suffering is not solely manifested in physical signs and symptoms but it has impact upon the whole person, his family and their psychosocial-spiritual well-being (32). Subscribing to the multidimensionality of suffering, Saunders held that “mental distress” afflicts patients the hardest and is apparent in their psychosocial-spiritual suffering, leading her to conclude that this would inevitably be linked to the patient’s physical problems (27,28). The relief of psychosocial-spiritual suffering, therefore, sits at the centre of her vision for palliative care (32).

The goals of care that underpin CDPS encompasses seeing suffering as being multidimensional in nature and entwined with the various “elements” of suffering extending far beyond their etiological focus. Acceptance that there are many elements of suffering speaks of an acknowledgement that suffering must be addressed by more than simply one professional or one approach but many, each experts in their own fields. The inevitable differentiation of care provision along
established lines of clinical specialities is merely pragmatic and a reflection of the fact that care is provided by specialists with specific areas of interests whose views of the dominant area of suffering would see it classified by that domain or area of speciality. However, whilst such a multidimensional view of suffering and the requisite holistic, multidimensional, multiprofessional review by the MDT represent the principles behind the position of CDPS on suffering, questions as to how they are practiced become a concern, particularly given that they do not feature in any of the guidelines discussed thus far (1-4).

This omission is instructive in highlighting the lack of a widely accepted definition for existential suffering despite the presence of multiple definitions (41,51-55). This serves to underline the complexities of understanding the features of this form of suffering at the end of life. Screening, diagnosing and treatment of existential suffering then come under scrutiny and raise concerns about how it is determined to be intractable. These shortcomings reaffirm Jansen and Sulmasy’s fears that PS and CDPS could be used as a means to euthanasia (5).

These guiding principles particularly in the manner that they are applied to existential suffering come under sharp focus. This practical bedside care and evidenced-based review makes up the second element of the triumvirate of considerations that underpin the manner that suffering is conceived within the CDPS framework (Fig 2.1). Conceiving effective, efficient and consistent review and assessment methods are but two elements of a larger consideration for the extension of treatment of CDPS to include all forms of suffering (Fig 2.2). However, there is scant guidance on making a diagnosis of existential suffering
much less a universally accepted means of screening for this form of suffering (52). Furthermore, even when diagnosed, there is little in the way of determining its intractability.

The issue of determining intractability of existential suffering is not addressed in either the KNMG nor EAPC guidelines for PS even though they do make provisions for the treatment of intractable existential suffering (21,22). Whilst the KNMG guidelines do state that intractable existential suffering is the “feeling that one’s existence is empty or meaningless”, which cannot be relieved despite spiritual and psychosocial support amongst patients with a prognosis of a week or two, they do not state how this may be diagnosed nor treated prior to a determination of intractability (22). The KNMG guidelines do however aid identification by stating that

“[e]xistential suffering may be expressed as feelings of pointlessness, emptiness, existential distress, a desire not to experience death or the dying process consciously, psychosocial problems, spiritual problems, or for instance the desire to preserve one’s dignity” (22).

The EAPC guidelines do not provide any indication as to how existential suffering can be screened for or how it may be diagnosed (21).

From a practical clinical and evidenced-based perspective, there is much that is left undeclared about how existential suffering is conceived and this affects the viability of considering existential suffering as an indication for CDPS. Prime amongst these are the oft-neglected issues of how existential suffering is clinically assessed, diagnosed, treated and reviewed (Fig 2.2). I will consider each
of these elements in due course and defer discussions with regards to
determinations of intractability to Chapter 3.

![Diagram](image)

**Figure 2.2  General requirements for appraisal of symptoms for CDPS**

### 2.4.2 Assessment and diagnosis

There is much that has been said of existential suffering though there is little in
the way of clear indicators of the presence of this form of suffering beyond what
may be garnered from a complete and thorough palliative history. Yet despite
being alert to its possible presence, all too often existential suffering is a
diagnosis of exclusion, one made in light of continued suffering despite the
treatment of psychological and physical suffering. Part of this problem moves
beyond a clear understanding of the goals of care or the remit of appropriate end
of life care but as a result of a lack of validated assessment tool or effective
screening tools.

At present there are no validated tools for the identification of suffering.
However, Schuman-Olivier et al do propose a clinical classification system for
existential suffering (41,51). Difficulties with validating this system include
language, cultural and social beliefs, differing personal values and religious
convictions. Furthermore, the general poor physical and cognitive conditions of these patients make concrete screening tools unwieldy and not easily portable across various care settings.

An acute shortage of trained staff in palliative care makes adoption of this more inclusive view of suffering difficult. Whilst the EAPC guidelines suggest the need for “a multidisciplinary case conference, including representatives from psychiatry, chaplaincy and ethics, as well as those providing care at the bedside, because of the complexity and frequently multifactorial nature of this situation”, such oversight may not always be possible (21).

Similarly, the requirement for “repeated assessment by clinicians skilled in psychological care who have established a relationship with the patient and their family” may be hampered by the general poor physical and cognitive conditions of these patients, and emphasizes the need for competent and practiced hands in such appraisals (21). The issue of competence of the appraiser is also a concern, particularly when one considers the Brongersma case, where “act[ing] outside the scope of his professional competence” led to Dr Philip Sutorius’ conviction for the treatment of existential suffering with physician assisted suicide (PAS) (54). It is interesting that the judges in this Dutch case – heard some four years before the enactment of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 2002 that legalized euthanasia and PAS in the Netherlands – focused in their judgment on the competence of the physician rather than the illegality of the act itself (54).

Palliative care appraisals, however, have evolved much since that time, with the adoption of a holistic review process; even the employment of smaller palliative
care MDTs is not in itself a significant obstacle to good care appraisals nor a significant impediment to a wider role for CDPS (51,55). Tan et al in their recent article in the American Journal of Hospice and Palliative Care entitled “The experience of suffering of palliative care patients in Malaysia: A Thematic Analysis” show that even in a multi-faith, multicultural, multi-ethnic, multilingual country such as Malaysia where specialist palliative care services are still in their infancy, multidimensional reviews of suffering can still be carried out effectively (51).

In this study, diagnosis of ten forms of suffering was made through interviews and thorough reviews of the case, devised upon existing standard palliative care reviews (51). This study reveals that only slight adaptations to standard palliative care appraisal processes are required and the appraisal needs only a healthcare professional (HCP) well versed in palliative care practices to undertake it (51). Kissane in forwarding his concept of “typology” of existential suffering” in his article entitled “The Relief of Existential Suffering” in the Archives of Internal Medicine further improves prevailing holistic appraisals (55). It is clear that so long as holistic and regular reviews are carried out, existential suffering will be identified.

2.4.3 Treatment and reviews

Tan et al’s data shows that treatments and reviews of existential suffering can be carried out by social workers and psychologists without the need for palliative care specialists (40). Many of the treatments suggested by Schuman-Olivier et al
are available in most psychology services (40). However, as an added precaution within the CDPS framework, a specialist palliative care physician is required to review the patient both to ascertain intractability and to act as an independent reviewer before CDPS can be applied. The study also reveals the requirement that suffering must be addressed by more than one professional or one approach, and by many MDT members, each experts in their own areas of interest.

This cautionary stance is in keeping with regnant clinical practices. A further requirement is a need for uniformity and social acceptability for this undertaking. These represent the third element of this triumvirate of considerations behind how existential suffering is conceived in CDPS (Fig 2.1). The Brongersma case, albeit related to the application of PAS rather than PS, crystallizes the need for social, legal and evidence-based acceptability before CDPS can be safely applied within a specific setting (54).

In the assessment and treatment of Patient C, for example, differentiation of care provision along established lines of clinical specialities is merely pragmatic and a reflection of the fact that care is provided by specialists with specific areas of interests and experience in various elements of care. This does not suggest exclusivity of this type of suffering but rather reflects the multidimensional approach to care that is adopted. It may be that Patient C does have physical suffering too, enmeshed within this existential suffering and whose relationship with the dominant form of suffering may be primary or secondary to his existential suffering. A multidimensional appraisal and treatment approach would be better suited to addressing these needs (8). In Patient C’s situation, his loss of interest in “carrying on” may be because he is no longer independent as a result
his own growing weakness and physical limitations and even possibly pain and shortness of breath. Treating only his physical symptomology to the neglect of his existential suffering denies the interrelated nature of suffering and the “traditional” palliative care approach that his care is under. This approach is also congruent with the overarching goals of CDPS.

2.5 THE GOALS OF MEDICINE

The goals of care adopted by CDPS build upon a Saunders-inspired palliative care framework for the relief of suffering within the domain of patient-centred care (23-26). In her 1995 paper “In Britain – Fewer Conflicts of Conscience”, Saunders states that under the auspices of palliative care, the goals of medical care move beyond the ideal of a restoration of health that is held by Jansen and Sulmasy and evolves to one akin to Cassell and Rich’s stance on relieving suffering (5,8,23-26). The point at which this change in goals occurs is when curative options are exhausted and focus is centred upon meeting the goals of care set out by the patient and the family. Under the aegis of these new goals, “there is still much for a doctor to do and he is entitled to do all that is proper and necessary to relieve pain and suffering, which include treatment options that may ‘incidentally’ shorten life” (26).

To meet this wide ranging objective, Saunders turns to the expertise of the multidisciplinary team guided by the patient and their carers and loved ones, to ensure the patient that adequate and timely spiritual, social, “mental” and physical support is provided in a manner appropriate to the specific demands of a case. As
part of the two-pronged approach of patient-centred goal-setting and holistic care provision through this multidisciplinary care approach, “all the anxiety, the loneliness and the despair of long pain as well as the galaxy of physical symptoms common to this phase of illness” are addressed (26). However, Saunders does not explain how these varied and frequently competing considerations are weighed up in the determination of the overall goals of care.

2.5.1 The Duty of Palliative Care (DoPC)

To overcome this lack of clarity in the determination of the overall goals of care, the CDPS guidelines adopt the Duty of Palliative Care (DoPC) in order to oversee the manner that care is provided (56). The concept of the DoPC provides guidance to health care professionals on balancing conflicting moral principles, providing each with a specific “weight” within this period of a waning duty to cure and prolong life and an ascension of the duty to maximise comfort (56).

First, the DoPC places more “weight” on the duties to optimize comfort and ameliorate suffering that allow them to override any duty to attempt to cure (56).

Second, the DoPC relies upon evidenced-based practices and best practice guidelines to inform case-specific deliberations on the appropriate course of action led by “a team who has undergone appropriate standardized training within the speciality and possesses the experience required to be accredited as a specialist by the local accrediting board” (56).

The DoPC is not prejudicial in holding onto predetermined ideas of the goals of care and is limited only by the laws of the land, culturally appropriate beliefs, the

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practical standards of care and what can reasonably and proportionately be met by a palliative care team (56).

2.5.2 The Duty of Palliative Care in practice

In the case of Patient D, aided by the MDT, particular issues such as the decision-making process, determinations of intractability, consent and proportionality that are particularly open to scrutiny and which will be discussed in the coming chapters are fully assessed before CDPS is employed. Importantly the flexibility within the DoPC, which allows for the changing of the goals of care as the disease progresses or as conditions alter, requires that multidimensional reviews be ongoing and sensitive to the changing circumstances and their effects (56).

The appropriateness of response also revolves upon such a review. Suffering by its very nature is personal and self-defined requiring some explication as appropriateness of response is assessed. In the case of Patient D, appropriateness of response moves beyond considerations of physical matters and clinical limitations. Critical to this consideration is the meaning that Patient D places on his suffering and if his goal of care is consistent and based upon logical rationale. A concern for the MDT team as they determine the appropriateness of the treatment of Patient D’s suffering is if it is in keeping with the patient’s best interests. A determination of appropriateness must be multidimensional and takes into account every aspect of the patient’s psychosocial, clinical, cultural, religious and emotional needs.
A determination of appropriateness also plays a role in the manner that the “rights” of the patient to health care are considered (57,58). Underpinning this “right” is Sen’s conception of what a “good society must have” and the overall goals of care (57,58). In the case of Patient A, it may be argued that he has a right to having his agent narrative and neurocognitive suffering addressed, as opposed to what Jansen and Sulmasy argue, that treating both forms with opioids is not appropriate. This right to health is supported by the premise that it will be tampered by appropriate and proportional response, rather than taking Cassell and Rich’s approach on face value (8). In the case of Patient B, his rights to treatment of his suffering ought to be balanced by his refusal to comply with appraisals; care by the various specialists precludes the possibility of applying CDPS simply because by definition, his symptoms cannot be considered intractable (8).

The fear that Patient B would become a candidate for injudicious application of CDPS as a means of hastening death underpins Jansen and Sulmasy’s concerns (6). Part of this problem is a failure of Jansen and Sulmasy to site their delineation both of end-of-life care and indeed of the treatment of suffering in this phase of life within the aegis of palliative care. This lack of application of both MDT-led palliative care appraisal, decision-making and care approaches and a lack of consideration of patients within this stage of life proves to be the undoing of this more inflexible view of suffering.
Ensuring the appropriate citing of the goals of care that underpin any treatment approach is critical to the manner that care is provided. In this chapter I have shown that as a result of evolving psychosocial expectations and clinical findings as well as a more inclusive concept of suffering, the goals of care must be appropriately situated within the palliative care setting complete with appropriate determination of the limits of care within the evolving disease process. These goals cannot be determined solely by the wishes of the patient but require due consideration of what can really be met by the MDT in the face of diverse access, the prevailing clinical, legal and professional standards and the particular requirements of a particular case. A fixed set of goals of care is not clinically viable in the face of patient-centred care and the ever changing requirements of the complex needs associated with intractable suffering.

Using the example of determining the place of existential suffering as an indication for CDPS under the aegis of goals of care that are focused on relieving suffering, the CDPS framework is shown to take all aspects of care into consideration with the aid of the combined insights of the MDT, the patient and their carers and families. This process is balanced by what can actually be met in an appropriate, proportional and coherent manner within the realities of the specific clinical setting. However, in doing so, it becomes clear that many elements of this process require elucidation. This includes the manner that decisions are made, the way that intractability is discerned, how proportionality is delineated and how consent is gained. These then become the topics of
consideration in the coming chapters. I will begin with a study of how decisions are made within the context of CDPS use.
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Chapter 3

DECISION-MAKING PROCESS

“Death in the end (in the Asian context) is not only about the individual but the family as well.”

~Radha Krishna S~

3.1 INTRODUCTION

One of the key areas of concern that has arisen from the study of the overall goals of care of continuous deep palliative sedation (CDPS) in the last chapter has been the manner that end-of-life decisions are made. These decisions have traditionally revolved around the patient-physician dyad but the advent of palliative care with its multidimensional, multi-professional practice has added a further dimension to these interactions. Discussions now involve a group of professionals and the patient and their family. How these decisions are made have not been appropriately determined. Aside from the variability in the number of parties involved in the decision-making process, decisions no longer appear to revolve around purely clinical considerations but also the psychosocial, religious, financial, cultural and societal factors that are pertinent to the patient’s situation.

The model of decision-making within this variable setting has not been specified and does vary significantly – not helped by variability in the availability of palliative care specialists, access to palliative care facilities, specialist drug access, clinical guidelines and even ancillary support – which as a result has far reaching
repercussions on care determinations (1). Within the practice of CDPS, one key area that is particularly sensitive to this variability in determinations is the determination of intractability.

In this chapter, I will study the decision-making process behind the determination of intractability of symptoms. This process requires a wide understanding of both clinical and psychosocial facets involved in the individual patient’s case. Evaluating these elements and their importance is the multidisciplinary team (MDT). It is the goal of this chapter to delineate the often unspecified decision-making process that exists between the MDT and the patient and their family in arriving at a diagnosis of intractability.

To begin, I offer a descriptive account of the MDT and its roles within palliative care.

3.2 THE MULTIDISCIPLINARY TEAM

The practice of palliative care revolves around the adoption of a MDT-led practice. The MDT is taken to be

“[a] group of people of different healthcare disciplines, which meets together at a given time (whether physically in one place, or by video or teleconferencing) to discuss a given patient and who are each able to contribute independently to the diagnostic and treatment decisions about the patient” (2).
Within the palliative care setting, this role extends to appraising, supporting and treating the various bio-psychosocial factors involved in the provision of holistic patient-centred care and support to patients and their families (2). Whilst its scope and general functions may be known, membership of the MDT remains unspecified (3,4). This variability is as a result of a lack of clear guidelines concerning the precise duties of the MDT across different care settings, a general lack of understanding of a palliative care led MDT approach, and in part due to a shortage of professionals (3,4). The MacMillan Organization suggests that the MDT consist of medical personnel such as surgeons, radiologists, histopathologists, oncologists, palliative care physicians and a clinical nurse specialist (3). Other professionals expected to be part of the MDT beyond these core members include physiotherapists, occupational therapists, psychologists, dieticians, speech therapists and pharmacists (3). The American Academy of Hospice and Palliative Medicine state that basic membership ought to include a social worker, chaplain, volunteers and most importantly the patient and their family (4). These variances in the composition of the MDT are instructive in highlighting a differing view in the precise role of the MDT within different care settings and also in different nations.

However, these differences do pose a problem given that differing membership can influence the manner of interactions between patients and the team and also how the team assesses a particular patient’s needs within the confines of a specific case (5). Deciphering the exact formula to a balanced MDT is therefore important if the general goals of the MDT are to be met appropriately.
This is relevant to palliative care services in developing nations where access to palliative care specialists, palliative care facilities, specialist drug access, clinical guidelines and even ancillary support is limited. Assembling a core group of professionals to form the basis of a balanced palliative care MDT that is capable of meeting its central objectives then becomes difficult and affects the manner that palliative care itself is practiced. A shortage of staff will impact upon the provision of holistic appraisals of a case, diagnoses and holistic care (5). The ethical significance of this shortfall moves beyond confines of health equality and access to care, to issues such as the manner that decisions are taken and how end-of-life care is practiced.

To highlight these deficits, consider the examples of Patients A and B in Jansen and Sulmasy’s paper, “Proportionality, terminal suffering and the restorative goals of medicine” where both patients are being assessed for application of palliative sedation (PS) (6). In the case of Patient A, who is “experiencing neurocognitive suffering brought on by severe phantom limb pain following traumatic amputation”, he would have struggled to have his symptoms addressed without the support of the specialists (6). Without appropriate care of his physical symptoms, his suffering would have progressed, given rise to other forms of suffering and invited inappropriate considerations of PS. In effect, a diagnosis of intractability would have been made at a much earlier juncture (7,8).

In the case of Patient B who is experiencing agent narrative suffering as a result of his progressive loss of independence from progressive amyotrophic lateral sclerosis, a lack of psychological therapy, palliative care, counselling and psychiatric support would have meant his symptoms would have been determined
at an early juncture and inappropriately to be intractable (6). This would have also ushered the injudicious application of PS.

There is an issue about health equality and access, which is slowly being addressed; however, further discussion about this matter lies outside the remit of this thesis (9). Setting this issue aside, how a MDT functions with limited access to specialist palliative care and amidst uncertainties regarding its complement becomes a central concern, particularly in how it sees to its other obligations.

To highlight these many issues in the deliberations that precede any application of CDPS, consider the case of Jaafar. Here the various roles occupied by the MDT within the multiple discussions that lead up to a determination of intractability and potentially CDPS are crystallized.

### 3.3 JAAFAAR’S CASE

Jaafar was an active man until about a year ago. He jogged daily and had done so since he was 16. Now even for a man of 52, he still managed a weekly game of football with his colleagues at the transport company where he worked as a supervisor for the last 16 years. About 18 months ago, he hurt his foot whilst preparing for his daughter’s engagement party. Over the following weeks, the wound on his foot did not heal, not helped by his insistence on continuing his routine runs, his regular games of football and his resistance to seeking medical help. By the time he did finally present to his general practitioner, gangrene had set in. He refused admission or investigations as he wished to continue with
preparations for his daughter’s wedding and only consented to taking a course of antibiotics and analgesia.

After much deliberation and pressure from his family in light of his worsening condition, he was admitted for an emergency “ray” amputation of his left fifth toe, the day after his daughter’s wedding. During the work up, he was found to have poorly controlled diabetes, hypertension, hypercholesterolemia and impaired renal function. As a result, his operation was delayed as these issues were addressed. It was also during this period that he refused further assessments of his vascular system, which posed a significant clinical problem for the surgical and medical teams caring for him. Despite this obstacle, his doctors proceeded with his operation, given that the condition of his toe was worsening. Within two days post-operatively, it became clear that the vascular damage was more extensive than first thought. He developed critical ischemia of his left leg then his right leg. Within a space of three months, Jaafar underwent consecutive above knee amputations.

Following his contralateral above knee amputation, he suffered a large myocardial infarction, which severely compromised his cardiac function and left him with an ejection fraction of 15%. Despite his continued difficulties and being warned of a risk of sudden death, Jaafar discharged himself against medical advice as soon as he was able to manage his pain on his own and continued to refuse many tests and medical reviews. He was convinced that his hospital stays were worsening his condition and he felt that he would recover better at home.

About a month later, at a rescheduled post-operative review, Jaafar began to complain of existential distress, shortness of breath and phantom limb pain. He
consented to and attended a palliative care consult where he was convinced to be
readmitted to hospital. However, despite the efforts of a number of specialists, the
palliative care team and two imams, Jaafar’s existential suffering worsened. With
his prognosis poor and the intractability of his symptoms still being determined,
his son Hussain requested that his father’s repeated wish for euthanasia be
honoured or a compromise sought. A family meeting was set up the next day,
during which time, Hussain being fully aware that the team would decline any
request for euthanasia or indeed physician assisted suicide (PAS), confronted the
team with the judgment of Justice O’Connor in the Glucksberg case, in which the
judge applied the “preferred alternative argument” to the issue of PAS (10,11).

In summing up the Glucksberg case, Justice O’Connor held that palliative
sedation (PS) ought to be seen as an ethically and legally preferable option to
PAS (11). Hussain believed that as a result of this precedent, his father’s
continued suffering, his wishes and his poor prognosis, PS or in this case
continuous deep palliative sedation (CDPS) could to be provided instead (10,11).

In order to meet Jaafar’s complex needs, a MDT was convened and tasked with
the following primary duties:

(1) to diagnose disease progression and the dying phase,
(2) to formulate a treatment plan both for the disease as well as the symptoms,
(3) to ensure that the plans meet ethical standards,
(4) to implement, monitor and formulate new plans as required,
(5) to provide comprehensive personal care, support, recognition of suffering,
   alleviation of distress,
(6) to facilitate preparations for proximate death,
(7) to provide professional support to family/carers (13).
In Jaafar’s case, the role of the MDT began with a determination as to whether Jaafar’s symptoms were intractable. This decision-making process is rarely discussed. I will address this short coming here, beginning with a review of the role of the MDT in determining a diagnosis of intractability.

### 3.4 THE ISSUE OF INTRACTABILITY

Determination of intractability is critical to the application of CDPS. Both the terms “intractable” and “refractory” will be applied interchangeably within this thesis, as it has been in the guidelines of the EAPC, Royal Dutch Medical Association (KNMG), Hospice and Palliative Nurse Association (HPNA), National Hospice and Palliative Care Organization (NHPCO), The National Ethics Committee of the Veterans Health Administration (VHA) and the American Medical Association Code of Medical Ethics on Sedation to Unconsciousness in the End of life protocols [Appendix 5 and 6]. The EAPC guidelines maintain that application of CDPS without a determination of intractability (refractory) symptoms is tantamount to abuse (15,16). Juth et al reiterate the importance of such a determination within the EAPC guidelines by stating

> “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” (16).
Eisenchlas maintains that the definition of treatments such as CDPS would be “meaningless if intolerable/refractory suffering is not also well defined” (17). Eisenchlas adds that stating that refractory symptoms are those that persist “when all other possible treatments have failed”, is also insufficient for the purposes of applying CDPS (17). Eisenchlas proposes the adoption of Cherny’s definition of refractoriness (17). Within Cherny’s definition, refractory symptoms are defined as those where a patient’s symptoms “cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness. The criterion for diagnosing refractory symptoms includes that further invasive and non-invasive interventions are incapable of providing adequate relief, are associated with excessive and intolerable acute or chronic morbidity, or are unlikely to provide relief within a tolerable time frame” (18).

Within Cherny’s definition, terms such as “intolerable” and “adequate” highlight the subjective nature of this diagnosis (18). Cherny and Portenoy add that this subjectivity within these determinations is only partly addressed by the application of a MDT-based appraisal, given the need for consensus-based decisions upon the severity of a symptom (19). These authors define a symptom as being 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” (19).
A further problem with this definition is its prioritizing of clinical signs and symptoms. Morita et al counter this by adopting a wider system of appraisal that includes “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” to circumnavigate concerns that diagnoses of refractoriness are clinically based (20). Morita et al explain that given that “our understanding of patients’ existential distress is still primitive and treatment strategies are far less established”, determinations of intractability must be holistic if care is to be provided in a manner that is congruent with the needs and goals of the patient (20).

3.4.1 The determination of intractability

Given the wide variety of definitions present, the process of determination of intractability needs discussion and has to my knowledge not been adequately considered in the medical literature. Despite its centrality in the application of CDPS, there has been little attention given to the process of arriving at a diagnosis of intractability. In the recent Canadian guidelines for PS, this factor remains obscured (21). To allow for a holistic, clinically relevant process, I propose that the diagnosis of intractability include the patient-related factors and MDT-determined factors summarized in Table 3.1 below.
<table>
<thead>
<tr>
<th>Patient-related factors</th>
<th>MDT-determined factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. the patient’s values, beliefs and goals</td>
<td>1. that aggressive efforts have been expended in an effort to ameliorate the patient’s symptoms</td>
</tr>
<tr>
<td>2. the determination that the symptoms endured amounted to suffering and that they are of a severe nature</td>
<td>2. that all non-sedating treatment options have been exhausted</td>
</tr>
<tr>
<td>3. the determination that attempted options thus far have been unacceptable, intolerable or unbearable</td>
<td>3. prognosis is less than two weeks</td>
</tr>
<tr>
<td>4. the determination that attempted options thus far have not achieved acceptable levels of relief</td>
<td>4. estimations of disease trajectory suggest that treatment options are unlikely to be effective within the given prognosis</td>
</tr>
<tr>
<td>5. the determination that proposed treatments options are unacceptable, intolerable or unbearable</td>
<td>5. delineation of “option sets” or a specific set of treatment modalities that are taken as viable within the confines of the particular case</td>
</tr>
<tr>
<td>6. the determination that proposed treatment options are liable to bring about intolerable or unacceptable morbidity</td>
<td>6. estimations that viable options within treatment sets are unlikely to be effective or adequate</td>
</tr>
<tr>
<td>7. the determination that proposed treatment options are unlikely to relieve symptoms within a tolerable time</td>
<td>7. determinations that attempted treatments have indeed failed rather than require further adjustment and/or time</td>
</tr>
<tr>
<td>8. determination that the views of the patient are justifiable</td>
<td></td>
</tr>
<tr>
<td>9. determination that the planned action is in fact in keeping with the patient’s beliefs, goals and values and free of coercion</td>
<td></td>
</tr>
<tr>
<td>10. differentiate between difficult to treat and intractable symptoms</td>
<td></td>
</tr>
</tbody>
</table>

Table 3.1 Diagnosis of intractability: Patient-related factors and MDT-related factors
3.4.2 Patient-related or subjective factors in the determination of intractability

3.4.2.1 Treatment that is in keeping with the patient’s goals, values and beliefs

A central feature of providing CDPS is that it ought to be in keeping with the patient’s wishes, goals and values and must be something that the patient would consent to. Recall Patient C who, like Patient B in Jansen and Sulmasy’s example, suffers from severe existential suffering, is unwilling to seek further support or evaluations, but is keen for CDPS based on the idea that it would help him meditate (6). This patient acts in keeping with his beliefs, values and goals, motivated by his view of suffering. Patient C must also deem that the treatments proposed are likely to be neither effective nor tolerable and are unlikely to alleviate his symptoms in an acceptable space of time without resulting in unacceptable acute and/or chronic morbidity.

Let us consider that Patient C is lucid, alert and competent when these goals are stated, and aware of the repercussions of his action and the possibility of CDPS being applied (which he would welcome) given that if he was not so, the determination for CDPS would be based upon a best interest determination (22-27). In these circumstances, it is unclear whether in the face of efforts to make the decision-making process leading up to the application of CDPS transparent, accountable and evidenced-based, Patient C would have to justify why and how he arrived at the set of goals that he adopts in the same manner that a MDT is required to given the implications of this position upon treatment options.

Recall Patient D from the previous chapter, who like Patient B in Jansen and Sulmasy’s example is identical in character and condition save for one point (6).
Patient D is a Buddhist and in keeping with his beliefs, despite his intractable existential suffering does not wish complete relief of his suffering. For him his suffering is seen as a means of “atoning for his past indiscretions”. For Patient D, “repaying karma” is the overarching goal of care, not relief of suffering. It would appear that in Patient D’s case, sedation would not be appropriate to meet his goals of care, thus ought not to be considered.

Different measures of endpoints are justified so long as a number of considerations are met. These include confirmation (i) that the patient made this decision whilst being competent and aware of the possibility of the present symptoms and suffering arising during the course of his illness when delineating his goals of care; (ii) that this option is not deemed to be a physical risk to the patient or to be in conflict with another equally weighted goal. Critical here is the patient’s competence. Should there be a suggestion that he or she is not, then this thesis maintains that decisions be made on a best interests determination. I will discuss this matter in Chapter 4.

Patient D’s situation highlights the fact that patients’ wishes, goals and beliefs help determine the “option set” or treatment modalities taken as viable for their respective conditions. Wirtz et al refer to this process as “framing” (28). Limiting treatment to a specific area or steering away from various forms of interventions and limiting the option set available for care create a limited option set from which a diagnosis of exhaustion of “all” treatment options may be easier to arrive at. Consequent reductions in the number of treatment option offered as a result of progressive disease or changes in other elements of a patient’s condition, is defined as “funnelling” (29). I will argue later that both these processes drawn
from Wirtz et al’s and Sandman and Munthe’s respective work in decision-making are critical to understanding the decision-making process in determinations of intractability (28,29). Given the gravity and scope of these determinations, the deeper question to be considered is to what extent this delineation of “option sets” or a specific set of treatment modalities ought to be taken as viable in the lead up to a determination of intractability.

Similarly consideration of a patient’s right to refuse treatment further complicates this situation. Repeated refusals of proffered treatment options will steer options sets towards an ever-tapering number of treatment modalities and will finally “usher in” the possibility of CDPS. In Patient C’s case, this outcome is what the patient desired from the outset. Treatment refusal at this juncture of care has very different connotations, and justifying this action falls upon the MDT who must apply objective measures to validate this position. I will discuss the role of objective appraisal of the situation in due course.

3.4.2.2 Other subjective elements in the determination of intractability

The patient determines the acceptability and tolerability of proposed and ongoing treatment modalities, the duration of a trial of treatment, the level of efficacy and anticipated relief seen and envisaged from them and the acceptability and extent of side effects. These determinations are all dependent upon the patient’s evaluations and perceptions. What factors influence their views and thinking may be difficult to discern but the result must nonetheless be considered within any deliberations.
Patient B might feel that the time spent with the psychologists and the social worker is entirely counterproductive and not in his interests to pursue further. He might feel that the relief that their interventions would provide would take too long to realize and require too much of an investment of his time and energy for what he may feel would be a small improvement in his condition. Influencing these judgments are his personality, cognitive styles, past experiences and present expectations as well as his perceptions of the interventions tried so far and the HCPs assigned to appraise and treat him.

The manner that information is provided to him regarding the nature, expected efficacy and duration of a treatment option, and the expected benefits and the time that it will take to realize them are also key in how Patient B determines acceptability. Cost and care impacts upon him and his family are also important in this decision-making process. Information provision within patient-family-physician interactive models and decision-making processes will be reviewed later.

Given the level of subjectivity within the key determinations for the application of treatment options, it is unsurprising that there are calls for this deliberative process to be moderated by objective determinants (22-26). The application of a professional’s input is thought to provide some balance to this process.

### 3.4.3 Professional factors in the determination of intractability

The MDT is tasked, amongst other roles, with providing accountability for the process, beginning with “framing” or construction of the “option set” of treatment
possibilities (28,29). This is based on an account of the patient’s wishes, goals and beliefs, the patient’s prognosis and disease course and trajectory, as well as the patient’s responses with ongoing and previous treatment approaches. This process of framing also involves an extrapolation of the HCPs’ own past experiences and knowledge about various other options and the MDT’s determinations of the likely benefits, risks, efficacy and efficiency of these possible treatment alternatives (28,29). Justification for neglecting certain options, discontinuing present treatments and opting for other modalities must be discussed within the MDT and documented clearly. The rationale for this decision must be based on prevailing clinical practice guidelines and evidenced-based medicine algorithms and shown to be relevant to the case in hand. It is believed that this type of objective review may help balance the subjective nature of the process.

What cannot be neglected is that there are other parties and other factors to be considered within the decision-making process. Balancing a patient’s own goals against the demands of the clinical needs and what can realistically and justifiably be provided is integral to any determination regarding intractability. The role of the MDT in this process of balancing expectations of the patient and the family is pivotal.

Treatments offered must be constructed upon what the patient and their family as well as the MDT deem is acceptable. In Jaafar’s case for example, if Jaafar felt that sedation would have inhibited his ability to recite verses from the Quran before he passed away or that it was inherently against his beliefs, it is unlikely that CDPS would even be considered. However, if no objection or preference is
voiced then a decision to offer sedation is only considered after discussions with
the family and the MDT.

However, concerns over this reliance upon previously stated wishes come to the
fore when it is suggested that Jaafar may have never contemplated such a
scenario where his best interests for comfort would be in conflict with his other
interests especially in light of a changing set of goals and clinical considerations.

In Jaafar’s situation, there were no clear determinations of his own personal goals
although Hussain’s request for PS was informative. Hussain was Jaafar’s
acknowledged proxy decision maker, who reported that sedation would have been
in keeping with the patient’s wishes. In view of Jaafar’s changing goals as
evidenced by his decision for readmission, the views of the family as a whole
were still sought. It was not immediately clear that within these changeable goals
that Jaafar would have wanted sedation. Hussain and Jaafar’s wife Yati both felt
that he did; however, there were members of the MDT that felt that this option
should not be offered. I will review the concerns of each of these parties.

3.4.3.1 The social workers’ concerns

The social workers involved in the patient’s care were of the opinion that undue
pressure was being exerted on Jaafar by the prospect of his family’s increasing
financial burdens as a result of his care needs. The social workers felt that these
same stressors also weighed heavy upon Hussain and Yati in their determination
to entertain the option of CDPS. However, the social workers’ were allayed by
the fact that costs were borne by the insurance companies and the unfa...
convictions of these key decision makers and most of Jaafar’s family that this would have been the patient’s wish.

The concerns of the social workers did also serve the further purpose of bringing to the fore the position and the motivations of the family within such deliberations. I will address this in Chapter 5.

3.4.3.2 The religious workers’ concerns

The two imams involved in providing for Jaafar’s spiritual interests were also opposed to the determination of intractability given that they held that the symptoms were still responsive to spiritual support, particularly after Jaafar appeared a little less distressed for a period of two days after the two imams’ initial involvement.

However, despite a further two weeks of intensive efforts of the imams and the counsellors, social workers and psychologists, his psychosocial condition did not improve. The imams, however, remained convinced that the situation was still “salvageable”. They felt that admission of intractability would be an abandonment of Jaafar. The imams also believed the application of CDPS would be detrimental to his “soul” given that he would not be able to recite his Quranic verses.
3.4.3.3 The concerns of Sharizah, Jaafar’s daughter

Sharizah, the patient’s daughter believed that the application of CDPS was not in the patient’s best interests. She was aware that comfort was the primary goal of the patient and that Jaafar had exhausted his treatment option. She was also aware that CDPS, which Hussain, her brother had requested for their father would not abbreviate his life nor was it against her father’s own beliefs so long as fluids were maintained.

However, she struggled to come to terms with his inevitable loss of consciousness and felt that it would reduce him to a “vegetable”. She did feel that it would mean mourning his loss twice, first upon the loss of his consciousness and personhood and again with the biological (total cellular) death of her father. She could not be swayed from her disapproving stance to this intervention.

This dissonance in views and the effect that it has within the determinations of the MDT is critical. In the context of an impasse there is little clarity on the expected course of action for the MDT. Opinions appear to diverge, with some calling for further discussions whilst others suggest reliance upon a majority decision amongst the MDT or even second and third opinions to validate the position of both sides of the argument. This lack of consensus shifts focus towards contemplation of the practice of shared decision-making (SDM) in the MDT setting.
3.5  SHARED DECISION-MAKING (SDM)

Impetus for adopting a shared decision-making process remain respect for autonomy, better compliance and active participation in care plans, higher satisfaction with services, better quality decisions and aiding in maintaining a therapeutic relationship (28-34). Additionally, familial satisfaction in the process will reinforce the family-HCP relationship and aid in the support that can be provided to the family during the bereavement process (35-37).

The complexities within Jaafar’s case highlight a lack of delineation as to how these decisions should be made. There was little attention paid to the deliberative process, which sees the many members of the MDT interacting with the patient and the various family members. There was also little consideration of how the various members of the team adopted SDM within the MDT itself. Even though Morita et al and Bruinsma et al have discussed the issue of family involvement in the decision-making process for PS, there has been little to describe how this decision comes about (35-37). Despite palliative care advocating SDM, nearly 70% of Portuguese and 63.3% of Italian decisions regarding the application of PS in some settings did not involve the patient or their families highlighting a lack of transparency in the deliberative process (38,39).

To address this lack of clarity on the deliberative process behind the applications of PS, a theoretical framework of SDM is required for the application of CDPS. To shed some light on the issue, I will review Sandman and Munthe’s position on this topic (29). Sandman and Munthe, in reviewing the extensive literature on SDM, formulate a number of models of decision-making and critically provide a
deliberative process that is useful in the present setting and potential applications within the small team MDT that this chapter proposes (29).

Building upon the early work of Charles et al, Wirtz et al and Makoul and Clayman, Sandman and Munthe state that SDM’s emphasis “on active participation from both patient and professional in the decision-making process, and agreement on the decision”, does not delineate the decision-making process that underpins it (28-32). As a result Sandman and Munthe attempt to define a practical process of SDM (29).

Applying Charles et al’s description of SDM, Sandman and Munthe show that at its core, SDM involves a physician-patient dyad that participates in a decision-making process that involves “sharing where the decision-making is being shared, or involves sharing”, and consensus where “the final decision is mutually agreed upon” (29-32). This process is said to meet the basic objectives of SDM stated below.

1. At a minimum, both the physician and patient are involved in the treatment decision-making process.
2. Both the physician and patient share information with each other.
3. Both the physician and the patient take steps to participate in the decision-making process by expressing treatment preferences.
4. A treatment decision is made and both the physician and patient agree on the treatment to implement” (29).

However, these central features can also be seen within “evolved” forms of patient choice and paternalistic decision-making models (28-32). To set SDM apart from these two models, Sandman and Munthe attempt to delineate SDM as a distinct decision-making model (29). Sandman and Munthe begin this process
by reviewing the main features of the paternalistic and patient choice models to highlight the differences that these approaches have with SDM (29).

Sandman and Munthe define paternalistic decision-making as being a decision-making process that “actively ignores to take into account the perspective of the patient” or “fails to treat the patient as an autonomous and/or rational being” or “even if it does not go against (or is believed to go against) the wants of the patient” (29). The more “evolved” form of paternalistic decision-making that may consider some elements of autonomy and does share elements of SDM is seen

“if a person, knowing someone’s preferences, acts to fulfil his preferences, without him either participating in the reasoning process leading up to the decision and partaking in the decision or having authorized the other person to make the decision on her own” (29).

This evolved paternalistic decision-making formulation highlights the finding that despite active participation and sharing of information within the dyad, there is neglect of authorization (29). Authorization is dependent upon the premise that the patient is autonomous, rational and willing to participate in the decision-making process (29). Decisions taken with an approximate idea of what the competent patient would have done and on the premise of “the professional as perfect agent” do not detract from a judgment of paternalism (29).

A patient choice decision-making process implies “that the patient somehow remains in authority over the decision as to what should be done” so long as they are “well-informed” and competent (29). “[I]n contrast to paternalism, this model allows for patients not only to make choices, but to choose options against their own best interest—as long as they are well-informed” (29). It is the responsibility
of the staff only to assist in providing information for the evaluative phase (29).

In the evolved form of patient choice decision-making, the physician may be able to frame the treatment options; this, however, does not detract from a judgment of patient choice decision-making (29).

From these definitions and highlighted differences, Sandman and Munthe isolate two features distinct to SDM (29). These are (i) the nature of reasoning in SDM, which highlights “the reasoning-communication represented in any process of joint decision-making”, and (ii) “framing”, which helps define the “construction of the option-set, which both frames decision-making and is, in part, a product of decision-making” (28,29). Both these facets are carried out with both the patient and the physician willing to discuss and alter their opinions as part of a conflict resolution process and are willing to share openly within this process. Sandman and Munthe add that neither of these “collaborative features” within the reasoning-communication and framing processes, are appropriately addressed by prevailing SDM theories (28,29).

![Figure 3.1 Spectrum of decision-making in the health setting](image)

There are also other differences to be considered. Paternalistic decision-making models and patient choice decision-making models are said to exist on opposite sides of a decision-making scale.
Movement centrally from either extreme reveals an increase in sharing and sees the more “passive” partner in the decision-making dyad provided with increasing involvement in the decision-making process and possibly the right to veto. For example in paternalism, the physician may make the decision but the patient is left with the decision to comply or not. Further steps towards the centre of this spectrum will see increasing consideration of the patient’s choices and values integrated into the deliberative process. However, it would be a mistake to consider such accommodations of wishes within these paternalistic practices to be SDM as “decisional authority” remains with the HCP (29). Similarly, movement centrally from the patient choice extreme, where a fully informed patient is solely responsible for the decisions he or she makes, see increasing consideration of the input of the physician, though the decision maker remains the patient. For both these decision-making processes, the decision-making process does not become a SDM process until they enter the central region of the spectrum occupied by SDM.

Movements toward a SDM perspective at the centre of Figure 3.1 also highlight a change in the evaluative basis of both parties within the decision-making process. This is characterized by

“discussion(s) where arguments and reasons have to be presented, compared and evaluated, making for a high-level dynamics where their evaluative basis may be revised and accommodated in the light of this”

(29).

This “high level dynamics” in sharing allows for both a means for conflict resolution and better prioritizing of information and adaptation of goals (29). The
“high degrees of sharing and high level dynamics” seen within SDM allow Sandman and Munthe to postulate that there are four types of shared decision-making process (29). These four discrete entities still lie within the spectrum of shared decision-making (Fig 3.2).

Figure 3.2  Forms of shared decision-making

In Shared Rational Deliberative Paternalism, the exchange of information, goals and facts is bilateral and open, but the physician decides on the course of action (29). Here a patient is still able to influence decisions whilst increasing their own understanding (29). In Shared Rational Deliberative Patient Choice, after an open exchange of ideas, reasons and facts, it is the patient that makes the final decision, emphasizing patient autonomy; however, this choice does sit within specific boundaries of acceptable practice (29).

In an ideal situation, the Shared Rational Deliberative Joint Decision Model envisages that all parties have an opportunity to take part and forward their views, suggestions, evaluations, needs and the rationale for them in an open manner (29). This concept is based on a Habermasian concept of “communicative action” (29,40).

“The communicative model of action does not equate action with communication. Language is a means of communication which serves
mutual understanding, whereas actors, in coming to an understanding with one another so as to coordinate their actions, pursue their particular aims. … The interpretive accomplishments on which cooperative processes [of situation definition] are based represent the mechanism for coordinating action; communicative action is not exhausted by the act of reaching understanding” (40).

This multidimensional review must be done whilst being aware of the needs and opinions of others and in the knowledge that the “actor’s” own position is being scrutinized (29,39). During these deliberations no specific weight is given to any one party and all interests are declared (29). Success is measured by a compromise agreement that all parties can agree upon (29). Should consensus not be reached, the physician in charge is tasked with carrying out what will “ideally benefit the patient the most” whilst being cognizant of the “institutionally sanctioned idea about the lowest acceptable limit for what could be offered to the patient” (29). Motivation for the physician to maintain this position is rooted in his or her professional obligations to ensure the best interests of the patient (29).

Unlike the Shared Rational Deliberative Joint Decision Model, which is not focused on “predetermined goals or interests of any of the parties”, a Professionally Driven Best Interest Compromise Model seeks to realize just such a goal (29). The patient is at least aware of this strategic goal and decisions are arrived at largely as a result of “framing” to protect the best interests of the patient (29). Sandman and Munthe describe this process as one where

“the professional is given the opportunity to achieve a compromise that as far as possible sees to the patient’s efficient best interest (from the
professional perspective) and at the same time is open to accommodate this to the value given to patient autonomy” (29).

Whilst these models explicate the various means that decisions may be shared, the exact nature that decisions are reached requires deliberation. Sandman and Munthe maintain that consensus agreements are desirable (29). In the event that this is not possible, Sandman and Munthe believe that “negotiations in terms of a mutual gains bargaining” is not a viable option given that both the physician and patient have limitations for what they will compromise and that compromise will lead to suboptimal decisions that compromise the patient’s care and best interests (29).

Sandman and Munthe state that where consensus cannot be gained with compromise to overall care, a “strategic decision-making mainly on the behalf of the professional” should be adopted (29). The assumptions underpinning this process are that the physician who has control over the decision-making process is committed to patient participation in the decision-making process and duly considers the preferences and best interests of the patient within this process (29). Limits to the decisions reached are set by institutionally sanctioned requirements and what is determined to be in the patient’s best interests. The adoption of this strategic action “aims to reproduce meaning (in the sense of a certain way to understand things) or to achieve a predetermined goal or interest of a person or system/structure” (29). Priority is afforded to best interests within the Professionally Driven Best Interest Compromise Model though efforts for compromise and accommodation are maintained (29). Protecting these best interests may be overt where the patient is aware of the goals of the physician or
be latent where the “parties manipulating the other, or through self-deceit by what is called systematically distorted communication” (29). “Framing” may be adopted. This is where

“the professional is required to (openly) frame the decisional situation so as to achieve what she wants to achieve, although, at the same time, involving the patient in the decision-making and ‘taking sharing all the way’ (thus caring for patient autonomy as far as is practically possible)” (29).

Whilst Sandman and Munthe offer an evolution in the SDM model, some concerns with respect to its applicability within the specific confines of end-of-life decision-making, remain.

### 3.5.1 Weakness in the current SDM framework

Sandman and Munthe’s SDM model appears to be based upon a patient-general practitioner/physician interactive model that might be envisaged to occur in clinic settings where discussions revolve around more routine care decisions (31). Sandman and Munthe’s neglect of wider deliberative models that are employed extensively in paediatric care, geriatrics, rehabilitative medicine and palliative care limits their model’s applicability within these fields and to care deliberations of a more complex and serious nature. These lapses raise four key issues. To begin, there is no consideration of changes in the patient’s condition and thus their ability to cogitate and communicate effectively, nor holistic review of their
particular psychosocial, spiritual and physical circumstances that have significant bearing upon interactions within the physician-patient dyad.

Furthermore, in such complex conditions, neglect in delineating the role of the various parties beyond the primary dyad or how the views and interests of these parties may often influence care practices, is telling (23-26). This omission also raises the question as to how multidimensional factors balance and frame healthcare decisions. There is an important issue here that pertains to transparency, accountability and compliance with clinical guidelines and practice safeguards.

Sandman and Munthe also do not consider the impact of professionalism of the physician within their framework (29). This failing is magnified within the MDT setting where professional conduct and standards define work practice and how many professionals interact with the patient and their families.

Finally, Sandman and Munthe’s insistence upon favouring high level dynamics and high degree of sharing over the application of framing within the decision-making process emphasizes the limits of their SDM model. Complex decision-making processes are not considered, neither are situations where limited patient participation have to be contended with (17-26,29). These limitations highlights the pivotal failings of Sandman and Munthe’s SDM model: the failure to consider a holistic account of the patient’s circumstances and the evolving nature of care provisions beyond simple medical interactions.

Addressing these shortcomings will be the focus of this next part of the chapter. I will begin my review of these issues with a study of the role of the MDT in the decision-making process.
I have discussed the general role of the MDT earlier and will focus now upon their position within the decision-making process. The MDT functions on the basis of open discussion underlined by professional respect and courtesy. It serves as a platform for considering the elements involved in the case, which are reviewed first in isolation then weighed up against the particularities, considerations, obligations and expectations within the confines of an individual case consideration (38). This process is not dependent upon the opinions of only the senior members of the MDT nor weighed solely upon clinical merits. “Weight” provided refers to the importance and pertinence a specific consideration holds within an overall review of a particular case (38). This balancing is also subject to professional standards and measures. I will discuss the influence of professionalism on the MDT later.

Aside from weighing up the importance of various considerations, the MDT occupies a central role in the reasoning and framing of the decision-making process. Within the MDT, the physician’s determination of the course of treatments available to the patient is tampered, evaluated and justified by input from the various members of the team and by second opinions.

Application of the MDT approach also serves to limit fears of bias that are seen when determinations are carried out by a single HCP. Studies of the decision-making process of physicians in the Netherlands reveal that the application of PS is influenced by demographic factors such as sex, age, place of care and education levels of the potential candidates for PS (41-43). Reviews by Rietjens et al and Onwuteaka-Philipsen et al in the Netherlands and Jaspers et al in
Germany show that it is younger male patients who were more likely to have potentially life-shortening treatments such as euthanasia rather than older, less educated female patients who tended to be administered PS (41,42). PS is also more likely to be employed for existential reasons in a hospice than hospital (42). The MDT approach also aids in countering the effects of external pressures upon this decision-making process (43). One in six Dutch general practitioners report being pressured to start terminal sedation by the patient’s family (44).

These issues are not considered within Sandman and Munthe’s strategic decision-making process because of a failure to site their model in care settings that involve many facets of care, multiple “interested” parties and a backdrop of evolving clinical and psychosocial considerations. How decisions within these contexts are arrived at is critical (45).

Variances in the number, type, level of expertise and experience within MDTs have been shown to affect the decisions that are made (46,47). Data does show that different professionals place different weight on different aspects of the deliberative process meaning that decisions reached by different complements of professionals will differ (46-48). For instance, nurses place more weight on familial and social considerations whilst physicians place more interest on the clinical aspects of the decision-making process (43-45). An imbalance in the membership would lead to a skewing of decisions. Janssens et al quoting a Dutch study by de Graeff et al reveal that in consultations with palliative care consult teams, 41% of decisions by general practitioners to apply PS were overruled, reiterating the need for more than a single practitioner’s view (45). The question then is who makes up the basic constituents of the MDT, particularly when there
continues to be significant shortages in palliative care access and support in many parts of the world?

3.6.1 The decision-making process in the context of small MDTs

In light of these shortages in care providers, would a simple second opinion meet requirements of a multidimensional, balanced review required by the various guidelines? The KNMG guidelines do maintain that PS can be applied based upon a singular physician’s review that is supported by a second opinion (45,49). The EAPC guidelines state that a limited review such as that suggested by the KNMG guidelines would constitute an inadequate assessment and would represent an injudicious application of PS (15,45,49).

A solution to this dissonance may come from a related practice that also uses a multi-professional approach in their practice. Institutional ethics committees (IEC) face a similar problem to palliative care MDTs and the American Academy of Pediatrics suggests three alternative models of practice to cope with a lack of adequately qualified personnel (50). These models consist of individual consults and second opinions, a small team IEC and the full Institutional Ethics Committee (50). Finding the appropriate form to adapt to the palliative care setting is key.
3.6.2 Individual consults and second opinions

Jansen and Sulmasy in their essay “Proportionality, terminal suffering and the restorative goals of medicine”, show in their example of Patient A and Patient B that the input of a single physician taken together with a second opinion from another professional who need not be a physician is adequate for the initiation of PS (6). Input from a palliative care physician is not mandatory (6).

This single physician approach to PS application is also seen within the KNMG guidelines (49). These guidelines are issued primarily for the application of PS within a community setting and mainly by general practitioners (GPs) who require only that the GPs “demonstrably possess the necessary expertise and experience” (49). The KNMG guidelines do not require the input of a palliative care specialist as they hold that PS lies within the remit of “normal medical practice” and “the responsibility for assessing medical indications, decision-making and implementation therefore lies with the attending physician” (49). The committee responsible for the KNMG guidelines states that

“[g]iven the nature and content of palliative sedation and the indications listed in this guideline, the committee sees no reason to impose the condition that a physician with specific expertise must always be consulted before making the decision to administer palliative sedation” (49).
As a result, the guidelines also state that

“the attending physician bears responsibility for determining whether the medical indications are present, for decision-making and for the practicalities of administration” (49).

The KNMG guidelines do, however, acknowledge that PS is part of the palliative care armamentarium and therefore requires a palliative care approach (49). To meet the holistic review process required and to provide balance and oversight, the KNMG guidelines recommend the involvement of a nurse to aid in the appraisal and employment of PS (49). It also recommends consultation with the “appropriate expert(s) with specialist knowledge of palliative care in good time” (49).

The KNMG guidelines are designed for a specific purpose and crafted to allow for the inevitable limitations that GPs will face both in terms of support in appraising these patients and on practical and monitoring considerations (49). Given similar constraints amongst physicians working in nations where access to palliative care expertise is still limited and complements of MDT personnel may still be lacking, could the KNMG guidelines be effectively employed there to meet the decision-making duties set out by a palliative care approach?

Whilst the KNMG guidelines do acknowledge the need for a holistic palliative care approach, they address the requirements in a manner that prevents simple translocation of practice to other settings (49). The KNMG guidelines takes into account a number of factors that may not be immediately reproducible in other settings. An established therapeutic relationship between these patients and the GP, which brings with it a long and well documented multidimensional appraisal
of a patient’s evolving symptoms and care, forms the primary requirement of the guidelines (49). This potentially negates the need for additional psychosocial input from a social worker particularly as GPs and nursing staff are well trained in palliative care techniques and appraisals (49).

The Dutch setting is also unique in its view of PS (49). The application of PS is seen as routine medical care accepted by the medical and legal fraternities as well as the society in general, and therefore does not succumb to scrutiny from these quarters, so long as the strict criteria set out by the guidelines are adhered to (49). This combination of elements is not always readily found in many developing palliative care settings, negating the widespread application of this process.

### 3.6.3 Small team MDTs

In most settings, the application of PS remains a treatment that warrants careful consideration and monitoring. Within the example of Singaporean practice, treatment which may be foreseen to potentially result in the deep and continuous sedation of the patient ostensibly until death would require the review and consensus of the core decision makers, which include the primary physician and the entire palliative care consultant team. This requirement is in keeping with the gravity of the situation and one that would demand an independent second opinion from a trained palliative care specialist as well as inputs from the patient and/or their family or surrogates, given the complicated nature of the patient’s condition and the implications of this treatment (22-27).
Pragmatically, it is the small team MDT that offers the most viable solution to counter the various concerns raised. The assumption behind the application of the small MDT is that there is sufficient coverage of the various essential areas of care to provide adequate flexibility, diversity and width to holistic considerations. Equally, the extant of this process is capped by the MDT’s determination of the patient’s best interests and the prevailing clinical and legal standards.

The decision-making process in turn is one that would hold to consensus decision-making under the aegis of SDM. In the event that this might not be possible, the KNMG guidelines state, “the responsibility for assessing medical indications, decision-making and implementation therefore lies with the attending physician” (49). Justification for decisions along with the reasons why objections to a specific decision were trumped must be recorded in the MDT proceedings and the patient’s case notes. Such accountability and transparency, bound by both legal standards and clinical guidelines, allow the small team MDT approach to overcome prevailing concerns and health care limitations.

With the basic complement of the deliberative process established, the manner that these professionals interact becomes central.

3.6.3.1 The overriding positions of professionalism upon the MDT and the decision-making process

A basic understanding of professionalism is required to proceed here and this thesis will adopt the practical definition of professionalism proposed by Rogers and Ballantine (51). This definition draws upon theoretical literature and working
practices that have then been validated by empirical evidence (51). It highlights five criteria that correspond to professionalism (51). These are responsibility, relationships with and respect for patients, probity and honesty, self-awareness and capacity for reflection, and collaboration and working with colleagues (51). These elements form the platform for inter-professional interactions within the MDT and with other professionals.

It is against this background that the physician in control of the treatment options ensures that discussions are open and transparent and in keeping with clinical standards of practice. Minimum standards of care that will be institutionally supported are also known to all involved so that whilst consensus may not always be immediately possible, acceptable compromises that do not subtract from the basic requirements of care of the patient are still possible. In the event that compromises are not forthcoming without endangering patient safety or best interests, more second opinions from both sides of the argument are sought, time permitting, if only to allow for a fair deliberative process rather than the perception that this is an attempt to replace “opposing” opinions. However, final authorization for the employment of CDPS comes from the physician in charge who is ultimately responsible for the patient’s care and the second independent physician (26).

3.6.3.2 The role of the family in the deliberative process

Emerging data would suggest that the role of the family cannot be excluded in any end-of-life decision-making process (23,24,46,47). Evidence from local data,
for example, would suggest that a significant proportion of patients still request the involvement of their family in end-of-life decision-making (46,47,52-56). This practice is observed across all the local races and cultures and not exclusively by the Chinese population or cultures influenced by familial-centric values (48,56). This is not surprising given the role of the family in care provisions in nations such as Singapore, where care provisions are intimately entwined with the role of the family (46-48).

The adoption of this family-centric approach has also raised other concerns, as there is growing evidence to show that the family tend to usurp or trump the position of the patient within these decision-making processes (46,47,52-56). Conversely, there is significant concordance between decisions made by the patient and their family (46,47,52-56). Buchannan and Brock’s theory explains that the family are better equipped at understanding the patient’s needs given their knowledge of the patient’s beliefs, values, preferences and background as well as being better equipped to honour their relationships and realize the patient’s true wishes (57). Given the regnant practice of family involvement reinforced by the palliative care ethic of support for the family and the patient in end-of-life care, it would seem that there is ample reason to involve the family in these decision-making processes (22-26).

However, the question that follows is not whether the family should be involved but how much “weight” ought they be given in these deliberations. On one extreme, Fan Ruiping argues for the primacy of a Confucian-led family determination process, whilst I have argued elsewhere to the contrary (58-60). My position is that the family ought to have a “voice” or a chance to speak their
minds and that their views are duly considered along with the other factors of holistic evaluations (22-26,60). However, in keeping with regnant legal and clinical standards, the final decision must lie with the physician who is ultimately responsible for the care of the patient (22-26,60). Further discussion of Jaafar’s case may serve to highlight the reasons for this position.

3.7 DECISION-MAKING IN DETERMINATIONS OF INTRACTABILITY

Having established the complement and manner of conduct for PS decisions, I will now consider how determinations of intractability come about. These decisions consider the entire evolution of the symptoms holistically and include a re-evaluation of all care decisions, a review of the rationale behind an employment of a certain treatment option and the reasons for disregarding the alternatives. Previously discarded treatment alternatives are revisited to review their feasibility to ensure that all alternative treatments have been considered and reconsidered during the decision-making process. This process is also carried out to see if an alternative can be found to the final product of the consecutive episodes of framing and reasoning: “nothing”.

The conclusion that “nothing” can be done is a product of “funnelling” and “framing” (28,29). Wirtz et al describe the process of “framing” as the manner upon which the scope of the “option set” of “medically reasonable alternatives” is determined (28). Determination of the option set is narrowed down with each process of framing until there exist only a few acceptable treatment options that
the patient, the family and the MDT would consider acceptable (28). Wirtz et al see the progressive factoring of influences as “funnels” that are formed by the choices and practical considerations of each case context as the situation changes and the disease progresses (28). The effects of these influences progressively work to reduce the treatment options available to a few “acceptable” treatment approaches (Fig 3.3) (28,29). The end result, however, is still a determination that there are no alternative treatment options available. a determination that there are no alternative treatment options available.

![Figure 3.3 The process of funnelling](image)

**Figure 3.3 The process of funnelling**
3.7.1 Reviewing the processes

The nature of the interactions between those involved in the decision-making and the content of the information that has been provided to the family and the patient are reviewed in this section, given that the manner that this information is organized and provided is critical to how the decision is taken and how authorization is acquired. Such information also plays a significant role in the funnelling process through the influencing of patient choice.

Disclosure of clinical findings, discussions regarding treatment options and attempts at consenting are subject to varying levels of influence or “guidance” by the professional (61). O’Neill argues that even when capable, competent and involved in the decision-making process, patient’s labour under the ideal of action under “certain descriptions” (61,62). There appear to be three aspects to these “descriptions”. The first relates to the internal or patient-dependent factors, which are associated with the patient’s bio-psychosocial considerations, personal goals, individual deliberative processes as well as affective factors. The second relates to the external factors that include the practical considerations, clinical factors and physician-led factors. The third is related to the contextual and temporal factors involved and straddle the two other considerations.

Whilst these elements of influence play a significant role within the decision-making process of a patient, in many cases it is the external factors that take precedence. Frequently, medical and practical considerations define the nature of the choices provided with only a passing consideration of the psychosocial, personal, spiritual, societal and cultural factors that may be involved in a case. The role of the physician cannot be underestimated. Deliens et al, Chambaere et
al, van den Block et al, Kwee et al, Wu et al and Foo et al show that the physician’s age, religion and attitudes as well as clinical experience are integral in influencing how care decisions are made (46-48,56,63-65). The physicians’ level of comfort in prognosticating and communicating their findings also impacts the decision-making process, which is also influenced by treatments that they fine conscionable (71-78). The willingness of physicians to share and involve the patients and their families in the framing process is also pivotal to the decision-making process (71-77).

Other factors that influence decisions include a patient’s ethnicity, cultural beliefs, societal expectations, social class and gender as well as their underlying illness and their level of education (51-55,59,64,66-70). All these factors form a part of the funnelling process that influences the final decision on intractability.

3.7.2 Considering Jaafar’s situation

In reviewing Jaafar’s case, the question that arises is what reasons were there to prompt a diagnosis of intractability? Was a motion to determine intractability in Jaafar’s case simply a means of acknowledging that all attempts had been tried and that the treatment of last resort should be opted for, or was it the result of an exhausted family and an overwhelmed MDT “resorting to sedation because [they] are fatigued and frustrated by the care of a complex symptomatic patient”? (15).

Sharizah’s concerns were instructive to the team and the family in scrutinizing the rationale for this formal determination. It also highlighted the gravity of this process and reiterated the implications. It also set Jaafar’s case apart from the
usual occurrences with patients with intractable suffering. In Jaafar’s case, the family’s request for CDPS triggered these reviews; however, this occurrence is a rarity. In most cases, in my experience, determinations of intractability do not take place due to medical resistance and familial strife, particularly as a conclusion that “nothing” more can be done except CDPS can seem like an abandonment of the patient.

In the ideal situation, a consensus decision between all the parties after confirming that the decisions taken up to this point were correct, would be in keeping with the goal of the MDT. When all parties agree that there are no options less risky or less sedating than CDPS exist, that all options that remain are either intolerable to bear or will take too long to work, a determination of intractability can be made.

However, in Jaafar’s case, this was not to be. The divisions both within the MDT and the family were too great. This made a thorough review of the case necessary. Overturning one view in favour of another is never easy especially when such divisions exist. This was not simply a decision made by the physician alone, either as the chairperson for the MDT or as the final arbiter of treatment decisions. Given the importance placed upon accountability and transparency, the decision-making process re-evaluated all the various facets involved in Jaafar’s case. This process was MDT-led. A final decision that was ultimately the physician’s did not, however, dilute the ability and function of the MDT to ensure that decisions were appropriately balanced. The physician’s “prerogative” to act as the final arbiter is one that is adopted “hesitantly” and only when divisions are insurmountable and time limitations prevent a convening of an ethics consult.
Within Jaafar’s case, given the dissent and the concerns within the MDT, a consensus decision was not forthcoming. When Sandman and Munthe’s strategic decision-making process adapted to the end-of-life situation was employed, it became evident that there were a number of considerations that needed to be addressed (29). These considerations included the fact that

(a) The MDT controls “what the decision is about”.
(b) The MDT “allow[s] patients to take part in decision-making to different extents”.
(c) The MDT maintains the institutionally sanctioned idea of “lowest acceptable limit of what could be offered to the patient”.
(d) The MDT has an “idea” of “what would ideally benefit the patient the most”.
(e) The MDT aims at consensus decisions.
(f) The MDT, in the event of discrepancy between what the patient wishes and what the physician offers, aims at compromise within the limits of points (c) and (d).
(g) The MDT is motivated to act out of “caring for the autonomy of the patient”.
(h) The MDT is motivated in securing adherence.
(i) The MDT will adapt to various circumstances in accordance “to the professional ideal”.
(j) In order to secure compromise, the MDT may act strategically by balancing patient autonomy and best interests.
(k) In the event that consensus is not attained, then the Professionally Driven Best Interest Compromise Model is adopted if best interests takes precedence; if autonomy is prized above best interests, then Shared Relational Deliberative Joint Decision Model or even the Shared Rational Deliberation Patient Choice is adopted. There is no advice as to how “weight” is given to each of these determinations (29).
3.7.3 Accepting that “nothing” is possible

Underlying the dissent of Sharizah and the imams was a fear of abandonment. For the imams, it was fear that they would not to be able to pray with Jaafar when death came; for Sharizah, it was more a sense that there was “nothing” more that medical science could offer her father beyond circumnavigating his awareness. Understanding her conception of “nothing” was enlightening to the deliberation. What is “nothing” within the end-of-life context?

The elucidation of what “nothing” means requires some “unpacking”. Jaafar had had a determination of “nothing” or no treatment options available a number of times before. Initially he had been told that there was “nothing” that could be done to cure him, and later “nothing” could be done to stem his disease progression. Later “nothing” could be offered to prevent his suffering, and finally, when a determination of “nothing” meant that there were no treatment modalities either medical or alternative available that could be used to ameliorate his suffering, “nothing” gave way to CDPS.

“Nothing” is also a matter of perspective. For Jaafar, “nothing” would seem to be the failure of conventional and alternative measures to relieve his suffering; however, in light of his continued suffering, “nothing” provided hope of relief. For the medical team, it was that there were no more viable treatment options available, save the application of CDPS. However, when Jaafar was comfortable and no longer distressed, many members of the MDT viewed it as a “success”. For his wife Yati and son Hussain, it was that their efforts, support and care had not brought about an appreciable difference in Jaafar’s condition. However, even for them, the level of comfort that Jaafar exhibited after CDPS was employed
proved to be an improvement. For Sharizah, it was that “nothing” was an abandonment of her father. For the imams it was a sign of a lack of faith that God would provide a solution.

“Nothing” is also a time-sensitive conclusion. For the imams, the situation was still salvageable, if given more time. Their position appears to resonate with that of Aldous Huxley who once commented that “[e]xperience is not what happens to a man; it is what a man does with what happens to him” (79). They believed that given sufficient time, Jaafar may see the means of improving his own experience of illness (79). In practice, CDPS was considered as there were no treatments available that would likely provide an appreciable improvement in an acceptable time frame. Remaining treatment options were deemed either likely to take too long to work to provide any sustained improvement in the patient’s condition, or would likely result in intolerable or unacceptable effects upon the patient. For the MDT, a significant consideration was the balancing of the possibility of success with the ongoing suffering that the patient would endure during any treatment.

“Nothing” is also a determination that can only be made after the patient’s condition has been thoroughly reviewed. A holistic review of treatment choices and their rationale for use and their selection over other options need to be considered. Review of the discarded options to see if in the present light, they may be viable, must be carried out. Balancing between expected benefits and estimated risks are also tampered by what the patient would have deemed to be acceptable and tolerable and what the family may feel on this issue.

The social and indeed familial repercussions of a determination of “nothing” cannot be ignored. I have in the past argued that the effects upon the family,
particularly in the presence of filial piety and larger social and familial expectations to continue to care of the patient, are pivotal (23,48,60). For Sharizah, there was a semblance of this feeling that she was remiss in her duty to protect her father’s life, particularly in a society where cultural and social expectations would hold a child to this wider obligation (24,60). Failure would be tantamount to an “abandonment” of the patient (24,60,80). Sharizah also found the sentiment, which Dyer offers, of simply “being there” for the patient or “journeying” with her father rather empty and “vacuous”, as did the imams who felt praying for Jaafar would be no substitute to praying with him (81).

The implications of a determination (or non-determination) of “nothing” is as critical as the diagnosis itself. For Jaafar, it meant that he would suffer without this determination being made. For his family and carers, it was that death would now not be stifled or delayed any further. A realignment of expectations and a further adaptation to the goals of care ensued. Anticipatory grief and preparations took place at different levels amongst the various parties and support by the MDT continued.

While the offer of an ethics committee referral was made, both Sharizah and the imams declined stating that they were satisfied that they had “said their piece”. In part it may have been that, on reflection, the option available was clearly unacceptable.
3.7.4 Considering CDPS

The decision for CDPS is the decision that follows a diagnosis of intractability. “Funnelling” has come to an end and we stand at the “sharp” end of Wirtz et al’s funnel (Fig 3.4) (28). The framing process replete with due considerations of all parties and factors and the revisiting of other options and alternatives has already been done. The options left before the patient, the MDT and the family is a stark one – whether to allow the patient to continue to suffer or to be sedated to unconsciousness. It is this decision that ultimately sits at the base of any diagnosis of intractability.

![Diagram showing progressively fewer treatment options as the symptoms and the disease progresses leading to a final diagnosis of intractability.]

**Figure 3.4** Wirtz et al’s funnel

Under the aegis of an overarching of goal of care for symptom relief, the decision that follows must be one that would see the patient sedated to unconsciousness unless there are very good reasons to the contrary. In Jaafar’s situation, the decision did not come easily for members of the extended team and some members of the family. In both the imams’ case and Sharizah’s situation, the decision to overturn their decisions was not without long and hard deliberations and upon a comprehensive assessment. It is clear too that complying with their requests breached clinical guidelines, ran against evidenced care options,
breached the minimum acceptable care standards and placed the best interests of
the patient in jeopardy. Both these parties were still offered support by the MDT
and counsellors who monitored Sharizah’s situation especially closely as did the
remaining members of the family.

For Jaafar, however, application of CDPS was brief as he suffered a massive
myocardial infarct two days after CDPS was commenced. He died peacefully and
in the company of his family and loved ones. The two imams were present at his
last breath and prayed for him.

3.8 CONCLUSION

In this chapter I have shown that whilst intractability is often discussed,
differences and limitations in case-specific clinical and practical considerations
leading up to its determinations make for significant variability that must be duly
considered. It is not the final decision of intractability that is left unclear but those
decisions that immediately precede it. Those decisions where treatment choices
were discarded, assumed to be unacceptable or intolerable to the patient and/or
the family are the factors that finally set the stage for a final decision, which is in
fact almost entirely the product of framing.

It is also those decisions that highlight the funnelling process that attention must
turn to. Sandman and Munthe’s strategic decision-making process does aid in
ensuring that professional and clinical standards are maintained. Guiding this
process must be a small MDT that will best ensure that a holistic review of the
case takes place and the other goals and roles of the MDT are met.
In the end the decision that sits at the sharp end of the funnel is one that must be led by a best interest decision delineated by the family, the patient, the MDT and the physician in charge with whom the final decision rests. An irresistible question that then arises is, what of the patient’s consent? Has the authorization for this intervention been entirely circumnavigated by the adoption of the small MDT? I will discuss the issue of consent in the next chapter.
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Chapter 4

THE ETHICAL JUSTIFICATION FOR APPLYING CONTINUOUS DEEP PALLIATIVE SEDATION WITHOUT CONSENT

4.1 INTRODUCTION

In the last chapter, it was demonstrated that the process of funnelling and framing would lead inextricably to the conclusion that continuous deep palliative sedation (CDPS) ought to be applied. This raises the question as to the position of consent within this apparent cascade of events. I am reminded of the quote by Lord Devlin in his summation of R v Adams where he states:

“If the first purpose of medicine, the restoration of health, can no longer be achieved there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life” (1).

The significance of this statement is highlighted by its prominent place in Australia’s Treatment of Terminally-ill Patient’s Bill 2002 and in the Attorney General’s response to the Select Committee on Assisted Dying for the Terminally Ill Bill in 2005 (1-6). Devlin J’s summation also formed the basis of Lord Goff’s judgment in Airedale NHS Trust v Bland and guided Justice Sir Stephen Brown’s clarification on the legal position on the use of sedatives and opioids at the end of life in the matter of Annie Lindsell (7,8). It is this rich legacy and its implication upon current clinical practice that underpins the use of Devlin J’s statement in this thesis (7-9).
Professor of law Peter Skegg applies this quote to suggest that the application of treatment that may potentially result in significant morbidity and indeed mortality is legitimate and justified within “the proper practice of medicine” if the goals of care are clearly focused upon relieving pain and suffering in the terminally ill (9). This opinion, echoing the position of the British Medical Association, might be applied to the practice of CDPS for a number of reasons (7,9).

As I have discussed in Chapter 2, the overarching goals of care under which CDPS is applied do acknowledge that “the restoration of health” is no longer possible (1). In its place, the goals of care that oversee the treatment of the patient now focus instead upon “reliev[ing] pain and suffering” (9-11). This meets the first of Lord Devlin’s requisites (9).

The second condition relates to the conclusions drawn from Chapter 3, where I argued that this palliative option sits at the sharp end of the funnel and represents the only means available to realize the goals of care for a specific group of patients who continue to suffer (12). This group of patients are those who are terminally ill, with a prognosis of less than two weeks and who have exhausted all “proper and necessary” means of alleviating their suffering; these patients continue to suffer (9-11).

Resistance to treatment of these patients by CDPS persist, however, led primarily by fears that this treatment of last resort “may incidentally shorten life” (9,13-17). Morita et al in 2001, Sykes and Thorns in 2003, Claessens et al in 2008 and Krishna et al in 2010 and 2012 have shown that this is not the case (18-24). Carefully monitored conservative applications of the lowest possible doses of sedating medications in tandem with the continued application of clinically
assisted nutrition and hydration (CANH) mitigates continued fears with regards to the objectives of the intervention, whilst enabling healthcare professionals (HCPs) to respond quickly, proportionally and effectively to any changes in the patient’s condition (10,11,13,14,16,25).

With clarification of the goals and practice of CDPS, the justification proposed by Lord Devlin and Professor Skegg for the treatment of patients whose goals of care are the relief of suffering and in whom suffering persist, can be used to support both the ethical and legal permissibility of using CDPS for patients with intractable suffering (9). This mere sketch of a justificatory framework does not provide, however, clear enough principles for lawful and ethical conduct in carrying out this practice even when it is clarified that the intent of this procedure is to circumnavigate awareness of suffering without intentionally hastening death through the maintenance of deep levels of sedation in a manner that is consistent with regnant guidelines and clinical standards, monitored and overseen by a MDT when the prerequisites of diagnoses of intractability, terminality and futility are made and the application of this treatment of last resort is in keeping with holistically appraised determinations of being in the patient’s best interest are met (9). In particular, at least three aspects of the practice of CDPS may come into conflict with the law. The first relates to the inclusion of existential suffering as an indication for the application of CDPS, which I defend in Chapter 2. The second relates to the application of this treatment without consent, which I will discuss here and the final aspect is the precipitation of “social death” as a result of the induction of unconsciousness in these patients (26). I will discuss this last matter in Chapter 6.
For now, I will focus upon the question as to whether Lord Devlin’s point that a physician “is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life” extends to the possibility of CDPS being applied without consent (9).

I will begin with a description of the current position of consent within the decision-making process for CDPS.

4.2 THE CURRENT POSITION OF CONSENT FOR THE APPLICATION OF SEDATION AT THE END OF LIFE

The issue of consent within the CDPS setting extends far beyond simply being a means of authorization of “bodily touching” that circumnavigates concerns of “criminal and civil liability” associated with any medical undertaking (9). At its core, consent within the CDPS setting is seen as a means of respecting the choices of patients and a means for patients to determine what should happen in their care and to their bodies and lives (9). This is the basis for the continued importance placed upon requirements for consent within the regnant terminal sedation (TS) guidelines [Appendix 1, 2 and 3] and the palliative sedation (PS) guidelines [Appendix 5 and 6]. The primacy of consent still sits as a central requisite for the application of PS for authors such as Levy and Cohen, Blondeau et al, Ventafridda et al, Seymour et al, Braun et al, Graeff and Dean, Davis and Ford, and Cherny, as well as guidelines such as the Fast Facts guidelines and the guidelines forwarded by the American Academy of Hospice and Palliative Medicine (AAHPM), the Norwegian Medical Association (NMA), the Hospice
and Palliative Care Federation of Massachusetts, the Veterans Health
Administration’s (VHA) National Center for Ethics in Health Care, the Hospice
and Palliative Nurse Association (HPNA) and the National Hospice and Palliative
Care Organization (NHPCO) (10,11,27-45).

It is unsurprising that Claessens et al reported that in their review of research
literature on PS practice and guidelines that spanned care approaches in Europe,
Asia and America, explicit consent remained a primary requirement within many
guidelines and for many physicians (46).

However, there is a growing body of professional opinion that holds that in most
cases the ability of patients to give voluntary and informed consent is limited (13-
15,47). As a result, proxy decision-making has been adopted by guidelines
proposed by Morita et al, Chiu et al, the American Medical Association Council
on Ethical and Judicial Affairs (CEJA) report on Sedation to Unconsciousness in
End-of-Life Care (CEJA Report 5-A-08), the American Medical Association’s
Code of Medical Ethics report on Sedation to Unconsciousness in the End of life,
the Royal Dutch Medical Association’s (KNMG) Committee on the National
Guideline for Palliative Sedation report and the European Association for
Palliative Care (EAPC) recommended framework for the use of sedation in
palliative care (10,11,34,38). The NMA guidelines revert to a best interest
principle as a source of alternative authorization (32).
4.3 THE CAPACITY FOR VALID CONSENT

Consider the case of Yip Chak, an 83-year-old Chinese man with lung cancer whose disease had already metastasized to his adrenal glands, liver, brain and contralateral lung by the time he was diagnosed. This aggressive tumour did not respond to three different lines of chemotherapy with progression noted in his lepto-meninges, bones and lymph nodes.

Not long after the failure of the third line of chemotherapy, Yip Chak was found to be suffering from severe headaches and hallucinations that left him in tears and distress. These symptoms persisted despite many lines of conventional and alternative treatment measures. The family, being aware of his critical clinical condition that was no longer amenable to curative measures, chose to adopt a change in his treatment stance, from one aimed at cure to one focused upon maximizing his comfort and relieving his suffering. As a result of this acceptance of an exhaustion of treatment options both for his underlying disease and for his increasingly difficult to manage symptoms, his continued suffering and very limited life expectancy, the multidisciplinary team (MDT) concluded that Yip Chak’s symptoms were intractable and that Yip Chak should be offered CDPS as a treatment of last resort.

However, questions arose as to his capacity to consent for this procedure, not least because of his episodes of confusion, which in turn may have been compounded by a number of factors. This included his ongoing chest infection that was made worse by the continued use of steroids for treatment of his brain and leptomeningeal disease and as part of his whole brain radiotherapy treatment regime, his background of emphysema and his predisposition to infections as a
result of his misshapen lung due to his extensive lung disease. Furthermore, Yip Chak’s mental state was also compromised by his poor glycemic control due to his steroid use and episodes of arrhythmias as a result of his valvular and coronary heart disease that predisposed him to small strokes. His brain metastasis only compounded the situation.

Whilst Yip Chak did have moments where he could communicate with others, they were brief and erratic. Medical staff and family found that they had little more than a chance to ask him a simple question before he would become confused or agitated again. He also had no memory of what he had said during his “communicative” moments, nor of what was told to him during these brief respite from his confused and agitated state. There was little in the way of assessing his competence, much less how much he understood of his present condition beyond a recognition that he was aware of his hallucinations and was becoming increasingly distressed by them.

It is only in understanding the various factors that influence the key facets of consent can the position of consent within the CDPS setting be truly appreciated. Yip Chak’s complicated clinical, familial, financial and psychosocial situation reveals the wider considerations regarding any determination of competence and the influence of these many factors upon the consent process.

It is clear from Yip Chak’s clinical and general physical condition that restoration of health can no longer be the prime focus of care. Yip Chak’s situation instead steers considerations towards an overarching goal of care that is focused on the relief of suffering, and the authorization of CDPS as the treatment of last resort. Yip Chak was unaware of his present situation and this situation was
compounded by the presence of his confusion and agitation. Whilst he did exhibit
brief periods of lucidity, they were erratic and of varying frequency, raising the
question as to how much information he may be able to receive and consider, and
whether it could be sufficient to enable him to make an informed decision and
communicate his wishes to his carers.

To elaborate on these points I will use the framework offered by Singapore’s
Mental Capacity Act of 2008 (MCA) to set standards and criteria for assessments
of capacity, and to review these various factors that affect the consent process that
Yip Chak would have to undergo (52). Latterly, I will review the alternate means
available to establishing authorization for any treatment decision proposed.

### 4.4 WHAT STANDARDS ARE TO BE MET IF CAPACITY IS

TO BE DEEMED PRESENT?

Singapore’s Mental Capacity Act of 2008, echoing the Law Commission on
Mental Capacity’s definition of incapacity, states that

> “a person lacks capacity in relation to a matter if at the material time he is
unable to make a decision for himself in relation to the matter because of
an impairment of, or a disturbance in the functioning of, the mind or
brain” (52,53).

Section 5(1) of the MCA also states that a person is unable to make a decision for
himself if he is unable

> “(a) to understand the information relevant to the decision;
(b) to retain that information;
(c) to use or weigh that information as part of the process of making the decision; or
(d) to communicate his decision (whether by talking, using sign language or any other means)” (52).

4.4.1 Ability to understand the information relevant to the decision

Appraisal of a patient’s understanding of the issues must include the scrutiny of the information imparted to the patient and their comprehension of this information. Given the importance of this facet, the effects of the various factors that influence the efficacy of this facet require close consideration.

The presence of delirium, a transient organic brain disorder characterized by acute onset of disordered attention and cognition that is present in up to 85% of cases of terminally ill patients, is telling (54-57). These symptoms tend to develop rapidly and fluctuate in severity and duration (55). Its presence in Yip Chak’s case constitutes an “impairment of, or a disturbance in the functioning of the mind or brain” (52-57). Although the effects of delirium can be reversed if the offending factors are removed, there were numerous potential causes for the predisposition and perpetuation of delirium in Yip Chak’s case (52-57). An understanding of these treatment sequelae and ill effects of the comorbid conditions that affected Yip Chak’s cognitive ability is required.

Yip Chak’s comorbid conditions were primarily attributable to his poorly controlled diabetes, ongoing ischemic and valvular heart disease and poor lung function. These compounding clinical complications were amongst the precipitating factors for delirium or were in fact causes of confusion in their own
right and required stabilization if Yip Chak was to have any chance of participating in the deliberations about his care options. The concomitant application of the sedatives used to ameliorate his agitation and shortness of breath, which clouded his consciousness; the steroids, applied to treat his cerebral oedema that predisposed to a worsening of his agitation; and the opioids, administered to treat his pain and his ongoing shortness of breath which appeared to sedate him; all restricted his ability to participate in the decision-making process, either on their own, in combination with one another or in tandem with his many comorbidities.

Addressing these factors and their immediate effects are a priority. Part II Section 6(4) of Singapore’s MCA is clear that these negative effects upon Yip Chak’s ability to consent should be countered:

“so far as is reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him” (52).

Yip Chak’s complex condition did not allow for this. Attempts to reduce the doses of steroids had little effect upon his agitation but did conversely precipitate a deterioration in his symptoms of dyspnea and headaches within 12 hours of its reduction. Trial of reducing either his opioids or sedatives also failed to clear his thinking and conversely precipitated an increase in his symptoms of agitation, dyspnea and confusion. All attempts to change the drugs being used to other equally effective alternatives in the hope that their side effect profiles might be less incapacitating were also attempted to improve Yip Chak’s condition. These efforts, too, were met with failure.
Concurrent efforts to address the presence of psychiatric symptoms that could impair the consent process, initially through psychological and counselling means so as not to complicate his clinical picture as pharmacological alterations were being carried out to address his physical symptoms, also failed. His symptoms such as anxiety, seen in about 25% of terminally ill patients, and depression, reported in about 50% of patients at the end of life, that can and do affect cognition and concentration were also addressed (13,14,57-60). It was only when these non-pharmacological attempts failed that they were supplemented by clinical interventions. These efforts failed too and a psychiatric review confirmed that Yip Chak remained incapable of making treatment decisions particularly as his periods of lucidity were inconsistent and erratic.

Alongside these attempts to correct his clouded mental function were efforts to address the other stumbling block to his participation in these deliberations. Concerns of the family about disclosure of information to the patient and attempts to overcome collusion and circumnavigate “gate-keeping” were also addressed. This in turn raised two considerations. As Beauchamp and Childress assert, there is a need to consider if patients such as Yip Chak would have wished to know of their condition, much less participate in their care determinations (61). Whilst Yip Chak has a right to participate in a decision-making process, there is no mandatory duty to do so and he may have simply been exercising his prerogative (61). The evidence accrued from the family and by the fact that he had until this point been content to allow his family to decide on the course of treatment despite having numerous opportunities to ask for further information himself should he have desired it, might be seen to suggest that he had no wish to participate in the
deliberative process and was quite content to delegate these responsibilities to his family.

Yip Chak’s wish to remain positive throughout his illness may have motivated the medical team and family to continue to gate-keep information, if only to “protect” the patient’s overall belief in the curative powers of “positive thinking”. Providing Yip Chak with information that would affect his outlook, particularly in his condition, where it would be revealed that little else can be done to ameliorate his symptoms, would have been counterproductive to the family’s efforts to promote positive thinking and hope. This is frequently a reason amongst many local families to collude with healthcare professionals not to brief patients on their “true” condition. In Yip Chak’s case, this underpinned the family’s wish to act beneficently and protect him from the “truth” of his condition (47,48,62,63).

However, there is also the counter argument. Some healthcare professionals raised concerns that he may in fact have changed his mind on not exercising his right to participate in his care decisions in light of his worsening condition. These team members argued that there may also be matters that he would wish to address if he was made aware of his true condition. Some members of the team felt that the option of asking him if he would wish to discuss his condition ought to be forwarded. The medical social worker’s review of Yip Chak’s case that revealed that there were now doubts as to whether his family, now emotionally and physically exhausted at having him in an agitated state, were acting in his best interest or out of fear that he might change his “will”, raised more concerns. There was a suggestion that the family may in fact have been keen for the
injudicious application of CDPS if only to alleviate their own concerns and distress.

Although these factors represent significant considerations, they were in reality, limited by Yip Chak’s ability to retain information provided.

### 4.4.2 Ability to retain that information

Retention of information is a prime concern particularly amongst patients being considered for CDPS. Here variability in consciousness, concentration and the coadunation of all those factors discussed in the earlier section compound concerns about the ability of a patient to retain information. This situation is complicated by the knowledge that even healthier patients who do not suffer from any limitations to their mental abilities struggle with information retention. Bryne et al found that only two to five days after information was provided to post-operative patients and consent attained, as many as 27% of patients were not sure of the nature of the intervention proposed and a further 44% were not aware of the basic facts about the process (64,65). Questions are naturally raised then as to whether CDPS patients in general and Yip Chak in particular would actually be capable of retaining clinical information about their conditions in a meaningful manner so as to be able to actively participate in the consent process.

In Yip Chak’s case, this was unlikely. His fleeting episodes of being communicative were too erratic, his recollections of previous conversations were impaired and his “cognitive continuity” diminished. He was not able to retain information from one period of lucid communication to another, raising questions
as to whether he could retain any information for a sufficient length of time to cogitate upon it. His steroids, his pain and his shortness of breath, which aggravated his general anxiety would have compounded this situation by limiting his ability to concentrate and thereby compromising his ability to retain information. Similarly his brain metastasis and his ongoing headaches further compounded his ability to be receptive of new information.

Overall, too, the actual ability of patients to retain any information in the face of intractable symptomology and progressive deterioration as a result of both the underlying disease and the ongoing symptomology and comorbidities has also raised questions as to the viability of the consent process amongst these patients (13,14,49). This is particularly so when many of these patients, are subject to a wide range of side effects as a result of the various treatments options applied to control their ongoing symptoms and as a result of the disease effects. This would suggest further compromise to the ability of such patients to appropriately weigh up the information provided in order to make an informed decision.

4.4.3 Ability to use or weigh that information as part of the process of making the decision

The worry as to the ability of patients to weigh up information provided is particularly vivid in the face of a coadunation of cognitive impairment and coercive factors, both internal and external, raising the question as to whether truly “free” consent exists (13,14,60,64,65).
In Yip Chak’s situation given his limited information, his relatively small window for communication and a lack of recollection between each lucid moment, it is unlikely that he would be able to fully balance the risks and benefits of the situation (13,14,60,64,65). As I have argued elsewhere, the presence of severe symptoms and general debility do compel patients to make decisions that may not consider any factor beyond the immediate relief of their suffering (13,14,49). In a discussion in the earlier stages of his illness and when Yip Chak was still competent but suffering from headaches, he was provided with a number of treatment options for his headaches; his response was instructive. He chose the treatment that would have most rapidly extinguish his suffering even though there were significant side effects to it and there were other less risky albeit slower means of treating his symptoms. Later on, when he was suffering from liver capsular pain as a result of his liver metastasis, Yip Chak opted for rapid relief of suffering over safe alternatives. This type of responses are regularly seen amongst many palliative care patients who are suffering – their suffering may prevent them from appropriately considering their alternatives. In many cases, in my experience, the pivotal consideration of these patients with intractable and frequently prolonged symptoms is the relief of suffering. It is for this reason that I argue that suffering ought to be considered a coercive influence upon the decision-making process (13,14,49).

These coercive factors upon the patient’s ability to weigh up information properly also come in the form of familial pressure (14,48). I have previously described how a young lady with a haematological malignancy decided to forego potentially life-prolonging treatment as a result of familial pressure and financial constraints (14,48). Awareness of the presence of these factors are key to HCPs’
ability to determine if patients can “appropriately” weigh up the information that is provided to them.

There is also a doubt as to whether Yip Chak could “use or weigh that information as part of the process of making the decision” due to his limited information on his condition as a result of ongoing collusion and gate-keeping amongst his family members (52). Additionally, given the erratic nature of his ability to communicate, there is concern as to whether he could make his decision known.

4.4.4 Ability to communicate his decision (whether by talking, using sign language or any other means)

The presence of physical impairment and cognitive problems as well as the coercive factors highlighted raise questions as to whether patients being considered for CDPS would be able to communicate their wishes appropriately. Data collected from dying palliative care patients reveals that 15% of patients were unconscious, a further 10% were drowsy, 14% were confused and 22% of cases were agitated during the last two weeks of life, which coincides with the time frame for the application of CDPS (25). Overall, 61% of patients within the patient population from which CDPS patients must come are physically incapable of communicating (25). The remaining 39% of patients in turn appear subject to other considerations.

The presence of psychological and existential causes for limitations in the capabilities of patients to communicate cannot be discounted. The Oxford
Textbook of Palliative Care states that up 25% of palliative care patients at this stage of life suffer from clinical depression and diagnosable psychological deficits, which will affect their capacity to participate in the decision-making processes (57). Whilst not completely impinging upon the ability to participate in clinical decisions, their decisional capacity is liable to fluctuate or remain weak as will their ability to communicate their wishes.

As discussed, Part II Section 6(4) of Singapore’s MCA requires that

“so far as is reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him” (52).

This envisages “the use of ‘simple language, visual aids and any other means’ appropriate to the circumstances of the person being evaluated” (64).

Psychologists, psychiatrists and counsellors as part of the MDT can act to support the patient in tandem with the implementations of pharmaceutical interventions to reverse the effects of psychological and physical compromises. In Yip Chak case, clinical measures were also attempted, in a controlled and carefully monitored way, to nullify or attenuate detrimental psychological and physical effects upon decisional capacity.

Practically, efforts must be made to engage these patients in a manner and level of communication that would be best suited to the abilities of these patients.

Without these measures, nearly 86% of patients may be expected to fail to meet prevailing competence requirements, much less communicate their decisions in a meaningful manner (23,24). In recognition of this fact and the requirements set out by the MCA, the MDT must consider
“(a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity); (b) the beliefs and values that would be likely to influence his decision if he had capacity; and (c) the other factors that he would be likely to consider if he were able to do so” (52).

This will help to ensure that the options offered to the patient and the preferences communicated are in keeping with the patient’s own views and consistent with their previously voiced positions.

In keeping with Part II Section 6(8) of Singapore’s MCA, the MDT is also tasked with taking into account the views of

“(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind; (b) anyone engaged in caring for the person or interested in his welfare; (c) any donee of a lasting power of attorney granted by the person; and (d) any deputy appointed for the person by the court” (52).

This then serves to reassure all parties that efforts are being expended to meet the informational needs to suit the patient’s specific requirements and also to equip the various parties involved with the background information and means to appropriately interpret the patient’s responses.

Continued efforts to involve the patient in conversation and decision-making can be therapeutic in itself (67-69). Kitwood, for instance, suggests that continued involvement with the decision-making process can be maintained simply by allowing for the interpretation of gestures and facial expressions (67-69). Here the concurrent presence of various family members and carers who know the patient
well provide an opportunity for these interpretations to be validated and confirmed to ensure their authenticity as much as practically possible.

The question that inevitably arises is, how much weight ought to be placed on the patient’s gesticulations and utterances, and sometimes the interpretations of the patient’s movements and utterances by others, within these determinations? In situations where the patient may only participate in some aspects of the decision-making process, the physician led by the MDT must engage other parties to appropriately assess the patient’s wishes and ascertain best interest. To do so, employment of Sandman and Munthe’s “strategic decision-making process at the end of life model” discussed in the previous chapter is required (70).

The adoption of a “strategic decision-making [process] mainly on behalf of the professional” form of shared decision-making is to ensure that in these circumstance where the patient is not able to fully participate in the decision-making process, the best interests of the patient are protected (70). However, the prime reason for its adoption at this juncture of the consent process is to ensure that in the near absence of high-level dynamics in these interactions with the patient, information and communication that involve the patient are focused upon facilitating their involvement in the decision-making process (70). It also prevents the interest of the family or other parties subverting this process, as it may have done in Yip Chak’s case (according to the medical social worker’s report).

The “Professionally Driven Best Interest Compromise Model” is “openly strategic” in that decisions on how much weight is to be placed on the input of the patient as a result of the information that is provided is defined by the MDT who have discerned the optimal medical course for alleviating the patient's suffering.
and what information can realistically be attained from the patient given their particular condition (70). All parties are also aware that the MDT is acting strategically around a predetermined goal of protecting the patient’s holistically determined best interests (70,71). There is acceptance that the inputs of the patient may help mould the manner that the MDT responds to his or her needs but overriding this is the requirement that this response must comply with the minimum standards of care set out by prevailing guidelines and clinical standards as well as be in keeping with the best interest determinations set out by the MDT in conjunction with the various parties involved (13,14,47-49).

The purpose of this stepwise review of each element of the consent process has been to highlight that within the context of CDPS applications, the prevailing consent process as it stands appears compromised at multiple levels.

At present there are two options – the traditionally applied surrogate decision-making process, where the role is traditionally played by the family within the local setting, or the best interests principle (BIP) that has been adopted by Singapore’s 2008 Mental Capacity Act (52). I will begin by considering proxy or surrogate decision-making.

4.5 THE POSSIBILITY OF PROXY OR SURROGATE DECISION-MAKING

Surrogate or proxy decision-making has often been seen as a means of ensuring that the patient’s opinions, values and beliefs continue to be considered in determinations about their care when they themselves may be incapable of doing
so. Surrogate or proxy decision-making, particularly by family members, is also seen to meet other objectives (72,73). The American Medical Association (AMA) hold within Opinion 2.20 of the Council of Ethical and Judicial Affairs (CEJA) that surrogate decision-making can also be used to soothe any tensions between medical decisions and the wishes of the family (72,73). Within the local setting, it would appear that it is this factor that drives indulgence in family participation in ongoing deliberative processes (14,49).

However, increasingly there has been data to suggest that family involvement has frequently derailed care approaches that a patient had decided upon when competent (47-51,62,63,74). More concerning is the fact that there is increasing data to suggest that even the determinations of a competent patient have been infringed (74-76). Underpinning this is a myriad of care, psychosocial and financial considerations that place family members in situations where competing interests may arise and compromise their ability to place the interests of the patient over their own (47-51,62,63,74). I submit that it is as a result of this data, clinical reports and increasing data that patients do wish to have their own voice in end-of-life decisions that the Mental Capacity Act of Singapore 2008 has attempted to steer away from dependence upon surrogate decision makers (47-52,62,63,74-76). Competing interests aside, the role of surrogate decision maker itself is strenuous and frequently “emotionally draining”, particularly in societies where filial decision-making is still practiced and expected (74-77). Having emotional pressures along with financial, psychosocial and caregiver strain may further hinder and potentially compromise the strategic decision-making process (47-50,78-80).
Furthermore, there is evidence that would show that the concordance rates between patients and their family are only slightly better than the chances gained from “a toss of a coin” (81,82). Krishna and Ho et al suggest that locally, some family members actually make decisions that protect the interests of the family rather than the patient’s best interests (14,48,49,62,63). The validity of complementary decisions between the patient and the family even in concordant decisions are thus called into question. The continued attempts of surrogates at decision-making even when in many cases wishes and plans are not discussed with or known to surrogates would confirm the suspicion that at least in some cases the decision is being led largely by familial rather than the patient’s interests (83).

Physicians appear to be aware of this potential for bias and do appear to act strategically to secure compromise in the shared decision-making process, ensuring that the best interests of the patient and the institutionally sanctioned idea of “lowest acceptable limit of what could be offered to the patient” are not compromised in any decision taken (70). Active framing in deliberations may explain why physicians report only infrequently wishing to overrule the wishes of the family (70,75).

The culmination of these points led largely by clinical experience and local data highlight the weaknesses and inadequacies of the consent and surrogate decision-making process that are well recognized in CDPS and perhaps end-of-life decisions as a whole (14). In its place the CDPS framework sets out to employ a best interest determination approach led by the MDT rather than solely by the physician in charge when considering the application of CDPS. In view of what
has been considered in relation to Yip Chak’s position, authority ought to shift to the MDT in keeping with a palliative care approach to determine the best course of action (14,48,49).

Guiding the practice of the MDT and justifying its actions is the Singapore Mental Capacity Act 2008 (52,84,85). This process in turn is based upon a number of assumptions, which include the fact that

• the patients are terminally ill as determined by a MDT and a set of independent clinicians following holistic evaluation of their situation (see section 1.2.2.3 page 29)

• these patients are being managed by a palliative care team or have consulted a palliative care specialist as an independent second opinion if CDPS is being considered (see section 3.6.3 page 171)

• all patients must be formally assessed for capacity by one independent and the team psychiatrist at two separate occasions as a result of concerns about their capacity to make informed decisions and in light of the gravity of this decision (see page 216)

• this process must not be influenced by the age, clinical condition or diagnosis of the patient even if there are known lesions, previous damage or previous or ongoing abnormalities within the brain and/or central nervous system (see Singapore Mental Capacity Act)

• all patients would have had confusion screens and treatment to reverse all potentially reversible causes of confusion and delirium

• previously stated views of the patient of their experiences with lesser levels of sedation and their goals, wishes and hopes must be considered by the MDT and an independent review undertaken by a palliative care physician, social worker and psychiatrist (see section 3.6.3 page 171)
Figure 4.1  Conceptualizing capacity within the end of life

Appraisal for the application of CDPS

Capable of participation in formal capacity assessment?

Yes

No

Involvement through facilitation

Physician guided by MDT determine treatment

Is this incapacity temporary?

Yes

No

Competent after formal capacity assessment?

Yes

No

Reverse the reversible and treat the treatable causes

Reversible?

Yes

No

Allow patient participation in decision-making process
• all these patients have and continue to be supported by a MDT where their multidimensional needs and care are constantly reviewed to ensure complications of prolonged sedation and continued feeding are prevented (see section 3.7.3 page 181)

• CDPS being considered a treatment that prevents serious deterioration in the patient’s condition and not as a means of hastening death (see section 3.7.4 page 184)

• any donee with lasting power of attorney or a court appointed deputy cannot make decisions regarding CDPS on their own, given that CDPS is considered treatment that will prevent a serious deterioration in the patient’s condition (see Singapore Advanced Medical Directive)

• whilst an advanced medical directive (AMD) would be valid, CDPS is not considered extraordinary life sustaining treatment and therefore will not be affected by the valid AMD (see Singapore Advanced Medical Directive) (71).

These factors underpin the manner that physicians act to determine capacity for participation decision-making for CDPS. Patients deemed to have capacity following a formal capacity assessment become active participants within the decision-making process, whilst those deemed not to be competent are “permitted and encouraged to participate as fully as possible in any act done for him or any decision affecting him” (66). Facilitation to maximize capacity and participation within the Best Interest Principle (BIP) deliberative process take the form of

“relaxing the person through a patient-centred approach, conducting the assessment at a time when patient is most alert, allowing support from close relatives, familiarization with the location where the decision will be carried out and offering privacy to the assessed person” (66).
Underpinning this model of authorization are the principles of necessity, best interests and further, appropriateness and proportionality.

4.6 APPLYING CDPS WITHOUT CONSENT: NECESSITY

The Principle of Necessity has previously been the guiding rationale for the application of treatment without consent in extreme or life saving situations. This principle has largely been incorporated within the best interest model with the advent of consent legislature in the form of the Mental Capacity Act (52,71,84-87). Under the very specific conditions that may be considered “palliative emergencies”, the Principle of Necessity comes into force emphasizing the urgency to act to relieve the patient’s suffering in a timely and appropriate manner particularly when consent may not be possible (52,74-77).

Underpinning this is the belief that in patients for whom CDPS is being considered, continuing intractable suffering at the end of life must be seen as an emergency, much like a life threatening event might be viewed within the accident and emergency setting. Both situations demand urgent attention under the aegis of their respective goals of care. Within the CDPS setting, the goals of care are no longer restorative or curative, as they are in the accident and emergency setting, but focused on the relief of suffering. As a result, within the confines of these evolved goals of care, the cessation of suffering is a priority and thus demands the same considerations as emergency life saving treatments do in an accident and emergency setting. It is in these “palliative care emergencies” that
the Principle of Necessity provides the “force majeure” to compel immediate action.

The necessity to act ought not to be hindered or delayed, particularly within the circumstances where CDPS is being considered and where limitations to the consent process are known and evidenced (81). In these end-of-life circumstances, as shown in Yip Chak’s case, there must be due acknowledgment that limitations to a patient’s autonomy grow as part of the natural progression of the conditions. Self-authorization, the capstone of care determinations, gives way to more practical determinants such as protection of dignity and the maximizing of comfort. The Principles of Necessity and Beneficence supported by the Principle of Best Interests determine the course of care and the maximization of a patient’s liberty.

The English and Welsh Mental Capacity Act 2007 define the Principle of Necessity as “the legal basis by which people who [do] not have capacity to make decisions about their medical treatment [are] given treatment” whilst in the United States Medicare defines “medical necessity” as “services or items reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member” (85,86). This sketch of some of the prevailing conceptions of the Principle of Necessity highlights the rationale for authors such as Bickenbach, Brudner and Moore to conclude that the central issue with regards to the Principle of Necessity is a lack of a universally accepted definition (88-94).

Traditionally, the Principle of Necessity is seen to encapsulate the ideas of the “choice of evils” where the only options open to a physician involve breaching
the interests and rights of the patient in order to protect the interests of the patient and provide meaningful, appropriate, evidenced and clinically accepted benefit to them in situations where consent is not possible (88-94). This thesis maintains that it is the oft unarticulated facet of “force majeure” that is the critical element of this principle particularly within the confines of the MCA (Fig 4.2). I will discuss each of these elements in due course.

**Figure 4.2 Conceptualizing the Principle of Necessity**

Turning first to the necessity for CDPS, it is important to state that the Principle of Necessity ought not to be seen as a means of justification for an action or even as exculpatory rationale but as a means of acting to sacrifice a lesser interest to save a greater one (88). Bickenbach argues that in keeping with the goals of care and in keeping with the demands of the circumstances, autonomy is sacrificed for beneficence (88).

There is precedence for such actions (95,96). In Re: F (1990) the extent that medical necessity can be pursued was revealed when a mentally incapacitated patient was sterilized after it was held by the House of Lords that it would be in
her best interests (95). The necessity to act was guided primarily by the fact that
despite being 36 years old, patient F had a verbal capacity of a two-year-old, the
“general mental capacity of a child of four or five” and was beginning to have
voluntary sexual intercourse with a fellow patient, P, at the mental hospital where
she had been since age 14 (95). Lord Brandon of Oakbrook in summing up his
decision for sterilization stated that this decision was taken as there were
significant problems with alternative contraceptive measures and

“[b]ecause of her mental disability, however, she could not cope at all
with pregnancy, labour or delivery, the meaning of which she would not
understand. Nor could she care for a baby if she ever had one. In these
circumstances it would, from a psychiatric point of view, be disastrous for
her to conceive a child” (95).

Borak and Veileux report further that translocations of the Principle of Necessity
to pain control and the amelioration of suffering is not unknown (97). At its core
is the second facet of necessity, protection of the interests and rights of the patient
(88-94). Necessity in these circumstances is seen to trump the need for informed
consent (91). Borak and Veileux also report that such is the concern about the
viability of consent in moments of extremis that “partial” disclosure in the
consent process is allowed as they argue that in the face of severe pain, for
instance, information is unlikely to be retained and thus consent is unlikely to be
valid (97). The authors add that lengthy and detailed consent is unlikely to be
possible in such circumstances (97). These authors also assert that other
prevailing means of acquiring consent are inherently biased or indeed
compromised by a general lack of clear definition and standards to determinations of competence (97).

As a result Borak and Veileux, like Hansson and Skegg respectively, maintain that applying treatment even without consent is authorized by the standards set by the Best Interest Principle (BIP) so long as there is a documented second opinion confirming the necessity to act (9,96,98). Validation for treating suffering and pain in this manner is endorsed by professional bodies and organizations such as the International Association for the Study of Pain and the Worldwide Palliative Care Alliance, which advocate that the appropriate and timely amelioration of pain as a basic human right (99-101). These bodies support the right to amelioration of suffering and validate the Principle of Necessity, particularly when the goals of care are so clearly articulated, validating the appropriateness and the evidenced-based position of this intervention (88,94).

However, a lack of a multidimensional, multiprofessional review within present applications of the Principle of Necessity proves telling and may underpin its encapsulation within the Best Interest Principle where any invocation of this principle must be accompanied by a holistic review (Fig 4.2) (97).

### 4.7 THE BEST INTEREST PRINCIPLE

Professor JJ Chin in his article on Singapore’s Mental Capacity Act (MCA) states that

“Sections 7 and 8 of MCA 2008 reaffirms that both the UK and Singapore common law positions, that where an adult lacks capacity to make
decisions on his or her own behalf, health interventions will be lawful where there is both a necessity to act and any action is in the best interests of the incapacitated adult” (66).

The MCA’s BIP attempts to articulate a more balanced combination of beneficence and autonomy than the Principle of Necessity taken on its own (52). Whilst protecting “the person against harmful decisions or actions by self, or by others” and “respecting the freedom and dignity of a person despite his incapacity”, the BIP set out by the MCA sets about to meet these goals through means that are “least restrictive of the person’s right and freedom of action” (52,66). Chin adds that this action, which is carried out to prevent serious deterioration in the patient’s condition, must be accompanied and guided by a holistic review of the patient’s condition that would “include reasonably ascertainable past and present wishes and feelings, beliefs and values of the person, and other factors of significance [section 6(7)(a)-(c)]” (66).

Harris adds that justification for BIP-inspired action lies in the fact that it is “not that the patient consented, nor that she would have, nor that it is safe to presume that she would have, nor that she will consent when she regains consciousness or when on ceasing to be a child she becomes competent, but because it is the right thing to do, and it is right precisely because it is in her or his best interests” (102).

Applying the Best Interest Principle must be based upon established clinical evidence that the patient is in fact incompetent or encumbered in such a way as to be unable to protect their interests and that there has arisen a situation that necessitates an agent to act on behalf of the patient to protect his or her interests.
Justification for proceeding with a BIP-based action is delineated by Harris’ statement that

“if we seek the reason why it is the right thing to do, the answer is that to fail or to omit to do it would injure the patient. It is the infliction of THAT injury by act or omission, that would constitute the violation or assault” (102).

In addition, the idea of best interests encompasses the “value of the life for the person who must live it”, set within a situation where the person is unable to ensure their own protection, well-being, survival and development, and is at a point where these interests are threatened (103-105). The BIP requires an agent to act “in the best course of action” to protect the interests of the patient to the “maximum extent possible” (103-105).

Preserving patients against harm and securing their well-being and interests are considered objective criteria of the best interests of the patient. However, the UK Mental Capacity Act 2005, the UNHCR Guidelines on Formal Determination of the Best Interests of the Child 2006 and the Singapore Mental Capacity Act 2008 also include subjective criteria that give expression to patient preferences so far as they are known (52,53,104,105). Combining these elements with determinations of intractability, the goals of care, the holistic evaluation of the case, the decision-making processes, “force majeure” and the practical considerations with regards to suffering and prevailing clinical practices related to sedation at the end of life discussed in Chapters 1, 2 and 3 means that the BIP within the CDPS framework entails that
1. each person has an inalienable right to relief of suffering through the application of appropriate, legitimate, evidenced-based treatment options that are deemed locally clinically and professionally acceptable within a particular clinical setting (see section 1.5.3 page 64)

2. any action must remain focused upon acting in their best interests as determined by a MDT and a set of independent clinicians following the holistic evaluation of their situation (see section 3.7.1 page 177)

3. the undertaking to act in the patient’s best interest must not be motivated by “a desire to bring about the person’s death” (see section 4.6 page 218, section 4.8 page 227).

4. any intervention that emanates from the BIP must be instigated by a clear necessity to act such as the presence of a “clear and present” threat to the interests of the patient; here evaluations of necessity must also be in keeping with a holistic evaluation by the MDT and a set of independent physicians, social workers and psychiatrists (see section 4.8 page 227)

5. the intervention proposed must be the least burdensome, risky and restrictive options possible; the intervention must be shown to be appropriate and proportional to the considerations of the particular case and the necessity of the situation; evaluations of the appropriateness, proportionality and necessity of the situation must be in keeping with the multiprofessional and multidimensional evaluations of the MDT and validated by a set of independent physicians, social workers and psychiatrists (see section 3.7.4 page 184, section 4.8 page 227)

6. during the deliberations on the best course of action and the extent that protection will be conferred, there must be no discrimination on the grounds of race, colour, sex, language, religion, political or other opinions, national, ethnic or social origin, property, disability, birth or status (see Singapore Mental Capacity Act)

7. all efforts to include the patient in the deliberative process should be made (see section 4.4.4 page 208, Singapore Mental Capacity Act)
8. the patient must be assured the right to express their views and that their beliefs, values, wishes and feeling will be considered and given “due weight” within the deliberative process (see section 4.4.4 page 208)

9. there must be consultations with “relevant others” such as the patient’s family, carers and loved ones who have powers to intervene or have interests in the patient’s affairs and personal welfare

10. wherever possible, a multi-professional review must take place; wherever this is not possible, documented second opinions and input from other practitioners and carers involved in the patient’s management must be obtained to confirm the diagnosis of intractable suffering; these are subject to a number of conditions:

(a) all discussions within the MDT and with carers, other professionals and wherever possible the patient must be clearly documented

(b) what, why and how particular considerations were provided with specific weight within these deliberations and how they were balanced must also be justified within the patient’s clinical notes and potentially within the MDT’s records

(c) the rationale for the decision itself and the reasons why alternative options were discounted must be carefully delineated and similarly justified and documented (52,104-106).

(d) in the event a minority decision is taken or where no consensus can be attained within the MDT deliberations, the decision taken by the physician who is legally responsible for the patient’s care must be carefully documented, as should the dissenting views; the rationale and the means that this decision is arrived at must be clearly documented and explained. (see section 4.6 page 218)
4.8 APPROPRIATENESS OF TREATMENT

Items 4 and 5 in the items listed above refer to two further principles; these are appropriateness and proportionality in the determination of treatment application in the best interests of patients for the relief of suffering. I will consider the issue of appropriateness here.

In Ost and Mullock’s review of the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 2002, they state that a key criterion to justifying this intervention of last resort is its appropriateness (107). In elucidating its character, Ost and Mullock describe an intervention to terminate the patient’s life as being appropriate if it fulfils the following:

“the patient’s request was ‘voluntary and carefully considered’; she was informed of her situation and prospects by the doctor; her suffering was ‘unbearable’ and there was ‘no prospect of improvement’ in her condition (the due care criteria have been interpreted as requiring a medical condition which may be physical or psychological in nature); both doctor and patient were convinced that the suffering could not be alleviated through any other reasonable means; the doctor acted with ‘due care and attention’; s/he consulted an independent physician who has given a written opinion as to the criteria being satisfied” (107).

Appropriateness appears to be subject to meeting simple criteria to ensure that treatment offered to a patient is timely and congruent with what the patient and their doctor have agreed to undertake and in line with clinical, psychosocial, spiritual and cultural considerations (108). However, in a series of articles, Fuchs
has argued that an intervention is appropriate if it is worth doing (109). Fuchs argues 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” (109).

“Appropriate health care”, Fuchs argues, must also be viewed in a more general health care setting (109). That the average US cancer patient has three times more MRI scans than a Canadian patient, with no improvement in their “health outcomes”, is instructive (109). According to Fuchs, this point highlights the continued reliance upon hard facts and clearly divisible data to generalize care decisions and validate both the wisdom and the costs of an intervention, which may be flawed (109).

Neither of the goals that Fuchs mentions earlier would actually be met within the CDPS setting by sole reliance upon statistical evidence or generalizable data (109). In the CDPS setting, generalizable data is insufficient for the purposes of a holistic review. It does not capture information about patient and family satisfaction, their spiritual and psychological health, their financial strains and carer burdens nor the severity of their ailments. As a result, judging the appropriateness of an intervention entirely upon clinical percentages and clinical outcome measures cannot be the sole arbiters of appropriateness. Like its sister indicators, holistic and case specific considerations are key.

Fuchs’ observations show that appropriateness is calibrated by the practical context in which interventions are proposed and administered (109). Fuchs adds
“the heterogeneity of patient populations and uncertainty about the response of individual patients to an intervention means that it is often difficult or impossible to determine in advance which ones will prove to help particular patients and which will turn out to have been unnecessary” (109).

In America, for instance, it would appear that “aggressive” investigations and interventions are deemed “appropriate” and has led to and been duly fed by the manner that the health care system is funded and managed (109). The same type of management may not be viewed as appropriate within the Singapore setting, for example (110,111).

Appropriateness is also dependent upon what can realistically be provided by the MDT within a specific setting, so long as it meets accepted clinical, professional, legal and psychosocial standards. Appropriateness of an intervention such as CDPS depends upon a number of factors that include,

“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” (112).

The competency and experience of the physician; training and expertise in end-of-life care; the relationship that they share with the patient and their family; their communication skills and their ability to appropriately understand, weigh and balance the various sometimes competing factors and obligations; and the
cultural, religious, ethical, psychosocial and clinical factors involved within a specific situation help define the appropriateness of both the timing and manner of their interventions. Appropriateness is also dependent upon the ability to harness the resources available to the professionals appropriately, their relationships with other professionals involved in the patient’s care and their ability to act within a MDT is critical to this judgment. Appropriateness is thus a factor of the nature and extent of involvement of various parties in the care deliberations and treatment provision (Fig 4.3).

![Figure 4.3 The interrelated nature of appropriateness](image-url)
4.9 FACTORS THAT IMPACT UPON THE APPROPRIATENESS OF CDPS INTERVENTION

The appropriateness of an application of CDPS depends upon an appraisal that the application of CDPS as a matter of last resort is in keeping the limitations that would be expected within the particular clinical context (Fig 4.3). Whilst it would be considered inappropriate to commence CDPS without “appropriate palliative care, access to ambulant hospice teams and networks, inter-professional co-ordinated teamwork, adequate pain relief, development and implementation of quality standards, research and training, and bringing palliative medicine to the awareness of the public”, there must be clear balance between expectations in an ideal setting and the limitations that the actual care situations create and what can realistically be provided by a MDT team (14,49,84).

One factor that also comes under consideration of appropriateness is the issue of treating existential suffering with CDPS. It is the position of this thesis that existential suffering deserves the same consideration and aggressive care alternatives as physical suffering does. Based on clinical data forwarded by Schuman-Oliviere et al and Cassell and Rich presented in Chapter 1, this thesis maintains that reliance upon a “Cartesian mind-body dualism” or a clear demarcation between physical suffering and existential suffering is antiquated (113-118). Instead as per all the major textbooks in palliative care, this thesis maintains that appropriate response to suffering must be holistic and reflective of the view that all forms of suffering are inherently interrelated and require multidimensional and multiprofessional care of the person rather than be focused upon treating the apparent etiology of the suffering (27-30).
This issue, too, serves to highlight the variability of judgements of appropriateness across time and context. Any application of CDPS must also be found to be appropriate to the cultural, social, religious and legal practices of the society that it is practiced. These same cultural, religious and societal considerations have ensured that the practice of routine cessation of hydration and nutrition at the end of life is not adopted locally, for example. This in turn has aided in the acceptance of palliative measures at the end of life.

An appropriate process and hence an appropriate intervention is one that is underpinned by informed, appropriately weighed, multidimensional and tempered review of all the salient factors, rather than one that is led by clinical considerations tempered by a few select ethical musings and sociocultural determinations. Fuchs noted that wisdom within these deliberations underlines the ability to appropriately balance all these factors whilst also considering and weighing the emotional factors that are involved such as compassion and empathy that may affect this balancing process on “both sides of the bedside” (109,118).

4.9.1 Can CDPS be applied if the patient has previously declined such treatment?

CDPS cannot be applied if the patient has consistently stated his objection to this intervention. However, if the situation that has arisen is not consistent with what the patient may have envisaged whilst in a competent state, the best interest process can be instituted to review and potentially override this position. If the
evaluation of the patient’s circumstances finds in favour of overriding the patients’ previously stated wishes, then as with all advance directives, there must be reasonable justification that the situation had now changed beyond what the patient had envisaged or that the goals that the patient had focused upon cannot be realized or that his secondary goals are now compromised.

4.9.2 Can CDPS be applied to a patient found to be incompetent but who persistently declines this treatment?

This question arises in light of the continued involvement of incompetent patients within the deliberative process. Chin reiterates that competence is not an all or nothing finding and

“the MCA recognizes that capacity can be task-specific and is therefore assessed according to the ability of a person to make a decision about a matter at a particular time, rather than an ability to make decisions in general [section 4(1), MCA]” (66).

The MCA, therefore, does recognize that there are patients that do not attain a level of competence to decide upon care decisions but who are able to consent on lesser matters and continue to participate within the deliberative process. The question that arises here is what ought to happen to a patient whose right to refusal is in doubt? This would include patients who have previously consented when competent but who now decline CDPS, or those who have not voiced any preferences when competent but now decline CDPS.
The response to this situation must be a complete review of the patient and the processes that had led up to this point either by a separate MDT where possible or by the original MDT, overseen by an independent palliative care specialist and/or a psychiatrist. After further holistic review of the patient and his personal situation, and after repeated efforts to both explain the reasons for this treatment and comprehend the patient’s reasons, his competence is reassessed. If the patient is deemed incompetent and if no reason can be provided for refusal of CDPS, then treatment ought to be carried out in his best interest. Such an approach is required particularly given local data that would suggest that in cases involving incompetent patients, healthcare professionals tended to comply with the wishes of the family even at the cost of overturning the wishes of the previously competent patient (75).

In those situations where the patient provides reasons for declining CDPS, and can foresee the circumstances that they are in, then the patient should be reassessed by two independent psychiatrists on two separate occasions. If competence can be confirmed, only then should the MDT be justified in proceeding to the extent the patient allows.

If, however, the patient still remains incompetent, the MDT must consider once again if proceeding with the treatment is justified by the BIP, informed by proportionality, necessity and appropriateness. This thorough and holistic review must continue despite any disquiet amongst the various parties. This stepwise review ought to be carried out considering if treatment can justifiably be applied against the patient’s present wishes or if it is reasonable to postpone the treatment further until consent can be gained. Underpinning this process of re-examining
the patient’s ability to provide meaningful informed consent are a review of the
goals of care, the holistic evaluation of the case, the decision making processes,
“force majeure” and the practical considerations related to the specific case as
discussed in Chapters 1, 2 and 3. This process takes into account the following
considerations:

1. There is acceptance that there has been a change in the goals of care, and
   symptom control and the relief of suffering are the overarching objectives
   replacing any duty to cure or restore health (see section 2.5 page 127).

2. The patient’s continued suffering are now seen as an “emergency” invoking a
   holistic review as to the appropriateness, necessity and proportionality of
   response in keeping with the patient’s BIP (see section 4.4.4 page 217, section
   4.7 page 222).

3. Treatment is considered to alleviate suffering and not to hasten death (see
   section 4.4.4 page 217).

4. The patient is incompetent of making a decision and all reversible causes and
   means of nullifying its effects have been exhausted (see section 4.4 page 200).

5. The MDT, the family and other parties, taking into account the patient’s
   wishes, have reviewed the best interests of the patient holistically (see section
   4.7 page 222).

6. This determination need “not always extend biological life for the longest
   time” and “advocates careful attention to comfort, care and pain control and
   must be better than the minimally accepted standards of care” (102).
7. At the crux of this argument is whether more time can be designated to reviewing the patient’s competence and if this will compromise the patient’s care. The answer to the latter part of the consideration is likely to be affirmative because under the aegis of the goals of care and under the present circumstances, the patient’s condition has been deemed to require immediate attention; it would be unreasonable to postpone treatment. However this must be balanced by the presence of an equally compelling rationale to delay treatment (see section 3.7.4 page 184). This wider review must also consider that despite the best efforts of the MDT to reverse the patient’s limitations to consent, the patient remains incapable of consenting and furthermore, a second competence evaluation carried out by at least two experienced psychiatrists on at least two separate occasions, each coinciding with the moments of the day when the patient was likely to be most alert and capable of consent, has also failed, thus reiterating the fact that further delay can no longer be justified (see Fig 4.4 page 237).

There may be those that would suggest a trial of intermittent sedation followed by a reassessment both of the patient’s wishes and competence. However, such a measure must been tried and found wanting before CDPS was considered. It is submitted that an application intermittent sedation would represent an injudicious delay in application of treatment as would allowing an incompetent patient to overrule a decision that they were deemed incapable of making.
Figure 4.4  Continued patient involvement in CDPS determinations

Appraisal for the application of CDPS

Capable of participation in formal capacity assessment?

Yes

Allow patient participation in decision-making process

Competent after formal capacity assessment?

Yes

Is this incapacity temporary?

Yes

Reverse the reversible and treat the treatable causes

No

Physician guided by MDT determine treatment

No

Incompetent patient refuses CDPS

Yes

One reappraisal by two independent psychiatrists

Reversible?

Yes

Capacity?

No

Continued patient involvement through facilitation
4.10 CONCLUSION

In this chapter I have argued that faith in the process of informed consent amongst patients being provided with CDPS is misplaced in most cases. Through the careful deconstruction of the consent process to highlight the impact of the various factors within the consent process, I have highlighted the impracticalities of continued reliance upon the consent process as it presently stands. Application to surrogate or proxy decision-making processes are equally fraught with lack of congruence between the views of the surrogate and those of the patient.

In its place, I have argued that in most cases where patients will be incompetent to consent to CDPS applications, the Principle of Necessity and the BIP can be employed to appraise the need for the use of CDPS as a treatment option of last resort for the relief of suffering, shepherded by the maxims of appropriateness and proportionality.

I will in the next chapter, I will expand upon the importance of proportionality in these considerations.
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Chapter 5
THE PRINCIPLE OF PROPORTIONALITY

5.1 INTRODUCTION

The Principle of Proportionality is a central maxim within the practice of continuous deep palliative sedation (CDPS), particularly given its role in tampering and guiding the application of this intervention when treatment is applied without consent (1,2). Fundamental to its place is the wish to ensure that any clinical response proposed is commensurate with the multidimensional appraisal of the conditions of the case.

Underpinning this are two primary considerations. The first is the belief that there is a direct relationship between the doses of drugs applied in employing CDPS and the risk of hastening death; an increase in dose is taken to be associated with an increased potential for hastening death. The second is that the induction of unconsciousness is an all or nothing process that once attained will negate any awareness of suffering.

However, these interpretations of proportionality of practice have been called into question in light of new clinical evidence (4-6). In particular, this data casts doubts upon the apparent homogeneity in the effects of unconsciousness in negating the awareness of suffering (4-6). The data, I shall argue, calls for a fundamental change in the manner that proportionality is viewed within the practice of CDPS. In order to proceed I will review the prevailing understanding of the Principle of Proportionality as articulated by Quill et al given its pivotal
position within prevailing clinical guidelines on palliative sedation (PS) and terminal sedation (TS) (1,2,7).

5.2 CONSIDERING QUILL’S CONCEPTION OF THE PRINCIPLE OF PROPORTIONALITY

Quill’s concept of proportionality continues to influence end-of-life practice in the United States of America and Europe and although I have previously touched upon Quill et al’s conception of the Principle of Proportionality in Chapter 2, I will examine its impact upon the practice of sedation at the end of life here in greater depth (1,2,8,9).

Quill presents an account of the Principle of Proportionality in a 1997 essay entitled “Palliative Options of Last Resort”, co-authored with Bernard Lo and Dan Brock and published in the Health Law and Ethics section of the Journal of the American Medical Association (JAMA) (7). In it, Quill, Lo and Brock review the ethical and clinical acceptability of physician assisted suicide (PAS), voluntary active euthanasia (VAE), voluntary stopping eating and drinking (VSED) and terminal sedation (TS) “in the face of ethical and legal controversy” that surrounds these interventions of last resort (7). Considered within this essay are the doctrine of double effect, patient voluntariness, proportionality between risks and benefits and the physician’s potential conflict of duties (7).

Of interest here is the manner that these authors view proportionality (7). The authors propose a rather novel means of viewing proportionality within these specific confines. The authors begin by extracting the Principle of Proportionality
from the Doctrine of Double Effect (DDE) and casting it in a central and independent role that displaces the DDE. They state that, “[a]lthough proportionality is an important element of the doctrine of double effect, proportionality can be applied independently of this doctrine” (7).

Quill and co-authors Brock and Lo then go on to explicate their interpretation by stating that

“[t]he concept of proportionality requires that the risk of causing harm must bear a direct relationship to the danger and immediacy of the patient's clinical situation and the expected benefit of the intervention. The greater the patient's suffering, the greater risk the physician can take of potentially contributing to the patient's death, so long as the patient understands and accepts that risk” (7).

Thus, according to the authors, the risks of applying opioids or sedatives to a terminally ill patient replete with the possibility of hastening death must be commensurate with the perceived benefits that such an intervention will bring to the patient’s condition. Underpinning this determination is a holistic appraisal of the exigencies of the situation and the urgency to act to alleviate this threat.

A pathological fracture of the femur for instance can be a very painful experience and one that would generally be regarded as an emergency situation. Thus, if there were two identical terminally ill patients with pathological fractures of their femur, both these patients would as a rule be expected to require immediate analgesia. However, the manner that these cases are responded to is also determined by a particularized review of the situation. For instance, what if the second patient has an indwelling epidural in situ that prevents his appreciation of
the pain of this fracture whilst the first patient doesn’t? In the first case, immediate response is required as the patient is found to be in distress whilst in the second case the response may be more measured and subject to reviews of his overall condition and symptoms.

Whilst in both cases the goals of care may have been the maximizing of comfort, in the second case provision of analgesia in anticipation of pain replete with its potential ill effects would not be seen as being proportional. On the other hand in the case of the first patient, analgesic associated risks are warranted given the patient’s distress.

Similarly, any appraisal of proportionality of response must also consider that the means employed represent the safest and most efficacious options available for the specific situation.

It would seem from the example above that Quill, Lo and Brock’s conception of the Principle of Proportionality pivots upon four prime determinants. These include the voluntariness of the patient to participate in the treatment and the necessity of the situation where the risks of the procedure must be commensurate with the gravity of the clinical situation. Additionally the procedure itself must also be in keeping with a holistic appraisal of the situation and be governed by the overall goals of care. This conception of proportionality is depicted in Figure 5.1.
Figure 5.1 Quill, Lo and Brock’s conception of proportionality

In truth, whilst attributed to these three authors, the Principle Of Proportionality as it stands owes much to Quill’s earlier work, honed over many years (7,8,10,11). Underpinning this repositioning of the Principle of Proportionality is Quill’s rejection of the viability of the Doctrine of Double Effect (DDE) within the end-of-life setting (7,8,10). Quill together with Lo and Brock describe the DDE as an almost ubiquitous framework applied as a means of

“distinguishing between the effects that a person intends (both the ends sought and the means taken to the end) and consequences that are foreseen but unintended. As long as the physician’s intentions are good, it is permissible to perform actions with foreseeable consequences that it would be wrong to intend” (7).

The authors report that the DDE, tasked with determining the “moral acceptability” of an action if “death comes unintentionally as the consequence of an otherwise well intentioned intervention, even if foreseen with a high probability”, ultimately fails to provide the required clarity or the assurance
sought by its invocation (7). The authors state that whilst it is often argued that
TS differs from VAE and PAS solely in respect of the intentions behind them,
Quill, Lo and Brock argue that in reality the intentions that underpin these
applications are complicated (7). This is especially so when routine cessation of
artificial hydration and nutrition within the practice of TS is believed to “make
death certain” (7). Quill and co-author Kimsma echo this point, believing that
“withholding fluids and nutrition is not needed to relieve pain, but is typically
taken to hasten the patient's wished-for death” (7,11). In this instance, the
apparent inability of the DDE to adequately delineate the acceptability of this
apparently controversial element and safeguard practices such as TS against
abuse is seen as a fatal flaw (7).

Quill and his co-authors also set about dismantling the DDE at its roots. Quill and
Kimsma argue that the DDE is “derived from Catholic tradition, and relies on a
rigid distinction between consequences that are intended and those that are
unintended” and is a “religious concept that is inadequate to cover complex end
of life decisions” (11).

Quill and co-authors Dresser and Brock echo this sentiment stating that neither
the application of the DDE nor the belief that “death should never be intentionally
hastened when unrelievable suffering is extreme and death is desired by the
patient” is universally acceptable to all groups (12). Similarly, Quill and Kimsma
declare that the DDE, “obfuscated by abstract and imprecise terminology” and
reliant upon explication of intentions, makes elucidation of the moral and legal
permissibility of an intervention difficult (8,11)
Furthermore, the DDE’s dependence upon the discernment of intention as a means of circumventing “moral culpability is felt to be psychologically and morally problematic” (11). Quill and Kimsma state that the

“notion that a clearly foreseen consequence that is not intended could be free of moral culpability is felt to be psychologically and morally problematic. The physician's potential, active, conscious role easing death in the face of unbearable suffering is not morally rejected out of hand” (11).

Quill, Dresser and Brock add that

“people are held responsible for all reasonably foreseeable consequences of their actions, not just the intended consequences. Physicians are not exempt from this expectation. This understanding of moral responsibility encourages people to exercise due care in their actions and holds them responsible for that which is under their control” (12).

Quill highlights the difficulties of discerning intentions by reviewing his own intentions in aiding in the suicide of Diane (13). Although exonerated for manslaughter by the grand jury, Quill concluded that his own intentions in this case were “complex, ambiguous and often contradictory” (13). As a result Quill concludes that continued reliance on elucidating intention to clarify justifiability of actions is untenable particularly when the deliberative and administrative process behind the application of TS involves many parties (10,11,13). Similarly, Quill believes that this process may also be ultimately harmful to patient care as he states
“[i]f we do not acknowledge the inescapable multiplicity of intentions in most double effect situations, physicians may retreat from aggressive palliative treatment out of fear of crossing the alleged bright line between allowing patients to die and causing their deaths” (13).

In an editorial for the Journal of Palliative Medicine in 1998, Quill also introduces the notion that the focus of attention of the DDE is in fact misguided and that there were more important issues to consider (15). As a result Quill states that the DDE “is not absolutely necessary, however, to respond to these challenging clinical problems, and is less fundamental than the following domains:

1. Is the patient's suffering proportionately severe to warrant the risks of the intervention?

2. Has the patient been fully informed about all likely outcomes of the intervention, both intended and foreseen, and is he or she aware of all reasonable alternatives? (If the patient is not capable of consent, then the family or surrogate decision maker must consent on the patient's behalf using the principle of substituted judgment.)

3. Is the intervention the least harmful one available, given the patient's clinical circumstances and personal values?” (15)

These pivotal domains then introduce what Quill and Kimsma consider to be more appropriate for the task at hand (11).

Quill then turns his attention to the concept of the Dutch “secular, legal concept of force majeure” (11). Quill characterizes the “force majeure” by the presence of unrelievable suffering in a terminally ill, imminently dying patient, which in turn dictates a need for “extraordinary” responses to the threat of continued suffering
(11). The presence of these “situations of necessity” is felt to better aid in the discernment of the legitimacy of any application of palliative sedation (PS) (10,14). It also serves as a precursor for the Principle of Proportionality (15).

The Principle of Proportionality as Quill conceives it is thus subject to a number of factors (Fig 5.2) (7,8,16-24). Prime amongst these are the overarching goals of care that drive the determination, the specific contextual aspects of the particular case, the voluntariness of the patient in the undertaking and the necessity of the situation (7,8,16-24). These four points are supplemented by three further facets to consider. These include balancing the case specific definition of “good” and “bad” outcomes, the temporal elements related to this determination and the legitimacy of the application of the treatment of last resort in question (7,8,16-24).

Figure 5.2   Quill’s conception of proportionality
Balancing the “good” and the “bad” effects of a specific case is complex. The “good” effect that an application of CDPS aspires to achieve is the relief of suffering (24). The “bad” effects, on the other hand, are the undesirable but foreseen side effects of death and respiratory depression (24). Quill holds that it is these fatal side effects that attention must remain focused upon, given that to focus upon the perpetuation of suffering as the “bad” outcome would invite controversy (24). This is because it leaves the door open to potential abuse. If the “bad” outcome is focused upon the prevention of further suffering, it may leave it possible for some HCPs to opt to dispense with proportional and monitored care and apply large unmonitored doses of sedatives and/or opioids to meet these objectives. Such actions would not be supported by either medical guidelines or prevailing legal statutes (7,23,25). As a result, maintaining that the “bad” outcome of any intervention remains death creates safeguards that protect this “small percentage of dying patients [who] will still experience suffering that can become intolerable and unacceptable” (8,16,17,24,26).

The ensuing safeguards set out to balance “flexibility and accountability as well as privacy and oversight” require that the following are carried out

- standard palliative care alternatives [have been] tried and found ineffective or unacceptable
- rigorous informed consent [gathered] (only the patient him- or herself could consent to PAD (physician assisted death) or voluntarily stopping eating and drinking; family members could potentially consent using substituted judgment for the other options)
- diagnostic and prognostic clarity [is established]
• independent second opinion by someone with expertise in palliative care [is sought]

• and documentation and review [is present]” (24).

A further proviso that Quill et al add later is the requirement to discern that the “patient’s suffering was proportionately severe enough to warrant taking the risk” (20).

Additionally Quill adds that the treatment itself must be “proportionate to the severity of the symptom” as well as commensurate with a multidimensional evaluation of the situation (7,24).

Aside from safeguards that stem from balancing the “good” outcomes with the “bad”, a further facet of proportionality is timeliness (21). Attention revolves around hasty applications and injudicious delays in employing TS (8). Temporal considerations in treatment application are a key part in determinations of proportionality (21). Hasty, poorly considered responses are taken by Quill et al to reflect a lack of holistic appreciation of the situation and raises concerns about the consent process (23). Quill highlights the importance of a holistic appreciation of the situation and argues that a hasty application of sedation at the end of life would suggest

“1) a lack of familiarity with appropriate measures to relieve suffering, 2) pressures for cost containment, or 3) the strain on health care providers or families of providing complex and emotionally demanding forms of terminal care” (23).
Similarly a poorly deliberated application of this intervention of last resort will also raise questions as to the “voluntariness” of this process, underpinning the importance of consent within Quill’s framework (23).

Quill and colleagues also stress that the proportionality of a response to suffering must be flexible and move beyond the perceived confines of organizational constraints (18). This translates to the understanding that a physician must not only consider treatment options that have not been tried at this juncture of an illness but also more aggressive treatment options that may have been discounted at an earlier juncture. For instance, radiotherapy that may have been dismissed at the earlier juncture may now be reconsidered. Care provisions should also not be restricted due to the placement of the patient. If the patient is willing and transfer is possible, transfer to alternate facilities where further treatment options can be explored ought to be undertaken. Therefore, if it is feasible, patients cared for at a hospice or even at home ought not to be prevented from considering treatment options or second opinions that may be readily available in a specialist centre for instance, if transfer is possible.

### 5.3 CRITIQUE OF QUILL’S POSITION

Whilst Quill’s conception of proportionality may appear balanced, in truth it seems to be underpinned by a wish to ensconce PAS and VAE within the armamentarium of valid palliative care options of last resort (22,27). Quill would appear to see the options of PAS and/or euthanasia as valid options of care “when suffering becomes intolerable in spite of excellent palliative care” (22,27). This
position seems to hark back to Quill’s actions in assisting in the death of Diane, a patient with acute myelomonocytic leukemia, through the supply of large doses of barbiturates that she later self-administered (28). In his 1991 article in the New England Journal of Medicine’s Sounding Board section entitled “Death and Dignity, a case of individualized decision-making” Quill sets out the rationale for his actions as a “proportional response” to the threat of “increasing discomfort, dependence and hard choices” (28).

The rationale for Quill’s efforts at relegating the DDE from its pivotal position appears clearer. The Principle of Proportionality would appear to be a means of legitimizing the application of VAE and PAS and circumventing the opposition that the DDE would have provided.

The evidence for these associations seems to be compelling. The Principle of Proportionality is constructed upon the same principles that underlie those used as a framework for the “Proposed Clinical Criteria for Physician Assisted Suicide” set out in 1992 by Quill together with Cassell and Meier, the safeguards for the application VAE and PAS set out with Lo and Brock in 1997, and finally, the framework presented in the article entitled “Physicians Should ‘Assist in Suicide’ When It Is Appropriate” in 2012 (7,24,29). Within this framework, PAS and VAE are portrayed as legitimate treatments of last resort (22,27). There are three main reasons employed to validate this position. They are the failure of palliative care, the physician’s duty to the patient and the patient’s rights to self-determination (Fig 5.3).
On the issue of the failings of palliative care, Quill states that

“[i]t is only when suffering becomes intolerable in spite of excellent palliative care that the possibility of physician-assisted death should be seriously considered” (22,27).

This would include situations

“when a patient is bleeding uncontrollably from an eroding lesion or a refractory coagulation disorder, cannot swallow secretions because of widespread oropharyngeal cancer, or has refractory diarrhea from the acquired immunodeficiency syndrome (AIDS)” (7).

Similarly, Quill with Lo and Brock argue that such failings also occur when limitations are set upon the patient’s rights and choices (7). For example TS is
said to limit the patient’s choice of a place of care at the end of life and this
obviates a measure of control that a patient ought to possess in determining their
care and how they are remembered (7). This sense of control serves not only to
introduce the second reason for Quill’s position on PAS and VAE but also to
show that these three reasons are in fact closely interrelated (7).

The issue of control is a significant consideration in the minds of Quill, Lo and
Brock (10). The authors are clear that patients should have a measure of self-
determination not only about their place of care but the manner and timing of
their demise (7). For these authors, this sense of control ought to involve the right
to decline treatments that would “needlessly prolong the dying phase” (7). Quill
argues further that such a position is valid as there is a shift in the goals of care
from one focused on restoration to one aimed at “allow[ing] hopelessly ill persons
to die with as much comfort, control and dignity as possible” (29). For Quill and
co-author, Kimsma, the Dutch ruling that maintained, “no physician should be
expected to continue to prolong life to the bitter end” provided legal validation to
this position (11).

Quill’s third point is by far the most controversial and revolves around Quill’s
view of the physician’s duty to patient and family (28). Quill argues that in
response to the threat of “increasing discomfort, dependence and hard choices”,
the physician must abide by his duty to care for the patient (28). This duty, it
would appear, outweighs concerns of local legislative prohibitions (28). Quill
believes that a “physician's moral obligation to his patient as a caregiver
outweighs his duty to obey the law as a citizen” (28). This position is
underpinned by the duty of non-abandonment, which Quill sees as a “physician’s
obligation to his or her patient and family to see the dying process through and to be as responsive as possible[, and this obligation] outweigh[s] other obligations and restrictions in these troubling circumstances” (30).

Quill further justifies this stance by stressing the duty of the physician to respect the choice of the patient and states that

“those who give considerable weight to patients’ rights to determine their own care believe that the patient’s informed consent to an action that may cause death is more fundamental than whether the physician intends to hasten death. From this perspective, the crucial moral considerations in evaluating any act that could cause death are the patient’s right to self-determination and bodily integrity, the provision of informed consent, the absence of less harmful alternatives, and the severity of the patient’s suffering” (12).

For Quill, it would appear that this immutable right trumps all other obligations and duties.

Quill also invokes the right to “compassionate care” within the holistic review of a case (25,31). He describes the remit of compassionate care as extending to all patients who are “suffering intolerably, feeling humiliated, and disintegrating with no escape other than death, given current prohibitions” (25). Quill appeals to the “covenant” between the patient and the physician that requires of a physician “to care about, advocate for and ultimately not desert such patients” (28,32). Quill states that
“if a patient’s pain and suffering cannot be sufficiently relieved with state-of-the-art palliative care, then the physician has an obligation to do everything within his or her power to relieve that suffering, even to the point of hastening death if there are no realistic alternatives acceptable to the patient” (30).

These three interrelated factors are not the only concerns with respect to Quill’s Principle of Proportionality. Briefly, other concerns include a failure to fully encapsulate the palliative care ethos and care approach into this work process. Here, I am not concerned with the intentions behind Quill’s use of the Principle of Proportionality as its application in the CDPS framework is clear; I am only concerned with the issue of the application of the Principle of Proportionality to the MDT setting. Quill does not consider the fact that palliative care adopts a MDT based review to end-of-life appraisals and deliberative processes but continues instead to practice a single-handed physician-led practice. This omission also affects the manner that appraisals of the “good” and “bad” effects of the case are made. There is no holistic multi-professional review of the patient’s situation and determinations of care appear led entirely by clinical determinations and concerns for the “rights” of the patient. This does not entirely capture modern end-of-life palliative care practice where a multitude of other considerations play a role.
5.4 THE POSITION OF THE PRINCIPLE OF PROPORTIONALITY IN THE CDPS FRAMEWORK

Given the concerns raised, it would seem logical to question the rationale for persisting with the Principle of Proportionality within the CDPS framework. To be clear, this thesis maintains that when applied within appropriate legal, clinical, professional, social and cultural boundaries and under the aegis of a palliative care approach, the Principle of Proportionality still remains a better alternative to the DDE as a means of legitimizing the practice of CDPS. Like Quill et al, McIntyre maintains that it is the Principle of Proportionality that represents the defining facet of the DDE, enhancing its position within the deliberations of physicians faced with difficult end of life determinations (7, 8, 23, 24, 33). There are also a number of other considerations that further impede routine application of the DDE in this setting. These concerns are taken up in the next section.

5.4.1 Concerns with regards to the Doctrine of Double Effect (DDE)

Concerns with regards to the DDE can be categorized into two groups: ethical and practical concerns. Aside from placing emphasis on the unrealistic elucidation of intentions within the multidimensional, multi-professional setting adopted here and the evolving conditions of the clinical situation, ethical concerns surrounding the DDE also include presupposing that balancing of the good and bad outcomes have appropriately been met and are in keeping with accepted clinical guidelines, social expectations and legal requirements, as well as the MDT’s holistic determination of the patient’s best interests; in fact there is no
stipulation for such requirements (33-35). This latter concern not only revolves around fears that such determinations remain largely clinically driven and arbitrated upon by a solitary clinician, but also that such determinations are susceptible to being inappropriately influenced by specific social, familial and cultural influences (33-35). This failure to engender a holistic appreciation of the situation also extends to concerns that the DDE still labours upon the assumption that it is death that is *summum malum*, a position that Quill and Kimsma suggest is not uniformly accepted by all parties irrespective of their religious beliefs (11). Underpinning this concern is the fact that the DDE is a religious framework that is built upon protecting the sanctity of life which Quill et al suggest is ill equipped to confront the complexities of end of life care determinations (11).

The presence of a MDT approach to care further complicates matters with little evidence to validate the assumption that the individuals appraising the acceptability of the situation are neutral and have consistent and discernible intentions. These assumptions not only neglect the impact of professionalism upon the actions of health care providers but their legal and professional duties to protect the patient’s best interests in the face of evolving holistic case-specific considerations particularly when Quill argues that intentions within end of life decision-making can be “complex, ambiguous and often arbitrary” (13).

A further ethical consideration brought to light by Quill et al is the suggestion that the DDE promotes the idea that its invocation “absolves” health care professionals of responsibility for their actions and the consequences of their actions particularly when some actions are based upon inaccurate information such as the suggestion that CDPS necessarily hastens death (33,34).
Practical considerations include the failure to encapsulate the requirement for holistic reviews in balancing the “good” outcomes and the potential “bad” consequences and the provision of guidance on how to balance the sometimes competing considerations particularly in light of evolving goals of care (33,34). Practical concerns with regards to the DDE also include worries as to whether there is appropriate elucidation of intentions of all the various parties involved and if these considerations extend beyond simply the acts of the various parties but also their unsuccessful acts both in this case and in the past (33). This is particularly salient where under the aegis of a palliative care, it is a multiprofessional MDT-led approach that aids in appraising, deliberating and overseeing care.

Together these concerns emphasize the position apportioned to the Principle of Proportionality within the practice of CDPS which sets out to ensure that all care within this specific setting is in keeping with the prevailing laws of the land, clinical guidelines and institutionally sanctioned minimum standards of care and affirms that whatever the wishes of the patient and the determinations of the physician may be, their actions are still subject to prevailing regulations (33). The various duties that Quill invokes cannot supplant legal and professional standards (21). Furthermore, it is the requirement of this framework that all treatments applied must also be in keeping with the prevailing sociocultural beliefs and values of the society. Taken together with the legal and clinical limitations, this proviso ensures that VAE and PAS cannot be adopted as treatments of last resort so long as they are not sanctioned by the regnant social, cultural, professional and legal standards of the specific society. These same conditions also affect the potential application of CDPS for the treatment of existential suffering.
Procedural compliance with established guidelines and work processes is also an important factor in proportionality determinations.

However, whilst these adaptations go some way to allaying the fears of misapplications of the Principle of Proportionality, it must now contend with a new problem. This new concern relates to the manner that a proportional dose response is viewed.

5.4.2 Reconsidering proportionality in the face of new data

The application of sedatives and other pharmacological interventions in CDPS is based on the belief that pain and suffering are “consciousness dependent phenomena” (36,37). The argument follows that an induction of unconsciousness will circumnavigate a patient’s perception of prevailing noxious experiences (36,37). Determining the success of this intervention ought to be the safe relief of the patient’s suffering. Safety and success of this process is monitored by observational parameters that assess the patient’s depth of sedation and its consistency, and that monitor safety and efficacy of these interventions in tandem with the conservative employment of opioids and/or sedatives within CDPS applications (1,2).

In reality little observations are made of sedation levels, given the belief that unconsciousness is an all or nothing phenomena and one that once attained will remain constant. As a result most of the attention in monitoring patients are focused upon ensuring that the primary side effects of CDPS do not occur and life is not threatened. Clinical observations, therefore, focus upon monitoring physical
parameters of distress such as random movements of body extremities, facial frowning/grimacing, asynchronous breathing patterns, as well as clinical parameters looking out for increases in blood pressure, heart rate and respiratory rate will ensure that the primary objective of inducing safe sedation are met whilst also safeguarding against any signs of unwanted side effects of cardiorespiratory compromise (7,38,39). These observations are sometimes complemented with sedation scores, which help to monitor the depth of sedation, and oxygen monitoring to provide additional warning of any impending danger of respiratory depression (40). The “stability” of these parameters during the monitoring process of an individual case is seen to reassure healthcare professionals (HCPs) that an adequate level of unconsciousness is attained without compromise to the patient’s safety (39,41).

This focus on safety is underpinned the need to prevent the risk of hastening of death, the “bad” outcome to be guarded against in a care intervention. Furthermore, given the realities of end-of-life care, it is the only element that is truly within the control of the HCP. Based on the belief that the patient is safely sedated and thus unaware of their suffering it is then left to the HCP to ensure the safety of this process through close monitoring of the patient for any signs of side effects. This process of surveillance is supplemented by minimizing the doses of “aggressive pharmacological measures” in order to reduce the potential for ill effects (24,42). This practice draws upon the dictum that “the level of sedation should be the lowest necessary to provide adequate relief of suffering” set out by the EAPC guidelines, and the KNMG guidelines that call “for level of unconsciousness depends on causeconsciousness to be lowered to the extent that is necessary and sufficient to relieve symptoms in the degree desired” (1,2). In
reality, as Cherny, the main author of the EAPC guidelines points out, this practice translates to the application of the lowest possible doses of medications (1,43).

Underpinning this practice, in turn, is the assumption that the lower the dose applied, the less likely the possibility of side effects are (7,24,42,43). Thus doses of sedation and/or opioids are applied only so far as to be “sufficient to relieve symptoms in the degree desired” (2,38,43). Clinically this has translated to the application of just sufficient medication to induce sedation to unconsciousness, which is then maintained on the premise that this level of sedation will meet the requirements of negating the patient’s awareness of suffering.

The practice of proportional sedation advocated by the KNMG and the EAPC guidelines are based on a number of assumptions. These include the premise that

1. unconsciousness is an all or nothing phenomena
2. once induced unconsciousness will negate a patient’s awareness of pain and suffering
3. inducing unconsciousness is a treatment with potential life-abbreviating characteristics that can be reduced by lowering the dose of sedative used
4. to reduce these risks further, close monitoring of the clinical parameters and the physical parameters of distress of a patient’s condition will warn HCPs of potential side effects (37,44-71).

All four of these assumptions are now under increasing threat in light of new data on consciousness and I will consider each of these issues in due course.
5.4.2.1 Unconsciousness is an all or nothing state

“Unconsciousness does not always consist of a general suppression of the entire activity of the central nervous system. Depending on the actual cause(s), many functions, such as protective reflexes and various cognitive processes, can remain intact” (51).

This statement by Flohr, validated by a number of studies, dismisses the first assumption behind the practice of proportional sedation (51).

Importantly, Flohr now shifts attention to the implication of this finding (51). According to Flohr, not only is unconsciousness not homogenous but, depending on the causes underpinning it, various brain functions are preserved (51). This raises issues about the levels of unconsciousness that are attained in pharmacological inductions of unconsciousness and more importantly the exact effects that these various levels of unconsciousness have upon a patient’s awareness of suffering (4-6,51-58).

<table>
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<tr>
<th>Level of consciousness</th>
<th>EEG wave form</th>
<th>BIS Score</th>
<th>Healthy</th>
<th>MCS</th>
<th>PVS</th>
<th>Midazolam induced</th>
<th>Propofol induced</th>
<th>Dying</th>
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Table 5.1 Levels of sedation in various states of consciousness and health
Table 5.1 highlights the various levels of sedation documented in different health states (52-58).

A further concern is the potential for variations between the different levels of sedation and the significance of this. Kulkarni et al for example revealed that persistent vegetative state (PVS) patients exhibited significant alterations between various levels of sedation (58). Translated to the CDPS setting where unconsciousness is drug induced, further concerns arise due to the variability of drug metabolism that will lead to changes in plasma levels of the drug, which in turn affect the ability of the drugs to maintain a constant level of unconsciousness (54,55). To highlight this point, I will focus on the effects of midazolam in attaining an adequate level of unconsciousness.

Spina and Ensom comment that “high intersubject variability in midazolam plasma concentrations makes it difficult to correlate a targeted plasma level with a particular degree of sedation” (61). Compounding this is also the fact that mood disorders, age, concomitant disease and drug treatment, adiposity and hypoalbuminemia, all affect the pharmacokinetics of midazolam and thus its ‘desired effects (62,63). Unsurprisingly the efficacy of midazolam in inducing sedation to unconsciousness is under scrutiny both in its ability to induce an adequate level of sedation and in its ability to maintain it.

I will address the matter of the levels of sedation first. To my knowledge there have been no studies using sophisticated means such as PET scans and fMRI studies that formally appraise the levels of sedation of patients who receive sedation at the end of life. However, there are a handful of studies that infer the efficacy of this intervention (49,52,60). There appears to be some data that
suggests that midazolam does reduce cortical and thalamic activity, the seat of consciousness, albeit not to a significant level that would fully stifle neuronal activity at these sites and thus induce the levels of sedation desired (5,6). The suggestion here is that midazolam cannot induce a state of pharmacological coma where there is no awareness of suffering but does appear to sedate patients to a level of “deep sedation” where there may be some awareness of suffering (53,64) (Table 5.1). This raises questions regarding the applicability of midazolam as the primary drug in the application of CDPS. The practice of CDPS as a whole is also under a cloud given that both Ogilvie et al and Koelsch et al suggest that propofol, the alternative to midazolam in CDPS, when applied either on its own or in combination with midazolam fares little better in inducing deeper levels of sedation (55,65). The implications of these findings are that there are patients in suboptimal states of lowered consciousness insufficient to fully relieve awareness of their suffering (53).

Barbato identifies a further complication to this treatment – fluctuations in the levels of sedation using Bispectral Index (BIS) monitoring (53). Indeed, in his study of sedated dying patients, he found

“[f]requent fluctuations in BIS were noted in most subjects throughout the period of monitoring. These periods of increased awareness were found to occur both in association with pain and in the absence of pain” (57).

This in effect renders sedated patients prone to periods of awareness or “breakthrough consciousness” (5,6,36,37,52-58). Here these periods of “breakthrough consciousness” may result in full awareness or even states of
subtherapeutic levels of unconsciousness where there may be some level of wakefulness (53).

Given the range of BIS fluctuations that have been observed, I propose a simple means of identifying levels of sedation that will better crystallize the arguments forwarded here (Fig 5.4). Given the fluctuations in levels of BIS scores and EEG waveforms observed in patients in light and deep sedation, the primary category of sedation is classified as MCS-like (minimally conscious state) level of sedation, reminiscent of the range of fluctuations in BIS witnessed in MCS patients (53). Importantly, similar levels of sedation are seen in Barbato’s study of sedated dying patients (53). Given the fluctuations in BIS seen in PVS patients, the PVS-like level of sedation encapsulates the fluctuations in BIS scores between the deep hypnotic level, general anaesthetic levels and coma levels of sedation (Fig 5.4 and Table 5.1) (53).

To be clear here, I am not suggesting that a vegetative or minimally conscious state is created but simply that variability in consciousness creates levels of reduced consciousness that fluctuate in the same manner as seen in PVS and MCS (59). Importantly, too, there is still overlap between those in the deeper ends of MCS-like levels of sedation and those in the more superficial PVS-like levels.
of sedation around the range of deep sedation BIS scores (Table 5.1 and Fig 5.4). This scale will be better able to confront fluctuating consciousness observed in a pharmacologically induced state of unconsciousness (61,62).

5.4.2.2 Once induced, unconsciousness will negate a patient's awareness of pain and suffering

The presence of evidence of variations in the state of unconsciousness refutes the second assumption that underpins the application of proportional sedation. Clearly with such fluctuations in levels of sedation, perception of pain and suffering are likely (66). Sheen and Oates reveal that patients who undergo “medically induced unconsciousness” for mechanical ventilation in intensive care settings reported being aware of existing in a state of “utter helplessness” (66). The authors reveal that sedated patients reported being aware of “pain, a loss of control, a sense of threat to personal safety, depersonalization and a sense of loneliness” (66). This reaffirms the suspicions of fluctuations in the efficacy of treatments and highlights two more worrying features. The first is that such fluctuations can occur even in a closely monitored environment and that it occurs unrecognized by the HCPs monitoring them (66).

Similar occurrences can be anticipated amongst patients undergoing CDPS. Morita et al’s report that about 49% of patients undergoing TS/PS re-emerge from their sedated states and 7.1% of patients were still communicative four hours after sedation was applied (60). Additionally, Morita et al’s data of 102 sedated patients revealed that the overall efficacy of PS was 83% (60,67,68). In Morita et
al’s study more than 63% of cases were induced with midazolam alone and a further 17% of cases had phenobarbital and midazolam (60).

In their review of the practice of PS, Claessens et al reporting on Menten et al’s and Chater et al’s respective studies reveal the efficacy of this process to be about 92–94% (69,70). In Menten et al’s study, midazolam was used exclusively whist in Chater et al’s midazolam was used as the primary drug of choice in most cases (70,71). Caraceni et al reveal an efficacy rate of about 83% where midazolam was the primary sedative in 46% of cases in his study sample (72).

A potential compounding factor to this consideration is the issue of tolerance to the effects of midazolam. De Graeff and Dean report that tolerance to midazolam and thus increasing inefficacy in inducing sedation was most likely amongst young patients who have had prolonged exposure to midazolam or other drugs in its class (67,73). Variability in the efficacy of midazolam is further complicated by the effects of the underlying disease or its sequelae on the patient’s renal and liver function and plasma protein and albumin levels as well as a result of interactions with other medications that may be applied (61,62,67,73).

Given the variability of drug efficacies, the questions that re-emerge are how deep a level of unconsciousness will midazolam induce and will it be sufficient to meet the requirements of CDPS? The suspicions based on research from Spina et al and Roberts et al respectively is that the best that may be hoped for from an infusion of midazolam is a level akin to MCS-like level of sedation (61,62). Concern then focuses on the fact that Laureys et al and Schneckers et al report that patients in a minimally conscious state do still perceive pain, there is a suggestion that midazolam-sedated patients may also be still aware of their
suffering (36,37,52). This raises questions about how better care may be provided. It is entirely possible, though, that closer to death, drug accumulation may result in a more sustained level of unconsciousness and even a PVS-like level of sedation. However, reliance upon these unpredictable changes is unsatisfactory. Instead, for those with a little longer to live where such accumulation may not be so pronounced, could reliance upon midazolam’s anxiolytic and amnesic effects be sufficient to “paper over the cracks”? (61,62). The suggestion here is that the amnesic effects of midazolam be utilized to prevent the patient from recalling their awareness of suffering in the sedated state. However, even this effect may be variable.

This leaves us with an important question: could increasing the dose of midazolam utilized, disregarding Cherny’s call for minimal use of sedation, improve the situation? (43).

Judge et al and Barrientos-Vega et al respectively suggest that this is possible (5,74). However, such a move must be balanced against the belief that an increase in the dose of midazolam would see an increase in the risks of ill effects (1,2). Could the concomitant application of propofol, the second line treatment for PS in the EAPC guidelines, provide an improvement? (1,2). Data on propofol when applied on its own would suggest otherwise (75,76). Present data would also suggest that there is no real difference in either efficacy or safety when midazolam was added to propofol or when compared to propofol on its own (75,76). The incidence of neuropsychiatric side effects between the two agents is also similar (77). Sandiumenge Camps et al found that in fact propofol was less
efficacious than midazolam in the initial few days of sedation and prone to treatment failures (78).

Paspatis et al and Kerker et al respectively suggest that combination therapy of midazolam and propofol would at least ensure the consistency of sedation levels and would have a comparable safety profile to midazolam alone (79,80). Whilst consistency in sedation levels is important, it is only part of the triumvirate of pivotal considerations here, the others being the depth of sedation and the safety of this procedure (Fig 5.5).

![Diagram](image)

**Figure 5.5** The triumvirate of factors affecting the efficacy of CDPS

Combination treatment may not act synergistically to increase the depth of sedation and thus may, for example, maintain a patient in a state akin to a MCS and thus liable to experience suffering (80). Paspatis et al report that sedation scores with midazolam and propofol either individually or in combination were similar suggesting no beneficial additive effect of this combination in terms of the depth of sedation, only consistency in the levels of sedation (80).
5.4.2.3 The potential life-abbreviating characteristics of end-of-life sedation can be reduced by lowering the dose of sedative used

From the data presented on the variations in levels of sedation experienced, this practice of using minimal doses comes at a cost. At the root of this premise is the issue of managing risks, which represents the third element of the triumvirate of factors that define the efficacy of CDPS (Fig 5.5). Thus if midazolam appears to compromise the overall efficacy of CDPS, what other options are there? I will review the applicability of each potential sedative that can be used for the purposes of CDPS.

Midazolam – with its well-studied pharmacodynamics and pharmacokinetic profiles that boast of a rapid onset of action, its potential to be administered through intravenous and subcutaneous routes, good bioavailability, a level of sedation that is dose dependent, a short half-life, and also because it can be readily reversed with flumazenil – meets these goals and thus continues to be the first line for CDPS in many centres (26,42,73,81,82). The alternatives to it, in reality, pose problems of their own and do not necessarily improve outcomes (73,74).

Barrientos-Vega et al suggest that propofol may be no more effective as midazolam, whilst Elsayem et al report that practically propofol is difficult to store and requires close monitoring (73,74). These practical considerations make propofol almost impossible to employ in many units outside an intensive care unit (73,74).

Meanwhile, another alternative, levomepromazine that the EAPC and the KNMG guidelines suggest, is not readily available locally (1,2). Haloperidol, which is
regularly used here, carries with it a health warning from the Singapore Ministry of Health due to its propensity to cause potentially fatal arrhythmias when used intravenously (83,84). Similarly, a relative lack of experience with the use of phenobarbital with its potential for tachyphylaxis and interactions with other medications makes its application difficult, particularly given the polypharmacy and the inherent metabolic changes seen amongst the dying (85-88). Importantly, Morita et al reported that phenobarbital either on its own or in addition to midazolam was relatively slow to induce sedation (60). This then leaves midazolam decidedly the legitimate and “safe” drug of choice for the purposes of CDPS.

Thus, given these considerations, attention must turn to monitoring techniques that will allow for better surveillance of side effects and ensure that the objectives of this process are met.

5.4.2.4 Monitoring will ensure that the risks to the patient are reduced

It is clear that present monitoring of physical parameters of distress and clinical parameters are both inadequate and unreliable (89). Li et al argue that reliance upon the belief that “in deeply sedated patients, certain cardiovascular measures, pupil reactivity, and cortical arousal responses were unique to noxious stimulation”, even when other pain related behaviours were absent, may be misplaced (39). Li et al reveal that these parameters are compromised by the attendant use of opioids and sedatives (39). Even consistent parameters such as changes in heart rate and pupil size are subject to the attenuating effects of opioids (39). Barbato noted that “breakthrough consciousness” occurred even
when patients appeared “at rest and seemingly at peace”, raising doubts as to the efficacy of observational scales for monitoring sedation (53). Hirata et al commented that midazolam also makes diagnosing brain death difficult given the effects it has upon clinical parameters (90). These factors make monitoring difficult and inaccurate, and would help explain why failures in sedation frequently go unrecognized by HCPs (36,41,50,91).

Given these concerns, and Barbato’s finding of erratic and sometimes spontaneous fluctuations in levels of unconsciousness amongst sedated dying patients, new monitoring protocols are required (53). The application of sedation scores to help monitor the depth of sedation and oxygen monitoring to provide additional warning of any impending danger of respiratory depression are insufficient, given their inconsistent use and their inability to address the concerns regarding fluctuations in levels of unconsciousness (5,6,36,37,52,53,89).

Barbato’s findings also makes the requirements of the KNMG guidelines to monitor a patient’s parameters once a day and the EAPC guidelines requirement that monitoring be carried out up to three times a day, inadequate (1,2).

Furthermore, both these guidelines do not use sedation scales or consistently monitor oxygen saturations (1,2).

Clearly, more consistent and accurate means of monitoring are called for. From Barbato’s report, this ought to include the applications of a Bispectral Index (BIS) monitor (53). Whilst cumbersome, Barbato has applied this method of monitoring on palliative care patients with “few minor problems” (53). Importantly, Barbato did not report that the use of the BIS monitor, which comprises “a single small flexible sensor applied to the forehead and temporal region”, impedes personal
contact or “medicalizes” the dying process (53). Such monitoring will also alert HCPs of the presence of “break through consciousness”. Taken together, continuous oxygen saturation and BIS monitoring appear to be the central parameters that must be included in the new monitoring protocols for the application of CDPS to ensure efficacy and safety of the procedure. This level of monitoring may be said to simply reflect the gravity of the situation.

Upon wider review, it is clear that the main considerations that underpin the interpretation of proportionality in the use of CDPS require “adjusting”. In summary:

1. unconsciousness is not an all or nothing phenomena but a constantly waxing and waning state that does see periods of “breakthrough” consciousness
2. in more superficial levels of unconsciousness, pain and suffering may still be perceived
3. minimization of sedative use may inhibit the realization of the goals of care
4. the parameters used to allow for the minimization of drugs do not appropriately capture the desired endpoints nor adequately forewarn of potential risks.

As a result there are a number of issues that need to be considered:

1. an endpoint aimed at superficial unconsciousness requires readjustment in keeping with the risks of continued suffering
2. monitored parameters need to be refined to meet these new endpoints.

Proportionality in response to this new data must consider interventions aimed at treating the “possibility of unobservable pain” as being in keeping with the goals of care (8). Allied to this must come adaptations to the manner that proportionality is appraised. Here I will review the manner proportionality should be reinterpreted in clinical practice in light of this new considerations.
5.4.3 A practical reinterpretation of the Proportionality Principle

The idea of proportional response lies rooted to the conception of attending to the needs of the patient in a manner commensurate with the demands of the situation, the risks involved in striving to meet the goals of care and those of failing to do so. This new data questions the ability of prevailing practices of meeting this goal.

Clinically, dual monitoring of oxygen saturation and BIS to ensure that sedation to the level required is attained is clearly only part of the solution. A deeper, more consistent level of sedation is also clearly required. This desired level of sedation ought to be at least to the level of general anaesthesia in order to adequately negate awareness of suffering (Fig 5.6). Practically, allowing for the inevitable variations in sedation, this would translate to a PVS-like level of sedation (Fig 5.4).

![Figure 5.6 Deepening levels of sedation](image)

However, attaining such a level of sedation is not without its risks. Chief amongst these potential hazards are respiratory depression and compromise of the sedated patient’s ability to maintain the integrity of their airways. Indeed, such a level of deep sedation would usually see patients requiring intubation or at least protection of their airways, which is neither easy nor practical within the end-of-life setting.
This then raises the concern that without due care to protect patients from these side effects, questions will be raised as to whether the risks taken to prevent “breakthrough consciousness” are commensurate with the perceived benefits. It is apparent that close monitoring and clear guidelines on monitoring techniques and practice, replete with how to respond to these potential side effects, are prime in ensuring that the trained HCPs charged with the patient’s care make the appropriate adjustments and provide the required care needed when side effects arise. Failure to do so would in effect question the objective of this intervention.

As a result, continued monitoring is pivotal to a proportional response. To begin with there has to be cognizance that there are two potentially conflicting effects at play. On the one hand is the possibility of tolerance to the effects of midazolam. As tolerance for midazolam occurs, its ability to sedate begins to wane and the possibility of “breakthrough consciousness” increases. On the other hand, despite the continued application of hydration, the patient is liable to suffer from a multitude of changes that may affect their ability to excrete midazolam, potentiating its sedative effects and potentially tipping patients into deep sedation that may in fact lead to respiratory depression and potential compromise of their airways. Monitoring to ensure that these side effects do not inadvertently hasten the demise of the patient and distancing this practice from euthanasia is imperative.

CDPS guidelines maintain that patients should be reviewed closely and on an hourly basis by an experienced HCP whilst oxygen saturation monitors and BIS monitors are constantly applied. The application of oxygen monitors circumnavigate dependence on the now questionable clinical parameters and
focuses directly upon an endpoint that appears to be the focus of much of the fears related to this practice. However, the implications of this need for such close professional monitoring as well as the application of the BIS monitor creates significant care concerns.

BIS monitoring is costly and can potentially interfere with basic care provisions and intimate family interactions. Furthermore it would mean that CDPS would not be able to be carried out at home given the heavy medical presence required both as a result of the use of sedation scales to monitor the depth of sedation and the need to continually monitor oxygen saturations. Additionally the presence of these hourly clinical reviews will impede the regular end-of-life care goals of making the dying process as unintrusive as possible.

Justification, however, may not be so difficult given the fact that care provisions associated with the application of CDPS must necessarily be intensive and commensurate with the risks upon the patient in changeable conditions. Boluses of midazolam and oxygen may be required if symptoms remain uncontrolled or if the levels of sedative ebb to the point where breakthrough consciousness and symptoms become manifest. Data would suggest that the frequency of breakthrough consciousness even when monitored using present clinical parameters maybe as high as 8-13% of cases (67-70,92). Morita et al’s findings suggest that a further 17% of cases are suboptimally sedated some four hours after the application of deep sedation (68). Porzio et al revealed that in one third of cases, “standard” doses of 1mg/hr of midazolam failed to control symptoms and required a doubling of doses and thus the presence of close monitoring (88). These failures of sedation highlight the importance of monitoring and the need for
a continuous professional presence during the application of CDPS so as to enable rapid and appropriate response to these changeable conditions. This is especially pertinent given that these numbers may reflect only a small proportion of patients who clearly manifest continuing distress and do not in fact account for the number of patients who may experience “breakthrough consciousness” unbeknownst to HCPs.

The presence of HCPs monitoring patients is also key, given that without the presence of trained personnel to take appropriate corrective measures should negative effects arise, the rationale for any monitoring becomes altogether superfluous. Decisions to administer flumazenil to reverse the potential respiratory depression caused by midazolam accumulation or indeed naloxone in the event of opioid-induced respiratory depression require careful consideration. Here delineating what may be an effect of the natural dying process and what might be a side effect requires clinical experience and expertise. The role of monitoring may help provide HCPs with tangible evidence for their actions and allows for clear oversight of the actions of HCPs.

Meanwhile, close monitoring is also required given the fallibility of present diagnostic techniques. Consider the fact that even with significantly more efficient imaging and monitoring capabilities, patients in a minimally conscious state are still frequently mistaken for being in a persistent vegetative state (47,48,50,59). The implications of such misclassification amongst patients in a MCS-like level of sedation from those in a PVS-like level of sedation cannot be overstated (53,59). Claessens et al revealed that the average survival on PS is around five days and Barbato showed that periods of “breakthrough
consciousness” often take a cyclical pattern of 20 minutes to an hour (53,59). The potential for repeated periods of awareness of suffering over this spell is thus a great concern.

These precautionary measures also serve a further purpose. They negate the potential for abuse by providing a constant record of proceedings that provide yet a further means of oversight and accountability. This continued attention will also negate the perception of abandonment that CDPS may give rise to amongst families and carers of these sedated patients.

Given the undoubted limitations of monitoring and the toll that it takes, there are wider considerations that arise. To begin, a significant implication of these provisos would see the prevention in the application of CDPS at home, given the compromise to safety (93). It would also suggest that contrary to previous arguments in favour of balanced holistic review where psychosocial, spiritual, cultural and indeed personal requirements are given equal consideration to clinical considerations, it is clinical considerations that once more take precedence and primarily for the benefit of the physician and the interests of the institution against wider scrutiny, rather than the interests of the particular patient.

A further implication would see these stringent policies alienating a large proportion of patients who cannot receive such monitoring or meet the rigid prerequisites for CDPS either through familial choices or practical considerations (93).

Clearly a holistic, case-specific appraisal of harm and benefit must be carried out by the MDT in tandem with the patient, the family and carers. Those endpoints that we are so eager to hold on to may obscure far more detrimental concerns just
as much as they may prevent worrisome practices. Only a case-specific review
under the oversight of prevailing clinical and legal processes is called for.
However, given the expectations set out by clinical guidelines and professional
standards, and the gravity of the potential repercussions of setting aside
monitoring measures, such an action must only be allowed following consultation
with the ethics committee (Fig 5.7).

Similarly, for those patients who meet the individual requirements for CDPS but
who are not able to find a specialist second opinion nor have access to these
forms of monitoring, a particularized review of the case by the ethics committee
should be undertaken, potentially with legal advice. Quite clearly CDPS as it is
aimed to be practiced needs to be given the same consideration as treatments such
as intubation and mechanical ventilation. Failure to follow proper guidelines will
undoubtedly plunge both the practice and the HCPs into controversy that will
inevitably affect the care of others (Fig 5.7).
5.5 THE FINAL TREATMENT OF LAST RESORT

After due consideration of these factors, the question that must be asked is what is to happen to those patients in whom CDPS fails?

Quite clearly pro-euthanasia groups would argue that if the best that a treatment of last resort can provide is suboptimal treatment of a patient in a state of suffering that cannot be monitored nor ameliorated, maintaining life in such conditions ought not to be acceptable.

A clear response to this beyond the obvious statement that treatments such as physician assisted suicide and euthanasia are illegal in many nations is that quite simply these forms of interventions cross one clear line that even the goal of ameliorating suffering does not cross, that of causing bodily damage. The application of CDPS is based upon the premise of ameliorating suffering rather than causing injury. Here, if there is doubt that an intervention will cause injury to the patient, which I will suggest is producing a state of irreversible cellular damage, then the procedure ought not to be applied if it runs against professional standards and legal statutes.

There are of course two significant objections to this position. The first is that adherence to a definition of injury that revolves around causing cellular damage is problematic in that it ignores a holistic view of the patient and the temporal effects of this intervention. In short, it raises questions as to how chemotherapy may be applied without breaching this stance, for example – chemotherapy does cause cellular damage to the individual and in some cases even irreversible damage to healthy cells in the endeavour to eliminate the malignancy. The same
may also be said of cranial irradiation for brain metastasis. The response to such questions is that whilst chemotherapy and cranial irradiation are applied even with the risks to healthy cells, these applications are in keeping with the MDT-determined best interests of the patient and their particular goals of care. Importantly such intervention are in keeping with the prevailing social, cultural, legal and clinical standards of care.

By these terms, if there was evidence that the application of sedation could be shown to cause clinical damage to the patient that is not reversible when the offending intervention is ceased, then the treatment itself is not held within this thesis to be an acceptable treatment option. Should either sedation to a level of PVS or MCS be found to result in irreversible damage upon discontinuation, as unlikely as it may be, these treatments would be deemed unacceptable treatment options. This application still hinges upon the wider concept of proportionality as highlighted by Quill (Fig 5.2).

However, one issue that requires closer scrutiny is the concern surrounding the effects of CDPS upon a patient’s personhood. Here the question being asked is if there is any merit to the concern that applying deep levels of unconsciousness to prevent suffering can be likened to sacrificing consciousness and thus personhood, which in turn invites comparisons with the sacrificing of life to attain the goal of amelioration of suffering. I will review the issue of personhood in the next chapter.
In this chapter I have shown that whilst the Principle of Proportionality may have been constructed under very specific pretences, it still occupies a credible place within the considerations of CDPS and under the aegis of a palliative care approach. However, I have also questioned the manner that it has been applied and shown it to be robust when equal attention is given to all its various elements and when the goals of care are clearly stipulated.

However, in light of new evidence as to the efficacy of sedative dosing in bringing about the desired levels of unconsciousness required to relieve awareness of suffering, the manner that it has been applied and the premises that it has been subject to have increasingly been viewed with suspicion. I show that in light of new data, the very manner that proportionality is adjudged requires adjustment and tempering. Realigning the manner that the efficacy of CDPS is measured, and the manner that its present endpoints are viewed requires evaluation.

However, balancing these new requirements with the undoubted limitations that this analysis creates requires closer attention to the clinical needs of the particular case and specifically its safety requirements. Whilst reaffirming the holistic traditions of this concept, there arises a more clinically-led flavour to proceedings that threaten to plunge this practice into a mire of paternalistic concerns.

Response to this must be measured and balanced as it becomes clear that the very foundations of palliative medicine are scrutinized. Here concerns of the slippery slope towards euthanasia are overcome by clarifying the limitations of the extent
of care, whilst concerns about the effects of this deep sedation upon personhood become the focus of consideration in the next chapter.
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Chapter 6

IS THE APPLICATION OF CONTINUOUS DEEP PALLIATIVE SEDATION EQUIVALENT TO EUTHANASIA OR PHYSICIAN ASSISTED SUICIDE?

6.1 INTRODUCTION

In the first chapter, I argued that there are significant differences between the practices of palliative sedation (PS), terminal sedation (TS) and continuous deep palliative sedation (CDPS) in rendering a patient unconscious to relieve their intractable symptoms. In subsequent chapters, I have scrutinized the overarching goals of care of this procedure, questioned the ability of present practices to realize these goals and forwarded alternative means of addressing potential failures in this treatment of intractable suffering. I have, during the course of this thesis, also highlighted three areas of particular concern with the application of CDPS: (i) the acceptability of extending the use of CDPS to include the treatment of existential suffering, (ii) the legitimacy of applying this treatment when the viability of informed consent is in doubt, and (iii) the implications for the personhood of terminally ill patients under deep sedation until death. Having addressed the first two concerns in Chapter 2 and Chapter 4 respectively, I turn my attention to the final issue highlighted – the effects of applying CDPS on a patient’s personhood.

Materstvedt and Bosshard, Juth et al and Rich respectively hold that personhood is characterized by a patient’s ability to exhibit self awareness, participate in social interaction and display a “capacity for human life” (1-4). This view defines
personhood “as a set of functions or abilities” (5-7). The loss of these functions or abilities has been seen to deny an individual their personhood and with this, a loss of their membership in a moral community, individual rights and privileges, and even a link to the Divine (8,9). The significance of personhood cannot be understated. It has even been said that a human life without personhood is a life without value (8,9).

An act that would sacrifice personhood is, therefore, viewed with concern. Within the context of the practice of palliative sedation (PS), Juth et al suggest that the practice of eliminating a patient’s consciousness would be just such an act (1).

The authors argue that an act that sacrifices consciousness, ostensibly until death, in order to relieve suffering is not morally dissimilar to aiding patients to end their biological existence in order to achieve “lasting” relief from their symptoms (1) (Fig 6.1). For Juth et al, Rich and Materstvedt and Bosshard, it is this wilful sacrifice of personhood that provokes comparisons between PS and the applications of euthanasia and physician assisted suicide (PAS) (2,3) (Fig 6.1).

**Figure 6.1** The slippery-slope argument of personhood and CDPS

Quill and Greenlaw define euthanasia as “painlessly killing or permitting the death of individuals who are ill or injured beyond hope of recovery” and describe physician assisted death (PAD) as “the practice of a physician providing the means for a patient to end his own life, usually with a prescription for barbiturates that the patient takes himself; sometimes also called physician-assisted suicide”
(4). In this chapter, the term PAD will be used interchangeably with the term physician assisted suicide (PAS) and no longer revolves solely around the prescription of barbiturates but any form of sedatives that may act to painlessly abbreviate life. In both the practices of euthanasia and PAD, the end result is the same: the patient as a matter of choice has his or her life abbreviated.

To establish a tenable position for Juth et al’s suggestion and Rich’s position – that an act that sacrifices consciousness is ethically equivalent to an act that ends biological existence – the critical elements that must be shown are that a state of unconsciousness is ethically analogous to social death and that social death is ethically equivalent to biological death (1,2).

Materstvedt had suggested, as part of his adaptation of Harris’ “potentiality” theory that so long as there was a potential for reversing sedation and the patient regaining their consciousness, the patient remained a person as a result of her retained “capacity” to “value her own existence” (3). In practice, the issue of reversibility of TS, PS and CDPS is set aside, given that these treatments in fact cannot be reversed without reigniting the awareness of suffering of the patient and breaching the goals of care and the duty of the physician. For all intents and purposes, TS, PS and CDPS are irreversible and applied continuously until the patient’s demise.

### 6.2 CONCEIVING PERSONHOOD

Whilst there is little doubt that many of the traditionally understood criteria for personhood are compromised as a result of applications of CDPS, the questions that must be asked are: is it right to hold that personhood is lost as a result of a
loss of consciousness; and if so, is it correct to ethically equate this loss of personhood to biological death? (7).

Figure 6.2  The cascading argument

Rich, Juth et al, and Farah and Haberlien employ a cascading argument to support their positions concerning the link between induced unconsciousness and a deliberate end to life (1,2,8). The argument sees a series of assumptions being made, each playing a critical role in the statement that follows within the cascade (Fig 6.2) (1,2,8). An unbroken stream of logic within this cascade is critical, with any lapse in the argument leading to a collapse of the cascade. Given the pivotal position of personhood within this cascade, this chapter will attempt to address the issue of personhood and how it is conceived from a local perspective in an effort to address this cascading argument.

From clinical experience and local data, the response by local palliative care patients, carers and families does appear to be a mix of the three dominant conceptions of personhood – the innate, the individual and the relational – and not
too dissimilar to Kitwood’s conception of personhood and Buron’s Personhood Model for Dementia (15-18). However, before delving into an amalgamated conception of personhood that I forward, it might be prudent to consider each of these conceptions separately to clarify their positions (17,18).

Within the example of Singapore, local beliefs – which appear to be a coadunation of Christian, Muslim, Hindu and Buddhist beliefs in association with prevailing relational and social views of personhood – see personhood as an evolution of Kitwood’s definition of personhood (15). From my local studies in Singapore, personhood maybe understood as a “standing or status bestowed upon one by the Divine and upheld by others in the context of relationship and social being” (17,18). This innate element of personhood, with its grounding in transcendental connections and imbued with religious doctrine, is taken to be present and unchanging in all humans from conception until death. This data also clearly shows that innate personhood is neither the sole nor the dominant guiding model of personhood evoked within the local context (17,18). This element of personhood is also not strictly demarcated and is seen to pervade other conceptions of personhood. The porousness of these conceptions will be a key issue to be discussed later.

One aspect particularly influenced by sociocultural beliefs is individual personhood. The individual aspects of personhood builds upon the presence of sentience and grows to involve the emotional, psychological, spiritual and intellectual, as well as the rationality, personality, moral agency, beliefs, values and actions of the individual, manifested most clearly in the person’s interactions with others (12-18). This aspect of personhood, within the local setting at least,
appears to revolve around the relationship between the person and the family and thus introduces another key element to personhood (17,18,20-26). Within the local setting at least, the relational element of personhood is dominated by one’s relationship with one’s family (17,18,20-26).

The concept of family within the perspective of relational personhood moves beyond genetic associations and can be defined as “all those who are emotionally or psychologically close to one another” (27). Ho forwards this definition based on observations of the influences of various parties within the medical decision-making process (27). Ho’s definition rather legitimately extends the concept of family to “include biological and adopted families as well as other domestic and intimate relationships” that would involve the larger family unit, clan and society as a whole (12,13,23). However, within the present care setting, I suggest that this concept is limited to those that have “powers to intervene or have direct influence in the patient’s affairs and personal welfare or share a personal relational link with the person which the patient themselves considered important”. The significance of this requirement and the Relational Significance Test which I will propose in due course will become clear in light of the complex psychosocial and cultural considerations that continue to influence care determinations.

For now, it is sufficient to note that the innate, individual and relational elements of personhood – or “rings” of personhood – may best be described through the Ring Theory of Personhood which I will discuss later (17,18). The presence of interactions between the various rings allows for the postulation that an amalgam of these present frameworks is possible. For instance, the influence of the
The relational element upon the individual element of personhood is described by Kitwood and Bredin, who affirm the importance of the relational element to the development of the individual part of personhood.

“[e]arly in life personhood is actually being created in relationship; small fragments of truly personal experience gradually coalesce, and a self, with a sense of psychological continuity, is formed. It is a process of development that absolutely needs the Other” (28).

Similarly, interrelationship of the innate and the relational elements of personhood are highlighted by Lyn Morgan’s review of feminist writings on the issue of the “ethical emotional value of the foetus” and “the changing notion of incipient (foetal and infant) personhood” (29). Morgan reveals that relational links between the mother and the foetus that commence as soon as the pregnancy is known, confers the foetus with relational and innate personhood long before it has developed a heart beat, much less a functioning nervous system (29).

The amalgam of these interrelated frameworks is evident in local practice and the manner that oncology patients perceive personhood. Yet to explicate this overarching framework, review of their fundamental constituents is called for. Each of these perspectives command support from various writers. I will not discuss the innate element of personhood beyond the brief and general review of regnant views on the subject. In order to review the individual element of personhood, I will review the works of Rich to scrutinize the concept of personhood that revolves solely upon consciousness and “psychological continuity” (2). Daniel Tsai whose conceptions on the relational nature of personhood within the medical context will guide discussions upon relational
personhood (13). Finally, I will study the work of Bill Buron and his explication of the changes in the various elements of personhood during illness (16). To do so, I will review the work of Tom Kitwood whose study of the subject of personhood amongst dementia patients has become the touchstone for present day research on the subject and importantly represents the starting point for Buron’s position (15,16,30).

On the basis of constituent elements of these several frameworks, I shall forward my account of personhood, which I refer to as the Ring Theory of Personhood. This framework, which has been evidenced within the local palliative and oncological settings, best captures local opinion and attitudes toward the subject of personhood amongst the terminally ill patient population (17,18).

The Ring Theory of Personhood represents an evolution of Buron’s Personhood Model of Dementia Patients, which as a result of its focus upon dementia patients only is deemed unrepresentative of the palliative care population (16-18). The Ring Theory of Personhood redresses these limitations and better captures the variability of cultural, psychosocial and clinical conditions within individual case contexts seen within the diverse adult palliative care population. It also serves to illustrate that the concept of personhood of palliative care patients are multidimensional and cannot be pigeon-holed into a specific conception of personhood without a holistic review of their beliefs, values, psychosocial and clinical considerations (17,18). Importantly, the Ring Theory of Personhood is also best suited to addressing the concerns regarding personhood of CDPS patients (17,18).
In order to set the stage for the Ring Theory of Personhood, I will begin with a review of the various elements of personhood, starting with Rich’s view of a concept of personhood that relies on the presence of consciousness.

6.3 RICH’S POSITION ON PERSONHOOD

In Ben Rich’s treatise “Postmodern Personhood: A Matter of Consciousness” the axiomatic capacity for “human personal life rather than merely biological life” and “the capacity for human life” are posited as the essential components to personhood (2). Inspired by Locke’s position, Rich maintains that

“we consider human beings to be persons because of their capacity for self-consciousness and development of a concept of right and wrong, rather than because they possess a body of a particular form or genetic composition” (2).

According to Rich, “the capacity for human personal life” forms the requisite platform for this evolved formulation (2). Rich adds that it is “not the same body, but the same continuing consciousness, which constitutes the criterion for the identity of persons” (2).

Rich’s formulation sets up two criteria that define personhood: the first is the capacity for self-evaluation and the second is continuing self-consciousness that supports the maintenance of identity over time and the capacity for human personal life (2). Rich believes that without acknowledging these two elements, “most of the discussion of the subject of personhood would become completely unintelligible, as well as much of moral philosophy” (2). Psychological continuity
is the presence of a “consistent” stream of consciousness that would ensure the “same continuing of consciousness” and thus the “sameness of a rational being” (2). The capacity for personal life proposed by Rich in turn is inspired by Fletcher’s criteria for personhood (2). Fletcher’s criteria includes “minimal intelligence, self awareness, self control, sense of time, sense of futurity, sense of past, concern for others, communication, control of existence, curiosity, change and changeability, balance of rationality and feeling, idiosyncrasy and neocortical function” (31,32).

Rich argues that within his framework, an anencephalic baby who lacks both these requisites and PVS patients who have lost both these faculties are denied their personhood (2). Rich maintains that even though

“they bear the physiology of the human being, but they permanently lack the most essential feature of the human being, which is its undisputed capacity for living the life of a person, or rational self-consciousness” (2).

However Rich does appear to refrain from suggesting that personhood is an “all or nothing” phenomena that is based entirely upon the presence of psychological continuity (2). Rich allows for the possibility of personhood even in the face of infractions in the stream of self consciousness, so long as “[s]ome tenuous link with their formerly competent selves” remains (2). An example of this would be seen in early dementia ostensibly as “the capacity for human life” remains (2).

Whilst Rich does not discuss the issue of sedation at the end of life, without self awareness and severance of continuity of consciousness, ostensibly until death, CDPS patients would on Rich’s account have lost personhood (2). In such circumstances even the raft of non-corporeal and corporeal factors set out to
overcome the consciousness-driven idea of personhood would prove deficient in arguing for continued attribution of personhood to these patients (2). Cultural, social, religious, personal and professional variations, as well as a variety of internal factors such as psychological stress, must eventually manifest their effects through the consciousness of the patient (2,33). These arguments are thus a “nonstarter” as a form of defence for continued personhood in Rich’s estimation when consciousness is lost permanently (2). It follows that as a result of Rich’s position, the issue of rights, moral action and responsibility that are party to personhood would in effect evaporate for CDPS patients, leaving them akin to biologically active husks.

6.3.1 Critique of Rich

Rich’s position is atomistic and does not appear to consider personhood to be anything beyond a sentient existence clothed in cultural, psychosocial and relational considerations when the patient is conscious and capable of exhibiting “psychological continuity” (2). For Rich, personhood is only possible when “it” is able to consider “it self as it self” in continuity over time and space in a manner that bears some psychological relationship with the person “it” is over time (2). Rich appears to build his position upon a Lockean definition of personhood which states,

“the term person belongs to intelligent agents capable of law, happiness and misery”
and specifically

“a thinking intelligent being that has reason and reflection. And can consider it self as it self, the same thinking thing in different times and places which it does only by that consciousness that is inseparable from thinking, and essential to it” (2).

An anencephalic or patients in a persistent vegetative state (PVS) cannot be imbued with the rights and privileges of personhood (2).

Rich is confident of his position and states

“[n]o one, to my knowledge, has seriously attempted to argue that we could or should ascribe the status of person to a being or entity that has never had, could never acquire, or has irretrievably lost the capacity for conscious experience” (2).

Yet this position ignores other cultural, societal, religious and feminist led definitions of personhood (12,13,28-30).

Rich also does not explain what exactly constitutes “tenuous link with their formerly competent selves” and only applies this consideration to PVS (3). Questions as to its impact upon the status of anencephalic babies pose yet more questions particularly given the fact that Rich’s position appears irreconcilable with observed behaviour and practices of family of these children that would suggest that these children are still loved and cared for and afforded all the same considerations that one would see in other pediatric deaths.
Many religious views revolve around the “ensoulment” of the non-sentient foetus and the relationship it shares with Transcendence, which in turn confers it with innate personhood long before sentience is manifested (14). The belief that we are created in God’s image necessitates particular respect for the person irrespective of their gestation, much less age, abilities, gender or preferences (19). From this perspective, all human life from the moment of conception are imbued with innate personhood. Support for the view that personhood begins at conception comes from feminist philosophers such as Lynn Morgan who argue that links between foetus and mother begin as early as conception and provides relational personhood to the foetus (29). From these perspectives, a baby born with anencephaly would, contrary to Rich’s position, still be considered to have elements of relational and innate personhood (29).

Kitwood and Buron from their respective studies of patients with dementia show that in fact the concept of personhood is held to be multifaceted and consciousness is but one part of a “standing or status bestowed upon one human being by others, in the context of relationship and social being” (15,16,28,30). These authors see cultural, relational and psychosocial factors as important criteria of personhood (15,16,28,30). For Kitwood and Buron, personhood is not confined to either the communicative, intelligence or cognitive abilities of the patient but draws upon the interrelatedness of individuals, not simply within a family web but within wider society (15,16,28,30). This wider view of personhood echoes how patients in a CDPS state or even patients with varying levels of consciousness as a result of delirium, for instance, are viewed (21).
Rich’s position also ignores the manner that patients with fluctuating consciousness are addressed and considers them to be lacking personhood so long as they do not even hold to a tenuous thread of psychological continuity or fail to display “the capacity of human” (2). There are two points of concern here. Whilst Rich does not consider such patients “dead,” denial of the respect of personhood may allow various care options to be withdrawn and denies their relational links (2). It also raises questions as to how these tenuous links are to be established. However, what is clear is that any condition that transects the continuity of consciousness, severing any “tenuous link with their formerly competent selves” and negating “the capacity for human life” would extinguish personhood (2). It may be argued that intractable delirium and encephalopathy at the end of life are themselves a cause for a loss of personhood given its effect upon the patient’s “capacity for human life” (2,21). It could be argued that patients for whom CDPS is applied for the amelioration of these symptoms could be considered to experience a negligible effect upon their personhood given that in truth personhood was already under threat of disruption before CDPS was applied. By such an argument, the intentional extinguishing of consciousness even for the purposes of ameliorating suffering cannot be seen to terminate personhood.

6.4 CONSIDERING THE RELATIONAL ASPECTS OF PERSONHOOD

The relational aspect of personhood highlighted in Kitwood’s definition, outlined below, occupies a pivotal role in populations where the prominent brand of
relational personhood is Confucianism (12,13,15,16,28,30). Described by Tsai, the Confucian concept of relational personhood revolves around seeing the individual as a reflection of a wider familial identity, extending considerations of individual personhood beyond a wholly atomistic view (13). Similar formulations of relational personhood are also seen amongst all the major ethnic groups and other local familial centric frameworks, irrespective of religious tendencies or cultural beliefs (20-26,34-43).

Tsai states that the Confucian idea of personhood is based on the “individual’s transactions with his fellow human beings”; these are made up of autonomous elements and the relational elements of personhood, highlighted by the presence of the “horizontal dimension” and the “vertical dimension” within this framework (13). The vertical or the autonomous element of personhood corresponds to personal responsibility, self-reliance and self-cultivation (13). The horizontal or relational aspect corresponds to the ideal of self-transformation or growth through one’s interactions with one’s “family, society and country and the world” (13).

According to Tsai, it is this horizontal aspect that is prime, underlined by the fact that the concept of self, defined within the vertical dimension of Confusion personhood, is seen not as an autonomous being but as a “centre of relations” closely associated with the “family, community, country and the world” (13,20). Tsai adds that a person “cannot become fully human without fulfilling his role-specified relation oriented responsibilities; the Confucian personhood is to be realized through interpersonal transactions in human society” (13,20). These roles define the individual’s place within the family and create the platform for individual and familial identities (20).
When the patient is no longer able to meet the obligations of their social and familial roles, they are imbued with the family’s identity (20). It is also within this setting that the related nature of the autonomous self becomes crystallized and highlights the bidirectional nature of this interaction within the family (20). The self, in wishing to evolve, must act responsibly and must do so in a manner that would fulfil its obligations (20). A filial son in assuming his father’s roles is extending his personhood, whilst his father in sharing, and indeed ceding his responsibilities, continues with his own role of guiding his son. It is in meeting these role-specific obligations that concepts such as filial piety arises and reaffirms the obligations of family members to one another within the family identity (13, 20).

This assumption of roles by the family can also be seen as a facilitating the continued ability for communication, the maintenance of the patient’s roles both within the family structure and within society. This facilitative role is also seen as integral in assuring that patients remain involved in their own care. The “buffering process” also preserves psychological stability within the family, which is imperative to maintaining a patient’s many roles and functions, particularly when considering agitated or delirious patients (28).

6.4.1 Concerns with familialism aspects of personhood

A potential worry about familialism is that the vertical components of individualism may be suppressed by the horizontal aspects of this framework (13). From the outset, Tsai alludes to the dominance of the latter over the former (13).
The end result may in fact be the abrogation of all conceptions of individual personhood in favour of a role within the family interests and identity (20). There is no clear delineation of the boundaries of the relational aspects of personhood and how these elements of personhood are preserved within familialism (20). Collusion and coercion in decision-making and consent processes as a result of familial determination have also affected the wider view of personhood (34-43).

Empirical studies conducted in Singapore suggest that within the context of decision-making at the end-of-life care, greater weight is given to the familial interests over the wishes of the patient (25,40,42). A recent Singapore study revealed that in the face of differences between the previously stated objectives of a now unconscious patient and that of the family, the wishes of the family have precedence (26). The question then is whether the persisting conception of personhood ascribed to the patient as a result of their relational personhood consistent with the patient’s own beliefs and wishes or even a true reflection of their individuality.

For many palliative care patients who suffer from disorders of cognition and consciousness at the end of life, how personhood is conceived is critical. Appreciating a more holistic view of personhood that maintain the integrity of individual characteristics whilst being sited within appropriate psychosocial and cultural factors is critical and brings to the fore, first Tom Kitwood’s idea of personhood, and then Bill Buron’s hierarchy of personhood (15,16,28,30). I will review both these positions.
6.5 KITWOOD’S AND BURON’S CONCEPT OF PERSONHOOD

In acknowledging that as “highly social species, we are actually endowed with instinct-like tendencies to develop strong affectionate social bonds” without which “human psyche disintegrates”, Kitwood maintains a view of personhood that is diametrically opposite to the atomistic stance taken by Rich (2,15,28,30). Kitwood believes that as a result of an “interdependence of human life … no one can flourish in isolation” (30). Kitwood, therefore, conceptualizes personhood as a balance between the individuality of the patient and inherent relational aspects of identity (30).

Within this view of personhood, the individual aspect of Kitwood’s concept of personhood is taken to include considerations of the patient’s own preferences, dislikes, views, values, beliefs, evaluative processes, their personal history, commitments and narratives (15,28,30). Significant, too, is the fact that emotional constitution, spiritual and psychological characteristics are given due consideration within this element of personhood (15,28,30).

The roles the patient played in society, culture and family are seen to enrich the individuality of the patient (30). This then forms the relational aspect of Kitwood’s conception of personhood. This complementary domain of personhood also sets out to acknowledge that in fact personhood is the “standing or status that is accorded by others” making appreciation of the bonds within human groupings central to the Kitwood view of personhood (30,44). Kitwood’s framework envisages personhood as being associated with continuity of self and the integrity of a social existence (30,44).
Building on Kitwood’s framework is Buron, whose work amongst nursing home (NH) residents living with dementia (RLWDs) has resulted in the proffering of a hierarchical construct of personhood based upon the manner that personhood is lost as dementia is diagnosed and progresses (16). Armed with clinical data, Buron modelled his framework upon regnant data and prevailing literature to delineate three levels of personhood, which evolved as changes in mental, social and clinical functions occur as a result of the dementing process. Buron classified these levels as biological personhood, individual personhood and sociological personhood (16).

Buron’s impetus for forwarding his Personhood Model for Dementia Care was a wish to provide a “structure for organizing existing person-centred interventions and strategies in dementia care” (16). The first level of Buron’s framework is biological personhood, which regards the inherent nature of personhood to be delineated by the presence of an underlying “human biological system” that confers “sentience and/or the ability to experience pleasure and pain” (16). Care for this level of personhood is characterized by the most basic of biological needs, which Buron states is met by the “provision of essential needs, including food, water, shelter, clothing, hygiene, and medication” (16).

Buron’s second level personhood within his framework is termed individual personhood, which coincides with a “higher level of personhood”. Within this level, there are considerations regarding “the past, roles, personality, values, self-worth, spirituality, and so on, combined and defined through years of living” as well as “affect, emotions, self awareness, moral agency, rationality” (16). Individual personhood pivots upon the ability of the patient to “establish a
connection between the past and present (psychological continuity)” and the “capacity to communicate” (16). Buron believes that with the loss of these critical functions and “when an individual can no longer connect life events”, focus shifts from individual personhood to the “biological being” and denigrates patients to a state where they are “not the same person as they were before or non-person” (16).

Within sociological personhood, the person expands both individually as well as within social circles. It is “strictly defined by the perceptions of society and others and of their treatment of the individual” (16). Sociologic personhood is, as Kitwood suggests, “bestowed by others”, highlighted by the fact that “[s]ocial relationships, culture, responsibility, ‘moral agency,’ and membership in professional and social groups often enable society to bestow the status of personhood upon others” (16). This loss of social and professional links, specifically the hampering of communication abilities disrupts individual, professional, familial and social responsibilities, moral agency and culture, which in turn derail societal perceptions of the person in the third level of Buron’s ladder (16). In this framework, the attainment of “sociologic personhood”, which takes the longest for a person to develop and is the first to be lost as a result of changes in the patient’s clinical situation, is critical (16). Social isolation and a loss of the attributes of “sociologic personhood” that inevitably follow may be delayed if such matters are attended to early and upon a holistic plane.

Comprehending these changes are critical if the psychological, physical and social needs of patient-centred care (PCC) processes are to be met (16). For both Kitwood and Buron, maintenance of personhood is critical to ensuring care provisions remain focused upon the prime goal of many RLWDs, which is to be
treated in a respectful, inclusive and positive manner (15,16). Failure to act appropriately creates or accelerates the spiral of depersonalization, loss of self, depression, social death and increased disruptive behaviour. Evidence would suggest, too, that maintaining personhood improves the patient’s overall quality of life. The importance of preservation of social connectivity reiterates the social nature of personhood and the interconnectedness of the various aspects of personhood.

6.5.1 Critique of Kitwood’s concept of personhood and Buron’s Personhood Model

Whilst Kitwood does consider a more holistic view of personhood than the previous authors, his work remains rooted in the dementia setting. Therefore, issues of surviving interests and changes in social, psychological and physical facets in progressive illnesses other than the dementia model are not considered. Kitwood’s and Buron’s frameworks are also limited in their consideration of the manner that culture, spirituality and familial involvement may evolve over time and the effects of these changes may play on a patient-centred care perspective. The assumption that appears to be underlining Kitwood’s position and Buron’s Personhood Model still relates to an atomistic view of personhood, wrapped in a patient-centric approach to care (15,16,28,30). Issues of familial or relational aspects of personhood appear to be secondary considerations to those of the patient as the individual.
There is little consideration of the family or of the role of the family and their wishes and care needs nor is there adequate consideration of the repercussions of these considerations upon a patient’s specific situation. There are two points to this issue. The first is that it demonstrates the dated approach of these models in not adopting a multidimensional approach to care that geriatrics, palliative care and neurology adopt. This would enable these models to embrace both better patient-centred care and flexibility to contend with the case based variances that are seen in end-of-life care. The second is a failure to appropriately consider prevailing data upon the influences of psychosocial, financial, cultural and familial factors in modern conceptions of personhood (20-26,29). Addressing the needs of the family directly impacts the manner that patients own “biological aspects”, as envisaged by Buron, are met (16). This is particularly the case within the clinical context where there is a porous and sometimes indistinct boundary between personal identity and interests and those of the family.

The family also influence the manner that an individual maybe viewed by others and thus influence the manner that their personhood maybe endowed. The influence of the family upon these views is instructive. The manner that an Asian family views a patriarch affects how others approach caring for that patient (17,18). Deciphering the influences of these various elements has largely been ignored by Kitwood and Buron (15,16).

Clinically, the transposition of Kitwood’s model and Buron’s Personhood Model of Dementia Care to a “wider audience” is also fraught by reliance upon a relatively predictable course of deterioration and clinical developments (15,16). It also focuses mainly upon a specific age group of patients (15,16). The wider
palliative care situation, however, is a little more complex. Predictability of disease trajectory, patterns of manifestation, complications and even disease course vary significantly. The impact and side effects of treatments, too, cannot be ignored.

Changes in personhood are not the result of physical and sociocultural change but affective and functional change. The variability in these areas adds to the complexity of adapting Buron’s framework to the palliative care setting. Social and financial considerations too tend to be more diverse given the wide spectra of diagnosis, age, settings, treatment options and complications that might be seen in cancer patients within the end of life.

Clinical variability and the frequent waxing and waning disease trajectory found throughout the spectra of palliative care cases leave a rigid unidirectional framework, such as Buron’s Personhood Model for Dementia appears to be, inflexible to the demands of case variability (16).

6.6 THE RING THEORY OF PERSONHOOD

The Ring Theory of Personhood offers to correct the failings of the Buron and Kitwood models by forwarding a more culturally cogent, ethically sensitive, clinically relevant framework of personhood that that draws from the experiences of this clinician and the results of a diverse collection of clinical studies carried out within the holistic platform of end-of-life palliative care (17,18,20-26,45-51).

Part of the impetus for this proffering lies in the fact that whilst palliative care is built upon the idea of the provision of holistic, person-centred care, there are little
in the way of transferable frameworks that would allow for its accomplishment. No framework is dynamic and flexible enough to contend with the variability of cultural, psychosocial, clinical, religious and familial factors within a particular case and yet maintain a coherent form that abides with the prevailing clinical, legal, professional, social and cultural standards (52).

Demo states that personhood “is subject to constant change, revision, editing, and updating as a function of variations in situation and situational demands”, but does so around a stable core of self-identity (52). This point is particularly evident amongst palliative care patients and their families. Elucidating a core image of personhood and its evolving features rather than charting “situation specific self images” is critical to the provision of patient centred care and the focus of concern for the Ring Theory of Personhood (17,18,52). Understanding and contending with these changes allows for a consistent and stable framework of personhood that will facilitate better care determinations and provisions (17,18).

The Ring Theory of Personhood is drawn from the narratives of palliative care patients at the end of life, my discussions with terminally ill patients from all demographic groups and care settings in end-of-life care on their goals of care and clinical studies carried out on oncology patients (17,18). Personhood as conceived by palliative care patients is not solely confined to considerations of a legal or moral nature but includes consideration of one’s social status, familial roles and religious beliefs (17,18). What makes the palliative care patient who they are involves the innate, the individual and the relational elements of personhood captured within the Ring Theory of Personhood (17,18).
Generally, no singular belief dominates the considerations of the general palliative population and no particular element within the Ring Theory is given precedence over the others (17,18). Personhood as it is seen in this group of patients, concerns itself with how a patient would like to be cared for, how they wish to be remembered and how they would like their interests protected. Individual patients, however, do place different weight upon the three main considerations contained within the Ring Theory of Personhood (17,18).

The Ring Theory of Personhood does not subscribe to a processual mechanism of change in personhood such as Buron forwards in his Personhood Model for Dementia Care (17,18,52). This is because within most palliative care settings the effects of disease, disability and comorbidities are highly variable (17,18). Furthermore the great number of cultural, societal, religious, personal and clinical factors involved prohibits any generalization of how personhood is viewed (17,18). The Ring Theory of Personhood instead sets out to view cases on an individualized basis guided by evidenced-based practice (17,18).

Its three rings correspond to the three elements outlined previously – the innate element of personhood as the innermost ring, the middle ring which is the individual element of personhood that revolves around the individual’s level of consciousness, and the outermost ring which relates to the relational elements of personhood (17,18). Within the confines of this chapter, the Ring Theory highlights that patients do not simply conceive themselves as being defined solely by their consciousness or their innate properties but by an intermix of wider considerations that proceed beyond purely familial considerations (17,18).
6.6.1 The innate element of personhood

The innate ring is constructed upon the Greco-Judeo-Christian idea of personhood that would see all persons as a reflection of God, imbued with human dignity and rights irrespective of the stage of development or degradation (19). This idea is echoed within Devine’s “species principle” that holds all members of “the ‘species homo sapiens’ are persons whereas non-human animals, robots or extraterrestrial life cannot be persons” (53). The idea of innate personhood then posits the concept that all humans are conferred with personhood simply as a result of being human irrespective of their stage of life (17,18). It has been observed that this conception appears to be held by patients across all the races and both religious and irreligious groups (17,18).

![Figure 6.3 The Ring Theory of Personhood](image)

Innate personhood as represented by the innermost ring in Figure 6.3, upon closer observation is defined by two sets of elements, represented by a further set of two rings (Fig 6.4). The core element of innate personhood is made up of a person’s biological aspects, which is their genetic make-up that endows them with the abiding status of being human (17,18). The secondary elements of innate
personhood are a patient’s cultural, religious and familial descriptors that a patient is born into (17,18). These secondary elements, unlike the core elements of innate personhood, can change and are particularly susceptible to the effects of suffering (17,18). The strength upon which each of these secondary elements is adopted by the patient affects the size of this outer ring (17,18). A new fervent, religious faith, for example, increases the size of this outer ring of innate personhood (17,18). An active adoption of cultural and familial identity that is increasingly resonant with the patient and increasingly portrayed by the individual, will affect the size of the rings.

I will discuss the dynamics of these two rings of innate personhood and the flexibility of this framework in Chapter 7 where I consider the effects of suffering upon personhood.

Whilst foetuses and the issues of their personhood lie outside the remit of this thesis, ostensibly, it might be concluded that this principle would grant them personhood from the point of conception. Similarly, patients, irrespective of their impaired consciousness or their terminal state, remain persons simply as a result of their continued resemblance to God and being part of the human species. From my clinical experience and clinical data, few subscribe to Goldenring’s
conception of a “brain-life theory”, which would view life as a human being beginning at the point when the foetal brain begins to function, nor Rich’s priori of consciousness (2,17,18,54). Adaptations of Englehardt’s “potentiality principle”, which suggests that personhood begins at the point of fertilization and pivots on the ability of an individual to attain full brain function, are also not unanimously adopted by the palliative care community (17,18,53). Many patients hold that how a pregnancy develops is very much the “will of God” and it is unacceptable and “arrogant” to place any expectations on what level of function one is to achieve in order to be deserving of respect (17,18,55). Ascriptions of personhood hold to three points. The first point is that it is not the potential for consciousness that is central but the potential for life in any form that is central (17,18). Once conceived, a person’s genetic and parental heritage, even in deteriorating function, at any stage of life remains unchanged, ensuring that personhood remains intact (17,18).

The second is that whilst the patient will unlikely redeem their ability to express and function as an independent person in the dying phase, the potential remains (3,17,18). This, however unlikely it may be, negates the possibility of fully discounting the potentiality for a reversal of fortune and thus renders the ‘potentiality principle’ useless (3). Thirdly, it ignores the third element within the Ring Theory, which considers the relational aspects of personhood and maintenance of some element of the patient’s selfhood within the family, social group or society as a whole by simply being a part of them (17,18). Within this Ring, relational bonds that form between the foetus and the mother and/or the father and the rest of the wider family will confer some elements of personhood
to the foetus (18). I will discuss the various aspects of the outermost ring a little later.

In summary, innate personhood confers personhood so long as the patient is alive, solely as a result of being born with the genetic make-up consistent with what could be considered a homo sapien (17,18). Even newborns with genetic abnormalities such as trisomy 21, Kleinfelter’s syndrome or even Turner’s syndrome where there is an excess of or deficiency in their chromosomal make-up, would still be conferred personhood, so long as the baby is born alive irrespective of any number of the physical disabilities encountered or their abnormalities upon appearance and functioning. Patients with mental and physical disorders at birth maintain a basic level of personhood deserving of rights and respect (17,18). Therefore, innate personhood is not lost even in anencephalic babies or in dying children who are abandoned or orphaned without any family to care for them, or those patients who may have been abandoned by family, and are destitute and alone without familial and social links (18). Innate personhood survives such isolation so long as the patient is alive. Death and the separation of the soul from the body are seen to end the connection with the Divine and thus end an individual’s personhood.

6.6.2 Individual personhood

The second ring of the Ring Theory is the individual ring and it encapsulates the innate ring (17,18). The individual ring depicts the second element of personhood, individual personhood. Individual personhood is associated with higher functions
of consciousness of the individual and would be akin to Buron’s own conception of individual personhood (16-18). Of particular importance to this aspect of personhood are its evolving nature, its dependence upon consciousness, its changeability in periods of altered consciousness and its association with the other elements of personhood seen upon the wider canvass of patient’s specific psychosocial, spiritual, cultural, familial, clinical and societal situation (17,18).

Individual personhood, unlike innate personhood, is entirely dependent upon conscious function and can be lost; the individual ring can experience alterations in its size depending on the ability of the individual to maintain the consciousness-defined elements of personhood that Fletcher and Rich hold to (3,17,18). Individual personhood is lost entirely during periods of unconsciousness but can be regained as soon as consciousness is returned. The extent to which individual personhood is re-established, however, is dependent upon the ability of the person to reclaim his self-awareness, self-control, sense of time, sense of futurity, sense of the past, capacity to relate to others, concern for others, communication with other persons, control of existence, curiosity, change and changeability, balance of rationality and feeling, idiosyncrasy, and neocortical function (3,17,18). Full restoration after unconsciousness would entail redeeming these functions to the level that was possessed before the period of unconsciousness. The appreciation of the multidimensional aspects of the patient’s specific context is important to appropriately appraise their abilities.

The capacity to communicate and maintain “psychological continuity”, moral agency and self-awareness are key in order for the individual to expand their potential for individuality (17,18). This ring grows as the various abilities mature
and become more consistent. From this ring of personhood, a patient develops
traits of their own that are specific to their character and enable them to exert their
independence from others, as would be the case in a maturing child. As a result of
these maturing abilities, the child would form their own relations that are
independent of the familial links and based on their own characteristics. This
independence increases their individual personhood. In so doing the individual
ring expands as personal identities replete with values, beliefs, psycho-spirituality,
roles, personality traits and preferences, personal goals and emotional maturity
grow.

Consistency in the abilities to maintain the various aspects of their individual
personhood is also important. This would involve the ability to control emotions
and manage the effects of external factors upon their ability to maintain their
cognitive and neurological functions. Concentration and temperance in mood and
responses affect the size of the ring, as do physical changes and psychosocial
factors. Control of these factors is key to a consistent individual ring.

Individual personhood, however, also begins to experience changes in periods of
semi-consciousness, confusion and with dementing processes too (17,18). Lapses
of concentration, emotional distress or psychological strain may all impair
function for a prolonged period, as can psychological states such as depression,
anxiety and mania.

In a dementing process, the extent and speed that personhood dissipates is
dependent upon how many of the prime characteristics are retained and how well
the person is able to exercise them. Dissipation of individual personhood contains
temporal and specificity aspects to considerations. How fast the impairment in
consciousness has been occurring and how long it lasts affects the speed of contraction and the re-expansion of the ring. Maturity of the various characteristics and the consistency of these elements of individual personhood do play a part in the speed of contraction in periods of impaired consciousness. A consistent, mature individual ring will be retained better than one that a child may possess. Similarly, the patient’s ability to recover is critical. A depressed patient after a stroke will take longer to recover than a stroke patient that is emotionally well. The speed of adaptations to physical deteriorations and the patient’s general health also play a role.

These factors highlight the importance of a holistic appreciation of the patient’s situation. A dementing patient who is slowly losing their abilities to communicate and mobilize may encounter a changing level of individual personhood similar to that experienced by a patient with severe depression or chronic illness. Reliance solely on the functional elements of consciousness does not fully capture the influences of other factors upon individual personhood.

It is also important to understand that change in the individual ring also influences the adjacent rings. An outward expansion of the individual ring does not to encroach upon the position of the adjacent rings but does usually institute a corresponding and proportional growth in the outer ring too. This is because such growth in the individual facilitates relationships that arise by virtue of the individual’s own personality and characteristics, such as friendships and romantic liaisons, rather than the relationships that arise as a result of familial connections. Similarly, a failing individual personhood will cause contractions in the size of the relational ring. Maturing and expanding individual personhood confers an
interest in the manner that these patients wish to be viewed and cared for when they are no longer able to do so themselves or help direct the manner that care would be afforded. This, then, forms the basis for surviving interests. I will discuss this aspect of personhood a little later.

This idea of size also reveals the rather arbitrary boundaries of each of these rings and reiterates their porous nature. Individual and innate personhood affect the next ring of the ring theory, which relates to relational personhood. The role of individual personhood in influencing and forming and maintaining relationships and social bonds is integral but not singular in its effects upon the relational ring. Innate personhood, simply by being born human and being cared for, creates inherent relational links that will manifest themselves as elements of relational personhood.

Given the direct interactions between the innate ring and the relational ring, the Ring Theory of Personhood is conceived as two un-centred rings within a third ring (Fig 6.3).

### 6.6.3 Relational personhood

The relational ring occupies the outermost ring of the Ring Theory of Personhood and is closely linked to the individual ring and the innate ring (17,18). The concept of relational personhood grows out of increasing data within palliative care settings that show that patients, whilst keen to exert their independence and individuality, do consider their families and carers as part of the most intimate and important elements of their extended selves (34-43). Furthermore, inspired by
Joseph Fletcher’s 15 criteria for the “status of person”, Rich acknowledges that interactions with others – highlighted by concern for others and being able to communicate with and relate to others – are essential elements of personhood (2,17,18). Kitwood holds that the family can facilitate the continued presence of these characteristics, particularly within the family unit itself where the partially incapacitated patient’s gestures, utterances, facial expressions and body movements, for instance, may be interpreted and understood by those who know the patient well (15).

Rather unsurprisingly, in a society that practices family centric beliefs, the definition for this final ring is heavily influenced by how “family” is conceived. Drawing on Anita Ho’s delineation of familial ties, as it best reflects the wide spectra of bonds and ties that are seen in care of palliative patients, those who are seen to influence the relational ring are those

“people who are emotionally or psychologically close to one another. Such definition can include biological and adopted families as well as other domestic and intimate relationships” (27).

At the centre of this definition is the need for the parties to be “emotionally or psychologically close to one another” ensuring the presence of a close bilateral relationship that would better communicate the nature and personhood of the patient (17,18,27). There are two prime elements to be considered here. The first is that there is acknowledgement of the family’s central role particularly where it is their influence that most frequently provides the best account of the person and, in turn, is instrumental in how others perceive the patient. As a result, it is the
family that are most frequently involved and play a part in directing the care of
the patient.

Secondly, there must be a mutual relationship present. As a result of this concept,
membership is limited to those that have “**powers to intervene or have direct
influence in the patient’s affairs and personal welfare or share a personal
relational link with the person which the patient themselves considered
important**” (27). For now at least, it is those relationships that are found within
the confines of these criteria that are important, with one significant exception –
the relationship between a foetus and its parents. I will explain the significance of
those relationships found within and those outside these limits later.

Based on communitarian ideas that see one’s identity preserved within a patient’s
community, a person’s unique imprint is held to persist for as long as they are
within the memories of the social groups that they are a party of. Enshrining these
characteristics are the **personal** links formed with others through social,
professional and/or familial roles. Underpinning these are four prime
considerations. The first is the basic premise that the more **personal** bonds that
are present in a patient’s life, the larger the size of the relational ring. These
personal links are those enduring associations between the patient and another
person where they influence each other, where thoughts are exchanged and
feelings shared (56). Within these interactions, there are no defining roles to be
played and each party “retains their character” in the interaction (56). It is further
characterized by a reciprocal relationship and may potentially be a co-dependent
interaction (57).
Secondly, there must be due consideration of the quality of relationships contained within the relational ring. The deeper or more established the relationships, the stronger and more abiding these relationships are, the denser the ring will be. This is highlighted in Figure 6.3 above where the darker green within the relational ring corresponds to the stronger deeper relationships, whilst the lighter shades of green correspond to “weaker” relationships. These weaker relationships would include friends and family with no significant personal, emotional or psychological ties. Aiding to determine the significance of these relationships within their roles in the relational ring is the Relational Significance Test, which I will explicate later.

The significance of relationships, however, does introduce the third point, which relates to the nature of persistence of personhood in a community. This centres on the point that how a person is remembered within their social, familial and professional groups helps to preserve their personhood. However, to be clear, this preservation of memories of the person and particularly by the roles they played within these entities are only seen to aid in the endowment of personhood if there is actual direct personal emotional or psychological links between the person and the members of the groups (27). This reiterates the importance of the personal links such as those seen in a family, in endowing personhood. An employer and employee may have a long association but their association may not be personal and thus the role each played cannot be seen to endow the person with personhood.

The fourth point is that patients do then have vested interests in how they are conceived, given that their retention in the memories of the community and
indeed family even upon their incapacity and eventual demise is dependent upon it. This creates a basis for surviving interests (17,18). I will discuss the influence of each of these factors in due course.

The quality and number of personal ties that arise from familial, societal and professional association are integral to the size and density of the individual’s relational ring. The quality of relationships provides the density of the ring whereas the number of these personal links increases the size of the ring. The quality of relationships is a measure of the strength of personal psychological and emotional bonds between the patient and another.

There is a need at this juncture to differentiate personal ties from ties formed as a result of roles that a person may have played. Having a personal friendship with the patient is very different from the emotional and psychological ties that may be formed between a person and the patient when the patient was playing the role of a leader, for instance. There is no doubt that these latter bonds may still engender close, strong emotional and psychological links; however, the fact remains that they do not fulfil the criteria for a personal relationship. Within the Ring Theory, it is the personal element that is the focus of the relational ring and the key element that influences the relational ring.

Therefore, for the purposes of density, it is those strong personal relationships then that are of interest. These would include those relationships with significant emotional investment and consistency, usually seen within those relationships that have been nourished and tendered over years and ones that would endure over long periods of unilateral interactions. A much loved patriarch, may be assumed to have stronger relationships and a denser relational ring than a
significantly brain damaged child whose only relationships are those endowed by its mother.

### 6.6.4 Linking the rings: Porousness

To highlight the porousness of the rings, consider once more the anencephalic child and its mother; it is clear from the relationship between the mother and child that some relationships arise from the start of life (2,17,18,29). The anencephalic child’s relational personhood is conferred by his or her mother, and sees the depth and size of this ring as a function of the mother’s ascriptions. This close association between the innate ring and the relational ring explicates the rationale for the displaced or “off centre” position of the innate ring within the individual ring. It highlights the relationship between the innate and the relational as well as the direct influence each has on the other. The child’s relational personhood is also personal though the child has but will never develop the ability to form relationships of his or her own. It is the biological link between the child and the mother that entitles him or her to this most basic personal bond. Many mothers form bonds and relationships with their unborn babies even before a beating heart is present or the symptoms of pregnancy begin (29). The link is entirely unilateral and does grow in most cases with the growing pregnancy as a result of the direct connection between a mother and her unborn child. The unborn child then has both the innate and relational ring before they are even born. This relational ring may grow still further as bonds between the foetus’ father, its siblings, its grandparents and wider members of the family begin to take root. It is clear then

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that there are some bonds within the relational ring that are almost innate, unilaterial and may remain strong throughout life.

Once born, denser rings will form when a person’s individual personhood begins to expand and create new bonds. Friendships and kinships strengthen and provide yet more density to an individual’s relational ring. As an individual matures some relationships such as his spousal and filial bonds become “cemented”. For a terminally ill patient who has developed such bonds, such bonds are consistent, unwavering and remain intact even when the patient himself begins to deteriorate and his mental faculties begin to fade. These links endure for as long as there is a continuing relational link with his family members and those who knew him personally. The strength of the bond is anticipated to resist deteriorations in the link over time, whilst less well “cemented” or indeed strong ties may begin to crumble after a brief space of time. Stronger bonds slow the degradation of the relational ring.

It may be argued, though, that this is not always the case; there are mothers and indeed parents who do not wish to have a relationship with their children at all, or may not even know of or chose to acknowledge their child’s presence until much later in its gestation. There are also assumptions as to how far the relational link extends and who may endow the child with personhood. Does the father not endow the child with relational personhood? Does it extend to grandparents, prospective godparents, siblings, aunts and uncles? The answer lies in the Relational Significance Test, which reviews the nature of the relationship and the quality of the bonds formed. I will discuss the quality of the bonds first.
6.6.5 The nature and quality of relational links

The quality of the bonds are critical to considerations and bears scrutiny. Within a family-centric society, for example, there remains a personal expectation upon the family members to comply with their filial roles. Consider the case of the terminally ill Mr Chong and the anencephalic child who are both members of their respective families and as a result are owed care by the family. These take the form of bidirectional interactions within the context of filial piety and familial and social expectations respectively that need not be personal but based entirely upon the roles played within the family. In Mr Chong’s case, family members are expected to carry out their filial duties and care for him. This would be true irrespective of whether they shared a personal relationship with one another. The familial link grants such a privilege and a duty upon all its members (20-22,34-43). These obligations would be maintained until death. Family members are also aware that failure to fulfil these duties would reflect badly upon them on a social and wider familial stage (20).

Additionally, in keeping with Confucian beliefs, for Mr Chong’s family members and the family members of the anencephalic child their duty of care for their family members is also part of their own growth and development (17,18,20,34,35). Therefore, family members have their own vested interests to meet these obligations appropriately (17,18,20,34,35). Such provisions of care are extended to any vulnerable member of the family (17,18,20,34,35). The anencephalic child would be owed care simply as a result of being a child within the family and the family as a whole would be remiss in their social and familial obligations if they fail to care for the child (17,18,20,34,35). The bonds that
would on the surface be influential to the size and density of the relational ring, may in fact be influenced by the interests of the carers.

So, what bonds truly affect the relational ring, and would these self-motivated actions of the wider family still be considered sufficiently important to be considered part of the patient’s personhood? How would these bonds be any different from those of the carers paid to look after the child? Is a familial link sufficient to trump all other forms of bonds? What about the concerns of a surrogate family who had yet to complete the adoption of a seriously ill child? More attention needs to be paid to these points and I will return to them at a more opportune time in this chapter.

“Strong” bonds may be unconventional in nature as was the case of Thava who was a cleaner at a local hospital. When the chief pediatrician at the hospital suffered a stroke, it was Thava who visited him daily for the three years that Dr Sam was an inpatient at a local nursing home. Here the bond was formed as a result of the respect Dr Sam showed Thava in simply acknowledging him on his ward rounds. They had barely exchanged more than simple pleasantries and yet Thava felt a kinship to this prominent man for the effort he made to be courteous to him.

Similar situations arise from those patients who have formed bonds with their carers and friends; temporal continuity imbues them with enduring bonds that allow for these patients’ identity and sense of self to persist in their external links. Yet the question arises as to whether this impacts on the individual’s personhood. In Dr Sam’s case, the staff went out of their way to care for him, regularly slipping a pot of orchids into his room, for the simple pleasure of caring for this
poor mute. In this “relationship”, the bonds that were formed with the staff of the nursing home arose as a result of his role as a patient and as a result of his past deeds. The personal care and affection that the staff showered upon the patient and the duration of these actions may be said to have led to “real” bonds being formed and genuine concern for the “person in the bed”. Would these links conceived by the staff that do not possess a personal bilateral association with the patient affect the patient’s personhood?

In Dr Sam’s case with the staff, and Mr Chong’s case with the grateful beneficiaries of his philanthropic work, these links did not affect their respective relational rings given that they did not contain a personal bidirectional aspect to them. These links, however, still played a part in ensuring that their respective positions in society and their roles in the lives of others remained intact. There is another element to be considered when others confer personhood in addition to considerations of the nature of the relationship: the will of the person conferring it.

6.7 THE RELATIONAL SIGNIFICANCE TEST

For Thava and the staff looking after Dr Sam, there was a will to promote Dr Sam’s well-being. Their influence ensured the protection of Dr Sam’s personhood. The greater their interest, the more they ensured that Dr Sam’s personhood was maintained. This will to continue to care was exhibited in Thava talking to Dr Sam and reading the newspapers to him and by the staff caring for him, providing flowers for him and ensuring that he was always well-groomed and treated with dignity. The impetus involved in protecting the personhood of these patients by
various parties is complex. Consider some of the fans of Michael Jackson whilst he was being resuscitated, or Tupac Shakur whilst he was on a ventilator, who believed that they had personal relationships with the artists themselves albeit through their recordings, films and books. These fans had an interest in protecting the personhood of the celebrities, much like Thava or the staff of Dr Sam’s nursing home had for Dr Sam to treat him as whole and deserving of respect. However, for the most part, their influence was limited to ensuring that the innate part of Dr Sam’s care were met. They did not have a personal relationship that the patient considered important when they were conscious and thus did not influence personhood.

The question then arises as to whether it was appropriate to allow the great-grandchildren who barely knew Dr Sam personally but who had come together to care for him out of their filial obligations to be conferred a place in determining the patient’s relational personhood, but not Thava or the staff of the nursing home. A multidimensional and individualized review of these relational links are called for. Such a review is called the Relational Significance Test.

The Relational Significance Test sets out to review a specific relationship on a multidimensional level. This process begins with a review of the situation objectively, based upon the information that is generally available concerning a relationship, such as a relationship between parents and a child or the relationship between a healthcare professional and a client. Objective standards based upon sociocultural expectations and, where appropriate, professional standards are applied. This is taken to provide a general framework upon which a relationship is reviewed.
To introduce the nuances, including specific social and case-specific considerations, a subjective review of the case is carried out. This combination of an objective review followed by a subjective review ensures a standardized process to this evaluation that does not neglect the nuances of the case-specific considerations to appropriately ensure that those relationships that ought to be considered within a patient’s personhood are afforded their due place in these deliberations.

Consider the relationship of a child and their mother. Objectively it is a relationship that is socioculturally, legally and professionally acknowledged. This relationship therefore passes the first part of the Relational Significance Test in having an objective basis for acceptance as a valid form of relationship.

The second part is the subjective element of the relationship. Consideration now shifts to the stance of the mother toward the pregnancy. Not all pregnancies are desired nor do all mothers choose to acknowledge their pregnancies. Llandra, for instance, was afraid to form any links with her foetus after suffering two consecutive miscarriages. Lee, on the other hand chose not to “get close” to the baby as she was acting as a surrogate for a friend and her partner and knew that she would have to “surrender” the baby. In both cases, the mothers did not wish to endow the child with a relational element beyond their innate personhood for very different reasons. In these cases, it cannot be assumed that the child has a relational element to their personhood any more than June’s child, whom the mother plans to abort. Kerry’s child is to be aborted, too, but only because Kerry is suffering severe preeclampsia that threatens her life. Kerry however has endowed this child with a name and even bonded with her. Ayrton, Kerry’s child
has a relational element to his personhood over and above his inherent innate personhood. In each of these cases the Relational Significance Test shows the importance of considering the subjective factors to a relationship.

The Relational Significance Test also helps with a more difficult yet just as important consideration: the position of the father’s relationship with the unborn baby. Objectively, there are two considerations; like the maternal relationship with the child, the paternal relationship is recognized by legal, professional and sociocultural standards, with the additional consideration of the Confucian element, which also reiterates the paternal link to the child. However, all relationships prior to the birth of the child occur through the mother and cannot be considered to endow the child with elements of relational personhood since there is no ongoing physiological connection between father and baby except through the mother. This argument sits rather precariously and is difficult to fully explicate particularly if it has been argued that the child has been said to already have its own personhood and thus is already considered an individual deserving of respect and consideration. One explication is that whilst the child is provided with innate and relational personhood in utero, these elements of personhood are framed and supported by the mother’s extension of her own relational and innate elements of personhood onto the child. Even when the mother does not desire to keep the child or chooses not to build a relationship with the unborn child, the physiological link remains and maintains the child’s innate personhood. The precise importance of this relationship within a specific case, however, requires application of the Relational Significance Test that lies outside the remit of this thesis.
The situation becomes a little clearer once the baby is born, where direct paternal relational links with the father can be formed should the father choose to. There must be due consideration to whether the father acknowledges the pregnancy to be his and wishes to participate in caring for the baby. The subjective element therefore will allow for the father to form a relational link with the child even though the child lacks consciousness, simply as a result of the biological link the child shares with the father and the father’s wish to care for the child.

The situation with extended family members also requires more consideration, even though objectively their relationships with the child may be considered valid particularly under a Confucian framework. Subjectively, the links shared between the child and the extended family must depend upon the subjective information concerning each person’s link with the child. This discussion maybe transposed to the situation involving the unconscious patient where as a result of the relationship between the now unconscious parent and the children, it is the elder whose personhood is encapsulated by the family. In the case of Dr Sam’s great-grandchildren, the objective question is whether they, as great-grandchildren, have a personal relationship with Dr Sam. The answer would be affirmative. Reviewing the situation subjectively, the fact that they did not really know Dr Sam is weighed up against the fact that they were all studying abroad and only saw Dr Sam during their school holidays. This did not relegate their relationship to be any less important than any other family member’s, especially as the great-grandchildren still loved Dr Sam dearly and had written to him regularly and had their emails and texts read to him by the staff even after he was reduced to an uncommunicative state. On the subjective level, too, the relationship was deemed
sufficiently close to allow for them to be determinative of Dr Sam’s relational
ring.

Of the staff involved in the care of Dr Sam, the objective review would ask if it
is possible for staff to develop relationships with their patients. The answer
would be no but yet there is also an acceptance that they do do so, as Quill so
vividly describes (57,58). A subjective review, however, reveals that part of the
close ties that developed was because some of the staff had previously heard
of Dr Sam and held him in high esteem and also because the owner of the
nursing home had been cared for by Dr Sam many years ago. The links were thus
not personal and based on the experiences of others with the patient. They thus
fail the Relational Significance Test.

Whilst relational personhood is led by Anita Ho’s definition of family, given the
prevailing family-centric views practiced widely around the world, it does not
gender a particularist view to each relationship that is considered using the
Relational Significance Test. This is because it is those who pass the Relational
Significance Test that are deemed to have “powers to intervene or have direct
influence in the patient’s affairs and personal welfare or share a personal
relational link with the person which the patient themselves considered
important” (27).

With this in mind, addressing Mr Chong’s case becomes clearer. Here the
presence of filial obligations alone do not endow strong relational links instead it
is those important and personal relationships with the various members of his
family that matter within these determinations.
An important element of clinical observation that this model explains is the discernible change in the manner that a patient is viewed upon the onset of iatrogenic sedation to unconsciousness or “natural” unconsciousness as a result of a disease process. Whilst the innate element of personhood remains intact, the individual ring is lost and the relational element becomes involute. For instance, as the duration of unconsciousness persists, visits and attention from acquaintances recede, the roles that the individual play in groups even in work settings are slowly revised and repealed. The lighter coloured rim of the outer circle does contract to leave the darker elements of the relational ring that correspond to those closest and dearest to the patient.

Inducing unconsciousness, therefore, does impact personhood and as a result cannot be considered to be an undertaking to be met lightly. However, it does not prove fatal to the patient’s personhood. Despite a change in how personhood is perceived, it not lost completely and thus does not fall victim to the belief that CDPS renders a person “socially inert” and thus dead (17,18). This distances the application of CDPS from inducing social death. Personhood is not sacrificed for the sake of symptom control; therefore, no comparison can be drawn with sacrificing life for comfort (17,18). The cascade argument crumbles.
6.9 CONCLUSION

In this chapter, I have confronted a new threat to the practice of CDPS and have addressed it by forwarding the clinically relevant framework of the Ring Theory of Personhood. I have argued that whilst there is a decrease in the extent of an individual’s personhood, in truth, it is not lost completely. With the help of the clinically based Ring Theory of Personhood, the cloistered views of personhood that would see the application of CDPS in the same light as social death are laid to rest.

Additionally, the Ring Theory helps reiterate the need to continue to respect and treat all patients with consideration and concern irrespective of their subjective psychosocial and clinical conditions. It also sets out to uphold the acknowledgement rights and surviving interests of patients in all stages of life and ensures that patients are cared for in a manner that is commensurate with their beliefs, values and wishes at all stages of life. The Ring Theory in sitting itself within palliative care also ensures that considerations move beyond narrow views of personhood to consider familial, psychosocial and spiritual considerations in a balanced and holistic manner. This is highlighted in the next chapter when I consider the effects of suffering upon personhood.
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Chapter 7

THE EFFECTS OFEXISTENTIAL SUFFERING ON PERSONHOOD

7.1 INTRODUCTION

There is general consensus that personhood is pivotal to palliative care considerations particularly given its central role within quality of life (QoL) determinations, the preservation of dignity and the provision of “active total care” (1-7). Understanding the effects of suffering upon personhood and its potential compromise of the central objectives is essential to care determinations (6-8). The Ring Theory of Personhood crystallizes the impact of suffering upon this wider social construct of personhood. Understanding these effects is invaluable to a care landscape that continues to adopt differing approaches to care of physical and existential suffering.

Part of this dissonance in approaches is due to a lack of consensus as to what forms of suffering lie within the remit of modern medical care and the limits to the efforts expended to address them (9,10). I have shown in Chapter 2 that deference to “alternative” treatment modalities that authors such as Jansen and Sulmasy employ can no longer be viewed as appropriate within a palliative care practice led by a multidisciplinary team (MDT) (9). However, resistance towards homogenous treatment of all forms of suffering persists (9). There are two issues. Firstly, there is a general unease about labelling suffering as intractable when a clear definition to the suffering is still lacking (9). I will return to Jansen and Sulmasy’s concern of a lack of a “concrete” diagnosis later on in this chapter (9).
The second issue revolves around a general lack of understanding of existential suffering and the precise limits of care that may be utilized to address this form of suffering (11,12). This is particularly clear within the Dutch setting where such determinations amongst the terminally ill could result in the iatrogenic demise of the patient (11,12).

I have argued that comprehending the full effects of suffering is integral to the provision of appropriate and proportionate care at the end of life. I submit that if the effects of existential suffering upon personhood is as far reaching and as severe as those seen with physical suffering, then the present differential approach to the treatment of intractable suffering at the end of life cannot be viable.

To begin, I accept the proposition that physical suffering is multidimensional and thus has the potential to affect all aspects of personhood. My task now is to investigate if the effects of existential suffering upon personhood have similar repercussions.

7.2 CONCEIVING EXISTENTIAL SUFFERING

There are two schools of thought with regard to existential suffering (12). I will refer to them as the “discrete” and the “holistic” views of suffering. The “discrete” perspective would see existential suffering delineated by “13 categories, including meaninglessness in present life, meaningless in past life, loss of social role functioning, feeling emotionally irrelevant, dependency, fear of being a burden on others, hopelessness, grief over
imminent separation, ‘why’ questions, guilt, unfinished business, life after death, and faith” (13).

This “discrete” view is best exemplified by Jansen and Sulmasy’s conception of “agent narrative suffering” and Morita’s refractory psycho-existential suffering (9,13,14). Morita states that

“[r]efractory psycho-existential suffering as an indication for palliative sedation was defined as psychological distress not accompanied by physical symptoms, such as feeling of meaninglessness / worthlessness, burden on others / dependency / inability to take care of oneself, death anxiety / fear / panic, wish to control the time of death by oneself, isolation / lack of social support, and economic burden” (14).

Morita circumscribes the presentation of psycho-existential suffering from physical suffering, creating two separate and unrelated entities (14). Like Jansen and Sulmasy, Morita holds that the effects of existential suffering do not permeate to other realms of care nor are they expected to impact upon the family and carers of the patient (9,14).

Bruce et al’s concept of “groundlessness” represents a more “evolved” form of Morita’s “discrete” view of existential suffering (14,15). Bruce et al hold that their “dynamic and fluid” perspective of existential suffering “compels health providers to acknowledge the complexity of fear and anxiety and the uniquely dynamic nature of these processes for each person” (15). The “groundlessness” that Bruce et al present results from being “shaken to the core” and is part of a social process, which the authors refer to as “longing for ground in a groundless
world” (15). The period of groundlessness is taken to symbolize existential suffering (15). Groundlessness

“is a time and place of raw experience and frayed emotions. Participants used emotional terms in describing it, talking about fears, losses, questioning, worrying, discontinuity, pain, despair, frustration and anger” (15).

Whilst Bruce et al conceive an evolving process to existential suffering, the effects remain confined to the “ultimate concerns that arise when a person is faced with mortality through illness, profound loss, or from deep reflection on what it means to be human” (15). Drawing from Yalom’s posits of “meaninglessness”, Bruce et al report that their concept of groundlessness “is a way of facing and leaning into the experience of loss, confusion, fear and uncertainty where loss of meaning is implicated” (15).

Bruce et al introduce a further “dimension” to considerations by stating that the effects of existential suffering are not localized to solely patients but affect those persons who care for them (15):

“Caregivers also experienced groundlessness. In situations when the patient’s suffering seemed irresolvable and no peaceful end was possible, an infectious or rippling suffering was evoked for some professional and family caregivers” (15).

Bruce et al also see this element of existential suffering as being changeable and state that “caregiver suffering was heightened as the patient’s suffering endured despite all efforts to relieve it” (15). Bruce et al also show that there is reciprocity
to this suffering, and that the suffering of family members does affect the
suffering of patients themselves highlighting a relatively new perspective of the
discrete view of suffering.

Unlike Bruce et al’s concepts that remains confined to “making sense and
reconstruct[ing] one’s sense of self and life when it has been unravelled”, Tan et
al provide a contrasting and holistic view of suffering (15,16). For these authors,
esthe existential suffering is a multidimensional experience “interwoven within the
broader complexity of suffering” (13,16). Tan et al hold that

“[p]ain and physical symptoms were experienced as existential realities
that were inseparable from the various emotional, cognitive, and spiritual
reactions triggered by the perception” (16).

Tan et al add that so pervasive is this interconnectedness of suffering that
suffering itself may be seen as an existential experience (16). For these authors
suffering is then “defined as an unpleasant existential experience that occurs
when the individual suffering threshold is exceeded” (16). This threshold is itself
dependent upon a wide range of psychosocial, spiritual, physical and emotional
considerations (16).

I will consider the effects both these clinically evidenced views of existential
suffering have upon personhood and palliative care objectives as a whole.
7.3 BRUCE ET AL’S “LONGING FOR GROUND IN A GROUNDLESS WORLD” THEORY

In their article “Longing for ground in a ground(less) world: a qualitative inquiry of existential suffering”, published in BMC Nursing in 2011, Bruce et al study the existential and spiritual concerns of six palliative care patients, six family caregivers and ten healthcare professionals (HCPs) in Canada (15). Bruce et al “used grounded theory, a qualitative, systematic approach used to explore processes in the context of situated interaction, to explore the process of existential suffering. It involves the concurrent collection and analysis of data to formulate theories that are grounded in the worlds of the participants” (15).

In this study, the authors note that the “participants’ understandings of existential suffering were as varied as seen in the literature”; however applying the social process of “longing for ground in a groundless world”, the authors are able to categorize the concerns of participants into three groups (15). The three groups are “engaging groundlessness, taking refuge in the habitual and living in the in-between” (15). The authors conclude that groundlessness is a “process [that] involves moving between engaging groundlessness, in which people turn toward the discomfort of groundlessness and learn to let go; taking refuge in the habitual, in which people turn away from the discomfort, attempting to keep it out of consciousness by clinging to the familiar; and living in-between, in which people may create a balance within groundlessness and potentially find comfort in the instability” (15).
The term “groundlessness” is derived from a description of

“‘being shaken to the core’. It also carried connotations such as ‘un’ terms such as feeling undone, unravelled, or unhinged to describe being groundless” (15).

The authors report that patients

“spoke of recognizing life is ending, having a profound sense of hopelessness, being unable to reconcile their experience with their spiritual faith, not understanding why God is doing this, having ones’ belief system shattered, experiencing extreme dissonance” (15).

Despite the difficulties in articulating this feeling of groundlessness, the authors, drawing from the narratives of patients, deduce that the experience of groundlessness is “profoundly distressing, in that a patient’s world is shattering and his/her fundamental beliefs are called into question” (15). The authors are clear that this form of suffering revolve around a discrete set of issues and is manifested by “the experience of loss, confusion, fear and uncertainty where loss of meaning is implicated” (15).

In “engaging groundlessness”, participants report “moving into the discomfort of being groundless and working with that instability” (15). Pivotal to this process is that “participants continuously renegotiate and reconfigure what is normal, as well as the sense of self, of relationships, and so forth” (15). The authors also report that this process continues, “as losses accumulate and one’s ability to actively engage groundlessness diminishes” (15). Participants spoke of “making new meaning of what is happening” to them during this process but admit that this effort at confronting the reality of their situation can be “too much” (15).
It is, therefore, not uncommon for patients to choose to take “refuge in the habitual” (15). Patients adopting this form of coping attempt to relate to things “as if nothing has changed” (15). Many do, however, accept that “compounding losses at the end of life … make[s] it harder to relate to the world through a veil of ideas that can no longer obscure those losses” (15). These patients may find it difficult to address many situations as a result of this stance.

There are some patients who choose to adopt a more flexible position:

“[L]iving in-between is an attempt to become comfortable with constant shifting within the experiences of losing ground, letting go of that loss, finding a new frame of reference only to realize that it, too, is a temporary ground that will slip away” (15).

The authors note that patients find it difficult to talk about “existing in this state” (15).

### 7.3.1 Reviewing Bruce et al’s data

In all these states, existential suffering results in significant effects upon personhood. Before I review these effects based upon the Ring Theory of Personhood, there are a number of significant concerns with respect to this framework that need to be addressed. The application of the “longing for ground in a groundless world” process remains unproven in end-of-life care and the manner that Bruce et al elucidate the themes of this small study is unclear (15). The “concurrent collection and analysis of data to formulate theories that are grounded in the worlds of the participants” raises questions as to the effects of the
interpretations and inferences the investigators make of the individual narratives. The small sample size also casts doubts as to the validity of these themes. It is unclear if these themes were deduced from the data or were led by Balfour Mount’s and Yalom’s findings that the authors refer to in their paper (15). Were the typology of coping with suffering predefined or were the authors biased towards analyzing their data to meet these predetermined types of coping mechanisms? With the vacillations seen in patients choosing to adopt an “engaging groundlessness” approach to their suffering, the “denial” seen amongst those “taking refuge in the habitual” and the patient’s difficulty at discussing “living in-between”, it is questionable as to how these states could be identified from a single interview of so few patients (15).

Biases also arise as a result of the participation of caregivers and HCPs in this study when reciprocal caregiver suffering is evident. In Strang et al’s study, there was a difference in the meaning and interpretation of the experience suffering amongst various HCPs, confirming fears of bias in reports (17). This suggests that not only were HCPs’ opinions better articulated than those of the ill patients but that their experiences are “tainted” with their own interpretations of the situation (17). These concerns reinforce earlier doubts that Bruce et al’s “concurrent collection and analysis of data to formulate theories that are grounded in the worlds of the participants” may be biased by the investigators own views (15).

The relatively small sample used and the preponderance of family members and HCPs raises concerns that what is being described is swayed by what these observers deduce from the patient’s actions and narratives as well as their own beliefs (17). That the “self identification” of participants “as having experience
with existential suffering at the end of life were included in the study” also raises questions about the generalizability of this data (15).

7.3.2 Implications of Bruce et al’s view of suffering upon personhood

The biases and concerns in Bruce et al’s study whilst significant still reflect prevailing data (15). A further point of temperance is the acceptance that caregiver suffering has reciprocal effects upon the patient, meaning that whilst the caregivers may make their positions more clearly than the ill patients, their own experience with suffering is evidenced to impact and play a part in the suffering of the patient (16). Therefore, even if the data is biased by the presence of so many caregivers, the views can be seen to provide both a wider view of the patient’s suffering over time and also a different perspective to the suffering of patients. Providing more weight to the views of family and caregivers also allows for insight into what HCPs identify as existential suffering in practice and how they address the various forms of coping with existential suffering.

Figure 7.1 The Ring Theory of Personhood
I will utilize an evolved form of the Ring Theory of Personhood to consider the implications of Bruce et al’s views of suffering.

7.3.3 Implications of Bruce et al’s conception of existential suffering on innate personhood

Innate personhood is founded upon the notion that personhood is inherent from birth, by virtue of all persons being reflections of God, imbued with human dignity and rights, irrespective of their stage of development or deterioration. This ring is lost when the soul of the patient “departs the body” and the link with God is severed.

Innate personhood is defined by two sets of elements. The core element of innate personhood is made up of a person’s biological aspects, which is their genetic make-up that endows them with the abiding status of being a human. The secondary elements of innate personhood are more changeable and are made up of the patient’s cultural, religious and familial descriptors that they were born into.

Figure 7.2 The constituents of innate personhood
Bruce et al show that groundlessness leads to an “uncertainty and quest for firm footing”, which for many patients does not result in positive effects upon a patient’s secondary elements of innate personhood (15). The resultant effect of being “shaken to the core” affects a patient’s faith and relationship with God (15). These effects challenge beliefs and may weaken religious affiliations thereby diminishing the patient’s secondary elements of innate personhood.

These effects can have wider repercussions. They may change the way patients think and determine their goals of care. Beliefs in a religion that sees suicide as a sin may be lost in these moments of “groundlessness” and new goals may now be focused upon securing an early demise (15). The patient’s goals of care and reasoning will reflect these changes in thinking. This also highlights a wider effect upon the individual ring, which I will address a little later.

The other secondary elements of the innate ring are also affected by these changes. It is not uncommon for some family members to withdraw from the patient’s side when their situation deteriorates. Patient F was conscious but weak and tearful when some of her family began to excuse themselves from her side, unable to cope with her emotional liability and constant demands for reassurance. Amongst those who remained by her side, there were some who chose only to participate in “practical care” such as turning her and washing her but chose not to engage her on a more emotional and existential level. As a result of her “isolation”, the “deeper” bonds between these family members and Patient F were lost. Patient F withdrew from her family sensing their own feelings of “groundlessness” (15). Shedding her familial links affected the secondary elements of her innate personhood, as it did her relational personhood.
In a society where causing suffering is viewed as a sin, Patient F also renounced her cultural heritage, upset that her suffering could cause such upset and distress, but also by the manner that her family acted on their cultural views and societal expectations. She stopped wearing her traditional clothes and refused to practice some of the cultural beliefs and mores.

A three-dimensional representation of the elements of the innate ring is applied to better articulate the depth, affinity and importance of these elements to the patient. “Groundlessness” may not result in a complete loss of old values, beliefs and links but does cause a reduction in them. This change in affinity and importance sees the globe that represents the secondary elements of the innate ring contract. Reductions in importance of any of the secondary elements result in a reduction of the global size that encompasses the “inert” disc of the core of the innate ring (Fig 7.3).

The effects of groundlessness, though, need not always be detrimental to a patient’s innate personhood. Bruce et al add that as a matter of “engaging groundlessness”, and the belief that “groundlessness is workable, that one can learn to let go”, this suffering may be overcome with an increase in the affinity and importance of the various secondary elements such as familial links as family
rally together to support a patient (15). The globe of the secondary elements may then increase.

Temporal comprehension of the effects of suffering then becomes important. At an early stage, the globe may be bigger as the families “rally around the patient”. As the situation evolves and the changes described occur, the globe may reduce in size before, given sufficient time and support and the ability to reconsider, the globe may re-expand. Understanding the effects of personhood must be a comprehension of the effects of suffering over time and not a “snapshot”. Understanding that these changes are possible helps the small MDT understand the thinking and rationale of the patient.

This change in rationale is also reflected in the patient’s individual ring.

7.3.4 Implications of Bruce et al’s conception of existential suffering on individual personhood

The effects of suffering upon how a patient exhibits their self-awareness, self-control, rationality, sense of time, sense of past, and sense of futurity affects the growth, maturity and consistency of individual personhood, and further highlights the dynamic nature of personhood. I argue that consistency and maturity of behaviour provide depth to the individual ring proffered in Chapter 6. The thickness of the individual ring is dependent upon the maturity and consistency of those characteristics associated with consciousness. Maturity is taken to mean the presence of more nuanced behaviours that one would expect of an adult, as opposed to the consistent behaviour of a child. Consistency in behaviour and
character is manifested in two forms. The first is the constancy in manifesting the various aspects of consciousness. When a patient’s beliefs and values change, are “shaken to the core”, or their mood and clinical conditions alter despite a constant level of consciousness, being able to maintain a consistent position and behaviour and temperament delineates consistency. Changes in behaviour and thought processes may result in vacillations in the way patients interact with others, in their rationality and in the temperance of their mood. This ability to tamper responses and to appropriately balance considerations goes hand in hand with maturity of character.

Consider Jansen and Sulmasy’s case of Patient B, a man with end-stage amyotrophic lateral sclerosis (ALS) (9). Reflecting Bruce et al’s findings upon Patient B’s case reveals that Patient’s B’s thoughts, decision-making processes, emotional responses, temperance in mood and rationality would be affected by his existential suffering (9). The ability of Patient B to behave in a manner that is both consistent with his previous thinking and previous characteristics is doubtful. Patient B’s individual ring reduces in size even without a change either in consciousness or in the number of elements of consciousness exhibited.

The effects of existential suffering as Bruce et al conceive it will also change the manner that Patient B interacts with others. Bruce et al state that “[s]ometimes people engage the world through strongly held beliefs that provide solace, but that may no longer work in the current reality” (15). In “taking refuge in the habitual”, Bruce et al report that patients control their interactions in their coping with their existential suffering, which in turn affects their ability to express many of their conscious facilities and compromises their personhood (15).
A diminution of Individual personhood also affects their ability to control the manner that they are regarded. Whilst professional, social, cultural and legal standards ensure that there is a general standard to care provisions, patients are clear that these standards do not fully capture their individuality nor ensures that they are cared for in a manner that is consistent with their beliefs, values and aspirations. These effects also affect the relational ring of personhood.

### 7.3.5 Implications of Bruce et al’s conception of existential suffering on relational personhood

Bruce et al’s introduction of a wider concept of existential suffering that acknowledges the effects of suffering of the patient upon the family and that of the family upon the patient’s suffering, provides a more clinically-relevant understanding of suffering (15). The relational ring, whose size is a factor of the number of relationships a person has, and whose depth is defined by the strength and enduring nature of these relationships within the evolved form of the Ring Theory, display changes in size resulting from the effects of suffering on relationships with family and friends.

Recall Patient F’s situation and her withdrawal from the family both as a result of their suffering and in response to their coping with her suffering, reveals a contraction in the relational ring.

From the analysis of the effects of Bruce et al’s conception of existential suffering upon the various rings within the Ring Theory of Personhood, it is clear that despite Bruce et al’s discrete view of existential suffering, all three rings
contained within the Ring Theory of Personhood are affected, revealing wider repercussions to this experience than the authors originally acknowledge (15). It also highlights that much like the effects of intractable physical suffering at the end of life, intractable existential suffering has a similarly extensive effect upon the patient’s being as evidenced by the effects upon their personhood. The wider implications of this finding will be discussed later in this chapter.

7.4 **TAN ET AL’S HOLISTIC VIEW OF SUFFERING UPON PERSONHOOD**

Tan et al hold that suffering in all its forms is a result of an overwhelming of a patient’s “suffering threshold” by various forms of distress (16). This “suffering threshold” is modulated by protective and risk factors that include the patient’s character and coping strategies, their support mechanism and stressors, their psychosocial and physical backgrounds, as well as their outlook and religious beliefs (16). Overwhelming of the threshold may arise from any form of distress and highlights the interconnected and holistic view of suffering that these authors expound in their “Existential-Experiential Model of Suffering” (16). Tan et al constructed the “Existential-Experiential Model of Suffering” from their thematic analysis of 20 semi-structured interviews of palliative care patients in Malaysia (16).

From this clinically evidenced stance, the authors conclude that the experience of suffering is unique to the patient and changeable in character over time and circumstances. However, despite this capriciousness, the various forms of
suffering maintain a constant overlap between one another and allows them to be loosely categorized into existential suffering and experiential suffering. The authors describe existential suffering as

“suffering from the perspective of existential realities, which include loss-related events, named as deprivational events in the study; and gain-related events, named as acquisitional events” (16).

Experiential suffering on the other hand is seen as

“suffering from the perspective of the inner experiences of the person, the unique, direct, first person experiences. It encompasses perceptual suffering that involves the experiences of suffering through the senses and reactional suffering that embraces all the unpleasant reactions triggered by perceptual suffering” (16).

From their clinical data, the authors identify 10 forms of overlapping types of suffering and conclude that a more holistic view of suffering is required to adequately address an evolving concept of suffering (16). They also conclude that the present failure to address suffering as a multidimensional experience is contributing to suffering of many patients. The authors state

“[p]ain and physical symptoms were experienced as existential realities that were inseparable from the various emotional, cognitive, and spiritual reactions triggered by the perception” (16).
7.4.1 Reviewing Tan et al’s data

Whilst Tan et al do set out to delineate a multidimensional view of suffering, their formulations of suffering are “deduced from the fact that a beginning point of suffering might exist where a threat just began to be experienced as suffering” (16). Delineation of suffering based on their apparent etiological origins make these concepts categorical in nature and reminiscent of Jansen and Sulmasy’s concept of a causal relationship of suffering (9,16). This defeats the authors’ attempts to overturn the prevailing dichotomous view of suffering (9,16). This approach is also flawed in its failure to consider the potential for more than one cause for each form of suffering that they identify (16).

Whilst the study was carried out in multicultural, multi-religious Malaysia, the participants were primarily from the minority Chinese population and did not reflect the multicultural beliefs present (16). There is little in the way of consideration of the influences of sociocultural, religious and familial factors in the determinations of the threshold of suffering. There are also other apparent oversights. A lack of explication upon the manner that each form of the 10 types of suffering are categorized under either existential or experiential themes casts further doubt on the analytic process (16). There is little explication as to why emotional suffering and spiritual suffering, which is defined as “suffering due to unmet spiritual needs”, are classified under experiential rather than the classically understood existential category of suffering (16).

There are also other conceptual concerns with Tan et al’s review. Tan et al suggest that experiential and not existential suffering is affected by perceptions (16). This position is highlighted in the apparent omission of interconnectedness
between the existential and the experiential arms of the Existential-Experiential Model of Suffering. This position sits diametrically opposite to received wisdom on suffering and palliative care opinion (16,18-20). Tan et al also fail to acknowledge the overlap between the experiential and existential forms of suffering, despite the data they present (16).

7.4.2 Implications of Tan et al’s view of suffering upon personhood

However, it is also in these oversights that the holistic nature of the suffering experience is brought to the fore. The authors do state that coded elements within the narrative analysis were applied more than once to describe the various forms of suffering (16). This highlights an overlap between the various forms and hints at, at least in part, the rationale behind the categorization of suffering into the various arms. On a larger scale, it also facilitates overlap between experiential and existential suffering, making the division of suffering between these two forms of “organizing themes” arbitrary (16). Tan et al final conclusion of a holistic view to suffering receives support from van Tol et al’s and Dees et al’s studies (11,16,21).

With existential suffering evidenced to affect all elements of personhood when viewed either as a discrete entity or within a holistic framework, the implications upon the manner that palliative care addresses existential suffering need to be reconsidered.
7.5 IMPLICATION OF EXISTENTIAL SUFFERING UPON PALLIATIVE CARE PROVISION

The findings from the applications of Bruce et al’s and Tan et al’s studies upon the Ring Theory of Personhood concur with the findings of Kissane, Rietjens et al, Schwartz and Lutfiyya, and Saunders on the growing evidence for a holistic view of suffering (5,7,22-24). A wider view of existential suffering and its effects is dawning with the advent of more clinical evidence in support of this more holistic view. Such understanding will be invaluable to the comprehension of suffering and the manner that patients address these issues, particularly how a patient’s views change and care decisions are affected.

Such repercussions are not unexpected with Chochinov et al revealing that existential suffering is associated with psychological distress, quality of life and suffering, and Kissane, Rietjens et al, Schwartz and Lutfiyya, and Saunders showing independently that this experience changes a patient’s beliefs and values (5,7,8,15,16,22-25). Rietjens et al state

“[m]any patients approaching the end of life suffer from more than physical symptoms alone: emotional and existential problems including hopelessness, death anxiety and disruption of personal identity may occur as well. This sometimes happens to the extent that patients attach no value to continuing to live or at least to consciously experiencing their life” (24)

Such changes and experiences trigger re-evaluations in the stances of patients upon many aspects of their own care, as well as in their goals of care and in the manner that it is provided (22). Kissane states that these responses may range
from avoidance of medical care and non-adherence to treatments so as to affect the ability of these patients to make decisions, questioning their cultural or ethnic values and beliefs, and an increase in religious doubt (22). LeMay and Wilson add that the presence of intractable existential suffering increases “a patient’s risk for suicidal ideation and desire for death” (25). Gonen et al also report that there is an increase in psychiatric morbidity amongst these patients, whilst Puchalski reports that it may worsen physical pain, “impact coping” and decision making (26,27). These issues alter a patient’s focus of care and compromise the manner patients protect their best interests and may potentially jeopardize competence (22,26-30).

Recall Patient B, who as a result of his existential suffering due to amyotrophic lateral sclerosis suffers from what Tan et al would refer to as “dependent suffering” (9,16). Patient B’s experience with the “compassionate psychiatric social worker” and the psychiatrist reveals that he also suffers from emotional, terminal, interactional, differential, cognitive and spiritual suffering (16). These forms of suffering straddle both experiential and existential forms of suffering within Tan et al’s Existential-Experiential Model of Suffering, highlighting the interlinking nature of these various forms of suffering (16). These findings are echoed in Bolmjo’s study of existential suffering amongst patients diagnosed with amyotrophic lateral sclerosis (31). The presence of this suffering results in a change in the manner that Patient B would act to protect his interests. Bolmjo’s study reveals that many patients like Patient B experience anxiety, suicidal thoughts and thoughts of euthanasia (31). For Patient B, an early demise or even palliative sedation (PS) would be better than his present state of existence. Patient B therefore acts to realize his goals that would remove him from this state
of distress. To do so, Patient B exhibits a change in his thinking and deliberation so as to realize these goals. The same argument will also apply to Jaafar’s case. It is this shift in thinking amongst patients that validates the need for a wider, balanced deliberative process under the aegis of a small multidisciplinary team (MDT) that I forward in Chapters 2 and 3.

What is clear from Patient B’s case and Jaafar’s case is that they developed existential suffering as a result of a coadunation of their individual psychological, social and physical state that overwhelmed their “suffering threshold” (16). These cases also reveal that the effects of existential suffering affect every element of the patient’s being and can be seen to impact upon the patient’s quality of life and comfort in a similar manner that intractable physical suffering does. The question that then arises is what rationale can be given to justify the dichotomous view taken on the treatment of existential suffering and physical suffering?

Could it be the concern articulated by Jansen and Sulmasy that there exists no pathological diagnosis for this suffering? (9,32). If, as Vehling et al reports, existential suffering is a response to physical suffering and disability, and if as Tan et al and Vehling et al suggest, the potential risk factors and protective factors are known, why is there no means of a firm, reproducible, evidenced-based means for a diagnosis of existential suffering? (16,33).

### 7.6 A DIAGNOSIS OF INTRACTABLE EXISTENTIAL SUFFERING

The lack of a succinct and universally accepted definition for existential suffering is a reflection of a failure to understand the process and to comprehend the extent
of its effects both temporally and holistically. A dearth of longitudinal studies in this field, particularly when the significant sociocultural factors need to be fully understood, and a lack of a flexible diagnostic framework that can address the subjectivity of these symptom reports merely hamper the process (34-36). However, there is no lack of recognition of the constellation of symptoms that make up existential suffering (31-46).

It is clear from the data provided thus far that general medicine’s present preoccupation with the American Psychiatric Association’s (APA) fifth edition of the Diagnostic and Statistical Manual of Mental Diseases to provide a “dimensional assessment” of existential suffering is misplaced (9,13-16,38). This hope merely highlights a poor understanding of the process of existential suffering and a continued reliance upon poorly conceived notions of existential suffering. Data that I have reviewed thus far will clearly substantiate the fact that existential suffering is not confined to psychiatric or solely emotional planes (13-16). A wider view is required.

The North American Nursing Diagnosis Association (NANDA) adopts just such a view and has recognized spiritual suffering as a nursing diagnosis since 1980 (34-36). Expansion of this idea to encapsulate the wider ideas of existential suffering is already on the way (34-37). The lesson that NANDA’s position highlights is that a wide and multidimensional view of this issue is required. Modern medicine, which has compartmentalized itself along various areas of subspecialties, is not best placed to address a multidimensional issue such as existential suffering. Palliative care on the other hand, with its diverse areas of interest and its multi-professional and multidimensional approach, offers a solution.
Intractable existential suffering at the end of life already lies within the remit of palliative care and a palliative care physician is required, under the guidelines set out here, to substantiate any diagnosis of intractability when continuous deep palliative sedation (CDPS) is being considered. Furthermore, its small multidisciplinary team (MDT) approach is better able to comprehend the experience holistically and across the patient’s family and carer circles, particularly given the reciprocity of this form of existential suffering.

A further response to Jansen and Sulmasy’s concern that no concrete diagnosis exists for existential suffering lies in reiterating that whilst there is a lack of consensus in the manner that existential suffering is perceived, there is no lack of recognition of this pathological process and its implications upon the patient and their family and carers (13-16,31-46). A lack of a diagnostic framework for dying, for example, does not in itself prevent acknowledgement that it occurs in a myriad of ways. Dying is recognized as a process and treated as one. Comprehending existential suffering in a similar light may offer a suitable solution for existential suffering. Vehling et al reiterate this “processual” concept (33). The authors state

“cancer patients face considerable existential challenges across all disease phases, despite the changing backgrounds of these concerns. Thus, the ‘shock of diagnosis’ frequently experienced by cancer patients is often attributed to the confrontation with the fundamental (existential) fact of the finiteness of one’s life and may be followed by an existential ‘plight’ over months. The phases of recurrence and/or metastization, however, often confront patients with limited life time and growing physical
constraints. The increase of distress in the palliative treatment phase found in the present study suggests a culmination of existential concerns toward the end of life” (33)

Morita et al and Tan et al report that existential suffering is subject to a great number of other considerations, particularly from a cultural and social point of view; unlike the entirely clinical presentation of the dying process, these other considerations merely complicate the situation and results in the need for further studies like that of Tan et al’s on various ethnic, religious and cultural groups (16,39).

The primary obstacle to the forwarding of a comprehensive diagnostic platform for intractable existential suffering is a failure to understand suffering itself. The data above shows that existential suffering and physical suffering are interrelated and that they both create equally adverse effects upon the patient and their family and carers. To attempt to forward a framework for the diagnosis of existential suffering akin to that expected of intractable physical suffering at the end of life is to continue to promote a dual view of suffering.

Forwarding a diagnostic platform for existential suffering is not about expanding or adapting the diagnostic platform for intractable physical suffering at the end of life since no firm diagnostic frameworks exists for intractable physical suffering. Thus far a diagnosis of intractable physical suffering has been a diagnosis of exclusion, a diagnosis made when physical suffering no longer responds to treatment measures and no viable alternative remains.

Intractable existential suffering does not exhibit any specific nor reproducible parametric changes in the patient’s condition, but its effects are equally
devastating to the patient, their family and carers. It is clear that to appraise these effects and treat them require a holistic review. Given that this form of suffering is discussed within the context of end-of-life care and requires multidimensional assessment and treatment, it becomes clear that diagnosis and care of existential suffering at the end of life must fall under the aegis of palliative care.

A multidimensional view of suffering is already a central precept of the palliative care ethos, as is a holistic view of suffering. A palliative care approach avoids discrimination in the extent of care on the basis of aetiology but instead adopts an inclusive view of care. This prevents it becoming mired within a specific form of treatment and enables it to adopt multipronged approaches to care that include alternative as well as traditional medical options. These approaches are in turn overseen by a MDT that in turn provides the balanced oversight required. These factors reinforce the position that the diagnosis and treatment of existential suffering should be a palliative care diagnosis.

### 7.7 Conclusion

It is a lack of comprehension of the process of suffering and its implications and a failure to appropriately site end-of-life care within a palliative care approach that underpins the primary reason why terminally ill patients experiencing existential suffering are not provided with the care that they require.

It is as a result of this oversight that many of the existing PS and TS guidelines remain compromised and not suitable to their allotted roles. Reliance upon preconceived ideas of goals of care and the limits of medical interventions leave
these options decidedly hamstrung particularly when addressing complex presentations of suffering. It is clear from the evidence provided that this approach is not tenable and reinforces the fact that reliance upon holistically-determined, case-based delineation of care that this thesis advocates is called for. Addressing these shortcomings ought to begin with appropriately providing a palliative care diagnosis to existential suffering within the complex and interrelated entity of suffering as a whole.


46. Lavoie M. Blondeau D, De Konnick T. The Dying Person: An existential being until the end of life. Nursing Philo 2008;9:89-97
Underpinning concerns with regards to the application of sedation at the end of life is a lack of understanding, not simply of end-of-life care in general, but of palliative care itself. This is highlighted by the continued dissonance in the manner that palliative care goals have been adopted beyond the realms of oncology (1,2). This situation is not helped by a failure to include a palliative care presence and approach to the assessment, diagnosis and care of all terminally ill patients, particularly those with complex needs.

It is thus no surprise that a palliative care approach has been largely neglected in the considerations for treatments such as palliative Sedation (PS) and terminal sedation (TS) until recently (3,4). It is this oversight that has propagated the continued controversies that have beset the practices of TS and PS. Whilst the European Association for Palliative Care (EAPC) and the Royal Dutch Medical Association (KNMG) have set about correcting this omission, more is required to address the procedural and ethical concerns that remain, particularly in light of the stark variances in care facilities and access to palliative care that is observed within diverse care settings (1-4).

Despite these efforts, concerns with regard to the practice of TS and PS are liable to perpetuate as healthcare professionals confront practical limitations in the form
of dissimilar understanding of palliative and supportive goals in caring for these imminently dying patients with intractable suffering, differences in general medical and end-of-life clinical practice, and diverse access to palliative and supportive care (1,2). These differences fan fears that the inevitable variances in care provisions will potentiate the risk of abuse of these treatments. The situation is compounded by an eagerness amongst healthcare providers to produce guidance and treatment frameworks that are “inclusive” and that will cope with stark differences in care facilities and access to palliative care observed within the various palliative care settings [Appendix 3, 5 and 6].

The pursuant “overly” inclusive and ultimately limited guidance upon the practice of TS and PS has not helped to alleviate concerns (5-11) [Appendix 3, 5 and 6]. Confronting these prevailing concerns and anticipating potential limitations – limitations that have moved beyond the well-documented fears of drug induced hastening of death, to involvement of the processes applied within the decisions to employ this treatment, as well the manner and means that it is employed and monitored – has been the focus of this thesis (8-20).

Under increasing clinical, professional and legal oversight, it is merely a matter of time before more pages of clinical, philosophy and ethics journals are expended on “new” areas of concern as healthcare professionals (HCPs) begin to grapple with the practical considerations of controversial treatments such as continuous deep palliative sedation (CDPS) (3-7). Already questions have shifted from fears of an iatrogenic cause of death to one increasingly concerned with “social death” and the demise of personhood (21-23). As scrutiny of this practice grows, practical and procedural inconsistencies will undoubtedly arise, which I have
highlighted earlier. Circumventing and pre-empting these inevitable questions – questions that will mire this treatment option in yet more dispute and further compromise care of vulnerable patients with intractable suffering at the end of life – has been the central theme of this thesis. In this thesis I have presented data and ethical review of a number of key issues in the hope of allying these concerns.

This thesis has argued for a holistic, palliative-care-led approach to the employment of sedation at the end of life in order to stem the evolving concerns about the various elements of CDPS practice. This thesis, by confronting present and potential areas of concern using prevailing clinical data and guidelines, as well as clarifying observed clinical practices to augment the overarching ethical review of the primary areas of concern, has addressed and negated many of the primary concerns with respect to the employment of CDPS. This is achieved, among other ways, by clarifying the process of determining the overall goals of care in Chapter 2 and the closely related process of decision-making involving palliative medical principles and practices, as well as the affirmation of the key role of the multidisciplinary team (MDT) within these proceedings in Chapter 3. These two areas are frequently neglected within prevailing guidelines on PS and commentaries by various clinicians and ethicists, a significant source of potential controversy for the practices of TS, PS and CDPS (Appendix 1-3, 5 and 6).

This thesis has also set out the inclusion criteria and the manner that care is determined. Grey areas are not papered over but are addressed by an explication of the manner that proportionality, necessity and appropriateness is sited and viewed within the holistic multidisciplinary team review of a particular case.
There is no obfuscation of the methods nor obscuring the manner in which a small group of professionals – guided by regnant clinical guidelines, prevailing laws and social norms, and overseen by an independent specialist palliative care review – will liaise with the family and patient to facilitate a balanced, transparent, justified and accountable process of determining the best interests of the patient, the overarching goals of care, and the viability for the application of CDPS. Such a multidimensional, multiprofessional and inclusive approach to overseeing this intervention is inspired by the guidance set out by the European Association of Palliative Care Guidelines on the application of PS (3). This approach attempts to correct the past failures to appropriately site the practice of PS under the banner of palliative medicine and under the aegis of evidenced-based medicine that have only served to compound the misconceptions about treatments such as PS and TS (9-16,24). It also lays to rest fear that this is a paternalistic, single-clinician based decision-making process. Standards of care and goals of care are guided by the Best Interest Principle and complemented by established clinical guidelines, legal expectations and social norms.

Yet the solutions may be as difficult as the problem to overcome. Finding a practical compromise to a more “demanding” monitoring protocol in the face of new clinical data and care limitations featured in Chapter 6 would be difficult without the decision-making process advocated in Chapter 3. Clearly compromises require a case-by-case review guided by prevailing legal, professional and societal expectations and a clear understanding of what can realistically be provided by a MDT.
There are, of course, issues that have not been addressed in this thesis. A key element for future focus is the determination of intention, particularly within the MDT. Such a study extends well beyond the remit of this thesis but must surely be an area of interest for any coming study on end-of-life practices.

It is hoped that this thesis will pave the way towards the production of clinically relevant, socioculturally sensitive, ethically appropriate practices that will address care of extremely ill and suffering patients whilst improving education about end-of-life care and general medical care as a whole.
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