Author/s:
Knight, Kerstin

Title:
The inconsistent philosophy of advance care planning

Date:
2016

Persistent Link:
https://hdl.handle.net/11343/122071

THE INCONSISTENT PHILOSOPHY OF ADVANCE CARE PLANNING

HOW CONCEPTUAL DIVERSITY LEADS TO UNPREDICTABLE PRACTICE

Kerstin Astrid Knight

Student No: 146442 November 2016
orcid.org/0000-0001-8996-4428

Thesis submitted for the full requirements of the degree of Doctor of Philosophy in the Center for Applied Philosophy and Public Ethics (CAPPE) within the School of Historical and Philosophical Studies in the Faculty of Arts at the University of Melbourne, Australia.

Produced on archival quality paper

For all who care.

SYNOPSIS

This thesis examines the coherence of the conceptual philosophical framework of Advance Care Planning (ACP). Focusing on ACP's three central concepts autonomy, beneficence and numerical personal identity, I examine how these concepts are interpreted in regards to ACP across the disciplines of philosophy, medicine and law and to what extent they can be seen as forming a coherent framework that leads to consistent, successful practice. As the most central goal of ACP is *respect for patient autonomy*, my particular emphasis rests on a practical examination of the concept of autonomy. Through the analysis of relevant medical cases as well as legal and philosophical scholarship I arrive at the conclusion that current ACP practice is not based on a coherent framework of ideas. I further find that it cannot claim convincingly to achieve its aims of respecting patient autonomy or being uncontroversially in the patient's best interest, and that there are serious metaphysical doubts whether ACP can be said to apply to one and the same patient at all.

In addition I examine whether the clarification of concepts and a resultant change of practice would be likely to achieve an improved situation. By using a Wittgensteinian game analogy to language, I arrive at the conclusion that many of the cross-disciplinary conceptual challenges that ACP faces, result from the inability to maintain a sufficiently shared discourse that would allow unambiguous cross-cultural and cross-professional concept matching. This inability is rooted in the diverse goals, which the various parties, involved in the ACP discourse, pursue, and which are intimately linked to the preservation of the discourse participants' identity. In so far as these goals are contradictory, mutually exclusive and essential to the identity of the discourse participants, they are likely to obstruct ACP practice and acceptance.

I thus conclude that ACP, as originally conceived and currently pursued, is an overambitious idea that incorporates contradictory goals, which arise out of the necessarily communal character of the practice. This supports my argument that many practical problems associated with ACP can be traced to underlying problems of conceptual diversity, and that these problems are resistant to liberal and universally acceptable solutions.

The final section explores how a coherent conceptual framework for ACP could be achieved in principle. I show that the most coherent way of connecting the three central concepts would involve the acceptance of a narrative concept of autonomy in conjunction with a subjective idea of beneficence and a biological account of numerical personal identity. However, an analysis of how such ideology would impact on medico–legal practice suggests that this kind of framework is equally problematic and unlikely to be acceptable to current practice. I therefore propose that care planning should favor a much less ambitious approach, which focuses on shared decision making, ongoing interpersonal communication and the prevention of social isolation, instead of raising expectations that it cannot fulfill. I am thus opposed to a position which dogmatically promotes ACP as a universally desirable benefit.

DECLARATION

This is to certify that

(i) this thesis, submitted for the degree of Doctor of Philosophy, comprises only my original work

(ii) due acknowledgment has been made in the text to all materials used

(iii) the main text of this thesis is less than 100,000 words in length, exclusive of the table of contents, declarations, bibliography and endnotes

signed: Kerstin Knight, November 2016 in Melbourne, Australia

ACKNOWLEDGMENT

I wish to express my gratitude to the many people who supported this project.

General thanks go to the University of Melbourne for space and resources, to my family for their patience and to the many friends who helped when help was needed.

I especially want to thank my honors supervisor John Armstrong for being inspiring, Graham Priest, emeritus Boyce Gibson Professor at the University of Melbourne, for giving me academic refuge, when times were difficult, my colleague Barbara Hayes, for persistent encouragement and exchange of ideas and my supervisors Neil Levy and Lynn Gillam - Neil, for the most amazingly prompt and constructive feed-back and Lynn for strategically placed advice.

Last but not least, my thanks and love go to my son Miles for being a constant source of joy.

CONTENTS

CHAPTER ONE – ADVANCE CARE PLANNING FROM ANTIQUITY UNTIL NOW

1 – INTRODUCTION

This chapter aims to introduce the territory of questions about advance care planning that this thesis will explore.

By using two prominent historical figures as hypothetical advance care planning subjects I will canvas the multitude of generic concerns that can be raised in terms of advance care planning irrespective of particular patient details.

I will then go on to recount the history and evolution of modern advance care planning ideas, relate these to the previously raised generic concerns and move on to give the justification and rationale of this project, which is to identify conceptual constraints within the advance care planning conceptual framework. This will then prepare the hypothesis that insight into the conceptual constraints can ground some important suggestions about limitations of the idea of advance care planning as a whole, and its likelihood of success.

2 – TWO ANCIENT PATIENTS

SOCRATES

A *All men are mortal. Socrates is a man. Therefore: Socrates is mortal.*

Thus goes one of the most famous logical syllogisms in the history of philosophy. It is mostly used in order to give an example of a well formed, concise and precise argument, but I want to use it for a slightly different purpose. I want to use it as a platform from which we may start an exploration of the concepts involved in advance care planning. And to this end I will not so much engage with the argument form, but more with its content and related historical events.

Many contemporaries considering the merits of advance care planning, particularly clinicians involved in medical care, would probably happily go on to say:

B Socrates is mortal; therefore he should have an advance care plan.

They would affirm this, I think, in order to express the general fact that no one can escape death (and dying) and that therefore, sooner or later, like it or not, everyone is forced to engage with it. For this reason of *universal mortality*, they think advance care planning is something that is relevant for everybody. In a similar vein the reasoning then proceeds to use the claim about *universal relevance* to support the assertion that everybody *ought to* engage in advance care planning.

We notice that the extended claim (a) has moved from an ‘is’ to a ‘ought' form, a signpost that we have moved from a description of a state of affairs towards an ethical consideration. We have also moved from a concise formal logical argument to an argument of a different kind. There may be many ways in which this difference can be described. I do not wish to dwell on this in particular, but just to point out that the move from the factual to the ethical domain has opened the extended argument up to a much greater scope of critical engagement.

The original factual argument has two premises and one conclusion, which may be refuted or affirmed (most likely by empirical evidence) and an inference which allows us to move from premise to conclusion. There can only be four ways by which to defeat the argument: we defeat at least one of the premises or the conclusion or show that there is something wrong with the inference. This is a pretty simple state of affairs.

This is not the case for the claim of the ethical argument. The ethical argument covertly presumes many silent co-premises, e.g. ‘all mortals should have an advance care plan’ or ‘advance care plans are beneficial for all mortals’ or ‘advance care plans are the right way to engage with death’ etc. These tacit co-premises themselves are open to critical evaluation, some of which leave the empirical domain entirely. The ethical argument, although it looks just as simple as the other one, carries a much greater hidden complexity, which makes it far more difficult to affirm or defeat. It is the exposure of this hidden complexity and its very practical consequences that will be the chief target of this thesis.

I chose the Socrates example for another reason, which may be recognized when contemplating Socrates' personal history. In some sense, Socrates could be seen as one of the very first people to actually give an advance care directive (in verbal form).

He was a man of advanced age who knew that he faced death. He had a chance to trade immediate death for a life of lesser quality[i], but chose not to do so, based on his beliefs and values about what was the right thing for him to do. Furthermore, he gave a very elaborately reasoned defense of his choices to many of those who questioned their wisdom and benefit.[ii] These are precisely the kinds of concerns, which can be found at the heart of modern advance care planning.

Of course, one can also point to various dissimilarities between contemporary ideas of advance care planning and Socrates' case: he was not a free man facing illness, but rather an elderly (though seemingly healthy) man in captivity facing capital punishment. Furthermore, he did not make choices about medical treatment and he did not have to engage with experts in a field other than his own expertise, thus he did not suffer a certain power imbalance and the particular kind of vulnerability associated with such power imbalances coming from lack of knowledge. Most importantly, Socrates considered himself a confidently rational man and did not envisage himself as being in danger of losing his wits. Thus he did not make his

---

[i] As Plato's dialogue Crito makes plain, Socrates could have easily escaped into life in exile. However he considered this a life of poor quality and therefore declined the offer.

[ii] Socrates defense and reasons are given in Plato's dialogues: *Apology*, *Crito* and *Phaedo.*

choices with a view to some future ‘proxy-self’ arrangement, which would be supposed to step in for him when he would not be competent to speak for himself.

In fact, given that he was facing capital punishment, i.e. a well-defined time of death of a certain nature, one may even say, that of all men Socrates was probably least in need of an advance care directive, since he would be very likely to competently speak for himself right until his final breath, which indeed he did, addressing his last words to his friend Crito saying lucidly: “Crito, I owe a cock to Asclepius; will you remember to pay the debt?”[1]

Apart from having just recounted one of the most restrained and controlled examples of a person’s encounter with death, I seem to also have produced a good counter-example to the proposal given in the opening of this chapter, which suggested that Socrates’ mortality alone was enough reason for him to engage in advance care planning. Have I contradicted the opening sentiments? Which was right? Is advance care planning for everyone or only for some? Does a man who faces a certain death at a certain time under fairly certain and predictable circumstances still need to plan for it? Does the fact that he chooses not to escape his death sentence when he could, carry any particular meaning? Is his choice in itself an advance care directive? Should such a ‘suicidal’ directive be considered valid? Are Socrates’ friends guilty of not saving him when they could? Were they right in accepting his position and watching on as he died? All these questions and many others are at the very heart of contemporary advance care planning, and yet many of these questions were already considered by Plato and Socrates over 2000 years ago.

ULYSSES[iii]

> *"So they sang, in sweet utterance, and the heart within me desired to listen, and I signaled my companions to set me free, nodding with my brows, but they leaned on and rowed hard, and Perimides and Eurylochos, rising up, straightway fastened me with even more lashings and squeezed me tighter."*[2]

Some 800 years prior to Socrates' death an ancient warrior set out on a perilous journey, which was to bring him close to death on many occasions. Yet, he had powerful allies who provided him with due warning and advice as to how not to perish. His aim was to get home to his wife and family, but in order to achieve this he had to face many life-endangering situations, some of which he was forewarned about by the gods.

Some modern patients face this kind of situation. They want to make it home to their families, but a fight with illness makes this a perilous journey: chemotherapy, immune suppression, dangerous surgery, experimental treatments etc. About some of the dangers they are forewarned by their doctors, fellow sufferers or other health carers and amidst these warnings they have to make decisions as to what to do.

One danger for the ancient hero was the beguiling song of the Sirens, which would entice him to want to stay and listen to their song forever and perish as a result. The goddess Circe warned the man that he should get his crew to tie him to the mast of his ship and that they should not under any circumstances listen to his pleas to unfasten him, but rather strengthen his ties; nor should they listen to the Sirens'

[iii] In this thesis Ulysses is used merely as the Latinized name of Odysseus.

song themselves, lest they fall prey to the same evil. Instead they should fill their ears with wax and keep on rowing to maintain the ship on track home.

The well-known hero of the Homeric myth, Ulysses, to this day lends his name to a type of contract which is of great relevance in ACP, because advance care planning only makes sense, if the person who issues an ACP expects or fears that future care decisions (either expressed by an incompetent future self or someone acting on one's behalf) will be contradictory or at least not clearly in line with what this person wants for their future. If such fears were not present then a binding ACP would not be necessary or it would merely function as a non-committal communication device. Yet this is not what ACP primarily aims at as further discussion will show.

In a Ulysses contract one binds oneself to a commitment at a particular time[iv] and then does not stray from it, does not change one's mind about where to go, what it is one wants or any other pertaining circumstance. Knowledge at one time becomes binding for a set of circumstances and steadfastly governs the future until it is competently revoked[3]. A Ulysses contract requires a lot of trust; trust in one's knowledge, trust in the others' goodwill, loyalty and capabilities, and trust in what it is that one wants to achieve.

Ulysses' story, of course, is neat: the advice given by the goddess Circe is failsafe; his men are united in spirit, loyal and steadfast. They don't quibble about wanting to listen to the Sirens themselves, nor would they dream about leaving Ulysses tied up at the end so that they might have his power and fortune. Furthermore, the

---

[iv] This particular time is to be understood as the *'time of competent mental state'*. Although during this time one may have the right to change one's mind and alter or withdraw from the contract, such changes are only feasible if they are not too erratic for practical purposes. Changes can no longer occur when the competent mental state expires.

experience of listening to the Sirens' song itself does not seem to materially affect the hero’s ongoing voyage. He does not, for example, complain to his men afterwards about not having stayed in the presence of the Sirens or that he no longer wishes to go home. Ulysses had optimal conditions for trust.

Modern advance care planning has strong elements of a Ulysses contract, but its circumstances are not usually as neat as in Ulysses’ case. Patients have advice from multiple sources, none of whom have the god-like status and infallibility of the goddess Circe and therefore it is hard to know whom to trust. If we view patients as Ulysses on the ship, they face frequent changes in the ‘ship’s crew’ and many members of the crew will have their own advice to give about what should be done. They may advocate different strategies of how to avoid the ‘sirens’ dangers’, some may not be convinced that there is a significant danger or they may dispute the aims of the journey. Some may not have wax in their ears and may listen to Ulysses’ cries to be untied. Some patients may find they are not quite like Ulysses and simply change their mind while bound to the mast; facing the dangers, they may decide genuinely that going home really isn’t worth it… What to do then? How to know?

3 – THE IDEA OF ADVANCE CARE PLANNING (ACP)

In order to explicate a more contemporary understanding of these questions it is best to examine the more recent history of the idea of advance care planning. For this purpose we need to fast forward our attention into the twentieth century, when the power of medical knowledge had not only learned to hasten death by poison, as in Socrates’ case, but also to delay physical death remarkably. With the advent of considerable medical advances and technology such as mechanical ventilation, powerful cardiovascular support, anesthesia, organ transplantation and many other advanced life support measures, mere physical survival has become possible to the point where the definition of death and the process of dying have become increasingly fuzzy, conceptually and practically.

Prior to the nineteenth century the domain of the physician was life. Death was the domain of the clergy. When nothing else could be done, the doctor was sent out of the room and the clergyman took over. In the late nineteenth century, when death became a scientific diagnosis based on the absence of respiration and circulation, doctors had the last word in the matter of life and death by declaring when life had passed away[4]. However, with the medical advances in the second half of the twentieth century, especially the success of live organ transplantation, cardiopulmonary death has become a thing of the past. We now have diagnoses of brain death and cardiac death and frequently the whole question of *survival* is re-phrased as a question of a person having a 'life worth living'[v]. Re-phrasing the question of survival thus has introduced the further complication that expertise about survival has once more slipped away from the scientific domain.

In a liberal environment expertise about who sets the boundaries for the definition of a 'life worth living' has very much opened up to the wider population. People are meant to examine their own life and consider what conditions they accept as sufficient for a 'life worth living'. With efforts to reduce medical paternalism in the clinician-patient relationship, patients are encouraged to voice their own ideas about increasingly many possible conditions of existence and this in turn leads to greater uncertainty about what to do in moments of medical choice. This is the background out of which the advance care planning movement has arisen and in which it attempts to operate.

In 1969 American human rights activist (and co-founder of Amnesty International) Luis Kutner, published a paper called "Due Process of Euthanasia: The Living Will, A Proposal"[5] . In this paper he described the fact that the American jurisdiction, as

---

[v] Interestingly we seem to thus have returned to Socrates, who engaged precisely in this activity: examining which kind of life was worth living!

many other jurisdictions, had no due process by which to distinguish mercy killings from other types of homicide. At the same time he showed that in legal practice mercy killers were treated quite differently from other murderers.

Kutner writes: *"An observation of what takes place at the trial level indicates that the law in practice deals differently with mercy killing than does the theory and letter of the law. The law in action is as malleable as the law in the books is uncompromising. There is a high incidence of failure to indict, acquittals, suspended sentences and reprieves where the killer had mercy as his motives."*[6]

The particular problem that Kutner pointed out was that although practice showed that society made a clear moral distinction between types of killing, based on the ***motivation*** of the perpetrator, the law had no reliable way of accounting for a perpetrator's motivation. The law only takes into account ***intention*** (to kill) which is the same[vi] in all cases of killing. As a consequence the moral standing of the 'mercy killer' was entirely at the mercy of the local legal interpretation of his actions and unprotected by due process in law. "*The accused in a mercy killing case must rely almost entirely on public sentimentality. Objective criteria are not operating*".[7] Thus a fear about being convicted of a crime would prevent many from relieving undue suffering, when they had the power and sufferer's permission to do so.

Kutner was not the first person to realize this, nor was he the first person to feel compassionate towards those who suffered excessively from medical conditions or those who had to brave legal and moral conviction for relieving such suffering. The

---

[vi] Intention: bringing about death – same in all types of killing ; motivation: relieve suffering or harm to person – different in various cases of killing.

euthanasia debate by then had already had a long history[vii] and an American proposal for legalizing euthanasia had just failed to succeed as a bill in the legislatives of Nebraska and New York. Kutner's compassion notwithstanding, he was keenly aware of the difficulties any euthanasia legislation faces, particularly its immense danger for abuse. He thus thought of a different way to address the problem of prolonged unwanted suffering, based on a human rights approach.

The notion of patient consent had been well recognized in medicine in the USA since 1914, when Justice Benjamin Cardozo used the 'right of self-determination' to justify obtaining a patient's consent for invasive medical procedures.[8] Based on the right to privacy (according to the fourth amendment to the US American constitution) in conjunction with the right to not suffer excessive cruel and inhumane punishment (as per the eighth amendment to the US American constitution), Kutner thought that the right of withholding consent could be extended by means of a written instruction in such a way that it would have validity even in situations in which the patient could not speak for himself[viii]. Here he imagined three types of situation.

1 – The patient faces an actual illness for which consent to treatment is sought.

For such a case Kutner envisaged the following:

"*The patient, however, while still retaining his mental faculties and the ability to convey his thoughts, could append to such a [consent] document with a clause that,*

[vii] In fact, we can already find its traces back in the times of Plato's dialogues. Socrates himself comments on the supposed moral wrong of taking one's own life in his last conversation with his friends.

[viii] I.e. Kutner postulated that these rights extended into times when people had lost mental competence.

if his condition becomes incurable and his bodily state vegetative with no possibility that he could recover his complete faculties, his consent to further treatment would be terminated."[9]

2 – Sudden grave illnesses without consent opportunity.

Here he says:

"*The patient may not have had, however, the opportunity to give his consent at any point before treatment. He may have become the victim of a sudden accident or a stroke or a coronary. Therefore, the suggested solution is that the individual, while fully in control of his faculties and his ability to express himself, indicate to what extent he would consent to treatment. The document indicating such consent may be referred to as 'a living will', a 'declaration determining the termination of life', 'testament permitting death', 'declaration for bodily autonomy', 'declaration for ending treatment', 'body trust' or a similar reference.*"[10]

3 – Intermittent mental illness

Here Kutner suggests: "*The living will may be used within another context affecting a mentally ill patient. In agreeing to be committed for treatment to a hospital, he could condition the kind of treatment to be given to him. By voluntarily committing himself he does not automatically confer upon the doctor the right to perform a lobotomy, insulin or electric shock therapy, to deny him the right to choose another doctor, to deny him the right to receive visitors or to enjoy other rights. The living will could provide that he be released from the hospital if he fails to receive any treatment or does not respond to therapy. If he is confined against his will, the living* *will could be used as a basis for invoking a writ of habeas corpus*[ix] *to effectuate his release*."[11]

With these suggestions Luis Kutner can be deemed to be the father of advance care planning. In the subsequent discussion his suggested term *living will* settled firmly, but seems to be now overtaken (at least in Anglo–Australian writings) by the term *advance care directive*. I will therefore continue to use the terms advance directive (AD) and advance care planning (ACP) for the remainder of the thesis, bearing in mind that they relate to the same concept unless otherwise indicated.[x]

Apart from the three basic scenarios mentioned above, Kutner made a number of other points, which clearly separated his ideas from the euthanasia debate and which are relevant to the contemporary discussion of ACP.

1 – An AD could only ever be understood as a refusal of consent to treatment, but never as a request for active measures to terminate life.[12]

2 – An AD can only ever be drawn up by a competent adult who is not coerced, but never by a proxy decision maker (e.g. parent or next of kin) on behalf of another who is not competent.[13]

3 – An AD is aimed at being used as definitive evidence in the legal system in order to exculpate any clinical carer from accusations of negligence or other wrong doing. As such, an AD was always envisaged as an appropriately witnessed, written document.[14]

[ix] My footnote: I.e. Kutner postulated that these rights extended into times when people had lost mental competence.

[x] In the final chapter I will make some distinctions between weak and strong forms of ACP, where the weak form does not observe all of Kutner's requirements.

4 – AD’s are meant to be patients’ assertions of their basic human rights to privacy and absence of excessive suffering and both these rights are clearly thought to extend past a person’s autonomous existence.[15]

5 – An AD is seen as a contractual arrangement; to quote Kutner directly: “*analogous to a revocable or conditional trust with the patient’s body as the ‘res’, the patient as the beneficiary and grantor and the doctor and hospital as the trustees”*.[16]

With Kutner’s original proposal thus in mind I want to briefly revisit Socrates’ case, before moving on to a further summary of the historical development of the ACP movement. I think this useful, because in examining this fairly simple case, one can already recognize some of the problems, which were to arise in relation to the original proposal of ACP.

Socrates’ death sentence was issued by a power beyond his control. The same can be said for most patients afflicted by severe illness, although the inflicting power would usually be different. Socrates’ friend Crito had organized for him a promising escape into exile, which would have had a high likelihood of success. This would have meant Socrates could have lived a fairly healthy life (by Crito’s reckoning) elsewhere, looking after his family, which included two young children, and engaging in much the same activities as he had pursued in Athens before his imprisonment. Such escape can be likened to modern therapy with promising prospects for success. If we accept this likeness, then how does Socrates’ refusal of consent to escape death fare against Kutner’s idea of a living will?

Socrates was elderly, but not deemed senile or incompetent, so he qualifies as eligible to speak for himself.

Crito objected to Socrates’ refusal to escape, by explaining that he could have quite a good life in exile. Although Crito did not mention it, one might even imagine that during Socrates’ proposed exile his friends might have labored on his behalf with a view to achieving a pardon, acquittal or altered sentence, which might have permitted Socrates' return later on[xi]. Crito further pointed out that Socrates was failing his duty of care towards his children and thereby doing them harm.

Socrates rejected both of Crito's objections. He felt that based on what he valued in life, life in exile would not possess a reasonable quality at his age and he denied that his children would be better off in exile under his care, rather than back home in Athens where they would be brought up by remaining friends and family. Socrates thus disagreed with Crito's account of what would be acceptable as a life worth living, and of what constitutes harm to others. Yet harm to others is a vital consideration in whether one's right to privacy, as per the fourth amendment to the American constitution, should prevail over other people's interests. Amongst other considerations, it is this right which needs to be invoked in order to give Socrates the right to choose that his private personal concerns outrank the communal and family concerns. If we agreed with Crito that Socrates was severely failing his children, perhaps he should have overpowered Socrates and abducted him into exile.

On Kutner's account we would also have to be convinced that Socrates' condition was terminal. What should we say here? Without escape, i.e. without treatment, Socrates condition was definitely terminal, yet with the treatment of "escape" he could have lived many more years. Does his condition count as terminal and thus make it eligible to fall under the patient's choice? Would Socrates' life in exile have constituted excessive suffering as per the eighth amendment? Would his escape

---

[xi] Socrates himself observed that his conviction was effected rather hastily, in less than a day, such that he did not get a chance to make a better case for himself. So he acknowledged that the death sentence was somewhat rash, yet he did not rebel against it or try to escape it.

have constituted ordinary or extraordinary treatment? Crito did not think it was extra-ordinary, nor did the many others who offered to help him.

Maybe Socrates experienced 'Thanos' – the death wish – a phenomenon described extensively in psychology and psychoanalysis, and recognized by Kutner[17] (and others) as one of the impermissible factors concerning termination of treatment. How do we tell when 'Thanos' is justified?

Who should set the standard as to what constitutes harm to others, what is seen as excessive suffering and what kind of treatment should be viewed as extraordinary? Kutner suggested that these issues should be settled by "that which is generally practiced". But "what is generally practiced" could either be an expression of some *wisdom informed expertise* or the *opinion of the multitude*. If it were the latter, which is more likely, Socrates himself would have objected severely, as the opinion of the multitude did not count as valuable or truth-forming with him at all.[18]

The very least we can see from this little exercise of examining Socrates' case in light of the living will idea is that right from the start some issues of interpretation arise. These issues and many others became evident in the time since Kutner's first description of the living will, yet his idea became and remained influential.

4 – THE EVOLUTION OF ACP

Since Kutner's first comprehensive description of the living will idea, several cases of patients lingering in various conditions between life and death came to prominent public awareness and kept the issue of patient self-determination alive in the public discussion in many countries.

In the United States the case of 21 year old Karen Quinlan (1975), who was left in a persistent vegetative state after a cardiac arrest, became the first hallmark case of asserting a patient's right to privacy after loss of competence, when the New Jersey Supreme Court decision gave her parents the right to remove her from advanced life support. Although Karen Quinlan's wishes were not known directly through an advance directive, her parents were able to argue successfully that she would not have wished aggressive therapy like the one she received. Yet, Karen Quinlan did not die after the removal of advance life support. She lived on for another 10 years on artificial nutrition and hydration, before eventually succumbing to an infection.

In the time following, the debate about how to ascertain a person's wishes for difficult circumstances like these remained prominent and further promoted the idea of advance directives to be used as evidence in court. In 1976 California's "Natural Death Act" was the first legislation to recognize advance directives. Many US American states were to follow. However, not knowing patients' wishes for treatment remained a problem, because even though there was increasing legal recognition of the idea of living wills, people did not actually take up the opportunity to write the appropriate legal documents, or the kind of documents written were useless for various reasons. They either did not comply with the proper state law, or the AD instructions were either too permissive or too restrictive in order to be interpreted with sufficient certainty in the eventual acute circumstances of the patient's illness.

In 1991 in the wake of yet another prolonged court battle concerning Nancy Cruzan, a young woman who was left in a persistent vegetative state after a car accident and who had not left a living will, the US Congress passed the Patient Self-Determination Act (PSDA), which was supposed to lift the awareness and completion rates for living wills in the US.

The PSDA required US health care facilities receiving Medicare and Medicaid funding to ask patients on admission whether they have an advance directive. It further required them to provide written information on treatment options, right-to-die information and advance directive forms to adult patients if they did not have an AD.[19]

However, now, more than twenty years after the passage of the PSDA, the consensus is that its effects have been very limited[20] and that advance care planning has not been embraced by the general population as much as was hoped by many. Thus the problem of ascertaining patients' wishes and making choices on behalf of those who can no longer communicate their wishes remains largely unresolved, in the US as much as in many other Western countries.

Australia experienced similar debates around the problem of unwanted, 'excessive' treatment since the 1970s, which resulted in various movements whose aim is best described as looking for ways of dying with dignity. Australia has had many cases similar to the ones described in the international literature, however, outside legal and some medical debates most of them have not risen to the same kind of public prominence as the Quinlan or Cruzan cases. Yet they have shaped Australian law in a similar way as have the landmark cases in other countries. For example, in 2003 the case of Gardner:re BWV in Victoria was brought to the Supreme Court in order to decide whether nutrition given via an enteral feeding tube was considered medical treatment or palliative care.[xii] Another case that rose to some public prominence in Victoria was the case of Maria Korp, who was left in a persistent vegetative state after suffering severe hypoxia from being assaulted and locked in a car boot. The accused perpetrator of the crime was her husband. The Korp case is interesting, as it involves not only questions about the type of medical treatments that are appropriate, but also conflicts about what one should do when the next of kin (NoK), who may normally be involved in the decision making, and may even be appointed as trusted guardian, seemingly abuses this trust or at least has a significant conflict of interest.[21]

[xii] Palliative care in law and ethics is considered separately from medical care. It is understood as the provision of basic food and water, and relief of suffering and pain, which must not be denied.

Australian law looks to its international counterparts, especially the UK, the US and Canada with interest and a view for comparison[22], and much of the discussion surrounding advance care planning has now become an international discourse.

In 1987 Victoria was the first Australian state to hold an inquiry into “dying with dignity”, which resulted a year later in the passing of the *Medical Treatment Act* (Vic 1988). The purpose of the Act (as stated in the Act) was to clarify the law relating to the right of patients to refuse medical treatment, to establish a procedure for clearly indicating a decision to refuse medical treatment and to enable an agent to make decisions about medical treatment on behalf of an incompetent person. Since its inception the Act has been amended on a number of occasions. The decision of the *Gardner:re BWV* case was for example the cause for one amendment in the Victorian Medical Treatment Act, clarifying that enteric tube feeding is considered treatment and not palliative care, which is excluded from the Act. This means that tube feeding is a treatment that patients may legally deny.

The kinds of solutions that the Medical Treatment Act outlined were a very far step from the original proposals for a living will, but they were grappling with the same basic problem identified by Kutner.

Similar acts were passed in other Australian states and many other countries around the (Western) world. They all differed in accordance with the local legal particulars, but uniformly tried to address the problem of how to deal with treatment choices concerning patients who could no longer speak for themselves and to clarify what kinds of actions actually do constitute medical treatment as opposed to the provision of basic care.

All jurisdictions over the years faced the phenomenon that although genuine attempts were made to improve the legal recognition and structures for the idea of advance care planning and the assertion of patient rights, the uptake of advance care planning options with few exceptions remained, and still remains, generally low. Reported completion rates of advance care plans vary enormously depending on the assumed base line population of the study group (ethnicity, age, gender, religion, pre-existing disease), the type of ACP intervention involved, the geographical location and many other modifying factors. Figures quoted range from as low as less than 1%[23] to 20–30%[24].

Apart from this, a separate question also arises as to what a completed advance care plan means in terms of advance care planning success, since the mere existence of such a plan at some point in time, in itself, neither ensures that it is up to date nor that it will be executed appropriately.[xiii]

The proportion of cases in which people prematurely lose their capacity to make health decisions through some tragic accident in most western societies is relatively small. Most societies with aging populations face the realities of having to deal with increasing numbers of people who will eventually lose decision-making capacities in later life. For this reason advance care planning is now generally perceived as a beneficial undertaking on a societal level. It is meant to provide a solution, which both respects the individual's choices for their future care and reduces the decision-making burden on the future carers. Furthermore, it also clearly aims to steer away from a default position of 'maximal medical care' and defensive medicine, which proves to be a burden on societies' health care resources. ACP is therefore increasingly seen as a means to contain ever exploding health care budgets.[25]

Thus what had started as a call for due process regarding patients' rights and the reliable exculpation of carers' genuine compassion has over the years developed into a project of much greater complexity than first envisaged. The assertion of

---

[xiii] There are for example several studies which indicate that advance care plan execution can be hampered in multiple ways. The plans or relevant instructions may not be available at the time of crisis, their content may be contested, they may not comply with current local legal standards, they may be too vague for proper interpretation etc.

patients' rights has over time become muddied to some extent by other concerns and now the reluctance of the general populous in taking up advance care planning options is viewed sometimes as a societal problem. This reluctance has thus prompted much research over the years, the aim of which is to find the reasons for this phenomenon and solutions to remedy the problem.

One problem ACP research faces is that what can be counted as success in advance care planning is not simple, because the potential benefits of advance care planning are no longer only seen in terms of assertion of patient rights, they are also seen in terms of many other related, but slightly different issues: economic benefits both for society and individuals, improved care perceptions, improved communication, lessened burden on carers, lessened depression, anxiety and stress of carers and families, etc.[26] It turns out that some of the benefits do not apply equally to all involved[27] and that sometimes one party's benefit may even entail another party's detriment.

What Luis Kutner identified as a problem of 'due process' turned out to be only the merest tip of an iceberg of problems that occur with end of life care. It is not only a problem for a distinct individual, but always a communal problem that involves many interests: patients' interests, (multiple) care interests and societal interests. And these problems are often not simply problems of *end of life* care, but commonly just problems of *care* as such, for as cases like Karen Quinlan, Nancy Cruzan, Terry Schiavo, Anthony Bland and many others have shown, it is not always a question of end of life that is at issue. All these patients lived for many years in very disabled states, before they died and thus it is a question of considerable conceptual ambiguity whether we say these patients had a very prolonged death or whether they had severely disabled later parts of their life.

5 – WHY THIS THESIS?

The *Living Will* started as a promising idea almost half a century ago and has raised many hopes. Yet many of its promises and expectations have not really been fulfilled. A great deal of research has presumed the reason for this to be difficulties of a practical nature, with the underlying assumption, that the concept of advance care direction in itself is a good and viable one. There are many examples of practical obstacles: e.g. in jurisdictions where a lawyer is required to witness an AD, legal costs may be prohibitive and make ACP accessible for only the rich. Legal expenses may then also become an obstacle to regularly updating an ACP, and thereby make the validity of the content of the ACP contestable. Funding concerns have been raised on many different levels and blamed for hindering progress. The PSDA demanded patient information and education on admission to a health facility, but there was no funding provided to achieve this.[28] In many regions, current and prospective patients have to seek and fund their own information and education, which again is prohibitive in nature.

Another obstacle that is frequently encountered is the multitude of forms ACP may take, many of which are not accepted across interstate boundaries or even between different institutions, thus leading to best intentions being frustrated.

All of these examples and many more are real obstacles to ACP. However, I want to contend that these are not the only obstacles and more importantly not the really difficult ones, since they have potentially (costly, but) achievable solutions. I think there is a much more difficult obstacle to ACP than the ones mentioned above, and this is the conceptual coherence of the whole idea.

For many the assumption that ACP is a sound idea is uncontested, and its lack of active use is seen simply as an expression of the fact that we are not (yet) very good at making the idea work. This conviction in turn fuels the attitude that with improved effort, funding, education and mobilization of resources, we can make it work. In consequence a considerable effort in terms of funding and resources is now dedicated towards finding the right way to do ACP.[xiv] In fact the step from the 'advance directive' to the notion of 'advance care planning' is itself already a kind of evolution of the concept, because practice has shown that the simple provision for writing an instructive AD does not work in the same way that an ordinary testamentary will about a person's belongings might work. It has been demonstrated many times that people will only engage in some form of advance care planning after considerable education and inclusion in advance care planning interventions, which usually have to be prompted by a health care provider[29]. Even then some doubts remain about what the advance care plan actually signifies.[30]

In terms of research, much less effort has gone towards examining whether advance care planning as a concept is actually viable in the way we presume it is. Or maybe it would be better to say, there has been much less effort in identifying what *kind of success* modern advance care planning efforts can realistically claim.

Although in the last ten years there have been some publications which have voiced considerable doubt concerning some conceptual dimensions of the idea of advance care planning, an in depth analysis of the coherence of the network of inherent philosophical concepts at play in the idea of advance care planning is missing.[31] This is true in particular in reference to the multi-dimensional application of these underlying philosophical concepts across the many professional disciplines involved in ACP.

[xiv] E.g. Since 2002 in Victoria considerable research and government funding has gone into trialing and implementing an ACP program called Respecting Choices. This is a program based on the Wisconsin Respecting Choices Program adapted to local Victorian and Australian conditions. The Wisconsin program was the first ACP program that could claim significant success at least in terms of ACP participation rates within a very unified and enclosed community.

The kind of conceptual doubts that have been voiced mainly concern supposedly mistaken background assumptions about patients' psychological or educational states.[32] And although psychological concerns regarding human nature are very important for successful implementation of ACP programs and to some extent for the explanation of people's moral intuitions, they do not look carefully at the concepts involved in the idea of advance care planning.

ACP is meant to assert, respect or maintain a person's autonomy and it is meant to benefit the ACP author. Thus the concepts of autonomy and beneficence are vital in any understanding of ACP planning. Furthermore, ACP involves a person's existence over time: thus ACP presupposes some concept of what constitutes a person's existence over time, i.e. numerical personal identity, which represents a metaphysical dimension. These three concepts, autonomy, beneficence and numerical personal identity are intimately linked within the idea of advance care planning. And although ACP is a very practical undertaking, without an understanding of these theoretical concepts, ACP does not make any sense. Yet each one of these concepts alone has many philosophical interpretations and dimensions and the overall sense and coherence of ACP depends very much on how these individual concepts are interpreted and networked. This is true whether we are aware of the concepts in operation or not.

For example whether we can accept ACP as a viable idea respecting autonomy depends very much on whether we think personal autonomy is the kind of thing that can be extended to a time when we are no longer autonomous. If we do not think this is possible, proposing ACP as a means of asserting or respecting autonomy would seem odd.[xv] ACP might still be beneficent for economical reasons or because it reduces stress and anxiety, but it would not really assert autonomy.

Likewise, if we thought autonomy is the kind of thing that needs the particular *authorship* of the autonomous person, then ACP in the form of appointing a proxy– decision maker is not really asserting patient autonomy in the same way a written directive would, since the health decisions made by the proxy come from the 'wrong author'. In such a circumstance some might feel for example that overriding a proxy-decision maker's instruction is more permissible than overriding a written personal directive. Some might not really see appointing a proxy-decision maker as 'proper' advance care planning in the sense that was first proposed by the living will idea.

If someone took autonomy to be the kind of thing which aims at a person's benefit, and benefit was by default equated to 'extension of life', then any decision which limits life could not be seen as an autonomous decision.

If decision making capacity were the feature which essentially maintains numerical personal identity, then losing one's autonomy would mean that one became a 'new' individual. Within such conceptualization it might be quite hard to see why the instructions of the previous autonomous individual should have any bearing on the life of the incapacitated being, since identity is not maintained. In such a view ACP may not make sense at all.

These are just some examples of how various conceptual variations might bear on the overall complex idea of ACP.

[xv] This explains to some extent, why the Quinlan Supreme Court decision had such significance, because it seemed to vindicate the idea of autonomy extension.

It is the aim of this thesis to contribute to a conceptual analysis of ACP in so far as it recognizes it as a complex idea, which is based on a network of a number of significant philosophical concepts. Furthermore, it is the particular aim of this work to illuminate how differences in interpretation and conceptual coherence (or incoherence) of these concepts lead to very practical difficulties in the clinical application of ACP and I thus hope to shed light on possible explanations for ACP failure that remain largely unexplored.

In a time where a lot of financial and personal effort is poured into ACP in practice this seems particularly important, as it may illuminate to what extent such efforts actually promise to yield the benefits hoped for.

If, for example, conceptual analysis shows that the idea of ACP is fundamentally flawed, inherently contradictory or fraught with unreasonable or incoherent expectations hidden in the multi-disciplinary facets of its participating professions, then allocating resources into areas, which predictably cannot work on conceptual grounds, would seem unwise.

Likewise if a conceptual analysis shows that success is only likely (or even possible) within the bounds of certain philosophical background assumptions or under certain ideological conditions, then one can tailor one's efforts to work within the kind of philosophical framework which promises maximum coherence and at the same time accept ACP's limitations in other conceptual settings.

The first step of any ACP effort should therefore be to check whether a coherent philosophical framework actually applies to the target setting envisaged.

It seems to me that this step has been widely neglected and that many very practical problems which eventually arose within the history of ACP, and which continue to arise in daily practice today, can actually be traced back to underlying conflicts of conceptual interpretation or the incoherence of its underlying conceptual framework. I also think that many of the problems encountered historically were reasonably predictable or at least not surprising, merely on conceptual grounds.

If we once more briefly return to the two ‘ancient patients’ of the previous section we can see some of the difficulties clearly visible without having to consider many of the clinical practicalities.

The loss of mental competence usually marks a point of no return, in the sense that it is the point at which one seems to lose the right or capacity to change one’s mind. So although we may preserve our right to privacy past incompetence, the right to change one’s mind disappears. If we accept this, then any ACP must be viewed as a kind of Ulysses contract which requires a great deal of trust.

The conditions for trust in the modern health care setting are very difficult, to say the least. The difficulty increases manifold the greater the unpredictability of the circumstances that need to be predicted. It is thus not surprising that a completely healthy and young person, like Nancy Cruzan or Anthony Bland, would find it difficult to engage in ACP, since any life threatening circumstance is a remote possibility. The uncertainty about likely medical conditions is slightly less for people with pre-existing illnesses, which may or may not be already considered life limiting, yet the uncertainties concerning many other personal and medical factors may be completely separate from a person’s health status and very much influence a person’s preparedness to enter into such a Ulysses contract. They may for example depend on the person's social setting, financial resources, ability to trust or nature of the health care setting.

Likewise, whether we grant a person the right of free choice is very dependent on communal circumstances. If a choice would harm others or be considered communally unjust we may not wish to allow it. Thus any health care wishes may not be honored on grounds of harm to others or the community as a whole. It would be foolish to invite or encourage such wishes. Thus autonomy’s bounds must be clear. At the same time what a person wishes for, may be significantly influenced by community or other expectations, therefore it must also be clear as to what we consider to be an *autonomous* wish.

Was Socrates autonomous in his choice to take the hemlock rather than flee? If so why? Was it because he banished his wife and children from his company[33], such that he would not have to suffer and be influenced by their grief? Was it because he convinced his friends that this was the right way for him? Was it because he convinced himself that this was the right way to go? Was it simply because he could make a coherent argument for his case?

Did Socrates suffer from *Thanos* (the death-wish), maybe inspired by his enticing views of what would happen to a philosopher's soul after physical death?[34] If he did, was this a reasonable wish to gratify? Under what circumstances is *Thanos* reasonable?

If Socrates was autonomous, should his autonomy have been respected, as it seemingly was? Would there have been reasonable grounds to curtail his choices? Should his wife and children have had a reasonable claim on him? Did his friends act in his best interest? Can best interest sometimes override concerns of autonomy?

All these questions are of a conceptual and interpretive nature, and not primarily concerning practical matters of communication, administration, education or lack of resources; yet they are very much at the heart of what may or may not allow advance care planning to work.

Plato's account of Socrates was very much the picture of a man who cherished the clarity of his mind and who valued clear and convincing arguments. In keeping with this it was befitting that his mind was the last part of him to perish. In his case, as given to us by Plato's account, the continuity question of his numerical personal identity does not really play as significant a part as it might in other cases. With a little imagination though, one might envisage a scenario in which Socrates was acquitted and went on to live to very old age developing dementia. Would we still think of a demented Socrates as the same person as the one we know from Plato's dialogues? Would Socrates have thought of himself as being *himself* and approved of himself being thus, or would he have requested the hemlock as a matter of mercy? Maybe he would have thought of his soul to having departed early and therefore not cared about what would happen to his physical body.

It would take a classical scholar or maybe an expert on Platonic philosophy to work out the most likely answers to this imaginary scenario. However, the actual answers are not as important as the questions raised, because they would only be answers to a hypothetical case and therefore of limited relevance. More importantly, even if they would capture accurately Plato's or Socrates' views on the matter, this would still only represent one view in a whole spectrum of views and one of the real difficulties in advance care planning is how to deal with a spectrum of views.

Socrates' case is neither contemporary nor really a medical case, but useful to show that conceptual difficulties within the idea of ACP can be seen even without particular clinical details. However, since modern ACP has many clinical facets and multi-disciplinary traps, and it is my intention to show in detail how the conceptual problems pervade clinical practice, I will base most of the ongoing discussion on actual medical cases. One of the main cases will be the case of Mrs T*,* introduced in the next chapter, whom I encountered during my own medical practice. Other cases, well known in the literature, will be used as illustrations where appropriate. Furthermore, even though I have made reference to a trinity of philosophical concepts (autonomy, beneficence and numerical personal identity), in this thesis the emphasis will concern a discussion of the concept of autonomy, because the claim to respect autonomy seems to be the most central to the moral justification of ACP. An equal discussion of all three concepts would either not allow demonstration of enough detail or go beyond the scope of one dissertation. The concepts of beneficence and numerical identity will be discussed in the later chapters in lesser philosophical detail, but with greater emphasis on difficulties arising from concept networking, which is necessary to generate the complex idea of ACP.

Finally, in so far as the primary focus is on respect for personal autonomy, my analysis of ACP success will be somewhat restricted to ACP in the form of direct personal directives as proposed by Kutner's original idea. This means that this thesis will discount medical Powers of Attorney (PoA), i.e. the appointment of a medical decision-maker, as being true advance care plans. PoAs do not fit Kutner's original ideas. They involve a significant amount of 'second guessing' on behalf of the patient in choosing the right person for the role, and on behalf of the chosen person to promote the patient's wishes, such that any discussion of the three central concepts becomes exceedingly difficult. However, I will say more about the distinction between PoA and advance directives in the last chapter, when I make a distinction between weak and strong forms of ACP.

6 – SUMMARY

This chapter was aimed at providing a brief historical summary of the origins of advance care planning as an idea and its subsequent development. In this context I have shown some generic questions and concerns that arise in the setting of ACP and which are identifiable independently of any empirical ACP research.

Most ACP research has arisen in response to the fact that not as many people as expected participate in ACP and that many attempts at improving ACP have encountered a variety of practical failures. I also suggested that ACP-failure is more commonly attributed to shortcomings of clinical practice or other relevant practical obstacles (e.g. lack of legal clarity) rather than to problems with ACP as a complex concept itself.

It is the object of this thesis to provide a better understanding of the conceptual difficulties of ACP as an idea and thus to provide a very different avenue of explanation for the observed limitations of ACP in practice.

CHAPTER TWO – A CASE STUDY ILLUSTRATING THE TERRAIN OF PROBLEMS

1 – INTRODUCTION

In contrast to the hypothetical ACP scenarios given in the last chapter, this chapter will use a detailed account of an actual case to illustrate the very practical bedside problems, which can result from diverse interpretations of the conceptual framework in dealing with an AD. I will then show how these particular problems are actually based on a generic problem which arises in the setting of diversity. From there I will move to an analysis of the applicable medico–legal guidelines and show their impotence of resolving the issues under question.

2 – THE CASE OF *MRS T*

The story of *Mrs T* furnishes an example, based on real clinical events, which helps to illuminate many of the practical and conceptual problems that arise when contemplating the nature and benefits of advance care directives for medical care.

Mrs T was a woman in her mid-40s who presented to the emergency department with abdominal pain, which was the result of a perforated duodenal ulcer that allowed faecal matter to spill into her abdominal cavity from her small intestine. If left untreated this condition would likely produce severe infection to the whole body and could easily result in her death. With treatment (relatively uncomplicated surgery and appropriate aftercare) however, this well known, common illness is eminently curable, often without significant residual ill effects.

Mrs T also had a significant past medical history. This was clinically important to the physicians treating her, but also personally important to *Mrs T*, as her past medical and illness experiences informed the choices she was to make.

Her notable past medical history included the following:

Mrs T

*__Thyroid carcinoma at age 28__ (for which she had curative treatment, consisting of total thyroidectomy plus chemo-radiotherapy).

***Residual chronic problems**: significant tracheal (upper airway) stricture from radiotherapy and previous tracheostomy and recurrent bilateral pharyngeal nerve palsy resulting in high risk of food/saliva aspiration.

***Refusal of medical treatment advice for a special diet**, which would prevent silent aspiration of food as demonstrated on video-fluoroscopy.

***Smoking and chronic obstructive airways disease** (COAD)

***Intensive care admission with invasive ventilation two years earlier.**

***Probable high Alcohol use** (as suggested by clinical observation and abnormal liver function tests) and a suspected degree of underlying mood depression.

***Chronic pain.**

Socially, *Mrs T* lived by herself. She was said to have a partner, who did not live with her, never visited her during her admission and was possibly a heavy drinker. Further details were not known, but it seemed to the clinical staff that the relationship was not happy or close.

Mrs T's closest relations seemed to be her parents, who visited her during her admission.

After her initial presentation *Mrs T* underwent successful emergency abdominal surgery. Given her history of airway problems she was transferred to the intensive care unit from the operating theatre, as it was deemed safer to cease her invasive ventilation there. This was done successfully. She received antibiotic treatment to treat residual abdominal sepsis, analgesia consisting of moderate amounts of morphine delivered initially via a patient controlled administration system, paracetamol and intravenous nutrition. These were fairly standard treatments for anyone with this kind of condition.

Although initially doing well, *Mrs T* deteriorated quickly. Adequate pain control became an issue going hand in hand with a rapid decline in respiratory function. She developed postoperative pneumonia within two days. She suffered from fevers, at least intermittent mental decline, distressing shortness of breath and anxiety, and had increasing oxygen requirements. By the end of her second postoperative day she required increasing bouts of non-invasive ventilation (BIPAP), which were delivered via a very tight fitting mask strapped to the face. Many patients find this treatment quite uncomfortable, especially when applied for prolonged periods (>30–60 minutes), some don't tolerate it at all. *Mrs T* could tolerate moderate amounts of this treatment during day and night.

The complicating factors in *Mrs T*'s case, apart from her smoking related underlying airways disease, were her significant tracheal stenosis and the 'silent' aspirations resulting from her recurrent laryngeal nerve palsy. This meant that she could not adequately clear the secretions, which her lungs were producing in consequence of small silent aspirations of saliva. It also meant that if she needed to be re-intubated for adequate ventilation, this could only be done with small ventilation tubes (to fit the narrowed trachea) making lung-toileting even more difficult. It was therefore foreseeable that this would lead to the need of a tracheostomy[xvi] which would then afford an adequately sized outlet for lung secretions to clear and through which secretions could be suctioned off.

Her abdominal condition was healing well and there was nothing to suggest that she could not eventually be cured well from her postoperative complications, but it would be a prolonged process, demanding moderately invasive technology.

When it was put to *Mrs T* that these measures might be required, should she continue to deteriorate, she withheld her consent for re-intubation; she especially and vehemently opposed the placement of a tracheostomy, even if this meant that she would die. She had experienced the prolonged need for a tracheostomy as part of her cancer treatment over twenty years ago and said she would not ever wish to undergo this treatment again. This was the directive she gave to the medical staff postoperatively, while acutely unwell. She was approached about this question several times by different staff at different times and remained consistent about the directive. Nursing staff also engaged *Mrs T*'s parents who visited that afternoon. After their visit *Mrs T* consented to possible re-intubation, but was still extremely reluctant about consenting to tracheostomy.

3 – MEDICAL STAFF APPRAISAL OF *MRS T'S* SITUATION

In this situation (on a weekend) the medical staff were required to think about what action to take, should *Mrs T* suffer a respiratory arrest. There was no consensus amongst the medical staff about what should happen.

The medical staff in this case consisted of three treating teams. She was admitted at the public hospital under the G*eneral Surgical Team*, but her current admission to

---

[xvi] A surgical airway below the level of the tracheal stenosis.

the intensive care unit meant that her daily medical decisions were made by the hospital's *Intensive Care Specialists*. General surgical input was provided usually only on a regular morning ward round or when called for by the intensive care specialists. Furthermore, the hospital's *Ear Nose and Throat (ENT) team* were consulted for advice about the nature, effects and treatment options of *Mrs T*'s tracheal narrowing. Each team consisted of a junior doctor, registrar and consultant who were supported by critical care nurses and allied health staff.

The G*eneral Surgeons,* who had labored through the night involved in her emergency surgery, thought that her directive was not in her best interest and was not sufficiently appreciative of her very good prognosis, thus showing a significant lack of insight. They did not think she was competent to make such a directive. Some were quite emphatic about this point.

When doubting her competence they firstly stressed the direct negative effects of her acute illness and medication on her capacity for sound reasoning. But secondly they regarded the very content of her directive as evidence of her failing competence. They felt that this lady was not acting in her best interests and that this in itself was evidence of her incompetence. Had she agreed with the recommended treatment, her competence would not have been questioned in the same way.

The *ENT Team*, who were only peripherally consulted about very specific treatment options, felt uncomfortable to issue an opinion on this lady's competence status. They felt one should do what this lady wants, but were decidedly unsure what significance to attach to the effects of drugs and illness and whether her directive would be consistent with what she really wanted.

The *Intensive Care Team* was divided in its opinion.

Some thought her competent, based mainly on the way she communicated. They were especially accepting of her position by her reference to her previous experience of a tracheostomy, even though they thought that this time such treatment would be a much shorter and less complicated matter.[xvii] However, they notably conceded that none of them had ever experienced the burden of a tracheostomy and narrowed trachea and were therefore prepared to grant that she had better knowledge of what it would mean for her.

Some thought that she was not competent, attributing greater significance to her fluctuating state of exhaustion, drug treatment, sleep deprivation and intermittent hypoxia. Some had the impression that her general life was not very happy and therefore she did not really have a great amount of will to live, i.e. they questioned some form of underlying depression, which would be treatable and which might have interfered with her sound judgment.

In the acute stages of an illness like this a formal psychiatric assessment is out of the question and so these members of staff felt that one should err on the safe side until such a diagnosis can be ruled out, given the severity of difference in outcome.[xviii]

4 – DEALING WITH *MRS T*'S DIRECTIVE

What is anyone to make of *Mrs T*'s directive about means of invasive ventilation? Should one accept her directive as an authoritative instruction about treatment choices and should this be guiding her therapy? Whose appreciation of her directive counts in this situation and whose judgment has the final say in the matter?

[xvii] E.g. this time around she would not have radiation associated complications (pain, inflammation, weakness), nor would she have the general background insecurity of long-term prognoses associated with a significant malignant condition.

[xviii] However, as will be discussed below, even if such an assessment would have been possible, it is not clear that this could have settled the matter.

One of the first questions that arises in cases like these (and did arise in this case), is whether the patient is in the right position to make such a directive; hence the question about her competence. However, this assumes the unspoken assumption that if she were competent, the discussion would end right there. This second, silent assumption is by no means uncontroversial. There are at least two critical questions here:

1 – Was the patient competent?

2 – Is the patient's competence the fact that invariably settles the matter? (If so, why?)

The first question superficially appears to ask for some kind of fact, something that can be ascertained after some sort of clinical assessment, whereas the second question seems to operate on a level that is removed from fact and wants to affirm a certain kind of value, i.e. say normatively something about a good to be attained.

I will leave the second question for later[xix] and start by exploring whether the answer to the first question is really as factual as it would appear and why competence seems so important in the first place.

[xix] The second question largely turns on ideas of values competing with autonomy, and the moral foundations of ACP, which will be discussed in the last three chapters.

5 – DIVERSITY, COMPETENCE AND AUTONOMY

Why do we take the question about someone’s competence in this scenario so seriously? What are we trying to get at when asking whether someone is competent?

Most people would agree that the answer to these question lies somewhere in the realm of the following sentiments: We want to acknowledge that people have a will and a substantial right to assert their will. We believe that it is through choices that a will is asserted and that it is right for people to make significant choices about their lives and thereby obtain a certain important good. We also want to acknowledge that people differ in their views regarding what is best for them and that they are the ones in the best position to know what are the best choices for them.[xx] At least we believe that (absent gross disability) most adult people get to this stage after a period of infantile immaturity.

When interacting with others, certainly when we encourage someone to make an advance directive, we acknowledge that the authorship of the choices is in some sense more important than the content. We honor that the *authorship* is in fact what makes a choice someone’s choice, i.e. their choice. This capacity of persons to make their (own) choices is usually referred to (or is at least related to) the person’s autonomy. We grant that people are diverse and that the assertion of their diversity in their very own way should be protected.

However, at the same time we are anxious to guard against choices that come from some other source than the true, mature will. So when someone makes a choice, and we pay less attention to the content in favor of the authorship, we want to be sure that they are choosing what they “really” want and not make just any kind of

---

[xx] At the very least they are the only ones who can really know what a situation is like for them.

choice that presents itself ‘on a whim’ or that is presented when they are somehow not their true self. Hence we are anxious that in making a choice, a person is as best in touch with their real wishes and their real self as possible. This we think is not the case, when someone is incompetent or immature in a significant sense. Incompetence of whatever nature (potentially) separates a person from asserting their real wishes and maybe from being in touch with their true self. Immaturity proposes that a self needs sufficient development before reaching a form of trueness and proper deliberative capacities.

E.g. we might think that someone who is under the influence of a mind-altering substance is not able to reason properly or able to be in touch with their usual values and therefore would come to regret their incompetent decision later after the effect has worn off.[xxi] Likewise we might think that someone who is not competent may lack the proper evaluative skills to see situations, consequences etc. in the right light, that is, in the same sort of light that they would see things if they were competent. Similarly, we do not think young children are fully competent, as they have not developed a mature will yet and may lack certain insights about life and the world, which would allow them an adequately informed judgment.

So on the one hand we see that people's choices are in a significant way highly subjective and individual, originating from something that is in an important sense unique, but on the other hand we believe that there are conditions which may impair a person’s ability to see their own ways clearly and therefore they are not reliably able to enact them.

[xxi] The mere presence of regret, of course, does not point to incompetence at the time of choice. However if all faculties were intact at the time of choice, we would not easily accept fault attributed to anyone else but the person who made the choice.

This leaves us with the conundrum of having to tell the two situations apart. Somehow we need to be able to tell when someone is 'for real'. In order to do this we need to have an idea of what sort of things can stop a person being their autonomous selves. This in turn depends on us being able to specify what sort of things actually make a person '*a someone, who can be said to genuinely be themselves and genuinely make their choices'* – in other words, a someone who can be regarded as satisfactorily autonomous.

It is not usually disputed that autonomy exists or that respecting it is a valuable good. However, there is notable disagreement on what factors are important for autonomy to come about, what phenomena indicate its presence (or absence) and what factors limit it.

The connection between competence and autonomy is important in at least the following way: no matter what the details of our account of autonomy are, competence is one of its necessary prerequisites. We might argue about whether a slave can be autonomous, but we cannot argue about whether an unconscious person is; one cannot be autonomous without being competent. Furthermore, we can only respect someone's autonomy if we think it is present and therefore in order to respect someone's autonomy the person must at least be found competent!

As ideas of autonomy vary in some significant other aspects, the role of competence sometimes seems somewhat blurry. Some accounts of autonomy seem to equate competence with autonomy (i.e. the difference is purely semantic) and some think autonomy is more than mere competence. Accounts of competence, vary also.

For those accounts of autonomy which equate autonomy with competence, competence conditions and conditions for autonomy are identical. Accounts which see autonomy as something more than mere competence, need to specify extra conditions as well. Any account of autonomy therefore needs to specify conditions of what is required for competence.

6 – DIFFERENT VIEWS

As was seen in the case study, when it came to forming an impression as to whether *Mrs T* was competent in regards to making an advance directive about her immediate future care, there were a number of different opinions on the matter, each based on different reasons and appreciation of different factors.

1 – There were those who deemed *Mrs T* competent. They appreciated the fact that she could give a seemingly valid and well informed reason for her refusal of treatment, namely that she knew from past experience what such treatment involved, that she could correctly link various implications to her current situation and that she appeared lucid enough in her manner of communication when she expressed her wishes.

2 – There were those who were undecided as to whether *Mrs T* was competent in regards to her treatment choice. They were uncertain, because they felt unable to judge whether the various clinical circumstances were severe enough to impair her competence. This was confounded by her fluctuating state of alertness, which made confident assessment very difficult. They did not know to what extent there were ‘silent’, perhaps memory impairing, effects of the medications she was taking, or how to judge the level of exhaustion on her overall decision making capacity. They also stressed that too little was known about her general life circumstances, as to make an accurate assessment.

3 – There were those who thought her incompetent. They took note of the fact that she consistently received medications which are well known to cause impairment of mental judgment (without appearing to do so), that she was sleep deprived and generally exhausted from her illness. The latter two features are well known from the psychology and circumstances of torture, i.e. a tortured person will do or say many things simply to ‘escape the terrible condition’, rather than think clearly and affirm what is true or what they want. Furthermore, they thought it inconsistent that a person who cared enough to consent to life saving emergency surgery would

then not be sufficiently interested in pursuing a fairly good chance of survival; the latter state also not being in keeping with what was strongly perceived as this person's best interest.

Whereas the first group focused more on the direct manner of communication and the seemingly coherent content of *Mrs T*'s statements, the third group paid more attention to the surrounding circumstances and the perceived best interest of the patient. They also pointed to an incongruence inpatient behavior from before and after the surgery. Furthermore, the third group included evidence from other situations (studies etc.) that would support the view of impaired competence. Their argument went something like this: although formal cognitive testing of *Mrs T* was not possible, because of her acute illness and struggle for survival (and although she appeared lucid at some of the times when she refused to consent for the suggested treatment), we know from many other studies, that her type of medication, intermittent hypoxia, anxiety and level of exhaustion commonly lead to impaired judgment and therefore we should not be fooled into thinking her competent even in those moments when she appeared lucid.

Two things strike me as important here. Firstly, each of the positions on its own seems reasonable. At least they are backed up by coherent arguments. Secondly, we cannot hold all positions at once and act in accordance with all of them, for they would have us pursue directly opposing paths of actions:

1) Those who thought *Mrs T* competent would not intubate her in the event of a cardio-respiratory arrest and she would most likely die during this illness, aged 45.

2) Those who could not decide whether she was competent or not, could not act at all(!), until they were forced into a decision by her failure to thrive – in the event that action would be forced by clinical deterioration of the patient, the most likely scenario for this group would be to err on the side of survival, given that the patient is young, has a perceived reasonable prognosis and that the circumstances

of her directive were dubious or at least unclear. However, this would mean that they err on the side of presuming the patient *incompetent until proven otherwise!*[xxii]

3) Those who thought her incompetent would intubate her in the event of a cardio-respiratory arrest, proceed to tracheostomy and a prolonged recovery. This cause of action may involve patient resentment, possible legal action, or alternatively (and hoped for), patient gratitude. Furthermore, should she recover, a similar situation could very likely happen again several more times during her future life.

In view of the last point mentioned, clinicians would argue that this is precisely why we need advance directives for medical care, just so that we do not keep running into situations like this, unprepared. However, this thesis will suggest that it is not at all clear that advance directives are the deciding factor here, the factor which would deliver the clarity and preparedness that is hoped for.

Mrs T gave an advance directive, but it was the confusion about its legitimacy which lead to the lack of clarity. Thus if we advocate that advance directives for medical care are a good thing, because they allow us to better respect a patient's autonomy, then we also have to provide clear conditions, which prevent contesting the legitimacy of any advance directive made. I want to contend that this may be quite difficult. A large part of this burden will fall into clarifying an understanding of patient autonomy in a way that is coherent, convincing and binding for all parties involved.

[xxii] As will be seen in the discussion further on, this is against the current legal presumption of autonomy until proven otherwise.

7 – DEALING WITH DIVERSITY

At this stage I can imagine three directions the discussion might take:

1 - *Mrs T's* case is not representative

It might be said that I am unfairly harsh on the notion of advance directives, by picking a particularly difficult acute case, in which there is very little time for deliberation and consultation, resulting in a large number of unknown factors and circumstances. One might either further contest that this is representative for a realistically large number of cases or one might simply move to a less ambitious position for advance care planning, e.g. one might say: 'ok, in these hard cases AD's may not work, but that doesn't mean they are useless in less complicated or less acute situations'. They should be used when the question about competence is not such a major issue at the time of making the directive.

E.g. *Mrs T's* advance directive was particularly opposed to invasive ventilation and especially against a tracheostomy. These may not have been considered by her, when she presented for care initially, and hence she did not advise against them when she was in a more competent position. However, one could imagine her surviving this illness. If her objection to possible future tracheostomy remained, then this would be exactly the kind of thing to put in an advance directive.

I contend that this would only remove *some* of the complex factors of competence assessment, but it does not remove the problems of competence assessment in itself. We would for example, still need to make a judgment about, whether we think certain living conditions, or forms of chronic alcohol use would impair *Mrs T's* competence. We still need to clarify what actually indicates impaired competence, so that we know what kind of tests would be appropriate for competence determination. We would also still have to deal with difficulties which arise from different ideas about what it means to be competent or autonomous, e.g. we would still have to say whether the content of a decision can in itself say something about competence or not.

2 – Concept clarity needs to be supplied by the law

One might acknowledge the problem I have raised and propose that we simply need clarification of the relevant competence and autonomy conditions. Given that these conditions have to be ‘binding’ for all parties involved, one suggestion would be that the problem can be solved by asking the legal profession to specify the rules concerning autonomy and competence. This is what is commonly done, but, as I want to suggest, this is also not without problems, as some of the diversity issues recur in the legal dialogue. This line of thought will be pursued in chapters 5 and 6. Chapter 5 will show that the legal profession is just as divided about these questions as other professions and chapter 6 will explore the degree to which the lack of conceptual clarity is irresolvable.

3 – Concept clarity needs to come from philosophical evaluation

Alternatively it could be said that conceptual clarity needs to come from philosophical evaluation of the problem in such a way that a clear universal approach can be found or that a conceptually diverse approach is not problematic. In other words, if we need clarity about concepts of autonomy and conditions of competence, we philosophize over the problem, find a distinctive universal (or at least contextually workable) solution and then proceed. This is problematic, because we would be trying to solve a problem of diversity with a requirement of universalization. It is unlikely that simply by thinking about it more, we will somehow arrive at universal agreement. Furthermore, it seems that any universalization is in a significant sense against the very fundamental spirit of ACP, which wants to defend individual difference against dogmatic universals. It seems at least somewhat incongruent to promote diversity in one area, but condemn it in another.

If however, we would want to accept (and even celebrate) conceptual diversity in line with the ACP spirit, we would need to find an approach which rids us of the practical problems that are associated with it. This is difficult to achieve in such a complex idea as ACP.

It could only be achieved in areas of conceptual thought which are sufficiently independent of each other, such that they can be contemplated in utter separation and therefore do not have to cohere within one framework. However, much of the later parts of this thesis will be dedicated to showing that this is exceedingly difficult to achieve and unlikely to result in ACP practices, which seem appealing.

None of the three positions mentioned above addresses what lies at the heart of the controversy, namely a disagreement over what it means to be competent and autonomous. The question about the nature of autonomy and competence keeps returning over and over again, not only in acute cases such as *Mrs T*'s, and not only at the bedside, but also in legal discussion.

Even if the staff had had a lot more time for deliberation, had had more time to become better acquainted with *Mrs T*'s personal values, circumstances and general quality of life etc., some fundamental differences would have remained. This is because the lack of clarity of advance directives does not (only) originate from the emergency nature of the case, but is rooted also in the diversity of ideas about what it means to be autonomous and what is involved in respecting someone's autonomy. In fact, the way we think about autonomy largely *prescribes* whether we think someone is autonomous or not, independently from the status of the person whose autonomy we are contemplating.

Accounts of autonomy (and what makes for competency) differ widely and it is not immediately obvious why one should choose one over another. The differing detail between versions of autonomy will be the subject of chapter 3, but as alluded to above, all accounts of autonomy revolve around the question of whether a person is competent. If someone is incompetent, they are not autonomous. Yet, as indicated in the case example above, ideas about what makes for competence can vary widely, too, and depending on the features of variation, differences may either be simply semantic or quite substantial.

8 – BASIC MEDICO-LEGAL GUIDELINES (A FIRST APPROACH)

It seems that this is the right point where an examination of the basic legal point of view should be considered.

Medico–legal guidelines in Victoria are very similar to most other western jurisdictions, especially those of the other Australian states, New Zealand, UK, Canada and the US. The similarities extend so far that the legal decisions within the above mentioned and other jurisdictions serve as a guide to thought and reasoning in Victoria and other Australian states.

Of note is that publications in the medico–legal area frequently talk of the need or desire to respect patient autonomy, but that patient autonomy is not directly defined as a term or concept. What is described are conditions to be met for 'informed consent' and 'legal capacity' for decision making and it remains unclear in what sense references to autonomy imply that legal capacity for decision making is to be equated with an understanding of autonomy or only taken to be a prerequisite for autonomy.

The legal capacity to issue or withholding consent is deemed present when a person is of sound mind, fully informed and able to understand the information, not coerced and able to adequately communicate. Some texts also recommend that the person should show perseverance with the choices made.[35] In line with World Health Organization (WHO) recommendation, adults are competent unless proven otherwise, i.e. competence is deemed to be the default status of an adult human being.[36]

What can be said about these parameters in *Mrs T*'s case?

Given .*Mrs T's* age, her maturity and adulthood were not under question. However, the other parameters considered in law deserve further scrutiny

1) WAS *MRS T* OF SOUND MIND?

She did not suffer from any obvious acquired or congenital mental incapacity, such as Down syndrome, that would draw her soundness of mind into question outright. However, her past history hinted at a background history of high alcohol use and depression, which may be the source for a diminished will to live or cognitive impairment.

Were there other factors, which may have acutely influenced her sound decision making ability? Yes, many: She was acutely ill, frequently in pain and very anxious facing the real possibility of death, experienced acutely through shortness of breath accompanied by fast heartbeat, sleep deprivation and tiredness, in a noisy intensive care environment. If her alcohol consumption prior to hospital admission was really significant, as was likely (but not known with certainty), this would have been exacerbated by a co-existing experience of alcohol withdrawal. She received sedative drugs for the treatment of her pain and anxiety. She was intermittently hypoxic.

Pain, anxiety, drug withdrawal, mind-altering drugs (such as opiates, ketamine, benzodiazepines) as well as hypoxia are well recognized as factors impairing a person's decision making capacity. *Mrs T* had all of these intermittently. Does this mean she could not have been competent simply because of the presence of these factors?

Here we have the first controversy.

Many would rightly say that it cannot be the case, that the mere presence of potentially mind altering factors alone should be enough to declare someone unfit. Such unfitness needs to be confirmed in some way in the phenomenology of their behavior and appearance. At least one needs to appreciate the intermittent nature of the mind altering effects and acknowledge the windows of clarity that ensue in between significant obtundation, otherwise one would be hard pressed to assume soundness of mind for most people at any one time, because stress, anxiety, pain, moderate stimulant consumption etc. occur frequently during everyone's daily life. One needs to have some form of indication of how severe and significant these factors are in the overall scheme of things.

If it were clearly understood that the mere presence of these factors alone would entail that *Mrs T* (or anyone) is mentally unfit, the decision making process in her case, as in many other cases, would not have been so difficult and controversial. So, apart from the knowledge about the presence of these factors, one needs some form of indicator or test, a normative scale, which indicates *Mrs T*'s *actual* mental state. Whether a certain clarity of mind in her actual mental state connects adequately to her true wishes remains controversial nevertheless.

At any rate, we need a test for actual soundness of mind!

2) WAS *MRS T* FULLY INFORMED AND DID SHE UNDERSTAND THE INFORMATION?

She was told that she might die without the suggested treatment and her verbal response, as well as her ensuing anxiety, seemed to suggest that she was not only informed about the outcome, but that she also understood the significance of this information.

However, how well she understood the actual nature of the treatment and what it would be like to undergo this treatment is more difficult to say. She certainly imagined it to be too burdensome to be endured and she gave a coherent reason for this view.

One might question though, whether her imagination adequately envisaged the clinical support she would get while having the treatment and whether she appreciated the possibility that it might feel quite differently to her previous experience. Was her assessment and imagination clouded by excessive fear, which was rooted in one bad previous experience, and should the possibly exaggerated fear be seen as something that needed treatment?

Is imagination the right sort of epistemic modality anyway to allow sufficient judgment and understanding? Often treatment descriptions given by an informer lack the right sort of sensory reality that might be felt necessary for an adequate understanding of a situation.

For example, one might on some level imagine what it would be like to be bald after chemotherapy, but imagination alone is often very inadequate to provide a good understanding, not only of the actual physical sensation, but also of its significance in the midst of other new circumstances: a level of malaise never experienced before for example, pain, inter-current illness or different social interactions.

Had *Mrs T* not been so breathless at the time of considering intubation and tracheostomy, would she have been so fearful?

Likewise, to imagine what it would be like to breathe through a straw[xxiii] and actually experiencing its immense difficulty and associated feeling of suffocation are quite different ways of understanding.[xxiv] A mere description of the practical nature of intubation from someone who would perform the procedure may not even generate the relevant type of imagination. Furthermore, imagining a certain amount of relief and ease to breathe through a large unimpeded opening, cut surgically into a person's throat, may again be difficult to imagine simply from a description of the procedure, especially when the description is given by someone who has either never performed the procedure herself or not experienced herself what it is like to have this done and live with it for some time.

To some extent this could have been the case in *Mrs T*'s situation.

[xxiii] I choose the example of 'breathing through a straw', because Mrs T's endotracheal ventilation tube was about the diameter of a large straw.

[xxiv] This is a simple experiment that any reader could easily try out.

However, *Mrs T* had recently been intubated for her operation, she had previously been intubated for an intensive care admission and she had actually experienced what it was like to have a tracheostomy twenty years earlier as part of her cancer treatment. Virtually none of the medical staff telling her about the treatment could boast such level of acquaintance with clinical, experiential reality. Some might say that *Mrs T* knew much better than any of her clinicians what would be involved with such treatment and therefore could not have been better informed.

Yet, twenty years is a long time in medical history in which significant changes in medical support and treatment have occurred. Furthermore, having a tracheostomy for an acute inter-current illness such as *Mrs T* experienced now and having this procedure in the setting of prolonged chemo-radiotherapy might be quite different, because the latter situation involved many other traumatic factors, which would not apply this time, e.g. uncertain survival chances, long duration, higher complication rate. Thus the question of whose judgment is better in this case, the patient's or the staff's, seems genuinely difficult to settle. To answer this question we would need to know what constitutes adequate knowing.[xxv]

Another point of contention is the question of consistency of treatment choices. One might think that if *Mrs T* was willing enough to consent to an emergency abdominal operation, which necessitated intubation in order to save her life, then it would only seem consistent that the same kind of intervention should be endured for the treatment of a lung infection.

In this case it becomes difficult to separate the question of *Mrs T*'s soundness of mind from her ability to understand the information given to her. If one thinks her

---

[xxv] This view might well need to be context sensitive, in that adequacy may differ in different situations of severity and risk, which is what some competence accounts suggest. This will be discussed further in chapter 3, p 79.

mental capacity is significantly impaired, this would very likely include her capacity to understand the information given to her. The seeming inconsistency in her treatment choices could therefore be taken as an indicator of irrationality or of a clouded mind.

Thus we need a view and test for what is deemed to be a reliable indicator of (sufficient) understanding.

3) WAS *MRS T* COERCED?

At what point does convincing someone to change their mind become coercion? It is clear that many of the clinical staff could not empathize with a position that chose to forgo a cure of an eminently curable illness, even if it was currently life-threatening.

For many of the clinical staff a tracheostomy was not an ‘especially big deal’. Tracheostomies are not uncommon. Clinical staff are used to seeing patients with this treatment, used to seeing patients get better with this treatment and used to seeing patients not being especially distressed by this treatment. It is not commonly seen as a particular source of distress in an environment where there are many other, much more distressing, states. Given this, staff certainly made their best effort to convince *Mrs T* to reconsider her choice against invasive ventilation.

Furthermore, it is clear that *Mrs T* changed her mind about allowing (at least) intubation immediately after her parents had visited and talked to her about her refusal. They had clearly talked her into accepting advanced life support. Does this constitute coercion? Did she simply ‘cave in’ or did she genuinely change her mind in view of new considerations? Again, this was not clear.

4) WAS *MRS T* ABLE TO COMMUNICATE?

Yes; even though talking was sometimes difficult because of the use of the non-invasive ventilation mask, she was quite able to write down at least short sentences or phrases.

5) DID *MRS T* PERSEVERE WITH HER CHOICES?

On her own account it could probably be said that she did. Even though she changed her mind in the end and consented to the possibility of invasive ventilation, she nevertheless remained deeply bothered by the possibility and kept voicing her severe dislike of these treatment options.

I note here that this is quite a different point from the one made above about the consistency of certain treatment choices. It seems to me that perseverance with a particular choice is subtly but significantly distinct from making rationally consistent treatment choices towards a particular goal. This is important, as it commonly occurs during the development of treatment that one's treatment goals get revised and that therefore a less or more aggressive treatment becomes less or more appropriate.

The interesting question in this case is whether the treatment goal had changed in *Mrs T*'s mind in the very short time (3–4 days) from her first presentation to the emergency department to her time in the intensive care unit, and whether her perception of the treatment goal was in a significant way heightened, changed, impaired or clouded simply by the fact that she experienced the acute distress of her illness. From a medical point of view her condition and her treatment goal was slightly more complicated than at admission, but essentially the same. However, there was a clear dissonance between various clinical staff about how accepting one should be of *Mrs T*'s perception of her illness, her treatment goals and efforts for cure.

Should she be treated like Odysseus, who had bound himself to the mast so that he could hear the sirens, but not perish by doing so? Were the conditions of *Mrs T*'s illness, like the Sirens, misleading.[xxvi] Should the sailors have respected Odysseus' pleas and freed him from the mast? Was Odysseus competent while bound to the mast?

The following table summarizes the medico–legal criteria concerning *Mrs T*'s capacity to deny or give consent.

QUALITY	YES	NO	UNCLEAR
adult	√		
sound mind			√
fully informed	?		√ (understanding?)
coerced			√
able to communicate	√		
perseverance	√ (?)		(coercion ?)

We note that the only parts that were entirely clear were the facts that she was an adult and able to communicate something. We also note that some attributes depend on the presence or absence of the other attributes: it would seem, that we can only be convinced that someone has been fully (relevantly) informed if they have a sound mind, and that we can only infer constancy of will, as reflected by perseverance, if someone was not coerced and their treatment goals had not been revised over the period which mattered.

9 – INITIAL DIFFICULTIES WITH THE MEDICO-LEGAL GUIDELINES

From the previous section we note two main difficulties:

[xxvi] Presumably the song of the Sirens were pleasurable and *Mrs. T* suffered fear and discomfort, however, both were temporary and giving in to either would lead to death.

1) In order to answer the competence questions we need tests for *soundness of mind* and presence of *understanding* and we need some account of what constitutes ‘adequate’ knowing or *epistemic access*. For information about this one has to turn to a further interpretation of the guidelines which is not directly part of the guidelines itself. The guidelines appear as if tests and parameters are mutually independent and fairly uncontentious, yet this is not the case: soundness of mind and understanding seem co-dependent and so do perseverance and levels of coercion.

Furthermore tests for the parameters in question have to be normative and they have to be consistent with our background understanding of competence and autonomy. E.g. it wouldn’t make sense to test for rational reasoning, if the presence of rational reasoning is not one of the features that are salient or relevant for competence or autonomy. Hence, at least in this sense, our tests are not independent from the details of our accounts of competence.

Inasmuch as the availability of appropriate tests for competence parameters depends on our conceptual understanding of what we are testing for, this point is very important. It may also influence our ideas of who is in the best position to test for these parameters. Who has the right expertise and are the people with the right expertise realistically available in clinical situations. What happens if this is not the case?

2) Simply turning to medico-legal guidelines does not necessarily help disambiguation. The guidelines help reflection, but they are only of limited help in principle. In cases where there is disagreement, as with *Mrs T*, one still needs to turn to the legal system proper and this is only of limited help, for the following reasons:

(i) Firstly, in cases like the one above, most would immediately recognize the impracticability of obtaining decisive advice in time. The legal system, even if it could resolve the conceptual problems and ambiguities, is far too slow and cumbersome to advise in matters of such urgency. *Mrs T*'s decision needed to be made within hours or at least over a couple of days. The appropriate legal system in this case was not even contactable out of ordinary office hours (*Mrs T*. deteriorated on a Friday night), thus the bedside decision can never be really wholly taken away from the people present at the bedside. They may be punished, chided, praised or responded to in some other form afterwards, but they cannot, in a very significant way, be removed as agents from what actually happens.[xxvii]

(ii) Secondly, and more importantly, I suggest, that there is a more pernicious problem which affects all cases, even those where there is a long time for deliberation and legal involvement is realistic and practical. This is that the legal system itself faces essentially the same conceptual difficulties as were seen above: i.e. members of the legal profession, too, vary in their appraisal of conceptual ideas and subscribe to varying, sometimes conflicting, accounts of autonomy and conflicting accounts about the necessary particulars for competence and it is not obvious why one account should prevail over another. This will be shown in a more detailed discussion of legal judgments and relevant commentary in chapter 5.

Often clinical and legal accounts of autonomy are simply not transparent at all. Sometimes they do not match. This is a significant problem, when one considers that the two are not independent of each other. Legal appraisals about matters of competence and autonomy heavily rely on:

[xxvii] This is an important point in another sense, which concerns the communal character of ACP: for although the people at the bedside may act as representatives of some larger institutions, they remain individual autonomous agents all the same, who may or may not act in accord with a heteronomous rule or guideline. Although I do not wish to dwell on this here, one may nevertheless consider that the role of conscientious objection may be very relevant here and always impact on the final execution of action. As I will argue later on, this is especially important for the communal acceptability of the idea of ACP.

a) a medical appraisal of a patient, and ,

b) a background philosophy which supplies an understanding of the concepts, for it is this understanding, which picks out the important features in a particular case.[xxviii]

Because legal advice heavily relies on medicine (and philosophy) for its verdict, we have a difficult interdependence: medicine turns to law asking for a verdict about competence and law turns to medicine returning (in some sense) the same question. Both disciplines need a philosophical background to fill out their understanding about which parameters to look for when settling conditions for competence and autonomy. But it is not clear that both disciplines, law and medicine, turn to the same philosophies, nor is it clear that one should (at least intuitively) expect them to, given that both disciplines operate in and are influenced by very different contexts.

Law is always strongly influenced by political considerations. Its self-understanding resides in questions concerned with rights and responsibilities, justice, fairness, precedence and consistency. It compares and generalizes; law applies to all; it operates predominantly in a macro-climate.

Medicine has a self-understanding of operating in an environment of care, trust, helpfulness and individuality. Its encounters are intimate, sometimes very intense and always personal. Clinical medicine operates in the micro-climate of the 'bed-

---

[xxviii] E.g. if soundness of mind is taken as displaying rational reasoning and adequate recall of public or recent information, then any person who reasons from intuition, caprice or other non-rational pathways, or who has short-term memory loss, or poor public knowledge or awareness, is not of sound mind.

side'; whenever it leaves this climate, it becomes politics. Bearing this in mind, it might be quite intelligible, and even expected, that the interaction between the two disciplines is difficult.

10 – SUMMARY

This chapter has tried to show some clinical difficulties in decision making which involved patient participation and an advance directive for patient care. These difficulties are only to some extent, difficulties of logistics and pragmatics, but rather reflect a number of diverse interpretations of the concepts involved. I believe, that the discrepancy of interpretations cannot really be taken as a result of inexperience or lack of expertise or lack of engagement of the people involved, but is a result of diverse conceptual interpretations.

The case example given provides a starting point of discussion in order to mark the territory of problems. In the following chapters these problems will be supplemented by alternative scenarios and examples where necessary. So far I only took a first glance at the legal guidelines and held back further attempts at disambiguation or more detailed legal accounts in favor of a better appreciation of actual bedside scenarios. All of the reflections above were or could be made at the bedside in a relatively short time.

A more detailed approach with attempts of conceptual disambiguation and finding solutions to the problems flagged above, will follow in the chapters below. Given that all concepts, whether viewed from a legal, clinical or private stance, need interpretational clarification and are therefore reliant on an underlying philosophy, the next chapter will focus on a description of the salient range of available philosophical ideas about autonomy, how these relate to the case example given and to ideas about advance care directives in general.[xxix]

[xxix] Although some of the conceptual questions above related to questions about ways of knowing and epistemic access, I will not pursue this problem in great detail as it is somewhat peripheral to the main enquiry.

CHAPTER THREE – PHILOSOPHIES OF AUTONOMY RELEVANT FOR ADVANCE CARE PLANNING

1 – INTRODUCTION

The last chapter showed that there is considerable variation in the way one can interpret the concept of autonomy. This chapter will look at the philosophy of autonomy as found in the philosophical literature. As this literature is voluminous and applicable to a large variety of different settings, I will start by delineating various kinds of accounts of autonomy and then go on to identify *personal autonomy* as the most appropriate kind within the framework of ACP. Following this I will give a brief outline of major differences between basic personal autonomy accounts and draw attention to particular aspects of autonomy accounts. These aspects are relevant to the questions that arise in the medico-legal and social settings of ACP, because they influence how we think about the obligations that arise in regards to respecting or enabling the autonomy of others. This will then pave the way for the next chapter, which will attempt to analyze the bedside differences in conceptual interpretations encountered in *Mrs T*'s case and prepare for the wider conceptual analysis undertaken in the later parts of this thesis.

2 – CHOOSING THE RIGHT KIND OF AUTONOMY

In the introductory chapters of her book *Self, Society and Personal Choice,*[37] Meyers summarizes in a convincing way how the idea of autonomy appears in a whole family of concepts which display related and overlapping themes. We can distinguish between political, economic, legal, moral and personal autonomy.

It is not difficult to see that economic and political autonomy are not at the heart of advance care planning. However, it is not so easy to see which of the other three, legal, personal or moral autonomy, is the most appropriate focus in this area.

The distinction between personal and legal autonomy seems important. The idea of legal autonomy aims mainly at equality before the law and at defining a private sphere in which individuals are free to pursue their own projects. However, the type of autonomy we aim to honor with advance care planning is more expansive than this. We want to honor personal and moral choice as well. Laws may be unduly restrictive or permissive, giving too much or not enough guidance. Many things may be legal which we find personally or morally offensive and some things may be illegal which we do not regard as immoral or wrong at all. We may not be able to legally pursue them, yet we may be quite prepared to either break the law or agitate for a change. If we understood the type of autonomy to be respected in the area of advance care planning as being only of the legal kind, our account would be lacking in a way that significantly discounts the form of moral engagement at play. It would forget that it is our moral outlook, which creates and shapes laws in the first place.[38] Especially when directives concern matters of life and death, people's personal moral involvement often becomes acute to the point to the point where the need to challenge current legal arrangements is sometimes felt deeply.

Yet it is not only the moral component of autonomy which is an important consideration in advance care planning. Hence focusing on accounts of moral autonomy, would be deficient too. There are many decisions within the morally 'permissible realm' which do not at all, or at least not significantly, depend on moral questions.

As Meyers points out, living well presumes that people fulfill their moral obligations, and it is often difficult to separate the moral dimensions from purely personal dimensions, but just because the distinction is difficult at times it does not mean that there is no distinction to be made. Questions like, whom should I marry?, should I have children?, should I take this job?, what makes me happy?, should I have this treatment?, should I continue to live?… etc. may have a moral side, but may also be entirely a matter of personal preference. To quote Meyers; "People do not hold one another morally responsible for all their decisions, and the decisions that people do not hold one another morally responsible for are personal."[39] A person making a treatment decision which is not conducive to life does not necessarily have to strike us as failing morally, nor does such a decision seem legally wrong. It may simply be a matter of personal choice.

In advance care planning therefore, at least as far as the patient is concerned, what is at issue is *personal* autonomy. This is what we aim to respect. Personal autonomy has features of legal and moral autonomy, inasmuch as a person has a right to equal standing before the law and is bound by current public laws and their own moral compass, but neither of these alone would capture entirely a person's real wishes for themselves.

As far as the patients are concerned, I think, the aforementioned is fairly uncontroversial. Views become more difficult when we consider what type of autonomy is at play for those who are in the position of interpreting and acting on advance directives. Should we consider them at all? As agents involved in the clinical situation they cannot be discounted: they are main players. Presumably they act autonomously in some sense, but it seems to me much less clear which kind of autonomy is most relevant in their case.

Some might question whether health carers and legal practitioners (in their role as professionals) have any significant autonomy at all, for they usually act as representatives of an institution. However, their involvement with the institution is presumably the result of some kind of autonomous choice. Likewise, they are usually chosen to fulfill their role not as 'puppets', but as someone who exercises autonomy in a responsible manner, thereby actively contributing and shaping the institution for which they work. At any rate, no matter how institutionalized the setting of illness and intervention is, when it comes to bedside interactions we have a case of immediate inter-personal contact in which personal and moral convictions of all (not just the patients) come to the foreground and, as alluded to before, do make a difference in actual proceedings and outcomes. Although I do not wish to focus on this particular problem here, it should at least be noted that advance care planning for patients may in some significant way restrict the autonomy of others, and this phenomenon may have implications for the overall success of advance care directives, as the execution of directives depends largely on the willingness or compliance of others.

At this point, I am mainly interested in specifying the concerns of patient autonomy, which, as I have pointed out, requires an account of personal autonomy.

3 – PERSONAL AUTONOMY – GENERAL FEATURES RELEVANT FOR ACP

Accounts of personal autonomy can be distinguished according to some of the characteristics of their features. Two types of classifications are commonly found in the literature. Distinctions are firstly made between individualist and relational accounts as types, and secondly between procedural and substantive accounts.

The individualist/relational account distinction picks out features regarding the independence of agents, whereas the procedural/substantive debate refers to distinctions between choice making and choice content. Because the various accounts focus on different features there can be overlap between the various classifications. Thus there are individualist-procedural (Frankfurt), individualist–substantive (Mill), relational–procedural (Christman, Meyers) and relational–substantive (Mackenzie, Oshana) accounts of autonomy.

The basic distinction between individual and relational accounts of autonomy lies in the way the autonomous subject is viewed.

A) INDIVIDUALIST ACCOUNTS

Individualist accounts see at the core of their theory an individual that is or ought to be essentially independent from its environment. Such theories see an autonomous individual as a unified self, capable of making uncoerced choices, an ability which confers agency and freedom.

Debates within these accounts of autonomy ask questions about the significance of rationality for autonomy, conditions of deliberation and reflexive engagement of the agent and sometimes about questions of practical deliberation, such as the significance of the coherence between thought and action, or the coherence of action over time.

These accounts usually ignore how autonomy is developed. They are largely silent about the significance of others in the process of becoming autonomous, the social environment and what an environment offers to the individual. These accounts will likely presuppose autonomous agency as a given and then go on to specify agency restrictive influences and/or offer some criteria for the legitimate permissibility of restricting autonomy in the setting of a community with conflicting wishes.

Individualist accounts of personal autonomy presume an agent as someone who has unified, settled values, who deliberates in (more or less) rational manner and who acts according to his convictions. Although Kant recognized pure *moral autonomy* as the only form of individual autonomy, i.e. any choices made based on emotions, goals or other personal criteria independent of rational will were seen as heteronomous. The Kantian moral agent who experiences and expresses freedom through uncoerced self-choice has become the prototype of many influential individualist accounts of personal autonomy. This agent is the origin of thoughts and actions, a creator of things and circumstances and therefore praiseworthy or culpable, i.e. responsible. He is self-sufficient, independent, self-relying and self-realizing.

Individualist accounts of autonomy often underlie related accounts of agency, which debate how our everyday observations match such a prototype. They enquire about what phenomena can motivate action (e.g. reason or desire), how opposing motivations (e.g. conflicting desires) are unified or deliberated about and what we have to say about agents, actions and autonomy that don’t fit such a schema, e.g. how we should think about phenomena like akrasia, caprice or weakness of will. At the heart of every individualist account of autonomy is first and foremost an individual, who makes independent, uncoerced choices.

Individualist accounts of autonomy are at the heart of the philosophies of Kant, Mill, Rawls and Frankfurt to name but a few prominent figures. These accounts have largely arisen historically from political and moral thought on liberty and agency, and some are heavily influenced by coexisting concerns for principles concerning justice, responsibility and objectivity.

Mill for example proposes that there is an age of maturity, after which a person can be considered to have capacity for making his or her own decisions and from then onward is counted as an independent individual. Although Mill recognizes situations of infirm capacity he does not consider them in great detail, even though they do provide one area of justification of paternalistic intervention. The Millian agent is either competent or not. Mill does not talk of competent actions, nor does he specify particular models of rational reflexion or procedural requirements for autonomy.

For Mill *age* is the main determinant of maturity[40] and if an individual by the time he comes of age has not learned well how to make choices which are prudent and in his best interest, society is no longer responsible for his choice making; nor are public mores, personal situations of ill fortune or power imbalance (although acknowledged) seen as a particular restriction on the person's autonomy.[41] They are rather seen as society's legitimate means of reasoning and enforcement of prudent and beneficial ideas, and the person is considered free to resist them, should he be in disagreement with them. Mill's version of liberal thought introduces the element of '*the personal*' to discussions of autonomy, in so far as he claims that there is a distinct personal sphere for autonomy which may not be justifiably restricted, provided its execution does not cause any significant harm to other members of society. In Mill's words:

"The only part of the conduct of any one for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, his own body and mind, the individual is sovereign." [42]

This principle is one of the very dominant themes in medico–legal and bio–ethical thought.

Rawls’ idea of an autonomous agent is that of someone who has a conception of his own good, and who would (in Kantian fashion) choose freely to act according to principles that he would wish everyone (including himself) to follow. However, given that Rawls was concerned with establishing principles of justice, which would be agreeable to all, his account of autonomy stays largely within the moral domain and specifically removes any personal concerns one may bring to bear in an account of autonomy. This is done specifically for reasons of objectivity and with the aim of achieving greatest possible agreement between members of society.[43]

Rawlsian autonomy expresses an individual’s right to participate in communal decisions according to their own conception of the good, but under conditions which have communal justice at heart. His idea of a ‘veil of ignorance’[xxx] is specifically designed to overrule individual interests in so far as they may prejudice fairness amongst all.[xxxi] It has as a background idea that such a provision would ensure that the most vulnerable people are as well off as possible (given the satisfaction of other liberal considerations)

[xxx] Rawls' ‘veil of ignorance’ is the idea that people ought to be governed by (and therefore choose) communal rules and conditions in ignorance of which position they would hold within a community. The thought is that anyone choosing rules under such a condition would choose what is genuinely fair and not be focused on their own best interest.

[xxxi] It might be noted here that although Rawls is in no way to be counted as communitarian, an account of autonomy which is thus aimed at communal interest and agreement might reflect poorly what is at heart in advance care planning, which aims at maximizing personal choice independent of ‘communal’ agreement. This connects in some sense with the problem of diversity alluded to in chapter 2.

A dominant feature of the Rawlsian (and Kantian) account of autonomy is an emphasis on rationality. Rawls sees individual choices governed by a background ‘life plan’, which is individually and freely chosen. He proposes that each individual has such a greater life plan and that individual choices are made such that they fit rationally within a person’s greater conception of the 'Good'. Rawls is, however, not explicit on whether there are legitimacy constraints on the formation of life plans and conceptions of the 'Good' and to what extent rationality is one of them. This is important when one needs to consider the possibility of illegitimate personal life plans, which may lead to disagreement in the common forum.

Rawls’ idea of individual life plans gives his account of autonomy a dimension of being about *personal* autonomy rather than *moral* autonomy. However, given its strong Kantian affiliations and rationality requirements, it is not entirely clear how far this distinction can be asserted.

Despite the fact that Rawls’ account has severe limitations in regards to being an account of personal rather than moral autonomy, it is commonly referred to in the personal autonomy literature, as it has a number of features that are considered important for making sense of personal autonomy.

These features are firstly, the discrete, individualistic, uncoerced nature of the agents and secondly, the particular mode of dynamic rational deliberation, which is aimed at justifying the unified character of the conclusions of deliberation. Rawls famously described this as *reflective equilibrium*[44], a notion, which has since appeared in many subsequent accounts of personal autonomy.

It is largely individualist accounts of autonomy that have provided a base for the initial discussions and formulations of contemporary bioethical thought. The established legal bioethical interpretations of personal autonomy take their inspiration from this kind of Kantian moral agent who lives in a Millian liberal political environment.

However, just as bioethical problems have developed as a result of changing and advancing medical and social practices, bioethical critique has developed, too, largely as a result of recognition of the complexities of social interaction bearing on questions concerning personal autonomy. In particular, feminist critique, but also thoughts in the greater realm of continental philosophy, phenomenology and sociology, have contributed much to appreciating certain shortcomings of individualist accounts.

These critiques are particularly relevant in the area of health care and, as we will see further on, are directly represented in the case example discussed in chapter 2.

B) RELATIONAL ACCOUNTS

Accounts of relational autonomy are a diverse group of accounts, which have arisen largely in response to individualist autonomy accounts. Their main critique aims at the perceived unrealistic portrayal of what it means to become and be an autonomous agent.

Although their critiques criticize the individualist accounts in a number of different ways[45], ranging in focus from metaphysical concerns, concerns of care, exaggerated individualism, modernist and postmodernist insights (á la Freud or Foucault), or diversity of personality, they all share the conviction that it is important to recognize the *social embeddedness* of agents. They all have in common that they see the individualist prototype agent as an extremely abstract entity that is not ever instantiated in real life, and therefore see it as an inappropriate type of agent to be used in considerations taken as guides for practical accounts.

As Mackenzie says, the focus of relational accounts *"is to analyze the implications of the inter-subjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency."*[46]

Relational accounts of autonomy point out that people usually do not make their choices in isolation from others. Others influence and/or bear some of the consequences of their choices. Thus the whole question of coercion and independence becomes much more complex and more difficult to settle. Even those who live in isolation and who in making choices for themselves have little impact on others, e.g. a hermit, have acquired from others their skills of deliberation, insightfulness and abilities to consider options, through means of socialization (or lack thereof) and hence are, in a sense, not as independent as the individualist prototype would have us believe.

Relational accounts of autonomy want to recognize that individual identity arises out of its social surroundings and in some sense is hostage to such surroundings in a way that is not usually included in the notion of coercion (and freedom). Acting at gun point or under conditions of black mail for example, is understood differently to the pressures and influences exerted by social attitudes (e.g. to child-rearing, body image or how to treat one's elderly). The first is clearly captured under the notion of coercion, the latter most likely wouldn't be,[xxxii] yet both may significantly influence an individual's choice.

Nor are our deliberative skills and motivations necessarily independent from others. A person who grows up in an environment where critical deliberation is encouraged and practiced will make choices in a different way to someone who grows up in an environment where such deliberation is not encouraged, frowned upon or seen as bad manners.

A person's self-conception, and therefore an understanding and imagination of what is achievable for them in the world, is powerfully dependent on their socialization and development and thus may influence choice and deliberation practices considerably.

[xxxii] This point will be discussed in further detail in chapter 5, p. 135.

Mackenzie, puts it like this:

"A widespread intuition in the literature is that normative authority derives in some way from the connection between autonomy and the agent's practical identity or evaluative first person perspective.[…] But a well-known problem with the different variants of this approach is that an agent's practical identity – or aspects of her identity – may have arisen from oppressive social relationships, conditioning and control; her practical identity may be shaped by false norms and beliefs and distorted values arising from unjust social practices or political institutions; it may incorporate destructive attitudes to herself, such as lack of self-respect or mistrust of her own judgments. These seem to be precisely the kind of factors that compromise autonomous agency …." [47]

Self-esteem, social power imbalances, religious or dogmatic pressures, a personal social history, etc. may all significantly influence a person's self-conception and choices in a way that is not reflected at all well in individualist accounts of autonomy. This is especially the case with accounts that are heavily influenced by wider considerations of equality, justice and objectivity, because these are precisely the sort of attributes which aim at commonality and agreement.[xxxiii]

Furthermore, all accounts of personal autonomy which presuppose a settled, unified character of an agent, may find it challenging to address a critique regarding

---

[xxxiii] A person who is to choose for herself under the constraint of being just with respect to others faces a significant constraint on her choice. Such an account of autonomy may be appropriate for choosing common societal rules, but not for purely personal choices.

notions of time, stability of character as well as the nature and possibility of change.[xxxiv]

Meyer’s account of autonomy competency, for example, tries to grapple with this issue to some extent and comes to a very different conclusion about autonomy than the current medico–legal guidelines would suggest. She elaborates on issues about personal and social dynamics involved in the formation and conception of personal autonomy and in her view the following holds:

“ …autonomous people need to be able to pose and answer the question “what do I really want, need, care about, believe, value, etc., etc.”; they must be able to act on the answer; and they must be able to correct themselves when they get the answer wrong. To perform these tasks, people must have autonomy competency – the repertory of skills that makes self-discovery, self-definition, and self-direction possible.[…]. To be autonomous then a person must possess and successfully use the skills constituting autonomy competency.”[48]

This she describes as a dynamic process in which self-portrayal, self-discovery and self-definition are not independent of each other and are permanently involved in revising self-referential responses. She makes no particular reference to age, in fact, she says that

“…people who never exercise autonomy competency can be presumed not to have it. Thus a person may be happy and productive – the individual’s life may be going entirely smoothly – and yet that person may not be autonomous. In the context of

---

[xxxiv] This is of particular importance when thinking about notions of autonomy in regards to time sensitive contexts such advance directives, where the expression of one’s will is non-contemporaneous with its execution. I will return to this point in detail in chapter 9, p. 250.

pervasive and powerful socializing influences, one cannot take autonomy for granted in the absence of proven heteronomy. It is autonomy that must be demonstrated.” [49]

This is very different from the currently approved legal position on autonomy in many areas.

C) AUTONOMY AND LIFE PLANS

Although life plans are not usually considered a classifying feature of accounts of personal autonomy, it is useful at this stage to consider them, because they commonly influence our thought about what we should honor in regards to personal autonomy and they do play a significant role in the philosophical framework of ACP.

Life plans are often seen as the background source for personal values, and departing from critical background values is at least viewed as a noteworthy event. How we interpret such an event or such departure from previous values may be under debate. For example, if we assume background values and life plans as generally stable and characteristic of who we are, then a choice conflicting with these background values could be seen as an indication of our “not being ourselves” and therefore as an indication of a non-competent or non-autonomous state. Yet, if we see life plans as relatively dynamic and changeable, such that even the more foundational values may change without indicating a departure from ‘ourselves’, then a doubt about autonomy cannot really arise out of such change of values and life plans. So, ultimately we need to have an opinion as to what the normative character of life plans might be.

Not all writers on personal autonomy comment on life plans. Mill, for example, does not mention them. He may have either tacitly assumed them to be present or may have discounted their importance for normativity. However others, like Rawls, Dworkin and Meyers emphasize their meaning.

Rawls writes:

"a rational plan of life establishes the basic point of view from which all judgments of value relating to a particular person are to be made".[50]

He furthermore characterizes the time structure and makes a comment on content:

"…a plan will have to make some provision for even the most distant future and for our death, but […]it becomes relatively less specific for later periods. [...] We must not imagine that a rational plan is a detailed blueprint for action stretching over a whole course of life. It consists of a hierarchy of plans, the more specific subplans being filled in at the appropriate time. [...] The structure of a plan not only reflects the lack of specific information but it also mirrors a hierarchy of desires proceeding in similar fashion from the more to the less general." [51]

Thus Rawls sees a life plan as something of a fixed, albeit loosely fixed, grid of hierarchies, into which every choice falls, rationally. The grid in itself does not seem to be under question.

Similarly, Dworkin offers an account of critical and experiential life interests which make up what accounts for the value of a life. His idea of critical interests[52] supports a view of life integrity, which may be interpreted along the lines of a life plan or life narrative. Critical values support the 'big life decisions' such as 'whom should I marry', 'what work should I do' etc. and the whole of a life's worth is seen in relief against the background of the critical interest of a person. Dworkin writes:

"It is important that we find a life ***good*** *and that we* ***find*** *it good. Integrity plays two parts in this story: it is the mark of conviction, of commitment, not just past choice; it also reflects investment, that the value of a life in part lies in its integrity, so that its having already been established as one kind of life argues, though of course far from conclusively, that it should go on being that kind of life."* [53]

Although Meyers also entertains a notion of life plans, she proposes a more dynamic account of life plans, which directly criticizes the Rawlsian account as incomplete.

Her point has particular relevance to all accounts of autonomy that place a central role on rationality, as Rawls' account does. The criticism against Rawls here is that his account reduces every substantial notion of self-knowledge to rationality, but ignores the fact that rationality has critical limitations when it comes to working out foundational values. Meyers aptly puts it like this:

"Evidently the power of the principle of rational choice is severely limited. I suspect that most people would say that, once their desires, values, aims and so forth are clear enough for the principles of rational choice to be applied, it is usually obvious what they should do. At this point, applying the principles is either superfluous or merely serves as a check on especially important decisions." [54]

Another criticism challenges the presumed independent nature of autonomy, insofar as self-knowledge, which she sees as vital ingredient of autonomy, may not be independent of others at all. Self-knowledge and self-definition may not be entirely up to one's own introspection and therefore are not as individualist as originally thought. Meyers says:

"But since people are not always able to discern the origins of a vexing self-referential response through simple introspective perception, this inquiry into possible sources of self-referential responses may bring five additional faculties – memory, imagination, verbal communication, reason, and volition – into the self-reading process. Both memory and imagination may join forces with instrumental reason to generate tentative explanations of the self-referential response under scrutiny. [...] Often, however, people need additional stimulation of others' interpretations of their situation in order to notice self-referential responses or in order to find plausible explanations of these responses. When this is so, conversation becomes central to the self-reading process." [55]

Meyers' idea of autonomy involves the notions of a life plan, but it seems to aspire to be a much more dynamic picture. However, it is not entirely clear how this settles the question of life integrity and the fixation of character. In response to the Rawlsian hierarchical account of choices within a life plan she observes, quite rightly that, "... a person who is feeling frustrated must determine whether this trouble stems from a particular condition which could be avoided without major alterations in the individual's life plans or whether it is symptomatic of a need for a radical change in life directions."[56]

It is not evident that cardinal, foundational or critical values are exempt from scrutiny and revision and therefore the stability of one's character is also open to doubt. Although Meyers makes the point above with reference to the limits of rationality and in respect of introspection, it can very well be viewed in relation to the stability of values and character.

If life plans are meant to inform us about the background values that inform individual choices, then presumably one ought to be able to judge the autonomy of someone's choices in reference to their overall plan. However, if we believe that our life plans inform our values, but our values, including 'foundational' ones such as those that ground life plans, may be subject to change, then knowing someone's life plan (or life narrative) is of little help, since we don't know whether a current decision is not one of those life (plan) changing ones.

What is clear though, and what will be shown in the later parts of this thesis, is that advance care planning really only makes sense in conjunction with views that accept ideas of character or value stability; for it is just such stability, which is supposed to endure past the loss of autonomy. Whether a departure from such values marks the loss of autonomy remains unsettled until it is clear what the normative background for autonomy is.

D) PROCEDURAL VERSUS SUBSTANTIVE ACCOUNTS.

Apart from distinctions arising from reflections on the social embeddedness of agents, another major factor in distinguishing types of accounts of personal autonomy appears in the philosophical literature.

This distinction concerns whether decision *content* has any bearing on whether someone can be autonomous.

Procedural accounts of autonomy hold that the way in which decision making proceeds is important for a verdict on whether someone or someone's decision is autonomous or not, but they are neutral as to the content of the decision; i.e.. on a procedural understanding of autonomy every choice is autonomous as long as it is arrived at by whatever is considered the proper procedure for arriving at a decision that is endorsable by the agent. So for the Kantian agent this would be rational deliberation. For an ethical intuitionist, it might be following the intuition about what is right at the time without particular reference to any particular method (other than one's intuition, e.g. one's personal sense of good or right) as proposed by Moore. [57] It may mean reflective endorsement of one's desires as described by Korsgaard [58], identification with one's will as per Frankfurt [59],or the dynamic reflection and revision of one's goals and life plans as described by Meyers [60]. The cardinal feature of purely procedural accounts of personal autonomy is that authorship, together with the right procedure, are what is required to express autonomy, independent of choice content.

As long as I (reflectively) endorse a decision as mine it can be in favor of anything at all, even (perhaps) the decision to forfeit my autonomy.

Substantive accounts hold the view that some decision contents disqualify a person from being autonomous. On these accounts it is not enough to reflexively endorse one's decisions, one's decisions must also honor certain values and beliefs in one's belief corpus in order to be seen as autonomous.

Mill for example explicitly thought that forfeiting one's liberty went outright against the value of liberty and therefore should not be permitted.[61] In a more contemporary example Oshana [62] cites a case of a Taliban woman, who once trained and practiced as a physician and lived an independent life. She later 'freely' chose a life of complete dependence upon and subservience to her husband and religious leaders. Because the decision of this Taliban woman forfeits any subsequent autonomy, i.e. does not value autonomy enough to honor it, Oshana (as would Mill) does not consider her autonomous. The content of the decision goes directly against the notion and value of autonomy itself and thereby is self-defeating.

E) AUTONOMY AS DISCRETE OR CONTINUOUS PARAMETER

There remains one other point of difference between accounts of autonomy which is important to mention, because it has a marked impact on what obligations arise in regards to respecting the autonomy of others. This is whether autonomy is to be considered as a discrete or continuous parameter.

Joel Feinberg in his discussion of autonomy makes the point that autonomy may refer to a number of different conceptions, one of which views autonomy as a capacity a person has. When autonomy is viewed as capacity, also called 'de jure' autonomy, it is seen as a discrete parameter which is present when a certain threshold competence is achieved. Any excess competence, so to speak, is irrelevant. As Feinberg states:

"Jellyfish, magnolia trees, rocks, newborn infants, lunatics and irrevocably comatose former "persons", if granted the right to make their own decisions, would be incapable of even making stupid choices. Being stupid, no less than being wise is the prerogative of the threshold-competent." [63]

Feinberg's idea of **threshold competence** refers to a particular, discrete sense of having a choice making capacity at all, where the quality of the choice or deliberation doesn't feature (unless they are specified as part of the threshold parameters).

The benefit of such a conception of autonomy is that it (usually) has very minimal requirements for counting a person as autonomous and it allows for a general account of autonomy in a global sense, which refers to the entire agent and not only to some of the agent's acts or capabilities. Furthermore, it allows for a conception of autonomy that permits us to view people as autonomous despite them performing (or favoring) capricious, intuitive, unreasoned for, unreasonable, unwise, superstitious, irrational or otherwise idiosyncratic acts. A threshold account of autonomy allows for autonomous cranks, who make their own stupid decisions, which nonetheless have to be respected. A global account of autonomy also allows for the extension of autonomy from one area of decision making to another; e.g. in accepting an age parameter or a minimal reasoning capacity as a threshold, we then justify competence in all areas of decision making, not just some.

The shortcoming of a threshold account of global autonomy is primarily that it does not allow us to count as non-autonomous many people whom we would like to protect from their disabilities or immaturity. Curiously, Feinberg includes lunatics (whatever is meant by the term) amongst the threshold incompetents, yet most 'lunatics' are quite capable of making poor decisions. In fact, this is mostly how we come to see them as lunatics. This leaves it a little uncertain as to what the relevant threshold for competence might be.

An alternative view of autonomy, which has become more widely held recently, sees autonomy as a graded phenomenon. Autonomy referred to in this model is refers usually to actual demonstrated autonomy rather than capacity, but the distinction is not always clear.

A **scalar model of autonomy** [xxxv] tries to legitimize the notion that someone may be perfectly autonomous and competent on one area of life, but not in another. The idea can be conceptualized in different ways. One version of 'autonomy by degrees' is the idea that people differ in their skills required for autonomy. A person may have very good self-knowledge, but poor conceptions of what they want or very limited ideas of self-realization. Others may be good at knowing what they want and at formulating life plans, but have poor insight into their own character, traits or capabilities. Others still may know well what they want, but have poor understanding of surrounding circumstances. To put it in Meyers' terms, all these types would be considered as lacking some competencies of autonomy, but they would differ in what it is that diminishes their autonomy.

A slightly different way would be to see autonomy partialized across areas of relative expertise or understanding, e.g. an experienced school teacher maybe autonomous in decisions concerning education, but completely at a loss in matters of finance or primary production; alternatively, one may envisage a person with dementia as autonomous in her choice of clothes or meals, but not in regards to treatment decisions.

What is more evident in scalar accounts of autonomy, is a pressure on being explicit about the factors which give rise to a person's autonomy or the factors that frustrate it. The different examples of school teacher and dementia patient consider two different types of cognitive impairment, the former a type of lack of information, the latter an inability to utilize information. These are factors

---

[xxxv] also sometimes referred to as partial autonomy

concerning the characteristic of the agent only. However, some authors do not only consider the characteristics of the agent, in terms of autonomy or cognitive ability, but also the risk involved in the action under consideration. These accounts are known under the name sliding scale accounts of autonomy. Sliding scale accounts of autonomy are interesting in a two ways. One, because some try to reconcile the differences between global and scalar models of autonomy and two, because their different conceptions throw some light on the a distinction between autonomous act and autonomous agent, which will be discussed further below.

A problem with scalar accounts of autonomy is that for practical purposes there still needs to be a discrete threshold point, at which one grants that a person is capable of making a decision that is to be respected. Thus some authors have proposed a 'combination view' that recognizes the scalar nature of autonomy, but names a threshold level at which global (or at least relevant) autonomy is said to be present. To make such an approach successful one must clarify the necessary threshold criteria, including the kinds of things that need to be consider, just agent qualities or also actions qualities. A complication then arises out of way one distinguishes between autonomous agents and autonomous actions (see below), which again influences what particular obligations arise in relation to respecting autonomy. For example it might bring up the question of whether act autonomy can have different thresholds than agent autonomy and whether respecting autonomy concerns the respect for actions, agents or both.

A perspective of **global or discrete autonomy** neglects or denies distinctions between agent and action autonomy. On a global conception of autonomy a person either is or is not autonomous. An autonomous person may make poor decisions or decisions which lead to poor outcomes, but this would be saying something about the merit of the decision and not the autonomy as a quality of the person. (Mill’s account, for example, falls into this category, as does Feinberg's 'de jure' autonomy) Some scalar accounts however are sensitive to distinctions between autonomous agents and action. This can lead to different conceptions of how one ought to go about assessing someone's autonomy, but maybe also about how we view the ontological nature of autonomy.

F) AUTONOMOUS ACTS AND AUTONOMOUS AGENTS

Many accounts of autonomy do not distinguish between autonomous agents and autonomous acts, but when we are in need to establish whether we need to respect someone's decision, we need to establish what informs our approach. Do we recognize someone's autonomy in virtue of the characteristics that the agent possesses and conclude from this that their actions and decisions are autonomous or do we observe their action and decisions and conclude from these, that the person must be autonomous. The act/agent distinction here is one of ontological priority. All acts of a queen are royal in virtue of them being performed by queen. If one understands autonomy like royalty in this sense, then all acts of autonomous people have to be respected in virtue of the autonomy of the person. However, if I can perform a royal (noble) act, because of a particular quality that the act has, then whether I am queen or not is not important. If autonomy is understood in this way, then the obligations that arise in relation to respecting autonomy change.

This question has moral significance for ACP, as ACP requires the appropriate attribution of autonomy in order to know whether a person is fit to draw up an ACP and in order to know when such a plan needs to be invoked due to autonomy loss. It is also of practical significance as it influences the way we go about establishing whether someone has autonomy or something is(can be) done autonomously.

It would seem odd to assert that a person is autonomous, but their action or decision isn't. An assertion that someone is autonomous seems global in character. Yet, it might not seem quite so counterintuitive to say that someone made an autonomous decision, although we do not recognize them as autonomous on the whole. The latter might be especially true, if we hold a scalar view of autonomy, which proposes a variety of thresholds for autonomous decision making in different realms or in regards to different risks. To make sense of how one might account for these different assertions about autonomous agents and acts it will be instructive to examine more closely the two different accounts for risk scaling that have been prominent in the literature.

The first group of proponents of a sliding scale model of autonomy, propose that decision making competence itself varies with the risk attached to a certain decision. Such a view might say that a person is 'autonomous enough' to make a certain decision. This position is argued for by Buchanan and Brock who say:

"Because the appropriate level of competence properly required for a particular decision must be adjusted to the consequences of acting on that decision, no single standard of decisions making competence is adequate. Instead, the level of competence appropriately required for decision making varies along a full range from low/minimum to high/maximal [...]. The greater the risk relative to other alternatives [...] [the] greater the level of communication, understanding, and reasoning skills required for competence to make that decision ...." [64]

An alternative model of the sliding scale view denies the gradation of competence itself, but demands more stringent evidence for the presence of competence in areas where the relative risk of a decision is high. Such a view is more global in character and its proponents would possibly frown about the expression of 'autonomous enough' as misconceived. Advocates of this view are Beauchamp and Childress who suggest that there is no basis to believe that *"risky decisions require more ability at decision making than less risky decisions."* [65]

The first model places autonomy on a scale, but maintains a steady threshold for evidence, whereas the second view holds the threshold for autonomy steady, but places the need for evidence on a scale. Both invoke a type of scale relative to the risk of outcome, but they propose different strategies as to what is required of those who wish to respect autonomy.

The first approach seems to say something about the agent. It requires that the agent be able to do different things relative to the risk involved. The second approach doesn't claim anything different about the agent's characteristics, but requires the assessor to be more certain about getting the 'autonomy assessment' right. It says: where the act is risky, a false attribution of autonomy is more detrimental and therefore we should take more care and apply higher standards in the way we assess someone who makes a risky decision.

It is these kinds of approach which underlie situations where higher levels of decision scrutiny for *denying* recommended treatment is demanded than for *accepting* treatment, or in which mature minors are allowed to consent to, but not to refuse recommended treatment.

Although both ways of risk stratification take reference to some consideration of action outcomes and thus consider the nature of the act, neither specify clearly the ontological priority of either act or agent.

One way of thinking about a scalar view of competence and how autonomy is developed might be to think of the scale in a linear way, which achieves a threshold at some time. On such a view a person who has performed many actions (or who has adhered to certain criteria) in a competent way is declared competent when they reach the set threshold. Many professional competencies are conceptualized like this and professional autonomy is granted at the threshold level. Someone who has demonstrated ten 'successful' episodes would be understood as more competent than someone who has only demonstrated two. Whether either of them is considered fully or only partially competent is a question of where one sets the threshold. On such a view the person becomes autonomous as a result of their demonstrated acts. Thus the act is clearly ontologically prior to the agent in the sense that the agent acquires the attribute 'competence' through demonstration of certain acts or decisions.

However, one might think that a competent act is so in virtue of some attribute the agent possesses (e.g. soberness). In this case the act acquires the attribute from the agent and thus the agent is ontologically prior.

Unfortunately, most writers do not specify in which way their scalar accounts of autonomy are conceived and therefore it is left open to interpretation. Yet this is important to know, for as we will see in the next chapter, it influences the way in which one may approach legitimate competence assessment.

Both risk sliding scale accounts suppose certain cognitive and environmental characteristics that have to be present in order to grant the attribution of competence, and the emphasis on agent cognitive factors could suggest an ontological priority of the agent. Yet this conclusion is premature without considering how the presence of cognitive factors is established. If the inference to cognitive abilities is made from a person's actual track record of their actions, especially action outcomes, then it would seem that the attribution of competence is a result of the nature of the person's actions indirectly, and thus actions seem to be ontologically prior after all.

However, if one considers an agent's cognitive factors independently from actions, or at least only invokes the nature of the actions as evidence of the presence of certain cognitive capacities, then the ontological priority of the agent is more convincing.

It seems to me a very short step from thinking that risky decisions need higher cognitive skills to the idea that poor action outcomes are the result of poorer cognitive ability. Perhaps Buchanan and Brock think the way they do, because they think that better cognitive ability[xxxvi] is a way of risk reduction. If that were true, then those with better cognitive abilities should have a track record of actions with better outcomes. I am not sure, whether this view is true of Brock and Buchanan, but a view like theirs could propose that agent competence should be seen, by and

---

[xxxvi] I take it that what Buchanan and Brock interpret as higher level of competence largely refers to cognitive ability

large, as a result of an agent's relevant action quality. This could lead to an approach that suggests that a good way of establishing someone's autonomy would be to look at a person's 'action track record', much in the way as we look at the 'skills demonstration' record of someone who was under a professional competence assessment. This style of thinking is act focused.

However, if one thought act quality, especially outcome, is no reflection of agent autonomy, then the question of whether a person is autonomous is simply solved by assessing whether a person satisfies a certain set of criteria that are independent of the qualitative nature of the acts. This style of thinking is agent focused. That these considerations matter in practice, will become more evident in the next two chapters where the practical and legal characterizations of competent decision making are considered in greater detail.

4 – SUMMARY

At the beginning of the chapter I suggested that the most appropriate conception of autonomy in regards to advance care planning was ‘personal autonomy’. I then pointed to a number of philosophical differences that can be found in accounts of personal autonomy and in particular in the debate as to what criteria should be involved in the characterization of autonomy.

The debate currently divides between individualistic and relational accounts of autonomy, both of which may then either be characterized further as to whether they are substantive or procedural accounts.

Apart from this, opinions divide as to the existence and role of life plans and whether autonomy is to be viewed as a discrete (global) or continuous (scalar) parameter. Finally, many accounts leave it unclear, whether they are characterizing autonomy as a property of agents or of acts, such that there is often ambiguity as to what is the autonomy-conferring entity.

Furthermore there are differences in the particular aims which the views of autonomy pursue: some views focus on being maximally inclusive in terms of population numbers, whereas others focus on being maximally intellectually sound and reflective. Some accounts focus on ideas of global agency of a person as a person, whereas others focus on focal competence of particular acts, irrespective of global capacities or capabilities. Some accounts incorporate the decision content into the assessment of autonomy and some accounts are content neutral. For some accounts the process of autonomy acquisition matters, for some it does not.

Although some accounts of autonomy are mutually complementary or lend themselves to coherent combinations in terms of their characteristics, some views are frankly contradictory in nature. Each view addresses particular problems and intuitions, but no view addresses all concerns convincingly; nor could this be expected, when some concerns are openly contradictory. With respect to some criteria (e.g. whether autonomy should be maximally inclusive or intellectually demanding) it is conceptually impossible to address all of them at once. Finally, as a number of conflicting demands seem to be of equal importance, no particular account of autonomy stands out as especially correct, commanding or dominant.

CHAPTER FOUR – CONCEPTS OF PERSONAL AUTONOMY IN APPLICATION

1 – INTRODUCTION

This chapter aims at examining how the clinical case of *Mrs. T*, introduced in chapter 2, can be analyzed in terms of the accounts of personal autonomy given in the last chapter, and showing through this analysis, that autonomy is not only dependent on the condition of the patient, but also on the operative concept employed by the assessor.

Treating autonomy as a quasi 'diagnosable condition', I will then have a closer look at the problems of autonomy and competence assessment in clinical life. Apart from pointing to significant practical difficulties that are evident in this area, I will pay particular attention to the dependence of competence testing on underlying accounts of personal autonomy and the limitations and puzzles this entails for deciding on adequate expertise and testing methods. This will lead to the conclusion that there are actually no good tests for competence (and autonomy) available and that the tests which do exist, while responding to quite different philosophical demands, are often extremely inadequate. This will then lead the discussion into the next chapter, which looks to a closer legal analysis of the concept of autonomy.

2 – ATTRIBUTION OF PERSONAL AUTONOMY IN THE CASE OF *MRS T*

After having examined a number of significant differences in philosophical accounts of personal autonomy it will be instructive to see how they translate into practice.

In the case example presented in chapter 2 we saw three different positions regarding the patient's autonomy and competence: *position 1)* found *Mrs T* competent, *position 2)* found her incompetent and *position 3)* was undecided regarding her competence to refuse life-saving treatment.

Each position can be described on the basis of a number of features discussed in the previous chapter.

POSITION 1 – COMPETENT

Mrs. T was deemed competent and therefore autonomous. Staff who took this position thought her instruction against invasive ventilation had to be respected, because this is what was required in order to respect her autonomy.

By looking at the reasons for their position we can characterize the type of personal autonomy account which these staff members might have entertained. Their idea of autonomy was predominantly procedural in nature, because they looked at the nature and manner in which *Mrs T* connected her choice to reasons. They looked for her understanding of the surroundings and circumstances and were convinced that she could adequately understand them. They discounted any significant interference or after-effects from medications, sleep deprivation or breathlessness to the point that they would have interfered with knowing and stating her will, because she did not appear impaired. The phenomena of her specific appearance and behavior outweighed any concerns which may have arisen from studies of similar cases or cases described in the literature.

People who thought *Mrs T* competent did not have a substantive account of autonomy, for the content of her choice was not linked to her competence status.

Neither did they think her coerced, thus they most likely held a more individualist type of account of autonomy. A relational account would have much more likely appreciated the coercive nature of power-imbalance of the situation, parental pressure and possibly given greater weight to her seemingly impoverished social background (alcoholism, disinterested partner, questionable self-esteem and self-knowledge and unemployment). If they did hold a relational account, it would have had to have a very *low* threshold for decision- making capacity. Those who thought her competent could have done so either based on a scalar or a discrete view of autonomy. If they had a scalar view, they might have held that the features *Mrs T* displayed were enough to put her over the competence/autonomy threshold. However, it is unlikely that they held a risk relative competence view, for treatment refusal in the face of death really constitutes the highest risk possible as far as decision making goes.

POSITION 2 – INCOMPETENT

Some of the staff who did not think *Mrs T* competent held a substantive view of autonomy, i.e. the content of *Mrs T*'s decision, the fact that she was prepared to give up life (autonomy as well as everything else), disqualified her from competency.

Furthermore, their procedural criteria were not met by *Mrs T*'s behavior: her introspection and understanding of the situation was challenged based on acute factors such as medication, pain and illness as well as on the basis of more chronic factors such as social background, possible alcoholism and low self-esteem. Staff in this group thought it insufficient to rely on patient appearance alone and referred to other evidence.

The rationality of behavior was questioned, based on the seeming inconsistency of *Mrs T's* actions, such as consenting to undergo life-saving surgery, but not life-saving medical therapy. This 'doubtful rationality' was then equated with incompetence, i.e. it was presumed that an irrational choice cannot be a competent one. Her behavior in this regard was not seen as a 'bona fide' change of mind.

Some doubts regarding her social background, general reasoning and introspection capacity seemed reminiscent of the autonomy–competency position expressed by Meyers. On this kind of view autonomy needs to be demonstrated and such demonstration, some staff felt, was lacking.

Several staff voiced relational concerns clearly as they were concerned about the general intensive care and illness environment, arguing that the power structures in place in this environment make autonomy very difficult at the best of times, even for a healthy person. Even though *Mrs T*'s refusal of treatment seemed to take a very independent stance superficially, they thought this unlikely to result from meritorious, independent contemplation of 'the overall best thing to do'. In their view, *Mrs T*'s directive could just as well (and maybe more likely) have been an expression of tiredness and the need to escape from this environment to anywhere, even death.

The fact that *Mrs T* changed her mind to some degree after talking with her parents seemed to support the phenomena of social embeddedness and questionable individual independence.

Lastly, all of the staff in this group may have held a global or scalar view of autonomy. They could have either seen her as failing in competence completely or felt that she did not get over the 'competence-threshold' for this particular, life-saving decision. They may also have subscribed to the idea that treatment refusal, incurring the higher risk, warranted an extra-high threshold, which could not be met in her case. The latter position would have represented the view of those who questioned her competence in respect to treatment refusal, but were quite happy to accept her as competent for treatment consent.

POSITION 3 – UNDECIDED

Staff members who were undecided in their verdict concerning *Mrs T*'s competence may be seen as either displaying a certain epistemic humility or as showing epistemic insecurity. Epistemic humility is often seen as a kind of virtue and can present in two forms:

a) One can acknowledge that the patient is competent, but not agree with her view. Then one is faced with deciding who is wrong or working out the overall importance of autonomy, i.e. whether it is more important to respect someone's autonomy than one's own convictions about what is good or right, or in the other's best interest. Deferring one's own judgment to another's is sometimes justified through the notion of epistemic humility. This is based on a belief in the *irreducibly* *subjective nature of first person experience* which precludes one from really knowing what something is like for another. This type of argument has been put forward in favor of respecting autonomy irrespective of the content of choice and disagreement.[66] However, as this view actually acknowledges the patient as competent, it does not well match a genuinely 'undecided' position about competence. It only reflects indecision about the significance that autonomy should carry in comparison to other considerations.

b) Another form of epistemic humility is inter-professional epistemic humility, i.e. one may show epistemic humility towards one's colleagues. In such a case one professional, based on her (limited) knowledge, holds a particular belief regarding the patient's competence, but acknowledges that she may not be the best person to judge this matter. This could be either, because she does not know enough or because she is not in the right position in the context of the case. Thus the ENT surgeons who held the 'uncertainty position' in *Mrs T*'s case, may have felt either that competence issues did not come under their expertise or that they were not connected to the patient in the right way, as they were 'only consulted' and not the main treating team, i.e. the treating team which assumes final responsibility for care.

Abstaining from putting forward a verdict under any of these circumstances may be viewed as humility. In chapter 2 (p. 58) I observed, that those who were undecided about *Mrs* T's competence were not really in a position to act. However, if their indecision had been a result of this kind of epistemic humility, then the charge that the ENT-team were not really able to act[xxxvii] would have been mistaken. Had this team been required to act, they would have acted from a position of

---

[xxxvii] By 'act' I mean actually institute or forgo active treatment at the time of need, i.e. perform invasive ventilation.

(acknowledged) epistemic inferiority. As pointed out in chapter 2, the most likely scenario in this event would have been the move to saving life at the risk of wrongly attributing incompetence, reflecting the position that it is a greater evil to forfeit life than to slight someone's autonomy. Such a position is commonly invoked (and recommended[67]) in emergency response cases, where insufficient knowledge is available due to severe time constraints. *Mrs T*'s case was not entirely a case of *severe* time constraint, but some time constraints applied.

Would it be better to describe the undecided position as epistemic insecurity?

Epistemic insecurity seems to be a lot less virtuous than humility. Whereas epistemic humility implies that it is okay or maybe even better to abstain from a verdict about competence in this case, epistemic insecurity does not do so in the same way. Humility simply asks for deference, whereas insecurity, at least in a professional sphere, asks for remedy!

Epistemic insecurity implies, firstly, that one should seek to overcome it and, secondly, that abstinence from action is not an option, should action be required. In situations where action is required, one simply has to make do as best as one can under the circumstances. This is definitely the case in acute medical treatment.

The contemplation of epistemic insecurity initially seems to be a long way from considerations concerning accounts of autonomy, yet it is very relevant in this case, as it draws attention to the problems and obligations of expertise. Reflection on epistemic insecurity leads us to recognize the multiplicity of factors involved in judging competence and autonomy.

3 – AUTONOMY AND EXPERTISE

One of the upshots of the 'undecided'- position, when viewed as epistemic insecurity, is that one needs to ask whose expertise is required in order to overcome the epistemic insecurity. What is the type of knowledge required and who can best provide it?

People in the ‘undecided position’ could either not have a view about what is necessary in order to be autonomous or they could have a view, but not know whether the patient genuinely matches their requirement for autonomy.

For example, some staff considered themselves insufficiently informed about what is required in order for an agent to count as autonomous. In this case the expertise would come from either a philosopher or (more likely, in practice) from a legal expert.

Alternatively, others who may have subscribed to a more relational model of personal autonomy felt that a lot more information about *Mrs T's* social and psychological background was needed. Maybe this suggests that they would consider verdicts of non-competence more likely. The relevant expertise for providing this type of knowledge would come from a social worker, psychologist or psychiatrist.

If the knowledge they lacked concerned the extent and durability of specific effects from drugs, sleep deprivation, stress of illness etc. on certain decision making qualities (specifically their effect on rational reasoning), the answers would come from experts on neuropsychology, pharmacology or physiology. Here a procedural account of autonomy, which demands certain reasoning competencies, would be at the heart of the question.

If one needed to know more about *Mrs T*’s usual values or whether her current directive seems to be in keeping with her usual self or professed life plans, and so forth, the relevant knowledge would more likely come from friends and family. Such enquiries would be more in keeping with a more individualist, procedural account of personal autonomy. Alternatively, if one holds a competency account like Meyers, then one would need to establish whether autonomy competency was presenting the first place. Such expertise may come from all sorts of ‘experts’, such as former health carers, friends, partners, social workers etc. Maybe *Mrs T* never reached autonomy competency even when she was well. Admittedly, this latter position is not really admissible under the current legal 'minimalist' environment (which we will examine in chapter 5), but it may nevertheless be at the heart of someone's insecure judgment regarding their patient's autonomy.

The point is that we do not necessarily know what kind of knowledge the 'uncertain' staff actually require in order to come to a conclusion about *Mrs T*'s competence status for decision-making. Do they need to know the effects of the sleep deprivation, or do they need to know whether to count them? Do they need to know more about her social sphere or do they need to know whether and how the social sphere matters? Do they think that questions of autonomy are not questions, which, strictly speaking, belong in the realm of medical knowledge? Furthermore, can we be confident that those members of staff who do pass a verdict about *Mrs T*'s competence status actually do so based on an appropriate account of autonomy?

Answers to these questions depend very significantly on how we understand personal autonomy in the area of advance care planning. Furthermore, any attempts at a scientific appraisal of autonomy, such as testing for certain qualities or skills, also need to utilize a pre-existing account of autonomy, otherwise one does not know what to test for or what to describe.

4 – AUTONOMY, SCIENCE, OBJECTIVITY AND TESTS

There is a school of thought, more pragmatic in nature, which approaches these questions in a different way. It says: let's see how our tests work and then decide whether the outcome of the test suggests to us that we should hold one particular view of autonomy.[68] So, instead of wondering whether to count e.g. sleep deprivation as an autonomy modifying factor, let's see whether the patient actually is sleep deprived and if she is not, then we do not even have to bother wondering about the question in the first place. Alternatively, if there were no test for sleep deprivation, then even if we did think it mattered, we could not practically expect to factor such an answer into our assessment, because we couldn’t find an answer anyway (and so it does not really matter).

I think this approach is very short sighted and does not fulfill one of the essential aims that we pursue when we test for something, namely an objective answer that will produce agreement within a community of thinkers (or variety of thought) about an issue.[xxxviii] It makes little sense to test for something unless one thinks the test is relevant to the issue in question, thus one must have an idea about its relevance first.

If the question is not relevant, one wastes resources and gives a false impression of scientific rigor, where none is required. Where the matter is relevant, but no relevant tests are available, one ought to acknowledge that an objective assessment is not possible and that disagreement is a reasonable thing to expect. Not having a test available, does not mean that the matter one would test for does not matter to autonomy (i.e. sleep deprivation may impair autonomy, even if we don't have a good test for it) and more importantly, again, employing poor methodology instead of acknowledging one's lack of adequate procedure, gives a false impression of scientific rigor and knowledge, where none such exists.

Where an objective assessment is not possible, an alternative assessment ought to replace the objective test for mainly pragmatic reasons, but also maybe for reasons of an underlying ethical nature. Such an alternative assessment may be influenced by many variables such as availability of resources, consequences of the action, the ‘care-factor’ of the people involved, “educated guesses”, cultural values etc., maybe

---

[xxxviii] It should by now be abundantly clear that advance care planning is a communal problem, in so far as more than one party (person) is involved in the venture. At the bare minimum there are two people involved in ACP, one to plan and one to act out the plan, but very commonly there are more than two parties involved.

even luck. However, this alternative arrangement can lay little claim towards accuracy or objectivity and is simply in place to ensure some possibility of action.

In light of this, the question arises whether our ability to test for competence or judge someone's autonomy is likely to be accurate and objective or whether it is more like a merely pragmatic arrangement that allows action in a setting of disagreement, with little objective claim towards accuracy. For the answer to this question, we must look at the available tests and how they are used.

1) TESTING FOR AUTONOMY/COMPETENCY/CAPACITY

If autonomy were akin to a simple organic condition, like diabetes mellitus, we could test for it with an appropriate organic marker, as we do by measuring fasting blood glucose levels for diagnosing diabetic people. However, autonomy (or competency) is not like this. It is a complex state, like health and there is no simple marker to detect it, at least in borderline cases.

Even with organic conditions there is a significant gap between the presence of some recognized pathology and the conclusion regarding someone's state of health. Someone may for example be diagnosed with diabetes, but feel and be completely healthy, i.e. they have not manifested any of the ill effects of the disease. A similar gap exists between recognized pathology and absence of autonomy. Without pressing the analogy between health and autonomy much further, we can see the point that any tests considered for competence testing cannot simply pursue the demonstration of organic pathologies, they must also convincingly demonstrate a functional impairment, unless the pathology necessarily goes hand in hand with a grave functional impairment (such as anencephaly, for example).

For this reason mere neuro–imaging techniques are inadequate unless they show extreme conditions, in which case there would not be any disagreement about competence in the first place.

Even tests showing quite dramatic abnormalities may have varied presentations. This is also true for some organic markers, such as genetic abnormalities, too. Certain genetic aberrations can still present within a spectrum of functional abilities. People with Down syndrome, for example, may exhibit quite different levels of cognitive function and independence, such that the simple genetic marker of Trisomy 21 may not be considered by some as universally mental capacity–condemning.[xxxix] This becomes more significant still when competence is considered in a risk- and decision-relative fashion, rather than a global and discrete personal attribute . Interestingly the knowledge that people with Down syndrome (and many other disabilities) can function on much higher levels than initially thought has only come through specialized support for the development of cognitive function and fostering independence. This rather illustrates the point that competence may be quite dependent on the surrounding environment rather than being dependent only on the patient. Alternatively, we may say that whom we can consider competent depends greatly on our ideas of what constitutes competence in the first place. Generally, testing for competence needs to be functional in nature and needs to appreciate the actual environment of the person being assessed.

From the previous section on accounts of autonomy we may derive an idea of which areas of enquiry are relevant for the type of tests needed. Most ideas of autonomy make reference to rationality, cognition and understanding, choice-making ability, and personal independence, as well as a sense of decision ownership and persistence with choice. Some accounts of autonomy (substantive accounts) expressly incorporate the requirement that an autonomous person has to value

---

[xxxix] Again differences in the concept of autonomy may play a role here. Someone may deny global autonomy to anyone with Trisomy 21, but happily grant partial autonomy. But some might even consider global autonomy with a low threshold possible for a high functioning person with Trisomy 21.

choice and outcomes.[xl] Thus a list of features which competence tests would need to demonstrate ought to include the following items: rationality, cognition and understanding, choice-making ability, ability for independence of thought and valuing capabilities.

Because competence tests aim at bringing clarity and agreement to a variety of people involved, these tests should be clear and have compelling results with regards to the questions asked. Thus the tests should perform to widely accepted standards.

Because competence tests aim at bringing clarity and agreement to a variety of people involved, these tests should be clear and have compelling results with regards to the questions asked. Thus the tests should perform to widely accepted standards.

Most of the available tests look for some abilities or capacities. Although the terms “ability” and “capacity” are often used interchangeably, there is actually a significant difference between the two and this becomes important when considering tests and test implications.

To see the distinction we might define ability and capacity as follows:

1 - Ability: A person has the ability to perform a task X iff she can perform task X, if she wants to (and is not hindered).

[xl] Even if we thought substantive autonomy accounts have to value some particular choices and outcomes, this implies that the choice itself must be valued, otherwise the value of the particular choice would not be grounded.

2 - Capacity: A person has the capacity to perform task X iff she has the ability to perform task X or she would have the ability to perform task X given appropriate training and propitious circumstances.

The capacity concept is wider in extension, multiply realizable and dependent on more than the person's will to perform task X. A demonstrated ability is the actualization of a capacity, but in cases where we think several abilities share the same origins in terms of disposition and environment, we take a demonstrated ability to be an indicator of another ability which is not demonstrated. We also may take it as an indicator that such ability if not currently present or demonstrable, could in principle be achieved given appropriate training and circumstance. So strictly speaking, one can only test rigorously for ability, but depending on the accuracy of our theory about which abilities arise from common capacities, the test which demonstrates a particular ability can be taken as a test for capacity also.

A capacity is inferred from the demonstrated ability in conjunction with related information about how the capacity enables certain abilities; capacity is a latent phenomenon and the inference to specific abilities can be more or less far-fetched, depending on the quality and quantity of the related information and interfering factors.

For example, if I want to make a claim about someone’s language-learning capacity, I could test whether a person speaks English to a certain standard. This will give me some indication about their capacity to learn natural languages in general, provided I assume that learning one language is similar to learning any natural language. Given this assumption I might infer that this person has the capacity to learn French.

What however, am I compelled to think if the person fails to learn French? There are several possible explanations: either they did not wish to learn French, despite their capacity and favorable conditions, or they wanted to, and had the natural capacity, but the environment was unfavorable. Alternatively, my assumptions about common conditions for language learning capacities could have been wrong. I may have been mistaken in my assumption that language learning capacity is independent of the actual language in question. Maybe there is something about the acquisition of French that is significantly different to learning English, which is not addressed by the person’s language learning capacity. Maybe their capacity was age-restricted and does not project to the future.

A similar difficulty operates when we observe someone’s decision-making capacity and ability. Does the fact that someone can make an appropriate decisions in one area indicate that they have the capacity to make decisions in other areas? E.g. The fact that someone can chose between two different types of clothing indicates that they have the ability to make a choice. Does this however indicate that they can make an appropriate decision in any area? Would this indicate the capacity to choose between different treatments? More importantly, how much and what can we infer when someone makes a seemingly poor decision (e.g. a really light top on a very cold day)?

We may either think she had the capacity to make a good decision, but did not actualize this capacity (she either didn't want to or she was in unfavorable circumstance) or we may claim she couldn’t make the wise decision, because he did not have the capacity to do so.

So the distinction between capacity and demonstrated ability is not one of art for two reasons:

One, in the absence of demonstrated ability, we cannot make an inference about the absence of a capacity, since the capacity may be realized in a different way; e.g. from the fact that someone isn't able to speak French, I cannot infer that they do not have natural language capacities, since they may speak English.

Two, because assertions about capacities rely on an accurate 'theory' about shared enabling conditions, the inference from one demonstrated ability to the presence of a more generalized capacity has a greater scope for error than ability testing.

The distinction between the two terms, capacity and demonstrated ability appears in legal discussions and is of notable consequence, because the distinction can have implications for our obligation towards patients and burdens of proof for adequate disclosure of information. This will be discussed further in chapter 5 (p.157) where legal commentators distinguish, for example, between the need for actual demonstrated understanding and a capacity to understand.

In regards to tests, distinguishing between capacity and ability allows the important realization that one may have one without the other. Thus, although the demonstration of ability is an indicator of capacity, the absence of a demonstrated ability is not necessarily an indicator of absent capacity. Strictly speaking tests can only show (actualized) abilities and the inference to capacity requires a second step. As this inferential step is not uncommonly a source of discord in discussions about competence assessment, I think it important to note when contemplating competence tests.

Imagine I wanted to find out whether someone has competence to manage her banking affairs. I may think that being proficient in basic arithmetic would be a good ability to test in order to get a good idea about this person's banking capacity, so I may use a basic math test as an indicator for a banking capacity. Someone who lives in a community where electronic banking in the only available form of banking may not succeed in banking, even though they may perform well on a math test, if they lack the ability (and possibly capacity) for negotiating electronic forms of communication. However, someone who fails their math test miserably may live in a supported and trustworthy community, where the bank teller reliably checks and completes the calculations and this person may have the capacity for banking in this situation. Despite having picked a very relevant demonstrable skill as capacity indicator for banking, we would be left to doubt, whether testing arithmetic is a good capacity indicator for banking capacity.

One component of inferring a capacity from testing certain abilities has to be an estimate about how likely the person is to use the ability in a given situation or whether there are significant hurdles which might prevent her from doing so. (Could she, at least in principle, use the demonstrated ability in a given situation and is this activity vital for success?) Thus a test needs not only make reference to the person tested, but also to the relevant environment surrounding them. To pick up on the earlier example of language acquisition, if I have shown my ability to learn a language and I actually have the capacity to learn French, but a consistently noisy environment prevents me from actualizing my capacity, it may be fair to think my capacity is nullified by the environment or at least not effective in a relevant sense. Similarly, if someone is capable of making independent decisions, but is permanently in an environment of domineering influences, their capacity is rendered ineffective. In terms of philosophy, these points are emphasized in some of the relational accounts of autonomy, which point out that people who operate in suppressive social environments can be systematically autonomy disabled even though they do have a relevant capacity. Where capacity is reliant on multiple factors such as in the banking example or the noisy environment language example, suppression of only some of the enabling factors may be enough to disable the person's success.

If the attribution of autonomy rested on the presence of demonstrated ability, then someone who is thus suppressed would count as non-autonomous, whereas if it rested on capacity they would be autonomous (provided we have an acceptable way of demonstrating the capacity). Yet, if I do not subscribe to a relational account of autonomy, then paying special consideration to the actual environment becomes less important or even counter intuitive. Thus whether we make claims about capacity or ability does not only change how we attribute autonomy[xli], but it also

---

[xli] the is legal relevance of this is further discussed in chapter 5) p. 159

influences our approach to methods for testing (see below) and perhaps even our view about the obligations we have towards those who fail to demonstrate ability.[xlii]

In terms of testing, this phenomenon is usually referred to as the question of the ecological validity of tests, i.e. the degree to which results obtained in the (controlled) testing situation are related to those obtained in the naturalistic environments. It is important to recognize that questions of e*cological validity do not doubt the validity of the test itself (to demonstrate a particular ability), but refer to the inferences which are drawn from the results* and it is this latter point which becomes really important in the general discussion of competence testing. For although many professionals point to the authority of their science by claiming that their tests have scientifically proven validity, they miss the point of the dispute. The tests are fine in terms of demonstrating absence or presence of abilities, just the inferences drawn from them are disputable and the solution to this problem does not come from a purely science-oriented sphere, but must respond correctly to the underlying philosophical thought about what actually needs to be established to account for autonomy (demonstrated ability or capacity).

2) GENERAL STANDARDS FOR AUTONOMY/COMPETENCE IN A DIVERSE COMMUNITY

The *first*, most basic requirement of any test must be that it answers the question asked. This seems almost too basic to mention, however it is surprising just how often this very issue is open to doubt.

[xlii] E.g. Someone who has capacity, but lacks ability may be owed enabling conditions for decision making, whereas someone who lacks capacity will need a substitute decision maker to make the decision for them

Secondly, the test has to have some kind of objectivity, which ensures that the result is not dependent on the enquirer but depends only on the issue to be tested, and that the results are repeatable independently of the enquirer. There are various sets of criteria that are designed to optimize objectivity. In a science-driven society, most would probably refer to these criteria as scientific principles. However, for the purpose of this setting I think it enough that, whatever these principles are called, they aim at ensuring that the results are convincing to a large, diverse, group of people; at least, all those people who are involved in advance care planning.[xliii]*Thirdly*, the test results have to be assessed within the right comparative setting . This means that they have to apply to what we believe to be the correct norm-giving background; e.g. if one were to test aspects of cognition of an adult it would be incorrect to use the average cognitive test results for 2 year olds as a comparative background norm, and vice versa. Thus one has an obligation to not only find the right test for a particular function, but also to ensure that we find and agree on the appropriate normative background for the test.

Finally, the results have to be adequately communicable to those involved in the ACP process, i.e. everybody involved in the ACP process has to share the same understanding of the test's meaning or significance, and the test has to be stable in the sense that the time frame to which the test applies, corresponds with the time frame when the question of competence arises. For example, yesterday's intoxication has no bearing on my competence today. If I my competence to drive yesterday was under question, my blood alcohol level of yesterday would be relevant, but it would mean nothing for my ability to drive today, when I am sober.

[xliii] If one were to pursue the strong line that advance care planning ought to be undertaken by all capable members of society, then the parameters involved would need to be acceptable to all those members.

This point is important as ACP involves multiple diachronic time frames, for which autonomy questions arise.

These *four* general points are by no means a comprehensive or in any way a complete list of adequate principles which ought to guide competence tests in the general medico–legal setting. I mention these ones in particular, because it is here that a lot of doubt arises in the discussion of the adequacy of competence tests.

3) AVAILABLE TESTS

After these general remarks, which apply to all manner of tests, it will be instructive to see what kind of tests are actually available in the area of competence testing and how they perform in light of the general criteria which were mentioned in the previous sections 1) and 2).

Relevant tests may either be grouped according to the format they take or according to the content they mean to elucidate. Looking at tests in terms of format has the advantage that format-based test limitations and advantages can be seen independent of the test setting or the type of expert who applies the test, and thus are easily recognized.

Different test formats are:

A) Imaging techniques and demonstration of certain biological markers,

B) Patient interviews (structured or unstructured), vignettes,[xliv]

[xliv] A vignette is a description of an imaginary situation regarding which the person is asked to decide on a proposed treatment or to elaborate about what they would do. Vignettes and interviews may be recorded and reviewed by others for increased objectivity – although this is usually restricted for study settings.

C) Formal neuropsychological tests (of fixed structure) and functional task assessments.

A) IMAGING TECHNIQUES AND BIOLOGICAL MARKERS

As mentioned before, imaging techniques and biological markers universally have limitations in demonstrating functional impairment. Imaging techniques, such as neuro–CTs, MRIs, PET–scans etc. cannot provide functional information.[xlv] They may only help explain a functional disability, which has been noted on clinical grounds.

Similarly, the presence of drugs and their metabolites cannot usually diagnose a functional deficit. The mere demonstration of a certain blood alcohol or opioid level, for example, does not per se rule out competence, even though certain levels are known to commonly correspond to certain cognitive alterations.

Drug-related bio–markers are examples of very unstable test parameters, as the levels tested will have changed by the time the result is available. Many of these changes occur with considerable interpersonal variations. Some drugs have longer lasting effects than their demonstrable presence in the bodily system. Some drugs have a variety of cognitive effects, which present over different time periods and are difficult to demonstrate at the time of their effects, even though when studied over time in a whole population, these effects can be demonstrated in hindsight.

The commonly used anxiolytic and sedative drug midazolam, for example, is known to have significant memory-impairing effects, which are not immediately obvious to an observer while present. They outlast the sedative effects. The patient may

---

[xlv] Functional MRI may be a slight exception here. However, it is mainly used in research settings, commonly contra-indicated for use in many patients, who cannot be exposed to the magnetism, and its functional information is usually not the kind of information required in the autonomy assessment.

interact normally and appear to answer questions normally and coherently, but later have no memory of the events. This effect is variable and can only be demonstrated after it has worn off, not during its presence. Effects which can only be demonstrated in hindsight are notoriously difficult to factor into a current assessment (other than by ensuring the absence of its possibility).

Genetic markers have already been mentioned (p. 115).

On the whole, there is wide agreement that no single bio-marker is known which may universally 'diagnose' lack of autonomy. The best a biological marker can do is to contribute to explanations of observed impairment or make one suspect the possibility of an impairment when it is not actually observed.

B) INTERVIEWS AND VIGNETTES

Patient interviews, in contrast, may be very informative about functional status and cognitive function. Such interviews may be held by a psychologist, psychiatrist, or, as is commonly the case for elderly people, by a geriatrician. A person's reasoning and evaluation strategies, especially, may be elucidated well in an interview and we recall that these parameters really were at the heart of most of the philosophical ideas about autonomy.

The problem with interviews, however, is that they are not standardized and are very dependent on the interviewer. They are not easily repeatable, like formal tests, and the overall impression gained from an interview is subject to considerable interpretive variation that has no standard other than the interviewer's opinion, and her educational and cultural background against which it can be verified.

Comparative normative background data for the type of information gathered in interviews, such as reasons for choices, reasoning coherence, independence of thought, rationality or personal values either do not properly belong in a normative background set or it is not clear what the appropriate norm-giving context should be. For example, should the interviewer probe reasoning ability in line with a particular logical structure, or should he compare the reasoning strategies of the interviewee to the performance of a particular peer age, or should it be assessed in reference to the achievement of a task or outcome? If so, which kind of logic, which peer group or what outcome should be adopted?[xlvi]

In an interview, the interviewer is the person, who sets the standard for what counts as 'rational enough', such that the patient is recorded as 'reasoning rationally', as 'demonstrating appropriate reason giving' or 'demonstrating appropriate understanding. Given that the type of professionals conducting these kinds of interviews share a significantly uniform background education and assessment framework, this introduces a particular bias. Such bias may become a very significant problem in culturally diverse populations, where communication differences and styles may masquerade as inadequacy of reasoning or failure to respond adequately in an assessment interview.[69] This problem does not only arise in the setting of anthropological cultural differences, but also in the setting of differences between certain sub-cultures, as can be recognized for example between different professional disciplines. For various reasons of unrelated professional co-commitments, reasoning abilities found sufficient for competence by the legal profession may differ considerably from what is found sufficient within the medical profession.[70]

[xlvi] With respect to peer group one may, for example, wonder how well age stratified it has to be. Given that we know cognitive decline in older age is as much age–related as cognitive development is in younger age, can we really justifiably hold that ‘adult’ is an appropriate comparative group for all adults? Is it right to compare the reasoning capacity of an octogenarian to that of someone half the age? We may also wonder whether it has to be gender or race specific. Even if these sub-groupings are not warranted, there are actually no real comparative cohort data available because of the situation specificity of the assessments.

There have been attempts to overcome some of these objectivity problems with interviews by introducing a pre-arranged structure to the interview. Such structure may limit topics, types of questions or permitted responses, etc. A structured interview is a slightly more standardized tool, which aids repeatability and objectivity to some extent, but it loses ground on options for obtaining relevant information outside the proposed interview structure, even if it is adjusted to culturally relevant background norms and styles of communication. Particularly where elucidation of personal values and individual trust are concerned, pre-structured interviews may miss important points. Any pre-structured format is ill equipped to catch a person's individuality, which is an important dimension in the question whether *a particular one person* is competent or not. Furthermore even pre-structured interviews are subject to interpretive variation and difficulties of repeatability.[71]

Vignettes have problems similar to those of ordinary interviews, although the subjective nature is supposedly somewhat reduced since the recording grants access for review by other observers. However, the recording process may itself have an effect on the interview performance, especially in regards to sensitive issues concerning trust and privacy.

Vignettes are also relatively labor and resource intensive, and they are relatively impotent in picking up fluctuations in competence, unless there is a decisive uni-directional trend over time.

In order to elucidate a person's functional status, interviews may also be held with third parties, who give reports about the person under assessment. Third party interviews, of course, share similar methodological problems to direct patient interviews. Furthermore, these interviews may gather information about the patient's ability to cope with various tasks, which then has to be verified independently, because third party accounts may conflict with the patient's own account. Hence *any* interview potentially needs further means by which the truths of its content can be verified..[xlvii]

C) FUNCTIONAL ASSESSMENTS AND NEUROPSYCHOLOGICAL TESTS

Such content verification can be attempted with a battery of neuro-psychological tests, (e.g. the Wechsler Adult Intelligence scale, Wechsler memory scale, Trail Making test and many others)[72], or by direct functional assessments, but ultimately all of these have distinct limitations. Direct functional assessments normally apply to very specific practical tasks, such as driving ability or home mobility or safety, but may sometimes be used to make inferences about a person's insight into their condition and environment.

Given that a great majority of competence discussions focus on mental abilities**,** neuro–psychological tests feature with increasing prominence in considerations concerning relevant expertise for competence testing, yet these tests are not without considerable problems. A 'condemning' neuro–psychological assessment carries considerable weight in terms of overall competence assessment and has considerable 'opinion–shaping' powers.[73] Given that this is the case, neuro–

[xlvii] Interesting comments in this regard can be found in an excellent review article about the ecological validity of neuro–psychological tests (see endnote 77). Although the article is in general concerned with the ecological validity of neuro–psychology tests it found that many executive function-based validity tests showed significant differences between patient self-ratings and third party ratings, where the executive function tests actually better correlated with third party ratings than with self-reports. This then leaves us with the question, whether *a test performs poorly in picking up deficits* accurately or whether *self-rating* (as may be obtained in an interview) *is a poor indicator of function*.

psychological test limitations warrant examination with a critical eye. These limitations concern practicability, standardization, ecological validity and methodology.

The most obvious limitation of neuro–psychological assessments is their practicability. A full neuro–psychological competence assessment for decision making capacity takes about 6 to 8 hours of patient testing[74] and requires the patient to be relatively fit. Partial assessments in order to answer more specific cognitive questions are possible and less time consuming, but still in many ways cumbersome[xlviii] and allow for even weaker conclusions than the full test. Such assessments are certainly out of the question in the acute care setting and are really only of any help in situations where competence questions are raised independent of an acute illness.

Although this may have some use, the validity of the test result at times of acute illness is then questionable for that time. Thus if a person is found competent when well, it does not help in answering questions about their competence when unwell. So the best such an assessment could do is aid to clarify whether a person was competent at the time of drawing up an advance care plan. It says nothing about the competence of the person at the time one may wish to invoke the care plan.

Of even greater concern are the questions of ecological validity and methodology.

Most neuro–psychological tests were developed for the purpose of diagnosing neuro-pathologies at a time when imaging techniques were far less sophisticated. Hence the general aim of the tests was to provide information about mental pathology in terms of disability. For this reason, it was an important feature of test design to elucidate best possible function under ideal conditions and not, as is

---

[xlviii] Completion of a full Wechsler Adult Intelligence test takes about 2 hours.

maybe more appropriate for competence testing, general function under natural world conditions.

Some useful quick screening tests, like the well-known (Folstein) Mini-Mental-State-Examination (MMSE), were developed expressly with a view to easily identifying areas which need further assessment in search of pathology. Such tests were not meant to be diagnostic tests, nor could they give an accurate functional assessment of a person. However, their ease of execution have paved their way into mainstream application and when time pressures do not permit more extensive evaluation, screening tests, especially the MMSE are commonly ‘abused’ as diagnostic devices, in the sense that they are used as (sometimes only) evidence to substantiate doubt about a person’s mental competence. They are not used because of their diagnostic power, but because of their ease of execution.[75]

A good correlation of a more standardized version of the MMSE, called S-MMSE, with other more extensive neuro–psychological tests has been put forward as justification of the validity of this strategy,[76] particularly in reference to measuring a capacity to complete an advance directive. However, the research which supports this finding did not take into account the fact that the comparative neuro–psychological tests suffer from similar general validity problems as the S-MMSE. Furthermore, it only looked for a very narrow outcome measure, i.e. the competence to make an advance directive in a non-acute setting, and it included intensive co-education about advance care planning.[xlix] A controversial point about this is that it presumes the capacity needed for issuing an advance directive to be less than the capacity required for consenting to or refusing treatment. This is controversial because it assumes a particular background philosophy about

---

[xlix] The co-education does not reduce the validity of the test, but it does make it significantly more cumbersome, since the education process took approximately 90 min.

competence, namely a risk stratified, scalar view of autonomy, which may not be universally shared or even shared by many.[l]

The short-coming of any 'situation specific competence assessment' is that it is not transferrable to other situations. Thus a 'risk-stratified and situation-specific' philosophy of testing may eventually prove very cumbersome as it may require frequent re-testing of the patient. This is labor and resource intensive. At best this will make the narrow focus tests impractical, but what is more concerning is that such impracticability will invariably be an incentive to stretch the interpretation of previously held assessments beyond their intended scope. This is an invitation for poor practice.

With the advent of better imaging techniques, diagnostic questions are less common in neuro–psychological referrals and functional assessment questions (i.e. questions about what a person can do) have increased. Yet, the tests used in the assessments have not changed significantly in keeping with the change in the referral questions; it is just that different inferences are made from the tests, often

---

[l] Firstly one may simply not be convinced that one should accept a risk relative view of competence. Secondly, even if one is, it is not immediately clear why a decision that has a global bearing on many future decisions about treatments should require less capacity than a single concrete decision about a concurrent illness (I will expand this in chapter 9). Furthermore, this test could at best help to elucidate a capacity for making an advance directive in the non-acute setting, but leaves unanswered the question as to whether an advance directive should be invoked in a particular treatment situation. We may cast our mind back to *Mrs T's* case. If she had scored sufficiently on a S-MMSE in order to be thought capable of issuing a valid directive, this would not have helped in her case because the questioning of her capacity was as much about her capacity to make a directive as it was about her capacity to refuse or consent to current and possible future treatment. So even if intellectually we can think of capacities as pertaining to different outcome measures, in the clinical setting the outcome measures are commonly not so distinct.

with doubtful validity. For an excellent review of the wider problem the reader is referred to Chaytor's paper[77] about this area of research, but a number of examples may illustrate some relevant points here.

As mentioned, neuro–psychological tests are usually conducted in controlled environments and aim at exposing best possible function. A person may be functioning well under quiet, best possible conditions, but be completely distracted under natural conditions.

Furthermore, tests for very specific cognitive tasks are sometimes used for inferring more complex functions; e.g. a deficit in spatial awareness may be used to infer orientation problems, or memory deficits may suggest that a person cannot readily access knowledge about prior events. However, these inferences do not take into consideration any other compensatory coping mechanisms that could be present and would also have to be tested for.

A test designed for unmasking disability (for the purpose of diagnosing pathology) specifically excludes compensatory strategies. Although being a valid test for demonstrating memory problems, it cannot tell whether these problems are actually interfering with competence. The person with memory dysfunction may, for example, use memory aids very efficiently, or the person with spatial orientation problems may overcome these by using significant social skills, such as asking for help to get from A to B. Tests designed for diagnostic purposes are aimed at finding the *disability*, whereas a functional assessment needs tests that look for *ability*.

Thus the inferences from the diagnostic test batteries are also sometimes very much strained in their interpretive scope.

One way to overcome this is through the development of better tests for this area of neuro–psychological assessment. This has been attempted, but is also not without problems. Validation methods of newer tests are difficult and the uptake of newer tests into current assessments is very slow and uncertain[78] and therefore without uniformity, especially if the need for better tests is not universally accepted. The above–mentioned MMSE may serve as example here.

Some representational validity problems, the fact that the testing process necessarily gathers only a small sample of a person's behavior in a single environment, while their behavior may actually be quite variable across time and situations, cannot really be ironed out of any testing procedure.

Furthermore, there are non-cognitive factors, which play a significant role in the test situation. Examples are mobility and emotional issues, which may impair a person's test performance and give wrongly adverse or sometimes wrongly reassuring results.[79] These interferences cannot be picked up within the scope of the test, but must be recorded separately or tested for by other means, such as several repeats or a third party observation.

Overall neuro–psychologists are divided in their opinions regarding the adequacy of the validity of their results and the role their tests should play in competence assessments. There is no recognized standardized approach to testing.[80] In 2009, in a parliamentary enquiry (for VCAT[li]) about the contribution neuro–psychologists could make in the field of competence assessment, the then head of the Australian psychologist's association said *"... neuropsychologists are uniquely positioned in this field because of their education and expertise...."* yet only 8 % of neuro–psychologists in an interviewed cohort agreed with the statement *"my training prepared me well for carrying out decision making assessments"*.[81]

A study asking an Australian cohort of neuro–psychologists to rate confidence about the correctness of their competence assessments gave very moderate results, with only 62% of neuro–psychologists agreeing with the statement "once the assessment

---

[li] Victorian Civil and Administrative Tribunal

is completed I usually feel confident about my conclusions". This study also astutely enquired into the reporting behaviors of practitioners in cases of borderline assessment outcomes and found the following noteworthy points:

1 – *"Very few stated that they would resolve borderline determinations by consciously erring on the side of the patient's rights or consciously erring on the side of protecting the patient from harm."*[82]

2 – *"...respondents who stated that they would approach borderline cases by writing a report stating that the decision is borderline, would mostly go on to give an opinion, despite the borderline nature of the findings."*[83]

The latter point illustrates that the actual 'science', i.e. the test results, were not the gold standard, but the standard resides with the assessor's opinion, which is supported by science in a dubious way.

Overall it can be said then that no single one of the scientific test methods does very well in regards to satisfying the four general parameters identified in sections 1) and 2): Organic markers are objective, but perform poorly in terms of functional assessment. Transient organic markers, such as drug levels, may also have difficulties in responding to timing requirements. Interviews and vignettes do well in terms of functional assessment and personal information gathering, but have trouble claiming objectivity and carry a substantial professional and cultural bias. Formal tests from the neuropsychological test battery perform poorly on requirements of acute timing, are insensitive to fluctuations of capacity, and although they lay claim to scientific objectivity have limited ecological validity, which renders their claim about objectivity decidedly deceptive in nature.

This state of affairs may explain why there is no accepted standardized way of competence testing and why all attempts at formal competence assessment are a 'best judgment only' mixture of different approaches of information gathering. None of the formal competence assessments are really suited to acute situations and many formal assessments in non-acute scenarios have to be approached with caution, unless the incompetence is so blatantly obvious, that formal assessments are unnecessary.

This, I think, justifies the position that the strategies taken in order to declare someone incompetent (or otherwise) are based more on pragmatic need rather than objective science. Science, or rather the underlying concepts of autonomy, which guide the science, are too permissive in order to draw clear distinctions between cases where conflicting interpretations about patient competence exist.

5 – SUMMARY

This chapter was aimed at examining what happens when we try to put the concept of autonomy into a practical clinical ACP context. It is not an exhaustive clinical review by any means, but one which is sufficient to draw out some of the concerns that arise as a direct consequence of the application of a concept that presents itself more like a cluster of ideas than a strictly defined term.

Firstly, I showed that the verdict about a person's autonomy is not only dependent on the patient's circumstances, but also highly dependent on what kind of philosophical concept of autonomy is employed by the person who is making the judgment about autonomy.

Secondly, I made clear that this conceptual dependence carries over directly into practical questions concerning relevant expertise and scientific testing and that we cannot expect science to solve any underlying conceptual problems, since the science involved in the application itself depends on the underlying conceptual framework.

Thirdly, I have tried to show that the current scientific methods used in competence assessments, when put into practice, perform quite poorly, especially in the borderline cases, where one would most want an independent answer, and that these methods can have little claim to objectivity and authority on an acceptable scientific basis.

In showing that differences in our underlying philosophies of autonomy can result in very practical differences about how we appraise, test and treat patients, I want to show that we encounter a problem when we simultaneously aspire to escape the charge of arbitrariness in treatment and arbitrariness in what it means to respect someone's autonomy. I would suggest that any attempt to remedy this problem has to involve a reduction in the permissiveness of our conceptual framework.

How could this be done? It seems to me that this could only be achieved by making obvious and consistent choices in our conceptual framework across all areas of advance care planning, including all disciplines that are involved in capacity assessments and all people who consider making an advance care plan or who are involved in executing an advance care plan. Whether this is possible, likely to happen or in the end really desirable shall be the task of the remainder of this thesis.

If such a consistent framework is required, one wonders who should have the task of providing it. One obvious possible answer is: the governing legal system. Hence, in the next chapter, I turn to a closer examination of how the concept of autonomy operates in the relevant legal areas and how it may adjudicate between the competing conceptual frameworks.

CHAPTER FIVE – LEGAL IDEAS OF PERSONAL AUTONOMY IN APPLICATION

1 – INTRODUCTION

In the last chapter I showed that a conceptual framework of autonomy which is too permissive can lead to serious problems for treatment decisions, because it can allow the promotion of contradictory treatment options without (non-arbitrary) solutions to the contradictions. In the chapter prior to that, I described some of the philosophical diversity which can lead to excessively permissive frameworks, and I suggested that no philosophical account presents itself as obviously superior to any of its rivals. We are therefore left with the task of making a choice as to which conception of autonomy should best be assumed within a framework of advance care planning, and so far it looks as if this choice could be somewhat arbitrary in nature. If it is not arbitrary, it must rest on some other parameters outside the philosophical accounts of autonomy, such as best coherence with other relevant concepts or pragmatism, for example.

Arbitration commonly falls to the law and it is therefore quite appropriate to enquire whether the legal system does any better in specifying which account of autonomy should be used in ACP (and what reasons might apply for the particular choice of account of autonomy).

In chapter 2, I made a preliminary attempt to approach this problem with the kind of scenario that might arise at the bedside in a very particular situation. By referring to the general medico–legal guidelines, which are generally accepted in clinical practice and meant to help in this kind of situation, I tried to resolve the question whether *Mrs T* specifically was to be regarded as competent or autonomous.[lii] However, I found that the general medico–legal guidelines did not provide enough detail for a confident answer, because the general guidelines do not specify in enough detail what it means to be of sound mind, to be fully informed, to have adequate understanding or what kind of acts count as coercion.

We are therefore left with the more complicated task of trying to capture which type of autonomy account is currently assumed within the legal system in regards to ACP. Unfortunately, there are no clear, detailed philosophical prescriptive statements available about the relevant autonomy conception for ACP. The only way of gaining insight into the current legal thought about what it means to be autonomous in regards to ACP is by analyzing legal judgments and comments on cases in this area of medicine, which have actually come before and influenced the law.

As the actual number of cases concerning ACP is quite small in any one jurisdiction, it is common practice to refer to cases which have occurred in other jurisdictions, either interstate or internationally. This is especially true for jurisdictions which are similar in kind, such as Australia, Great Britain, Canada and the US, where case law and statutory law coexist. (But even jurisdictions that have a dissimilar legal structure to Australia in this regard may nonetheless be influential, although their laws lead to technical differences in actual application.)

The questions the law needs to answer concerning autonomy and ACP have a dual nature. On the one hand, we need some very practical answers about the kind of features which signify the autonomy and competence of a person. As was shown in the previous chapters, we need to know what indicates adequate understanding,

---

[lii] A further discussion about a possible legal difference between autonomy and competence appears towards the end of this chapter.

coercion, a sound mind and adequate information, so that we can test for these features and have a chance to note their absence. On the other hand, we want to know what conceptual background we should assume in regards to autonomy, such that we can tell what ideas these practical answers are based on.

If the law were to prescribe the conceptual nature of autonomy in ACP, the practical answers should become clear. However, although I have pointed out in the last chapter that this would do much to clarify testing strategies and help in identifying the right kind of expertise, this path does not prevail in practice: the legal conceptual background of autonomy in ACP is not easily apparent. It rather seems the case that current clinical practice is put to the test intermittently in the law courts and a conceptual background has to be inferred from the practical deliberations of these cases. Hence the main task of this chapter is to engage in a process of distilling an insight into the prevailing legal account of autonomy for ACP in Victoria (and related jurisdictions) from the published cases and scholarly legal literature and to assess whether the problem of conceptual diversity is prevalent in legal practice as much as in medical practice. Such an assessment is of important consequence, as it may significantly influence our expectations of consistent, clear and predictable governance.

This assessment will then pave the way for the second half of this thesis, which will engage in an analysis and discussion of problems, and possibilities for solutions, which arise from the underlying philosophical diversity in the network of ideas on which ACP is based.

2 – PRACTICAL LEGAL ANSWERS

The chief concern of this chapter is to establish a more detailed appraisal of what the legal system regards as capacity indicators, why it chooses these particular ones and how these parameters relate to any underlying concept of autonomy[liii].

In chapter 2, when considering the general medico-legal guidelines, I noted as particularly problematic the following terms: sound mind, adequate understanding[liv], adequate information and coercion[lv] Another capacity indicator, which was not under scrutiny in the case of *Mrs T* but is sometimes equally contested, is maturity. The medico–legal guidelines acknowledge this by referring to the need for decisions to herald from an *'adult'* sound mind. This is of relevance in many cases, where treatment decisions concern under-age patients or patients with developmental delay.

The legal capacity scholarship favors the grouping of capacity concepts into three different types:[84] 1) outcome approaches, 2) status based capacity definitions and

---

[liii] A further discussion about a possible legal difference between autonomy and competence appears towards the end of this chapter.

[liv] Although I treated understanding and information under one heading in the table in chapter 2, it is worthwhile to separate the two in this section, firstly, because they are treated separately in legal terms, and secondly, because understanding is dependent mainly on the patient's capacities whereas information also depends highly on the person who provides it. Conceptually this is important, as one of the many disagreements arises around whether an under-informed patient should be considered competent or not.

[lv] Coercion, although not strictly regarded as a capacity indicator, is nevertheless an important consideration in the attribution of competence and autonomy, and therefore is included here.

3) functional approaches. This is helpful as it allows the appreciation of overarching problems within each group.[lvi]

> *Outcome approaches* see capacity of a person indicated by conformity with a certain 'objective' standard (i.e. an outcome).
>
> Capacity determined by conformity with certain standards, i.e. the achievement of an outcome (e.g. survival), may sometimes be seen as appealing, because of its objective nature. However, the general problem with this approach is that capacity, the primary indicator of autonomy, ought to be based on values that are internal to the individual who is assessed. The idea of their individual values conforming to an external standard, i.e. a standard outcome, thus necessarily poses a direct contradiction.[lvii]
>
> *Status based definitions* of personal capacity look out for easily identifiable features of a person, such as age, race, gender or some other social status, along which capacity can be attributed. Certain illness diagnoses (e.g. mental illness), may also function as status indicators, if the diagnoses separate people into groups irrespective of further differences.

[lvi] All the while acknowledging that capacity is the default position for an adult, i.e. a person aged 18, or above, unless contested.

[lvii] .The approach taken here is consistent with a non-substantive idea of autonomy, which may be debated, but is suggested by B. Collier, in *Mental Capacity*, p. 62. (see endnote 36). A substantive approach may well demand that certain external values must be honored by the patient in order to be taken as autonomous. However this is clearly not advocated by these authors, who see a contradiction between the application of external standards and autonomy.

The attractiveness of status indicators consists in their simplicity and ease of application, but their justification largely relies on beliefs about legal competence which are now mostly outdated.

Gender and racist views are clearly outdated in the laws of most liberal Western societies today, because it is no longer supported that racial or gender based features are associated with a particular ‘autonomy disability’ (although some of these beliefs may survive in some non-liberal cultures or within certain social attitudes, e.g. “the woman driver”).

‘Numerical’ age, taken as mere status, although frequently referred to in law for matters of practicality (e.g. voting, alcohol consumption etc.), is not a sensible indicator for its own sake; rather it is supposed to be a general marker of one or more of the following: rationality, maturity or understanding. This is evident in the fact that the age of consent for various treatment decisions is well below the legal general maturity age of 18. (People who are considered competent decision makers below the age of 18 are referred to as *mature* minors.)

Likewise, mere diagnoses of illnesses (e.g. Alzheimer’s disease), without information about actual functional ability is currently not believed to be a sufficient indicator for incapacity, although it may help to raise suspicions in this direction.

Functional capacity definitions, such as ‘rationality’, ‘maturity’ and/or ‘understanding’ look for reasoning related abilities, which are taken to be vital for competent decision-making.

Relating decision-making capacity, competence and autonomy to functional indicators has been the legal standard for quite some time now, certainly for the time which seems relevant in consideration of modern medical practice

> and ACP. Therefore the functional capacity indicators and their various problems[85] will have most of the attention in this discussion. However, as will become clear further on, clinical practice actually finds it very difficult to survive without the other two approaches.

One of the most difficult tasks in the field of competence assessment is how to make sense independently of the notions of 'sound mind' and understanding. Why is this so? Why should one even think about separating the two notions, do they not point to the same capacity? (The terms certainly seem to be used as if they are referring to the same thing.)

Surprisingly, this does not seem to be the case, when one looks at an aggregate number of legal hallmark decisions as a totality of guiding principles. Although both notions, 'sound mind' and 'understanding', clearly refer to some cognitive ability (or capacity) they do not seem to pick out the same thing in a congruent way, and the reasons for this relate directly to the various conceptions of autonomy that were referred to in chapter 3.

The notion of mind refers to a whole. Although there may be quite a number of metaphysical differences in how we understand 'what' a mind actually consists of, or how we are to understand it, it is pretty uncontroversial that whatever the mind is, it is a *whole* thing and not just one particular faculty. Thus, if someone suffers from delusions, hallucinations or from paranoid ideation they clearly do not have a *sound* mind, even though some or even most of their cognitive faculties might be quite normal[lviii] (e.g. normal memory, normal ability to do arithmetic, etc.). So we might understand generally that, whatever the mind is, it is greater than the notion of understanding, and it refers to the whole person who is being assessed in regards

---

[lviii] I take 'sound' here to mean roughly the same as 'normal'.

to their capacity (and autonomy). Hence if a 'sound mind' was the capacity (and autonomy) bestowing faculty, anyone with any disturbance of this sound mind could not be considered as having decision making capacity or being genuinely autonomous.

The same cannot be said for understanding. Understanding can be partial (or partially impaired), even if the mind is sound. Understanding can be impaired for several reasons, only some of which have to do with the soundness of mind of the person in question. Someone may for example lack adequate information and therefore not have sufficient understanding. This is why we think it necessary for information to be given in a sufficient way, such that consent can be deemed to rest on a basic opportunity to have adequate understanding. Likewise a 4 year old child may be of quite sound mind but have very limited understanding of complex situations, because she is lacking cognitive maturity.

What we are lacking at this point is the proper connection between understanding, a partial feature, and soundness of mind, a whole feature. We need to know how soundness of mind and understanding are related.

Soundness of mind does not seem to give us maturity or understanding. So what does it give us? It must be some sort of capacity or function that enables us to determine what choices to make. Many would refer to this capacity as rationality or ability to reason. Yet, here we meet with an uncomfortable tension in the legal discourse. This becomes evident when looking at a number of prominent, influential legal decisions, which favored the attribution of legal capacity to patients whose capacity was under question. The following three court decisions, for example made a point of distinguishing features of rationality from a sound mind.

1) In the case *Airedale NHS Trust vs Bland,* Lord Goff said that doctors must give effect to the wishes of “an adult patient of sound mind [who] refuses, *however unreasonably,*[lix] to consent to [life-sustaining] treatment … even though [the doctors] do not consider it to be in his best interests to do so.”[86]

2) In *ReB (adult refusal of treatment)* Dame Butler-Sloss stated: “A decision to refuse medical treatment by a patient capable of making the decision does not have to be sensible, rational or well considered”.[87]

3) In *ReT (adult refusal of treatment)* Lord Donaldson pronounced that a refusal of treatment may issue from reasons which are “rational, irrational or for no reason”.[88]

These three cases, consistent with each other, therefore lead us to believe that a patient’s soundness of mind can be established independently from reasoning and rationality. The question then looms large however, how one actually does proceeds to establish ‘soundness of mind’?

In Australia at least this seems to have played out by resorting to the more limited notion of ‘particular understanding’, which seems to abandon the ‘whole person’ concept.

One of the influential court decisions quoted in this regard is the case *ReC (adult refusal of treatment)*, where an adult male suffering from acute paranoid schizophrenia and a gangrenous foot, was judged to be competent to refuse the life-saving amputation of the foot. The test to be applied regarding competence in this case defined by Thorpe J was *a sufficient understanding* of the nature, purpose

---

[lix] My emphasis.

and effects of the proffered treatment. The mechanics of such understanding according to Stewart are as follows:

> *"1. comprehension and retention of treatment information*
>
> *2. believing the information; and*
>
> *3. weighing it amongst other factors to reach a decision."*[89]

It was held that in the case *ReC* the particular mental condition (paranoid schizophrenia, including the delusional belief that he was a doctor[90]) did not interfere with the patient's ability to understand all the relevant factors pertaining to the decision about consent for a limb amputation. The way this could be derived was by examining the reasoning of this man, who said that after weighing all the factors, he would rather be dead with two legs than alive with one.

In relation to the judicial decisions quoted above, the notable tension arises from the fact that one cannot make any claims about someone's understanding without access to the person's reasoning and the rationality supporting such reasoning. The patient concerned in *ReC* clearly was not of sound mind as he suffered from active paranoid schizophrenia. Presumably if he had believed that the doctors wished to punish him by amputating his leg, as part of his paranoia, the judgment may have been different, because his mental condition clearly would have interfered with his understanding and the correctness of his beliefs.[lx] Nonetheless he was deemed competent, precisely because it was established to the court that such a mechanism was not at work in this man's situation.

[lx] In fact one wonders why his delusional belief about being a doctor was not considered to interfere with his judgment.

This leaves us with the problem that on the one hand we need to establish correct understanding in terms of comprehending, believing and weighing information, but on the other hand (as per Donaldson in ReT) must not demand deliberations leading to this understanding to be rational, reasonable or to be present at all.

The former is possible in terms of understanding as a partial feature of the mind, the latter is only possible if we presuppose a sound mind to be a feature which ensures the presence of sufficient understanding without need for further questioning.

One might disagree with my idea that soundness of mind in these cases refers to 'the whole mind'. One could say that the legal notion of 'sound mind' really just refers to 'a general capacity for sufficient understanding' in reference to a general reasoning capacity (the establishment of which is attempted by employing some of the more general clinical tests that were considered in the last chapter). However, this objection is not convincing.

Firstly, it sits ill in regards to the particular case of ReC, and secondly (even if one were to see ReC as an aberrant judgment) there are common law and statutory provisions in Australia, which make it quite clear that the relevant understanding has to be of the particulars of the situation and not a general capacity for understanding.

The Australian common law test for capacity states:

> *"The mental capacity required by the law in respect of any instrument is relative to the particular transaction which is being effected by means of the instrument, and may be described as the capacity to understand the nature of that transaction when it is explained."*[91]

This formulation results from a Australian high court decision in the case *Gibbins vs Wright* from 1954 and has since been reflected in statutory law throughout the nation.[lxi]

The rule that legal capacity is a particular notion also counteracts an objection which may stem from a big debate about the nature of rationality which was held in the social sciences, especially anthropology, in the 1960s. One claim that was often made was that the anthropologist could appreciate her informants' deliberations as instances of reasoning without having the capacity to seriously entertain them herself. The flaw in this objection is that if the observer of the deliberation does not seriously entertain the instances herself, she cannot make a reasonable judgment about whether the person in question has sufficient understanding of the particular transaction.

The nature of this objection can be seen in the following example. If a person denies consent to a life-saving operation, because she thinks operations should only be done in a month starting with the letter N and the proposed urgent operation happens to fall into February, what can be said about her understanding? Sure, I can appreciate that this person has reasoned (which more than satisfies the Donaldson demand), but can I say she has understood or believed the particular information about the urgency? She may even repeat to me the reasons given for the urgency and claim to believe them. Yet, she may weigh them against her beliefs about surgery to be done only in months starting with the letter N and find her beliefs to be overriding. What do I say about her understanding? I can either claim

---

[lxi] Examples are: the *Guardianship and Administration Act 1986 Victoria*, the *Guardianship Act 1987 NSW* and the *Guardianship and Administration Act 2002 QLD*, where the definition of a person who is 'incapable of giving consent' has been given as someone incapable of understanding the general nature and effect of the proposed procedure or treatment.

she has understood and weighed the information and found competently that she did not want to have an operation in the February (because the name of the month does not start with the letter N), even though I cannot entertain the significance of this factor in this deliberation myself, or I can claim that she has a delusional belief which interferes with her proper understanding of the nature of surgery or of what urgency means. Unless I have recourse in my argument to some independent notion of rationality or outcome preference, I cannot really decide.

The crux of the interpretation lies in what I want to achieve with my assessment! Why is it that we demand competence assessments at all? The reason is that we think some people are vulnerable to their own ‘madness’ and therefore we want to have a tool at hand, which allows us to protect people from themselves.

On the other hand the law wants to give maximal liberties to people’s individuality, personal expression and ideas of what is good and what is or isn’t to be done. Thus we arrive at practical advice, which might be summarized as follows in terms of competence assessment:

1 – We are required to take (adult) people as competent irrespective of the outcomes of their decisions;

2 – We ought to protect their well-being, especially when they are vulnerable, but not assume that we know better than them what is good for them;

3 – We are required to question someone’s competence when we have sufficient reason to think them incompetent, which is usually when either their reasoning or the likely outcome of their decisions vary from what we expect or would generally regard as good for them; and

4 – When we are suspicious that a lack of competence is present, we are meant to establish whether the person in question has a sound mind ***without*** *recourse to their* ***particular*** *reasoning or rationality (according to Donaldson and Butler-Sloss),* but nevertheless need to establish whether they have adequate understanding of

the ***particular*** *facts and circumstances (according to common law consent requirement)*.

This seems impossible!

One local legal scholar, Skene, commented on this type of contradictory requirement by saying that *"a patient who refuses treatment for irrational reasons, or for no reasons at all, is probably unlikely to be assessed as competent to make such an important decision*."[92]

This would certainly be one practical way of solving the conundrum regarding competence assessment, but it must be seen that it blatantly ignores point 4, and that it also subscribes covertly to an 'external standard approach' of competence assessment, whereby the competence of the person is judged by comparing their reasoning to the reasoning standards deemed acceptable by the person doing the assessment. Although this is what seems to happen in practice in various forms, it is certainly not in line with what ought to happen according to the totality of legal considerations as given in the cases above.

Another way of solving this puzzle would be to abandon the global sound mind approach as redundant and simply focus on localized questions of particular understanding and particular competence only. This would be very much in keeping with the common law test regarding capacity to consent, but it is at least debatable whether such an approach seems appropriate for ACP. The main reason for doubt is that advance care plans are often not specifically aimed at a localized specific treatment or questions pertaining to particular situations.

In instances where advance care planning simply involves appointing another decision maker or making specific instructions about very particular treatments, such as the withholding of blood products for Jehovah's Witnesses, a limited notion of understanding might suffice as a basis for competence assessment, but these are only a very limited sub–group of ACP instances (and even here we may question whether an idea of partial autonomy is convincing, based on the fact that life forfeiting decisions affect all areas of life).

Commonly ACPs are aimed at dealing with global life issues and global treatment instructions such as non-admission to an acute care facility or refusal of moving into a nursing facility or requests for general comfort measurements in keeping with certain imagined outcome values, etc. It is very difficult to demonstrate particular understanding for instructions of such a global nature.

3 – CONCEPTUAL DIVERSITY IN LEGAL AUTONOMY DISCOURSE

Having drawn out some pertinent tensions within the legal framework and illustrated how this impacts on practice, I want to attempt to identify what kind of personal autonomy concepts must or could be assumed as the basis of the present legal understanding governing medical practice and ACP, with reference to the personal autonomy concepts described in chapter 3.

In medical practice we generally find two situations: either competence is assumed by (a) default or (b) competence is under question. A third position (c) can furthermore be distinguished in reference to situations of coercion. Legally this seems to be the only point where the term 'effective autonomy' and competence are treated separately and a variety of different default positions exist. I will elaborate on this a little further on. For now I will concentrate on the first two positions, as they both revolve around the 'sound mind' requirement. Interestingly enough, even in the very basic division of the first two situations we seem to find different basic conceptions of autonomy, depending on whether we operate in the default position or not.

(A) COMPETENCE AS DEFAULT POSITION OF AN ADULT PERSON:

An attitude which asks for competence to be assumed as a default state for all (adult) people, and which recommends that the notion of a *sound mind* should not be based on a person's reason giving, rationality or any outcome parameters, appears to have the following features:

I) It is global and absolute.[lxii] It regards competence (and thereby personal autonomy) as a feature of a person, not an act! It sees autonomy as a feature of a whole being, not as a feature of a task or as a situation specific ability, not as risk dependent, not really as a sliding scale phenomenon and not as only present in some concerns of life and not others.

II) It attempts to be maximally inclusive (in terms of who can be competent) by requiring the least amount of proof for particular faculties or capacities. It is also non-substantive in that a person may choose to forfeit their autonomy! It does not ask (or care) how a person arrived at their autonomous state or how the person made their choices. Thus, it has very low procedural demands and it seems to be highly individualistic and non-relational.

Such an approach to autonomy considers it a worse fate to be falsely declared non-autonomous than to be falsely declared autonomous; i.e. it has less ambition to over–protect the vulnerable from adverse consequences of their choices. Its ambition is to maximally preserve choice making for any particular individual and for as many individuals as possible..

Thus the **default legal position**, which asks us to treat every adult person as an autonomous being, most likely presupposes a global, individualistic, non-relational, non-substantive, whole person based model of personal autonomy, which does not take into account notions of life plans or life-narratives, nor whether the person in question has actually deliberated at all (as long as we have no doubt about deeming him capable of sufficient deliberation).

[lxii] Absolute in the sense that it is either absent or present.

(B) WHEN AUTONOMY IS UNDER QUESTION:

When we doubt someone's autonomy, the legal attitude towards competence becomes quite different. When incompetence is suspected, underlying accounts differ considerably, as we now have a position which requires seeking out a patient's *particular* understanding in a *particular* situation. This may be done based on a variety of accounts of autonomy: a global account with person/act distinction or a partial (scalar) account without act/person distinction. Furthermore, differences regarding risk relativity and relational features may be operational.[lxiii]

We remember that in accounts which distinguish between the autonomy of an act and the autonomy of a person the former does not flow from the latter, i.e. autonomous people can perform incompetent acts and vice versa.

It would be possible to account for the court decision in ReC based on such a philosophy, but I think it not very convincing to interpret the judges' decisions in this instance as focusing on the competence of the patient's acts rather than the competence of the person in regards to the act. It is therefore much more likely that in this and many similar cases we can assume that the legal approach to autonomy is based on an account of autonomy as a partial or scalar phenomenon.

Nonetheless, there are cases where the opposite seems true, e.g. when we consider cases of negligence. Here we do not wish to declare a person incompetent, due to a lack of information or mis-information. When we think someone made a poor decision, because they had insufficient information, we more likely think the person competent, but not the act.[lxiv] We also think that the extra information would have

---

[lxiii] One could even imagine these circumstances enquiring after life plans, although I have not identified such a particular case.

[lxiv] This distinction is defended by Stewart & Biegler, for see more detail below, p.150.

given this person a better chance to act otherwise, in which case the competence of the decision flows directly from the competence of the person (namely the competence to use the information to one's advantage) and the account of autonomy would be more global in nature.

The law is also inconsistent (and sometimes unclear) as to whether it employs a scalar risk-relative concept or risk-independent philosophy of autonomy.

This can be demonstrated when analyzing the legal discourse on which type of understanding has to be demonstrated by a patient (and under what circumstances) in order for someone to count as competent.

If all that matters in the assessment of a person's competence in regards to understanding is the understanding of a particular transaction, then a risk dependent account of autonomy is not really at play. However, if it is demanded that the relevant understanding for a transaction also includes the understanding of the associated risks involved, or requires a higher level of understanding for transactions carrying a higher risk, then a risk dependent autonomy model is clearly assumed in the assessment.

This distinction is apparent in legal discourse in several areas: e.g. the level of maturity and understanding required for refusal of life–saving treatment is set differently in different areas. Although minors in Victoria may consent to sexual conduct, termination of pregnancy or contraception, they may not refuse life-saving treatment. The minimum age for this decision is 18 irrespective of demonstrated understanding. In Queensland a similar distinction is in place for consent to anal and vaginal sex, where the valid consent age for vaginal sex is 16, but for anal sex is 18, irrespective of understanding.

Incidentally, a person may also not actively participate in political decision making until they are 18. This does not make sense on a risk based understanding for political participation, since the personal risk of consenting to termination of pregnancy, for example, is higher than the risk for adversity from political participation. Even on a non-risk based understanding of capacity for decision making, one would have to question whether understanding how to vote requires greater capacity than many of the 'mature minor' type medical decisions.[93] Furthermore, although adults may consent to all kinds of procedures, even for illnesses that they currently do not suffer from, they may (in Victoria) not issue a refusal of treatment certificate for a condition from which they do not (yet) suffer.[94] The latter most likely reflects the concern that when it comes to risking one's life, sufficient understanding must incorporate the actual experience of the disease in question. Interestingly enough, advance directives do not incorporate this precaution. Here procedures can be refused without actually suffering the disease in question, e.g. one may make life restrictive treatment instructions in an ACP for the eventuality of suffering a stroke, even if one has never suffered a stroke or TIA[lxv] before. In fact, this is precisely the circumstance for which ACP is often advocated.

Thus a risk-relative philosophy of personal autonomy seems to operate in the Victorian medical treatment Act and with respect to attributing capacity to mature minors, but not in regards to advance directives and age status adults.

Underlying philosophical differences regarding risk relativity also seem to be present across different jurisdictions and in regards to the type of offence that is under consideration (battery or negligence).

E.g. in Australia the definition of a person who is 'incapable of giving consent' has been given as: 'incapable of understanding the general nature and *effect*[lxvi] of the proposed procedure or treatment',[95] yet this leaves unclear what is meant by 'effect', in particular whether it includes an understanding of the risks. As Skene

---

[lxv] TIA is the common abbreviation for transient ischaemic attack, a condition which produces all the symptoms of a stroke, but resolves without residual loss of function.

[lxvi] My italics

points out in her discussion of this topic,[96] neither English nor Australian law are entirely clear in this regard. On the one hand, under the law of negligence doctors are required to disclose the material risks of a procedure, but on the other hand, the defense against battery only requires a patient to understand in 'broad terms what is proposed'.

Furthermore some legal decisions (e.g. Rogers vs Whitaker 1992[97]) can be seen to justify and encourage doctors in providing different levels of information to different patients[lxvii], because they judge their patients to attach different levels of significance to different facts or they judge their patients to have different capacities for comprehension. As such it would seem justified that mentally impaired or simply less intelligent patients would be informed to a different degree in order to obtain consent or advance care instructions about their future treatment than their higher–functioning fellow sufferers.

What does this say about a patient's competence and their ability to appreciate risks and whether this matters in regards to personal autonomy?

Here the legal positions seem divided. Is a person who is under-informed, but capable of using any extra information, more autonomous than a person who has the same limited information, but could not use any further information to his advantage? In terms of actual decision-making ability from the patient's perspective there seems to be no difference between the two. Is the first person more autonomous, based on her greater capacity, even if the capacity cannot bear on the actual situation?

[lxvii] Among other points, the Whittaker case is particularly well known for the fact that a doctor must disclose risks that the patient is likely to attach significance to, even if the doctor does not.

According to Skene, English law-makers seem to be as divided on this point as Australian ones. She quotes Professors Kennedy and Grubb as saying: “Logically, the capacity or ability to understand 'what is involved' must embrace this further information [that the doctor is required by the law of negligence to provide] since the basis for requiring disclosure is to allow the patient to make an informed choice and this can only be achieved if the patient has this further information [about the risks]”. At the same time the English Mental Health Act 1983 says that the words ‘likely effects’ suggest a ‘capacity to understand the more limited information necessary for a doctor to avoid a claim in battery’, i.e. information which characterizes in broad terms what is proposed.

In the United States the distinction in competence levels for battery and negligence does not exist, according to Stewart and Biegler.[98] There, a patient is apparently only deemed competent if she understands the ‘nature of the illness and proposed treatment, as well as the risks and benefits of that treatment, of alternative treatments and of no treatment at all’. This would suggest a more risk relative concept of personal autonomy as the basis of U S American law, although it is not entirely clear from Stewart and Biegler's information whether higher risk procedures are deemed to need a higher level of understanding. It also does not entirely clarify whether the level of information provided to patients of different intelligence is permitted to be different.

A separate discussion (which turns on very similar arguments) is not so much concerned with the question of whether competence is risk relative, but rather with whether it is seen as an actual (demonstrated) ability or an assumed capacity.

For the Australian situation, Stewart and Biegler[99] suggest that the legal test for competence rests on a functional (ability) view, i.e. competence rests on actual understanding, not on a capacity to understand.[lxviii] However, at the same time these authors do not wish to attribute incompetence to under-informed patients (as this would presumably render a vast number of people incompetent!) and therefore they favor a distinction between an autonomous patient and an autonomous act.

The problem with this, however, is that with such a distinction it becomes very difficult to determine what constitutes an autonomous act and in what way one can actually respect the autonomy of a person. I have alluded to this problem in chapter 3, but it is worthwhile to retrace it in the legal context, because it shows the philosophical tensions embedded in the law.

What is the aim of the act/person distinction? Stewart and Biegler make this very clear in their discussion. Distinguishing between an autonomous person and an autonomous act allows the claim that a person with normal autonomous capacity can be rendered non-autonomous by lack of information. In law this allows a suit of negligence to succeed in such a way that the responsibility for making an adverse choice[lxix] can be transferred away from the choice maker.

[lxviii] The term ‘functional‘ here refers to the fact that competence has to be demonstrated in a functional sense and cannot be inferred from some other capacity, e.g. the fact that someone can or cannot demonstrate the capacity to add sums does not allow the conclusion that the same person can or cannot calculate compound interest or manage his banking. In this example, general mathematical understanding does not equate to the particular functional ability for which this understanding is required. Likewise a person who has the capacity to understand medical information generally cannot be inferred to have understood it actually (in a particular case) if the information has not been made explicit to her.

[lxix] Maybe one should rather refer to this as a choice with an adverse outcome, as choices with positive outcomes are rarely contested under negligence!

However, this entails the problem that autonomous acts do not flow from the choice maker, but (at least) partially from the information provider. The patient's autonomy or at least the autonomy of their acts suddenly becomes dependent on the treating doctor. This seems odd, a situation which Kennedy and Grubb reject as follows: "*Competence or incompetence is a state inherent in the individual patient, which cannot depend [on] how much the doctor tells his patient.*"[100]

Stewart and Biegler acknowledge this point, but make it quite clear that the aim of this distinction is not to have a consistent philosophy of autonomy, but rather that adopting a particular philosophy pursues a particular aim, namely that of 'protecting' the patient from negligent or incomplete advice, without at the same time calling him incompetent. The thought behind this is that it would maximize *respect* for autonomy by abstaining from a general incompetence verdict. However, it is not clear to me how a person's autonomy is effectively respected when someone else is allowed to call his particular acts (choices) non-autonomous all the same, and can override or not attach responsibility to them. [lxx] This would only be possible on a global view of autonomy, which separates the question of *person* autonomy from the question of *act* autonomy.

Yet Stewart and Biegler do not hold a global view of autonomy as they distinctly emphasize the point that even people with limited capacity , such as a woman with Down syndrome, may show sufficient understanding for giving a valid consent to have a serious cut surgically repaired. This is representative of a partial/scalar account of autonomy. However, I rather think Stewart and Biegler fail to see the

---

[lxx] It is not disputed here that it is beneficial for a person not to be held responsible for acts that have an adverse outcome. However, since questions of competence seem to arise especially in situations of adverse outcome, questions of autonomy and responsibility seem intertwined significantly in such a way that the thought about responsibility forms a bias towards certain personal autonomy accounts over others.

difference between *agreemen*t and *consent* in this case. A woman with impaired mental capacity may agree to a suggestion that such a cut ‘needs’ repair, as suggested by a surgeon. The question is though, whether she would be allowed also to refuse the suggested treatment, based on the fact that she can sufficiently demonstrate understanding that the cut ‘needs to be repaired surgically’, but does not want to have it done? This I find doubtful. In this case one would not say she is competent (partially or globally) but her choice is not; rather one would deny her relevant competence (partial, global or risk-relative).

As I mentioned before, it seems to me that the act/person distinction aims particularly at preserving a notion of personal autonomy, which is global and which sees autonomy flowing from person to act, i.e. an act becomes autonomous, because it is performed by an autonomous person.

Stewart and Biegler seem to defend an act/person distinction against the background of a partial autonomy account. On their view, it looks as though the autonomy of the person is a result of the competent act. This account seems counter-intuitive to me, but I am not sure that I can defend my intuition any further than to observe the following:

1) the account seems excessive, as it can find a person incompetent in two ways, either by lacking the particular capacity or the particular understanding; and

2) it reverts to an outcome approach.

Stewart and Biegler reject the global (or ‘minimal’) capacity account, because they think it deprives some people of competence in much the same way as a status approach does (i.e. Down Syndrome status = incompetence). However, their suggestion of a partial account reverts back to the equally unacceptable objective standard approach for the following reason: in order to demonstrate understanding, one has to have the relevant capacity. Capacity for understanding is necessary for ability and hence prior to it, even if it is partial. On their account, the capacity is only demonstrable via proof of direct ability, yet the ability can only be seen in reference to an accepted objective standard. Hence, their version of the ability test is not purely functional at all. It leads to an outcome approach, which covertly says that a person is autonomous only when their acts are autonomous (as observable by third persons).

However, even if my intuitions about the global and partial autonomy accounts and the act/person distinction are wrong, I think I am correct in observing and in agreement with many commentators (including Stewart and Biegler[101]) that the legal discourse is rather divided and diverse in its approaches to concepts of personal autonomy. This division of opinion appears locally and internationally.

So far I have concentrated on showing differences in concepts of autonomy, focusing on global versus partial parameters, risk relativity and the act/person distinction. Another way to understand legal differences in interpretation of what matters in competence assessments could be in reference to relational features of autonomy accounts.

We may for example regard an account which allows autonomy to derive partially from others (e.g. Stewart and Biegler) as a relational account. On such view, it would seem perfectly normal to say that a person is not autonomous when relevant information is not provided to them, because relational accounts see a person's autonomy as not just based on the individual itself.

Thus the differences between Kennedy and Grubb and Stewart and Biegler's interpretations still remain, but they may be explained with reference to a difference in philosophy that has to do with their attitude towards individuality. Kennedy and Grubb's analysis is more consistent with an individualist autonomy account (maybe in the tradition of Mill), whereas it could be said that Stewart and Biegler accept the importance of features external to the individual as relevant, which is more consistent with relational autonomy approaches.

Maybe one could even interpret Australian law in such a way that it engages different autonomy accounts for different crimes, e.g. a relational autonomy approach for the civil crime of negligence and an individualist autonomy philosophy for the criminal offence of battery.[lxxi] Whichever interpretation is most convincing, the fact remains that several philosophical differences are present within the legal discipline and that such a relativist approach makes the interpretation of legal governance difficult and insecure.

(C) SITUATIONS OF POSSIBLE COERCION

Up to this point, attention was focused mainly on features of understanding and how we relate these to global, partial, risk relative and relational accounts of autonomy. This all relates to the ‘sound mind’ requirements of the medico–legal guidelines.

However, another point of concern that was indicated in the case of *Mrs T* in chapter 2 and which is of relevance in regards to ideas of personal autonomy is the question of coercion.

In the discussion in chapter 3, I noted that relational accounts of autonomy pay particular respect to the idea that people do not live in a ‘social vacuum’ and that most decisions, if not all, are influenced by relations to other people. Furthermore, and this is important to notions of understanding, I discussed how relational accounts of autonomy take seriously the fact that our abilities to reason and our vision about what is possible for us in terms of achievement (i.e. our practical identity) heavily relies on our social circumstances. Bearing this in mind, it is important to ask whether and how the law accommodates these concerns.

[lxxi] This would however, have the very uncomfortable consequence that for any competence assessment one would have to have a particular offence in mind! E.g. doctors would have to judge *Mrs T’s* competence based on whether they might worry about being found negligent or performing battery in her treatment, when realistically they don’t want to commit any offence at all!

Above, I suggested that in practice, concerns of personal autonomy and competence fall into two broad classes: a default position and a position of doubt. However, coercion must be dealt with as a significant relevant third concern, since the law views questions of undue influence and coercion as separate from competence, but includes it in a notion of autonomy.

In his discussion on undue influence, consent and medical treatment Stewart makes the following point: *"The doctrine of undue influence does not question the person's ability to understand the choice that they made. Rather it looks at the issue of whether the decision was made freely, to the extent that it reflects the exercise of the person's autonomy."* [102]

According to this view, effective autonomy is only achieved when we have determined a positive competence status and excluded undue influence. So autonomy legally seems to demand a 'freedom of mind' assessment, which is taken to be separate from notions of understanding.

How is this to be done, according to the law, and how does this relate to differences in concepts of personal autonomy?

If we follow Stewart's writings[103] on this topic, the following can be said about the legal ideas about 'undue influence' and the test for it:

Firstly, undue influence is taken to be the result of a power imbalance.

Secondly, undue influence is taken to be the overbearing of another's will.

Thirdly, the law recognizes certain relationships as containing a significant power imbalance in virtue of the relationship itself, that, should a transfer of a benefit arise towards the stronger party, the onus of proof resides with the stronger party to show that the benefit was not the result of undue influence. Relationships thus recognized under law for example are between solicitors and clients, religious leaders and followers as well as between parents and children.[lxxii]

The reason for the distribution of onus of proof in these cases is “the unlikelihood that the weaker party would freely confer a benefit by means of a gift on the stronger”[104]. In cases, where a ‘relationship-power imbalance’ is not presumed by default, the onus of proof lies with the party which claims to be the weaker one.

It is notable here that there is no general default state of ‘non-coercion’ or ‘non-power imbalance’, unlike with the cognitive capacity of adults, who are presumed to be competent by default. This means that technically everybody needs a non-coercion assessment as part of their ACP or consent.

The legal test for undue influence requires that it must be shown that “the weaker party’s will must have been so overborne as to prevent its independent exercise”,[105] and although the philosophy concerning undue influence originates mainly from cases of transfer of property (as the benefit under question), Stewart points out that the general test for undue influence is not restricted to actual property transfers, but applies to questions of consent as well, where benefits may be of quite different kinds.

Stewart’s discussion and case examples make it clear that apart from the power relationship between the two parties under scrutiny, the assumed *benefit* in question plays a significant role in the legal judgment about the nature of the pressure that may have been exerted and whether this pressure can be considered enough to overbear a person’s will. It turns out that the benefit under question seems to act as an indicator for the level of coercion that may be at play in a given

---

[lxxii] The first mentioned in each pair are deemed to be the more powerful parties by default.

situation. Although intuitively convincing, this setup has the difficulty of requiring us to show the right sensitivity to what might be regarded as benefit by each of the parties involved, because it is the benefit which is seen to act as the motivator for influence. A further difficulty is the need for an assessment of the vulnerability or weakness of the will of the person in question, a feature which is widely discussed in relational autonomy accounts, but not so much credited in individualist accounts.

One legal example illustrating these points is given by Stewart.[106] It discusses is the case of Mr. U, who had consented to sperm donation for IFV treatment and who had successfully donated the sperm, but died unexpectedly during the treatment period. The man's earlier consent had allowed for his sperm to be stored and used posthumously, but was later amended to lifetime use only. This amendment was a result of the request of one of the treatment facility's representatives, Ms Hinks, in order to bring Mr U's consent into line with the facility's ethics policy. Ms Hinks also subscribed to this policy personally. After Mr U's death, his wife who wanted to continue the IVF therapy, claimed that her husband was under the impression that if he did not amend his consent, IVF therapy could not continue at all, even during his lifetime and therefore was under pressure to amend the form. This claim was not contested and some pressure was admitted by the court. However, the court denied that the pressure alone was enough to show undue influence. The court decision stated that:

"… it is difficult to say that an able, intelligent, educated man of 47, with a responsible job and in good health, could have his will overborne so that the act of altering the form and initialing the alterations was done in circumstances in which Mr U no longer thought and decided for himself …He succumbed to the firmly expressed request of Ms Hinks and under some pressure. But to prove undue influence, Mrs U has to show something more than pressure."[107]

At this point one may ponder what is considered to be freedom of decision making.

Mr U wanted to continue IVF therapy by donating his sperm. He would have preferred not to have to alter his consent, but he believed that his failure to do so would stop the IVF option altogether. Thus, Mr U had to formulate his wishes under undesirable circumstances: namely, that he could only have some of his wishes fulfilled, but not all. This is a common situation. We simply cannot get everything we want, e.g. we may get the dream job, but not in the town we want; a person who has cancer may have the chance of a cure, but only by accepting many adverse effects along the way.

In these cases, we really find the circumstances coercive, but not the people representing the circumstances. Yet in Mr U’s case it was not entirely clear that the circumstances were the main factors in determining his action, for it seems that Ms Hinks represented the circumstances in a certain manner, which made Mr U believe that certain circumstances obtained which possibly did not: namely Mr U could have continued IVF, even if he had not altered his consent. If that had been the case, Ms Hinks would have clearly misrepresented the circumstances. Does this mean Ms Hinks pressured Mr U into a false belief and unduly influenced his choice? If she was merely representing the institution's policy and Mr U could not have continued IVF without altering the consent, would he have been coerced by the institution, whose rules are made by people?

Did Mr U fail to be assertive enough or did he give too little credence to the possibility that the nature of the alteration of the consent would actually really matter (and therefore be worth a fight), given that he was healthy and probably did not suspect his untimely demise to be likely?

In the process of appeal, Mrs U argued that the court had set the test for undue influence too high and that it should simply consider whether Mr U had a real choice to refuse the consent alteration.

There are quite a variety of conceptions as to what would constitute effective *freedom* of choice or effective autonomy: for some it will mainly concern the mental freedom of deliberation, for others it will represent the independence of understanding plus the freedom to assert one's will. Some may feel circumstances alone curtail one's freedom of choice so significantly that we cannot ever make 'free' choices. Not many people seem to defend this latter, skeptical view seriously in an applied context and I will therefore not consider it here. Yet where circumstances are created by other people's choices or their particular representation of available options, one can find it increasingly convincing that the decision making ability of one person is deliberately influenced by others. It is this feature of autonomy which relational autonomy accounts want to represent and which, I think, can be found embedded in the legal discourse on undue influence.

Although Mrs U's appeal was ultimately rejected, the court of appeal acknowledged that *"… the equitable concepts of misrepresentation and undue influence may have a part to play …"* in the valid consent consideration, but added that *"… the courts should be slow to find them established in such a way as to supply a center with a consent which they would not otherwise have."*[108]

How exactly this 'slow establishment' is to be translated into the practical context is difficult to interpret, not the least because we now also have the added complexity that the free consent must not only fulfill requirements of effective patient autonomy, but also the *practicalities* of institutional requirements.

One of the important considerations in Mrs U's appeal was the role played by the possible transfer of a benefit. In this case it was said that the reproductive service provider was not deemed to stand to benefit from the withdrawal of the consent. This was taken to indicate that undue pressure was unlikely to be present, because there was no significant gain for the institution.

It thus seems that our guidance as to the severity of pressure is taken to relate to the extent of the benefit transfer under question. It seems to be inferred that the importance of the benefit to one party is in some direct proportionality to the likely pressure exerted; in other words, the higher the gain for one party, the harder they are going to chase it, possibly even by undue means.

Although not an unreasonable assumption, the problem with this is that it takes the right sort of sensitivity to recognize what counts as a significant benefit to whom.

As was pointed out earlier, most of the legal consideration for undue influence has come from property law, where the benefit in question is the transfer of property. Traditionally, the transfer of property is accepted as an important transfer of benefit. However, this is a matter which is highly sensitive to multiple factors, such as age, gender, personal values and culture. If a patient bequeaths a physical property to a professional carer, why should this automatically be presumed to be the effect of undue pressure, when the effect of the loss of property will never even be felt by the deceased posthumously? At best the injury is felt by the parties who would have inherited. Why should we presume a kind of 'pre-humous' blackmail rather than a genuine expression of gratitude as a default position?

Stewart suggests that this is because of the prominent power imbalance between carer and patient and an assumed unlikelihood of the weaker party conferring a benefit on the stronger. However, the presumption of exploitation could just as well be explained by the fact that we tend to attach greater significance to property as a benefit than to an improved psychological state as a benefit, a state which a patient may derive from expressing gratitude financially. If we were to attach greater significance to the latter, the benefit would be the patient's!

Maybe such a scenario seems too far-fetched for most readers, but if we apply this line of thought to Mr U's case, the matter of benefit is not so very far-fetched, because in scenarios involving validity of free consent, the nature of a transfer of benefit is far more obscure.

It may not be true that the IVF center or its representative did not stand a benefit from Mr U's amendment of consent. If the amendment meant that Ms Hink's (or the center's) moral stance was gratified or endorsed, they may have derived a significant benefit from the patient's compliance with the request. The benefit may have been of a psychological, personal, social or political nature rather than material benefit.

It seems that what really swayed this case against Mrs U's appeal was that the possible benefits were not recognized by the court as significant enough, such that they would be assumed to have led to enough pressure to have interfered with Mr U's freedom of decision-making. Furthermore, Mr U was not considered to be in a vulnerable position. Mrs U however, clearly thought otherwise.

Why is it important to dwell on these matters in such detail?

These details are important, because they show a number of aspects of practical autonomy accounts, which are not discerned easily otherwise.

Firstly, they show that some aspects of autonomy, which are usually considered valid and important in relational autonomy accounts, also play a role in the applied legal setting. At the same time, it becomes clear that many relational aspects of autonomy are not usually taken to be matters of mental phenomena or deliberation capacity, but they rather appear to be concerns about limitations of the *assertion* of freedom, even though from a philosophical and clinical point[lxxiii] of view this approach is contestable.[109]

[lxxiii] Some relational accounts of autonomy might be quite at odds with this position, by claiming that even the extent to which we can understand things are dependent on our social relations, and not only on our intellectual capacities, hence the legal claim for power relations not to influence understanding is not justified. .Jodi Halpern (see endnote 109) gives a case of a patient who was abandoned by her partner and this interfered directly with the decision making capacity of the patient. This case would seem at odds with the above–mentioned legal presumption of mental capacity as individualist and socially independent, and illustrate the relational position. It might also

Secondly, these observations show that the law does seem to make a distinction between competence and 'effective autonomy'. However, this distinction is not obvious and the question of coercion is sometimes obscured by the fact that the terms autonomy and competence are often conflated, because it is tacitly assumed that if someone is mentally competent they are also effective in asserting their will.

Nonetheless, the law has provisions for recording the difference. Yet, they are not without difficulty, as they are highly dependent on a social understanding of what counts as an exchange of a significant benefit, what counts as significant (i.e. undue) pressure to overbear someone's will, what counts as being robust enough to assert one's will and whether these considerations are recognized at all as a significant factor within an advance care planning situation in the first place.

Stewart points out that, although in the case of Mr U the pressure by the health professional was not found to have been significant enough to overbear Mr U's will, the recognition of the presence of *some pressure* at least makes it feasible that consent or the refusal of treatment can be unduly influenced by health professionals (and maybe others as well).

This shows that our findings in this regard are highly dependent on what credence we give to relational aspects of autonomy, which under the current law may be quite variable from setting to setting and therefore difficult to predict.

We could apply some of these thoughts to the case of *Mrs T*. Her deliberation about consenting to invasive ventilation treatments involved discussions with several

---

make a case for challenging the legal approach, which claims that direct personal influences are not considered relevant for understanding, and it shows again how the medical profession can differ in its interpretation of the law, and as a consequence, in their interpretation of what the law would require them to do.

different health professionals (doctors and nurses etc.) and her parents. All of these relationships contained a significant power imbalance, none of the possible benefits referred to property and some senior staff deemed her competent in regards to relevant understanding.

After talking with her parents she consented for the first time (after surgery) to invasive ventilation via endo-tracheal tube, but not via tracheostomy. Was she coerced by her parents? They were clearly the more powerful party, because they were healthy and because they were in a parental role, which is one of the legally recognized default positions of power.[lxxiv]

The case of *Mrs T* can be compared to a case discussed by Stewart, ReT, which concerned an adult woman who the court found coerced into the denial of consenting to a blood transfusion by her mother, who was a Jehovah's Witness.

However, one significant difference in these two cases is that the outcome of talking with her parents brought the treatment options for *Mrs T* into line with what would ordinarily be recommended for her situation, whereas in the case ReT the parental influence was against the usually recommended treatment. Do we still consider the coercive element of the parent’s involvement as relevant under these circumstances? Are we obliged to recognize the relational aspects of the situation? If we are, would we have to discard this later consent to treatment with invasive ventilation as invalid and return to *Mrs T*’s earlier refusal (unless there were other grounds for finding the refusal invalid)?

Imagine *Mrs T* recovered completely and was well enough at home for a while. She would still have the tracheal stenosis, which is a chronic condition and may well

---

[lxxiv] As is apparent from the case description of ReT, by Stewart, the parental role of power does not cease with maturity, but continues into adulthood.

entail that the patient will have similar health difficulties in the future. In order to prevent this she might want to draw up an ACP about future ventilation options. She might then again talk to her parents about these matters, who again oppose her choices. If she failed to make a directive would we consider her to be coerced into abstaining from making a directive?

If she did make a directive to curtail treatment options and the parents later claimed that the directive was invalid because their daughter appeared depressed at the time of making the directive (or something along those lines), should they succeed in invalidating the ACP? Whose benefits are of significance in these social transactions and whose benefits are even apparent?

Likewise, in drawing up an ACP *Mrs T* would likely need to speak with a health professional. The health professional may encourage or discourage the ACP. What benefits that might influence the direction of advice could be imagined for the health professional in this kind of transaction?

The following table imagines some non-property related benefits a health professional might contemplate:

BENEFITS OF **ENCOURAGING** TREATMENT LIMITATION:

- Workload reduction
- Guarding the public purse and resources

BENEFITS OF **DISCOURAGING** TREATMENT LIMITATION:

- Personal gratification
- Increased professional prestige
- Increased professional advancement
- Upholding professional ethic
- Possible research opportunities or prestige

Could any of these benefits be so significant that they become a coercive factor such that the patient's freedom of will may be unduly influenced, even in a person who is not as sick as *Mrs T* was? How disempowered would the patient have to be, and how do we test for disempowerment, given that this is held to be separate from understanding and competence? Should these kinds of motivational pressures, these *relational aspects* of effective autonomy, count at all when we consider the validity of consent or an ACP?

The answer to these questions relies very heavily on how much influence we grant some relational aspects of autonomy and it does not seem clear to what extent the legal setting has a consistent approach in this regard or is even predictable on this. The case of Mr U seemed to suggest a more individualist position; the case of ReT suggested a more relational approach.

4 – SUMMARY

This concludes my attempt to identify a prominent prevailing legal concept of personal autonomy. In the foregoing discussion, I have shown that concepts of personal autonomy are not applied consistently throughout medico–legal legislation and are under debate by the legal experts. The scholarship sometimes even seems to incorporate outright inconsistent demands when considered in totality. Functional approaches often need to revert to outcome strategies and minimalist concepts of autonomy collapse into status approaches. Scalar concepts of autonomy co-exist with global concepts and we find evidence of relational as well as individualist positions, all within the one relevant body of law. It also seems evident that the specific approaches advocated within the law are chosen in order to satisfy particular external requirements, such as to enable a particular cause of legal action (e.g. avenues for suits of negligence) or institutional practicalities. Thus autonomy, legally does not appear as one discrete legal concept; at best it can be seen as a vaguely related cluster of ideas.

Furthermore, some concerns discussed in the philosophical literature concerning personal autonomy, and in the literature considering the merits and justifications of advance care planning, do not seem to feature in the practical legal concerns of autonomy at all. There are, for example, no references to life plans, narrative accounts or stability of character, and there seems very little reference to stability of preference or the need for consistency of choice.

This chapter has thus identified the existence of significant conceptual variety regarding autonomy within the governing body of law for ACP, which has a significant impact on the clinical situation. In regards to concerns of arbitrariness in the assessment of autonomy and the consequent treatment obligations that were identified at the end of the last chapter, we can therefore conclude that the current governing body of law is not especially reassuring or clear.

In the next chapter therefore, I want to attempt an explanation as to why we have this (inconsistent) conceptual diversity, why it might not even be surprising and whether this situation should and/or could be remedied.

CHAPTER SIX – PERSONAL AUTONOMY: AN IMPRECISE CLUSTER-CONCEPT

1 – INTRODUCTION

The central argument of this thesis revolves around the claim that many of the practical failures and difficulties of advance care planning are due to possibly intractable conceptual problems. The task of this chapter will be to elaborate, discuss and advance this claim, with particular interest in the nature of the intractability.

The main feature of the conceptual problems that I am referring to is the imprecision of the conceptual particulars and its associated benefits and pitfalls, and the worry that such imprecision may in some respects arise necessarily. I will illustrate this with the insights from the previous chapters and then generalize to the greater conceptual framework of advance care planning.

In the last three chapters I described several different ways of conceptualizing ideas of personal autonomy and I looked at how these seem to feature in the applied medico–legal setting with reference to ACP. One of the particular findings, I suggested, was that there is no *one* compelling concept of personal autonomy, which can be identified as operational in the medico–legal system as a whole, and in regards to advance care planning in particular. It therefore now remains to show how this conceptual imprecision might arise necessarily and why I think that it is an intractable problem for ACP.

2 – CONCEPTUAL IMPRECISION IN THE AUTONOMY DISCOURSE

If the exposition of my last chapters succeeded, then it will be accepted that the use of the concept of autonomy is inconsistent and fraught with difficulty throughout the medico–legal discourse. Such inconsistency of concept application is a problem for professional and practical reasons.

Firstly, consistency is commonly held to be a virtue in itself. It is deemed to be sign of professionalism, rationality and in some cases a sign of justice, in the sense that like cases should be treated alike. On some occasions there may be relevant reasons that one should have a relativized approach and that one may be justified to use different autonomy concepts for different applications; however, since ACP has to be taken as one and the same application, even though it may be considered in the context of different disciplines, I think there is a very strong case for demanding that autonomy concepts concerning ACP should be consistent throughout the entire ACP planning discussion, whether it be in medical, legal or philosophical terms.

Secondly, even if this point is deemed contentious, practicalities of the ACP process demand at least legal consistency of an underlying autonomy concept for the following reasons: it was said that philosophically it is not self-evident which autonomy concept should be used in reference to ACP, therefore we need a guide to decide which conceptual interpretation to use. This guide is the law. It is well accepted, that ultimately the decision about whether someone is deemed to have decision making capacity and effective autonomy is a legal matter, even though the law may consider a wide range of expertise in reaching its verdict. For ACP this is an especially important consideration, because in ACP autonomy concerns feature frequently: capacity needs to be present when the ACP is first made, each time it is updated and each time a treatment decision needs to be made, since it must be established each time whether it is the patient or the ACP who gives the treatment instruction.[lxxv]

[lxxv] One cannot presuppose that a competent patient is necessarily in unison with the instructions of their ACP at all times, since an autonomous patient may well adjust her preferences in light of new situations. An ACP cannot make such adjustments. And although one would naturally expect such a situation to prompt the alteration and updating of an advance care plan, one needs to first establish whether the patient is autonomous or not, should a discrepancy occur.

Since the legal system is a slow and reactive arbiter in terms of practical solutions and it cannot be called upon or be expected to be involved in each individual case and with each individual decision, it must be easily and consistently interpreted by those who have to act within its sphere of governance. Yet, if the law itself displays inconsistent or unclear notions of autonomy, any third party will have trouble interpreting it, because it cannot be sure which set of parameters to adhere to. This will lead to inconsistency of treatment and general uncertainty about what is legally permissible or obligatory.

In practice this means that if the legal appraisal of what constitutes effective autonomy is vague or imprecise, medical practitioners as well as patients cannot be sure when a person is deemed competent to make a decision for herself, which may lead to some very concerning arbitrariness in treatment, as we have seen with the case of *Mrs T*. Furthermore, I think, it disables the claim that advance care planning respects autonomy. This is because one does not really know what it actually respects, when it may concern variable parameters according to different interpretations all the time. The term 'autonomy' becomes vacuous.

The central question then is, what can be done about the conceptual vagueness of autonomy in regards to ACP? In order to approach this question I think it useful to explore its origins.

3 – ORIGINS OF CONCEPTUAL VAGUENESS

Conceptual vagueness encountered so far could be characterized in the following three different ways:

A) INCONSISTENCY

Firstly, we could say that the concept users involved in the ACP discourse all understand autonomy in different ways. Or maybe it is more the case that in the general discourse on ACP autonomy is understood in different ways, and no one has actually checked whether any particular autonomy concept lends itself better to a discourse about advance care planning than others. This is the way in which I drew attention to differences in accounts of personal autonomy in chapter 3, and it is much reflected in the way that the philosophical personal autonomy discourse presents itself in the literature.

B) IMPRECISION

Secondly, anyone who promotes a more contextualized approach may object that autonomy as a concept should not be seen as a rigid attribute, but rather as a context-sensitive concept and that we should see it as a cluster of particular attributes which all make up the bigger notion of autonomy. Another way of understanding the conceptual vagueness would be to claim that the concept users understand autonomy in the same (or similar) way, but that the concept itself has many different dimensions, and different users emphasize different aspects of the concept as important.

This way has recently been promoted by Mackenzie and other feminist philosophers.[110] They think of autonomy as a tripartite concept concerned with self-governance, self-determination and self-authorization; nonetheless, they seem reluctant to claim that any of these may be properly abandoned or neglected in favor of a less complex conceptual understanding.

C) IGNORANCE

Thirdly, we could postulate that the language users are ignorant of the different ways in which the concept of autonomy may be understood, and by simply using the term without further explanation remain vague about the details. This vagueness then leads to problems when the concept is applied. This, as I have shown in the case of *Mrs T*, is commonly the situation in the applied setting, where consistency of language use is simply presupposed and room for conceptual discussion is very limited, because of other pressing professional demands.

The first two characterizations postulate that those involved in the discourse are aware of the differences, but disagree about what autonomy consists in. These are largely the case in the academic discussions. The third scenario presumes conceptual failure and practical difficulties as a result of ignorance, not uncommon in the clinical setting.

All three ways of characterization have in common that there is some disagreement or ambiguity in the use of language, i.e. the concept to which the word refers lacks clarity.

Thus the origins of the conceptual vagueness about autonomy can be traced to a lack of sufficiently shared discourse, which eventually causes practical problems.

4 – THE LANGUAGE ‘GAME’

Discourse problems have been discussed in the philosophical literature in various forms, but in reference to this particular situation I find Wittgenstein’s analysis of language use helpful. In the quote below, he uses the analogy of a ball game to draw attention to problems with communication rules:

”83. Doesn't the analogy between language and games throw light here? We can easily imagine people amusing themselves in a field by playing with a ball so as to start various existing games, but playing many without finishing them and in between throwing the ball aimlessly into the air, chasing one another with the ball and bombarding one another for a joke and so on. And now someone says: The whole time they are playing a ball-game and following definite rules at every throw.

And is there not also the case where we play and – make up the rules as we go along? And there is even one where we alter them – as we go along. “[111]

If we imagined the ball game to be ‘the application of the term autonomy’ we could easily achieve a similar view. From the outside it looks as if everybody who refers to autonomy plays along the same prearranged rules. On first glance the ‘autonomy game’ signifies in some sense no more than the word use. Yet, when one looks in more detail at what rules are employed, things become difficult to analyze. My characterizations of the vagueness could be likened to the game analogy. Imagine proponents of each of the characterizations as members of a team.

a) Team 1 players may insist on the notion that some rules should not be accepted at all in the game, as would be the case for the proponents of the idea that autonomy refers to a very particular, narrow conception, which is dimensionless and denies that certain parameters, e.g. relational aspects or risk relativity, have anything to do with a proper understanding of autonomy.

b) Team 2 players are aware of several sets of rules, but think some rules more important than others, as could be said for the people who advocate autonomy to be understood as a multi-dimensional or cluster concept.

c) Team 3 players just play the ball; they throw it up in the air without any reference or awareness of any kind of rules, just like some people use the term 'autonomy' without any awareness that someone else might see their application of the term as problematic or inconsistent.

The question is, how do we achieve a game that is consistent and recognizable as one game; in other words, how do we ensure that the ACP discourse uses the term 'autonomy' consistently and without misunderstanding?

DISAMBIGUATION STRATEGIES

There are two basic strategies that would work: (i) we either reduce the number of players or (ii) we find a definitive way to clarify the rules.

I) REDUCING THE NUMBER OF PLAYERS:

The simplest strategy would be to reduce the number of players, or (in this case) communicators! On mere probabilities, the less people are involved in the discourse, the lower is the likelihood for misunderstanding and disagreement. However, this is of limited use in the context of advance care planning, because one of the essential aspects of ACP is that it necessarily happens in a social context. The absolute minimum number of 'players' involved is two – the patient and the person enacting the ACP – but when one considers that ACP operates in an environment, which is governed by public law, one has to concede that the minimum discourse really principally involves three parties, even though the legal input is somewhat passive until it is invoked as an adjudicator or instructor.

However, as we have seen in the previous chapters, the number of people involved in the ACP-related autonomy discourse can rapidly increase when the status of a person's autonomy needs to be established. People who now enter the autonomy discourse include next of kin (NoK), a multitude of health professionals, allied health professionals and legal practitioners. All of these are involved in the 'autonomy language game', and even though on mere probabilities the reduction of people involved would improve our chances of agreement and consistent discourse, the player reduction strategy seems a little odd, since the maximization of expertise intuitively should provide us with better, not worse results.

This tension illuminates another interesting and poorly addressed question in ACP: is it more important that we get agreement in discourse, or is it more important to be objectively right about the discourse content?[lxxvi] Reduction of players promotes agreement; maximization of expertise supports correctness of content.

[lxxvi] It is in itself a question worthy of philosophical debate whether autonomy is the kind of thing about which one can be objectively right. For the moment I want to bracket this question (other than to the extent that this question is reflected in the positions of teams 1 and2.) and run with the feasibility of a contextual approach, which seems to be most reflected in the practical setting as we have encountered it so far. I will address dimensions of the metaphysical reality of autonomy in chapter 9.

Although ‘reduction of players’ on first contemplation seems like a counter-intuitive strategy in its undemocratic and illiberal nature and is only a very limited possibility in ACP, it is actually the most universally used strategy to achieve unity. It happens in any hierarchical structure, where the move up the hierarchy reduces the people involved. In situations where agreement cannot be achieved, it is also the only effective remedy available to enforce decision making! Although not attractive in a liberally–minded project like ACP, we will in fact have to return to this point later, when facing the overall conceptual conundrum of ACP, which is given by the diverse commitments of its communal context.

II) CONCEPTUAL CLARIFICATION

Given the unappealing nature of the player reduction strategy, let’s explore options of conceptual clarification.

On this point, Wittgenstein’s account of the language game has further contributions to make. He suggests that in order to succeed in discourse, we need to find a particular degree of precision for the use of the language in question, i.e. one must have sufficient explanation for one’s terms as to remove any seriously doubtful communication. This precision must not be trivial, but sit in the proper context of the language use and the language users, for otherwise we have problems of either infinite regress or inappropriate inaccuracy (vagueness). Wittgenstein illustrates as follows:

”87. Suppose I give this explanation: *"I take 'Moses' to mean the man, if there was such a man, who led the Israelites out of Egypt, whatever he was called then and whatever he may or may not have done besides."—But similar doubts to those about "Moses" are possible about the words of this explanation (what are you calling "Egypt", whom the "Israelites" etc.?). Nor would these questions come to an end when we got down to words like "red", "dark", "sweet".—But then how does an explanation help me to understand, if after all it is not the final one? In that case the explanation is never completed; so I still don't understand what he means, and never* *shall!"—As though an explanation as it were hung in the air unless supported by another one. Whereas an explanation may indeed rest on another one that has been given, but none stands in need of another—unless we require it to prevent a misunderstanding. One might say: an explanation serves to remove or to avert a misunderstanding—one, that is, that would occur but for the explanation; not every one that I can imagine*." [112]

Wittgenstein then goes on to suggest how we arrive at the right level of explanation for the language used. He gives an analysis, which is much more informative and constructive than the terms 'reasonable' or 'common sense', which we find sometimes in professional or plain discourse. He says:

"88.We understand what it means to set a pocket watch to the exact time or to regulate it to be exact. But what if it were asked: is this exactness ideal exactness, or how nearly does it approach the ideal?—Of course, we can speak of measurements of time in which there is a different, and as we should say a greater, exactness than in the measurement of time by a pocket-watch; in which the words "to set the clock to the exact time" have a different, though related meaning, and 'to tell the time' is a different process and so on.—Now, if I tell someone: "You should come to dinner more punctually; you know it begins at one o'clock exactly"—is there really no question of exactness here? because it is possible to say: "Think of the determination of time in the laboratory or the observatory; there you see what 'exactness' means"?

"Inexact" is really a reproach, and "exact" is praise. And that is to say that what is inexact attains its goal less perfectly than what is more exact. Thus the point here is what we call "the goal". Am I inexact when I do not give our distance from the sun to the nearest foot, or tell a joiner the width of a table to the nearest thousandth of an inch?

No single ideal of exactness has been laid down; we do not know what we should be supposed to imagine under this head—unless you yourself lay down what is to be so *called. But you will find it difficult to hit upon such a convention; at least any that satisfies you.“*[113]

From these points we can see the following: in order to prevent an infinite regress of absurd doubtfulness about the use of language and in order to achieve any substantial discourse, it is paramount that the discourse is shared to the degree that each conversation participant is reasonably satisfied with what the language denotes. Hence if any members of the autonomy discourse in the setting of ACP are significantly dissatisfied with the characterization about what the concept of autonomy refers to (or are even just unclear about it), the discourse fails (or could easily fail) and hence ACP fails in as much as its central aim is to respect autonomy.

If I demand that someone respects my autonomy, but they have a completely different understanding of what autonomy is, they may easily fail to show the appropriate respect. The same is true for someone who is willing to accept my understanding, but cannot interpret me correctly, because I am unclear about it.

The autonomy discourse also fails or becomes meaningless, if it is too permissive; when any action, and especially completely opposite actions, can qualify as respecting autonomy,[lxxvii] the idea of respecting autonomy becomes simply vacuous.

As I hoped to show in chapters 3 – 5, elements of all three scenarios are currently present in the ACP setting. There is conceptual disagreement, lack of conceptual clarity and difficulty with interpreting the law reliably in a correct and consistent way, and as demonstrated in the case of *Mrs T,* a degree of conceptual vacuity. The pressing question is, can these issues be resolved? Can the autonomy discourse be sufficiently disambiguated such that general agreement is reached and ‘respecting autonomy’ becomes a meaningful, clear term in word and *deed*?

[lxxvii] Or any action can be claimed to *not fail* to respect autonomy.

5 – PROBLEMATIC DISAMBIGUATION AND GOAL DIRECTED DISCOURSE

The autonomy discourse can be pursued in different ways. One can try to say what kind of thing autonomy is. Answers to this question are purely descriptive. They say something like: ‘it is a right (or capacity or ability) to make a choice’, or ‘it’s a human attribute’. This however, does not help very much in an applied setting, as it leaves no clue how to *identify* autonomy. Even if autonomy is a human attribute, it is not like a colour or smell for which we have a recognition sense organ and it is very clear that there are many human individuals who are not autonomous, e.g. newborns, the comatose etc.; humanity alone is not diagnostic enough. The reference to a right (capacity or ability) for choice, as we have seen in the previous chapters, also leaves a lot of room for disagreement and lacks diagnostic acumen.

A more sensitive way of identifying autonomy as an attribute is to specify necessary and sufficient conditions for when personal autonomy is present. This might include specifying which kind of features are operative in bestowing autonomy on the person, i.e. in virtue of what someone can be said to be autonomous. Candidates for autonomy identifiers might be: humanity, right mental state, health status, age, gender, proper function, sensible decision making record, etc. Some of these may be necessary, but not sufficient, like humanity, some of these may be sufficient, but not necessary, e.g. health or age.

This latter approach is often evident in the discussion of the previous chapters. However, this approach neglects important functional dimensions of the discourse itself. This functional aspect may on the one hand refer to what autonomy does for the person who is autonomous, but it may also include what the concept of autonomy does for the person who uses the concept, i.e. the language user. These functional considerations are intertwined and important in the consideration of why a language user may use or advocate the use of a term or concept in a particular way.

Wittgenstein's analysis makes a correct observation about the importance of goal directedness in our discourse, when he claims that our ideas about correctness of language or concepts is only characterized as sufficiently exact (and thereby acceptable), when it satisfactorily meets our goals. It is this goal directedness to which I want to draw attention, as this is what makes the autonomy discourse difficult and embeds into it some necessary, but fatal contradictions, especially in multi-disciplinary and multicultural settings.

My analysis of the medico–legal and philosophical discourse is highly suggestive that all the necessary parties involved in the autonomy-discourse concerned in ACP have divergent goals, which they want to achieve ***all*** under the name of the same concept. This is problematic, if the goals of use are necessary for the maintenance of the integrity of the concept user.

The basic problem structure is this: if two parties need to pursue mutually exclusive goals by reference to the same concept, their concept use must necessarily fail to the degree that the goals must be maintained. Any attempt at disambiguating and finding sufficient agreement in the autonomy discourse in regards to ACP must therefore be aware of the goals of the autonomy concept user. It must also appreciate to what extent these goals are essential in maintaining the integrity of the concept user, for it is likely that the loss of essential integrity (personal or professional) is likely to be a main cause for disagreement in the concept use.

I therefore want to identify some of the goals that seem to be embedded in the autonomy discourse. In keeping with the previous structure, I will maintain a tripartite approach, in that I will characterize the autonomy discourse within the perspectival approaches of the three major disciplines involved: philosophy, medicine, and law. Parameters under contention within the autonomy discourse were whether to have a substantive or non-substantive approach, whether to count relational factors (if so which and to what degree), whether to set high or low cognitive standards, whether to have a risk sensitive or risk independent autonomy conception and whether autonomy is a partial or global attribute, as well as whether it is a threshold concept and where the threshold should be.

I am aware that this discipline specific approach is in many cases artificial and that in many particular instances a high degree of overlap occurs between the disciplines and that equally a degree of discord appears within the same discipline. Nonetheless, I think there is something to be gained from a discipline perspectival approach, because some of the more general goals applied in the discourse make particular sense when viewed in relation to each discipline's particular intellectual and functional co-commitments. It also makes sense in light of my analogy of the minimum number of 'language game players' in ACP (patient, carer, legal environment), whereby the diversity within philosophy may represent the different perspectives any patient might hold, but may also represent a certain distance between the theoretical and the practical realm.

A) DIFFERENT NORMATIVE PERSPECTIVES

With this in mind it is probably best to explore first which aims in the autonomy discourse are undisputed. There are few. The most uncontroversial and best shared claim which all participants in the autonomy discourse adhere to is that autonomy is an important *good*.

Identifying something as a *good* means it has value of some kind. Judgments of value are normative judgments, hence the autonomy discourse, insofar as it concerns autonomy as a *good*, is a normative discourse.

Something can be of value because of its precious or rare character, like gold for example. We only accept something as genuine gold, because of its special physical characteristics (and not merely because of its color) for it is these special characteristics that make it preciously rare.

Now it is pretty clear that autonomy is not a good in this sense, otherwise it should seem odd that we would want as many people to count as autonomous as possible.

Another way to find something valuable is through its usefulness or the benefit that it confers. Such benefit can be seen either in terms of functionality or some intrinsic feature. This seems a much more apt characterization of autonomy's value.

So why is autonomy important, what benefit does it confer?

Broadly one could say that most answers concerning the benefit of autonomy will revolve around the notions of independence, freedom and separation, and depending on which of these notions we emphasize we may already find normative diversity, which can show traces of profession-specific preference.[lxxviii]

Autonomy as independence allows a view of selfhood, which distinguishes self from others synchronically, and self from previous self diachronically. On this view, my thought and choices become truly *mine* only as the final say is generated by me, now. The emphasis here is placed on notions of self-awareness, authorship, authority of the self and presence. It is largely a first person perspective and has a philosophical, psychological and individualist flavor. It is this first person perspective, which unites the variety of philosophical approaches, for even an individualistic account shares with any relational account the view of the self by the self, even though they may disagree about the factors, which can be legitimately accepted as undermining the self or curtailing the sphere in which the self should dominate.

[lxxviii] I note that many recent philosophical discussions here might analyze the good of autonomy in terms of self-government, self-determination and self-authorization. However, since this is fairly specific to the philosophical debate I want to keep things even broader at this point in order to be inclusive of the other disciplines. Furthermore, I think, that the notions of self-government, self-determination and self-authorization fall also within conceptions of independence and freedom.

Autonomy as a notion of freedom is similar, but has a slightly different emphasis. Autonomy as freedom emphasizes the absence of constraint more than any self-awareness or personal separation. This may be seen from first or third person perspective and seems to be most at home in a political and legal setting.

Autonomy as simple separation from other, i.e. 'functioning independently', merely places an emphasis on separation, rather than anything else. It is a third person approach and very akin to biological observations. It thus gains the scientific perspective of medicine.[lxxix]

Each of the emphasized characteristics are goods: authority, self-awareness, authorship, authenticity, absence of constraint and independent function; yet they are all different in kind and of different importance in different contexts, which in turn is specified by the contextual commitments of the discourse at hand.

The medical discourse has strong commitments to notions of care for the individual, trust, confidentiality, well-being, quality and high standards. The legal discourse in turn has strong commitments to ideas of justice (including responsibility for action and punishment), equality and the public (i.e. a multitude of people). In rough caricature, the medical discourse (at least as far as it concerns ACP) is diachronic and individualistic in flavor (one patient's concern over time) and it tends to see autonomy as a benefit. The legal discourse is synchronic and pluralistic – many people's concerns now - and it tends to see autonomy as a right.

The philosophical discourse is fluid and has as many or few commitments as it chooses, just as any individual might have. It may see autonomy as a right, capacity, benefit or identity-conferring attribute. Whereas the constraints of the professional

---

[lxxix] Note that for example medicine uses the term 'autonomic nervous system', as a descriptor for that part of the nervous system which is independent of the higher brain centers.

discourse come from within the professional integrity requirements of the profession, the individual's (and philosophy's) constraints come from within their individual aims, which can be diverse indeed.

But why, an objection could be raised, would we look at the rough caricature, when we know full well that all the disciplines take a great deal of trouble to consider multiple, complex and competing notions as well?

Medicine, it could be claimed, operates very much within synchronic concerns as well as diachronic problems and it tries to accommodate pluralistic interests. After all, the medical principlism movement, which identified autonomy as only one of the four cardinal medical ethical principles[lxxx] tried to take this complexity into account. Medicine considers the patient now, and also his relatives, and the other patients, and the public, etc. Likewise, law looks towards diachronic consequences of its decisions and considers the individual's private concerns within the public and tries to protect those.

I think that looking at the more skeletal version of professional commitments helps in identifying and explaining why certain aspects of autonomy may be more valued over others within the discourse.[lxxxi] It is the general, reductionist version of professional characterization which lets us see where the conflicted integral part of the professional (and personal) identity is located and which aspects of that identity must maintain coherence within the autonomy discourse. Apart from practical aspects, it is these conflicted characteristics, which best explain why some autonomy aspects are more likely to be discounted compared to others in the perspectival ACP setting. It is also these aspects that address the other functional

---

[lxxx] Alongside beneficence, non-maleficence and justice as the other three.

[lxxxi] Principlism, for example, has never been able to convincingly address the tensions that arise within its conflicting commitments.

aspect of the autonomy discourse, in that they identify what the discourse must do for the concept user.

B) PERSPECTIVAL CO-COMMITMENTS IN THE AUTONOMY DISCOURSE

Within the perspectival normative debate, autonomy is not an absolute *good*. Most discourse participants would deny that autonomy (or its various aspects) should be obtained (or granted) at *all* costs, but the interlocutors vary as to just what price is to be paid in the trade-off between autonomy and other possible benefits. This can play out in two different ways: firstly through the question of whether autonomy should be respected,[lxxxii] and secondly through the way in which we define autonomy.

Some may see autonomy as a valuable good only as long as it will not do significant harm to the person in question; some see autonomy as a valuable good as long as it does not harm others; some see autonomy only as valuable in so far as it is a cognitive tool for working out one's best interest; and some do not see autonomy as a cognitive (or any type of) tool at all, but as a right that can be augmented by supplying cognitive help, where needed.[114] Again, we can see a perspectival, goal-directed, tripartite diversity, which is constrained and shaped by the co-considerations of the professional sphere.

[lxxxii] Since the notion of respect for autonomy has such strong moral currency, I suspect most constraints on autonomy will be found in the second way, such that the charge of disrespect will not apply.

1) MEDICAL PERSPECTIVE – CARE, TRUST, QUALITY

A carer, let's say a doctor or other medical professional, in the direct patient interaction is concerned foremost with the well-being of this individual. She operates in the immediacy of the bedside microclimate in which harm to third parties only figures as a second thought. An expected part, in fact, the central issue of her expertise, is to determine what constitutes well-being for this patient and her actions in regards to this patient are judged in reference to the care of her efforts and the standards of the outcome that her care produces. Many of her actions are required to be proactive and preventative in nature. Her participation in the autonomy discourse is therefore likely to be consistent with these considerations. When patient self-harm is at issue, for example, concerns for diachronic well-–being and cognitive standards are likely to be strong and high, whereas concerns for a patient's personal ideas of self-definition, authenticity or harm to others may rate lower in importance. She might well argue substantively that self-definition and authenticity lose all meaning, if the outcome is a dead or extremely incapacitated person; i.e. when there is no one left to be authentic or self-defining. The not uncommon clinical attitude of 'I may have disrespected the patient's autonomy, but at least he can now complain about it' may reflect this substantive approach. Autonomy as a *good* in itself therefore becomes less important when significant self-harm is at issue, or alternatively the consideration and strategies used to establish the presence of autonomy may become more demanding.

Of course, the force of the discussion now shifts to who can be considered to have the appropriate authority on what constitutes harm. Are physical harm and the harm to a person's sense of self to be treated equally? In what sense are they even comparable? It is here that the professional integrity and source for conflict becomes apparent: for on the one hand, the medical professional is considered the 'expert' on well-being and functional bodily matters and she has to incorporate such a role into her self-definition – it is this particular trust in the doctor's expertise, which is the foundation of the doctor–patient relationship – but on the other hand she is required to deny her own expertise on well-being by putting the patients 'expertise' above her recommendations, when demands for personal autonomy require it. Such a tension is difficult to resolve and it is easy to see that the health professional, who is held to high cognitive and care standards, is likely to demand fairly high standards of patient abilities or capacities, such that considerations for well-being remain reasonably on par. The medical autonomy perspective is embedded in a discourse which has strong co-commitments to quality of process and outcome. Further tensions arise from the fact that the medical professional has a duty to act beneficently, whereas, of course, the patient does not have any such duty at all. The medical role then becomes confusingly contentious as to whether the beneficence duty of the doctor must involve preventing the patient from being ’reckless’ and how this is to be determined. After all, many aspects of the autonomy discourse seem only one step away from questions of negligence, reflected in the well-known modern phenomenon of ‘defensive medicine’. Either way, the autonomy concept in play directly impacts on the integrity concerns of the medical professional and therefore has to cohere with the concerns of this particular discourse. It is easy to see that within the medical perspective, autonomy would more likely be a substantive, demonstrative, risk relative concept, which has a strong cognitive component.

2) LEGAL PERSPECTIVE – RIGHTS, JUSTICE, RESPONSIBILITY, SOCIAL INCLUSION

The law operates in a public macro-climate. It is first interested in preventing public harm, and harm to self, although important, is a secondary concern after this. At the same time, the law takes a highly protective stance against interference from others, and attempts to enshrine individual rights. It defines many of the basic rights in terms of our humanity (i.e. human rights), which is minimalist and vague in the extreme. It defines only where it is asked to define, and tends to be reactive rather than proactive in nature, which tends to make its approach more synchronic than diachronic.

The legal discourse also has strong concerns for issues concerning responsibility, especially when harm raises a claim for justice and punishment. Responsibility and just punishment are heavily tied to notions of autonomy. Since the eighteenth century it has been felt unjust to see those as responsible who are not considered to be able to choose their actions.[115] Hence autonomy is one of the foremost prerequisites for concerns of justice, but is also heavily connected to issues of cognitive capacity. However, since autonomy is also viewed as a basic human right,[lxxxiii] which ought to be maximally inclusive,[116] severe constraints and tensions arise in terms of tight quality cognitive concerns, since any raise in cognitive quality demands necessarily becomes exclusive.

Legal autonomy must emphasize characteristics which enable maximum participation, responsibility for actions more than outcomes, freedom from interference and prevention of harm to the public as well as individual harm, all at the same time – no mean feat! Given these conflicting demands, it can be seen why autonomy therefore may gain in importance relatively independently of self-harm issues, when self-harm is no public concern, and why self-harm may receive lesser emphasis in the overall picture. And although cognitive concerns are of basic necessity to maintain a discourse of capacity for responsibility, the same cognitive demands must be low enough to allow maximum participation and preserve notions of private individuality.

Whereas medicine is always particularly concerned with the 'evil' of physical threat, as this is the basic thread in its overall discourse, the legal discourse sees its moral adversary in terms of breaches of justice (reflected as breaches of right) and hindrances to private flourishing. Hence it is not difficult to see that breach of

---

[lxxxiii] We remember that ACP was first justified within the body of law based on the human right to privacy and freedom from bodily interference from others as described by Kutner.

autonomy, insofar as it constitutes the breach of a right, may be seen as a greater evil than mere physical harm. A threat to the governing principle, i.e. the right, must be of greater concern than a threat to the individual, who is covered by the right; hence the law seems to take a more procedural stance in this respect. Furthermore, given its drive for maximum inclusiveness, it is likely to set standards as low as reasonably possible. Other autonomy parameters may be inconsistent given that the aim of protecting the individual may conflict with the aim of protecting the public and that the aim of setting professional ethical standards (e.g. in terms of negligence proceedings) may conflict with the aim of not wanting to set ethical standards for individuals and with the aim of being maximally inclusive.[lxxxiv]

3) PHILOSOPHICAL/INDIVIDUAL PERSPECTIVES – ANYTHING!

Individuals may hold any variety of concerns regarding harm. An individual who wants to push for his freedom, may discount harm to others or self altogether. He may disagree in regards to what can be counted as self-harm, or attach different significance to different kinds of harm (such was the disagreement between Socrates and Crito). An extremely altruistic individual, e.g. Jesus or someone following in his name, may see harm to others as a great evil which is to be avoided at all cost, even at cost to his own well-being. An individual has the least amount of pressure to adhere to any particular *shared* discourse, except of course, when the need to share is required to achieve a personal goal. To what extent this is the case in ACP is interesting and may be highly contentious. For on the one hand, ACP seems to hold the ambition of wanting to ensure the preservation of individual independence, and on the other hand, a shared discourse is needed in order to be

---

[lxxxiv] We remember here for example the conflict arising from not wanting to call ‘under-informed’ people non-autonomous, but at the same time wanting to ensure minimum standards for the provision of information in the name of enabling autonomy.

heard within the 'language game'. Insofar as the individual needs to adjust her own goals in order to even be recognized within the discourse, her individuality and first person perspective are in direct conflict with the social requirements of ACP. This is the direct result of the fact that ACP has a liberal aim, but is paternalist (in a protective sense), in nature. ACP will only protect insofar as the patient, who is meant to be protected by it, agrees with the rules of engagement; yet at the same time these rules of engagement are removed from her authority.

C) IMPORTANCE OF INTEGRITY CONCERNS

When a disagreement about the correct bounds of autonomy happens on an interpersonal level, it threatens only the moral integrity of the individuals and the conflict is relatively contained. It is also more likely to be resolved as it involves fewer players! However, if the disagreement happens on a level where it is bound to the professionally enshrined duties of due care or due justice, larger issues are at stake. In this case the reconciliation of a discourse disagreement is less likely to occur, because of the multitude of participants involved and the threat to the coherence of their professional nature. Thus the likelihood of discourse failure (i.e. sustained disagreement) increases.

Integrity concerns are not trivial concerns, because they are identity threatening!

Here is the dilemma: within a discourse on ensuring rights and justice, the discourse of trust and care are ill at ease, and within the realm of care and trust a discourse on the ensurance of rights seems misplaced. Yet, if the law could not be confident in its authority on the determination, nature and extent of rights and justice, and if it would have to subject its central concerns to extra-legal parameters, it would lose its meaning and purpose. It would substantially lose its own identity. Likewise, if medicine would lose its central emphasis on care and well-being, it would become a puppet on the strings of various external dictating forces and lose essential aspects of *its* identity. The same can be said for a person. If she cannot be considered the authority on what is central to herself, she loses *her* essential self-definition.

Rights, well-being, authority and self-definition: autonomy has a foot in each camp. It is a multi-footed monster of polymorphic appearance that stands in front of a mirror and projects its likeness across the universe, happily prostituting its services to whoever needs to use it in their projects!

Those who see forms of personal constraint and interference as a great evil will likely argue that autonomy, understood as lack of interference, is a very important *good* (or right), which should be available to the maximum number of people possible; and they will say that therefore the hurdle of what counts as autonomous should be set low, such that many will escape the evil of interference. Such discourse has strong commitments to privacy and equality, which are political or legal concerns, but it is silent about quality issues.

Those who are interested predominantly in certain quality outcomes or at least quality processes, as is common in medical, scientific and to some extent philosophical and individual discourses, may tend to set the bar for certain autonomy considerations higher and trade off more easily concerns for the inclusion of a maximum number of people, and the individuality or the protection of others.

Interestingly enough, all these approaches to autonomy are somewhat *paternalistic* in nature, if paternalism is understood in the sense of 'protectionism'. They all want to protect from something; they just identify different evils as more pressing than others. Libertarians want to protect from lack of freedom, carers from lack of quality care, individuals from lack of individual self expression. The heart of the normative autonomy discourse in this sense is as much a debate about respect for autonomy, as it is a defense of paternalism – albeit, a debate about the right kind of paternalism.

One aims more at protection of the self from the self over a period of extended time, which is the integral business of medicine in the sense that medical care helps a person manage their body, when it does something the person essentially does not want[lxxxv]. The other aims at protection of the self from others at any one time, the integral function of the law. The patient, culturally diverse and not necessarily in allegiance with either the medical or the legal project, may have variable concerns of protection of her own: she may wish to protect critical diachronic interests over time, she may wish to ensure the preservation of experiential interests at any one time or she may simply eschew any interference from anyone at all, but find herself too powerless to enforce her wishes. She may even reserve the right to be inconsistent in her wishes over time, as autonomy is precisely meant to ensure that, too!

Seen like this, it is not surprising that views of autonomy are discordant at times, because what we appreciate about autonomy has to cohere with a network of other concerns and projects, which are variable across time, place and context and which are important for maintaining integrity. These wider concerns can be and sometimes are antagonistic.

Thus integrity concerns strongly limit the possibilities for autonomy discourse disambiguation.

Of course, in some sense vagueness can be seen as a benefit, as it allows a collection of views to come together without being explicitly exclusive. To put it in Wittgenstein's picture, it allows everyone onto the playing field. Viewed from this angle it may be seen at least as a starting point for a discourse or as a unifying envelope for diverse, but related concepts. This may initially look appealing,

---

[lxxxv] E.g. medicine helps to protect the person from a cancerous growth of their tissue, from acquiring or suffering an infectious disease, from adverse outcomes of mental illness, etc. Where 'protection' or help of that sort is not needed, medicine's role is miniscule. Given that disease takes place 'within' the self, practicing medicine can be understood as protecting what the self wants, from something that (part of) the self does.

especially in culturally diverse circumstances and it is particularly obliging to the legal perspective, in that it panders to the reactive and quietist aspects of the law (unasked questions are not answered), and that it is maximally inclusive. However, vagueness is directly antagonistic to certainty requirements and it does not allow the particular determination of specifics other than in a very permissive way. This may be of advantage in situations where local conflict is rare, but regional differences exist.

For example one could imagine a situation within one institution, e.g. a local hospital, where all parties concerned agree that certain high cognitive standards or a non-risk relative view of autonomy should be employed. This would be permissible if the term autonomy was free to be interpreted that way. If no discord appears between the parties involved in that institution, the process remains legal. Likewise, if all parties settled on a different version of autonomy interpretation without discord in the next hospital that also could be legal. However, such permissive nature makes the law somewhat redundant, as it does not solve anything. It only permits differences subject to self-regulation. However, agreement isn't really the problem!

The problem is where differences in the dialogue about autonomy persist in virtue of their necessary contextual constraints. As I have suggested in light of the many clinical cases which have been disputed over time, it is reasonable to claim that ACP has a conceptual framework where such contextual constraints persist to a high degree and attempts at disambiguation are unsuccessful in resolving disagreement.

Where the discourse on autonomy fails in such a way, a hierarchical approach is necessary in order to obtain coherence and consistently predictable solutions. This means that we must limit the authority of the discourse participants in applying their own interpretation of what autonomy refers to. The question then is who should have to give in?

The immediate natural answer would be to say that of course the legal interpretation prevails, since the law is what governs our codified social interactions and is where we seek recourse for adjudication. And indeed this is what happens in practice: where there is pronounced discord and enough time, legal decisions are often sought. Yet, as we have seen in the case of *Mrs T*, many cases simply cannot wait for a legal appraisal, for practical reasons. In some cases, where the conflict has come and passed without concurrent legal appraisal, a retroactive decision may seem moot.[117] Medicine in these circumstances often needs to make fast decisions and the law is slow. Often the conflict will not even be recognized as a primary question of autonomy concerns for a long time, as many clinical matters may obscure the situation. There may, for example, be many elaborations on whether a person is depressed or whether a certain treatment is suitable, but not whether depression should actually count as autonomy impairing or whether autonomy is an issue. This may especially be the case where autonomy is falsely attributed to a non-competent person, if the person is in agreement (or at least not in disagreement) with a medical opinion and competence is not questioned.

Furthermore, the law is abstract and remote from the bedside. It may be argued that this puts it in a poor position to be the decisive arbitrator, since it neither has to bear the practical consequences of the treatment (which fall to the patient) nor the immediate moral burden of being the treatment administrator (the judge does not flip the ventilator switch and examine the dead body for a declaration of death). Others think this remoteness is precisely what ensures justice.

Even if we cannot agree on the latter point, it is unmistakably so that *effectively* the practical interpretation of the law at the bedside in most cases is up to the treating team and the patient (and the patient’s kin). Therefore the law needs to be understood and embodied correctly and easily enough by these parties.[lxxxvi] If the legal conception is markedly different or confusing or counter-intuitive, especially to the treating team, the 'correct' legal interpretation will not eventuate *at the bedside at the time when it matters*. This is true even if the retrospective legal judgment should declare the medical treatment team as incorrect in their interpretation of autonomy![lxxxvii] So even if the formal authority on autonomy in a cross-disciplinary conflict is the law, the medical perspective will often be the practically effective one.

Insofar as the patient's ideas about her own autonomy conflict with any hierarchically effective interpretation of autonomy, there is a direct tension with the ACP intent of putting the patient in charge of her future.

In the end the price of social cohesion is lack of freedom of choice.

6 – ANTAGONISTIC GOALS AND PARADOXICAL STRATEGIES

A complicating factor to this already difficult situation is that forms of conceptual vagueness about autonomy do not only arise in an inter-disciplinary context, but can be found within the same disciplines, for even within the same disciplinary context different goals can be at issue at any one time.[lxxxviii] This complicates any

---

[lxxxvi] For practical reasons this needs to happen without the need for lengthy or complicated legal education, since the medical curriculum is already complex and difficult, just as one could not expect a lawyer to perform complex medical diagnostics when determining the client's suitability to sign a legal will.

[lxxxvii] At best the treating team can be called 'ignorant' in these circumstances, and given the previous explanation of how these circumstances arise, it would seem a pretty harsh charge at that.

[lxxxviii] The greater understanding of disciplinary differences here is also meant to include all sorts of cultural differences concerning autonomy which may stem from the multitude of cultural backgrounds of the people involved in ACP and the patients it is meant to affect.

hierarchical solutions, because we cannot simply ascribe the hierarchy along the lines of different disciplines (e.g. law as the governing body at the top), but we must identify and clarify the goals of the autonomy discourse even within the disciplines and then put these into a clear hierarchical order and make this order clearly interpretable. This is probably one of the most difficult obstacles to ACP. Most medical practitioners (and patients) understand and agree with the need to function within the prevailing legal bounds, however it seems practically so difficult to discern, how to translate these into *correct* action.[lxxxix]

For example, in chapter 5 I summarized four contradictory legal requirements, which seemed to apply to health practitioners in regards to determining whether a patient is competent to make her own decisions.

I recall them here for ease of reference:

> 1 – They are required to take (adult) people as competent irrespective of the outcomes of their decisions;
>
> 2 – They ought to protect their well-being, especially when they are vulnerable, but not assume that they know better than them what is good for them;
>
> 3 – They are required to question someone's competence when they have sufficient reason to think them incompetent, which is usually when either their reasoning or the likely outcome of their

---

[lxxxix] This application problem is no doubt intensified by the fact that Australia has a large multicultural population of **recent** diverse origin. This diversity is present not only amongst patients, but also in the medical and legal community and the kind of 'common sense' which arises as a result of long shared cultural traditions may not be as common here as in communities which are culturally homogeneous. This is important as it explains fractured common sense on other grounds than decreased mental capacity!

> decisions vary from what one would expect or would generally regard as good for them;
>
> 4 – When they are suspicious that a lack of competence is present, they are meant to establish whether the person in question has a sound mind ***without*** *recourse to their* **particular** *reasoning or rationality,* but need to establish whether they have adequate understanding of the ***particular*** *facts and circumstances*.

The contradictory elements in these requirements can be explained by the fact that they arose on the basis of insufficient attention to the particular different aspects of autonomy and the subtle pursuit of different particular goals, which each of the requirement aims to pursue separately.

For example, being dismissive of rationality or lack of reasoning[xc] aims at preserving an individual's right to be unwise, not too intelligent or as lazy as they wish to be in their reasoning efforts. It preserves our characteristics as individuals and it takes a clear normative stance in favor of individuality as a valuable good in itself. It also seems to make a statement in favor of autonomy as a holistic concept. It guards against others' paternalistic interference. It is the cornerstone of personal liberty. However, it does not protect the vulnerable very well, nor does it make any attempt to define what it might mean to be vulnerable.

The aim of protecting the vulnerable forces us to set explicit norms; it demands the setting of standards about what a person must be able and willing to do for themselves in order to count as capable of self-protection. Yet, the aim of respecting and enabling individuality antagonizes this. We are loath to specify such

---

[xc] As expressed in the judges' verdicts in ReB (Dame Butler-Sloss), Airedaile NHS Trust vs Bland (Lord Goff) and ReT (Lord Donaldson)

norms, firstly because we have trouble finding a common denominator which satisfies everyone's (or at least a convincing majority's) ideas about which norms are correct in this respect, and secondly, because setting external norms itself seems to contravene the liberal project of non-interference.

A further difficulty arises from the fact that our aims cannot only be antagonistic, but our strategies to achieve these aims can have paradoxical effects and be claimed to support antagonistic goals.

The aim of protecting the vulnerable, for example, can explain the strategy of shying away from making *global* statements about a person's capacities and prefer to look only at particular instances under question. The same approach can support the aim of valuing individuality. By looking at the minimal circumstances involved, one is allowed to be quietist about distant or non-related aspects of life. In restricting questions to particular transactions and their associated particular understanding one is least interfering, yet seemingly not disengaged.

This strategy has at least two advantages: firstly, damage control: if one gets a competence assessment wrong, the person is not wronged completely, the damage is localized to this one transaction only. Secondly, minimization of social exclusion: we hope to maximize an individual's independence for as long as possible, given that one incidence of failing capacity does not jeopardize the person's global independence and we hope that we can maximize thus the number of people in the competent cohort.

On the other hand, this can also have two significant disadvantages:

Firstly, it commits us to re- and re- and re-assessments, which is cumbersome and costly and often outright impossible. As a result we may be furtive, non-diligent or non-attentive to re-assessments. We may resort to easy, but invalid shortcuts, such as employing a test which is not really sufficient to test complex competence issues,[xci] or taking previous assessments as current or being guided by results from tests in other areas, which are not validly relevant to the area under examination. Secondly, as was pointed out to me by a legal practitioner, the idea of autonomy as a being *partially* absent or present can also have quite adverse effects in terms of protecting a person from undue paternalism: because the denial of 'partial autonomy' appears as a lesser wrong than the denial of 'autonomy totalis', it becomes a lesser and more easily overlooked offence.

So even though a concept of partial autonomy may include people with lesser ability or capacity, the threshold of denying capacity may actually also be lower, as it is felt to not be completely denying the person's autonomy, but only autonomy in one instance. Thus by incrementalizing the effect of competence verdicts on the person as a *whole person*, we may lessen the moral impact of the judgment both in a positive and a negative way. This means one and the same strategy can have unforeseeable and paradoxical moral consequences.

All of these aims, protecting individuality for the maximum number of people, reducing paternalism, maximizing independence, protecting the vulnerable, minimizing the impact of wrong decisions, etc., are very valuable aims. However, the problem is that they seem to require contradictory measures for realization in practice, and that one and the same strategy can have two completely opposing effects.

[xci] This criticism is, for example, widely made about the mini-mental-state examination or other more crude forms of orientation testing, e.g. whether someone is oriented to time, place and person, or knows the prime minister or can do basic arithmetic

A further problem of seeing autonomy as a partial phenomenon arises when we consider the particular nature of ACP decision making, which is quite different in nature from most of the decisions in ordinary informed consent considerations. ACP concerns are special, because they generally are patient 'holistic' in that they particularly affect the person's whole life – all aspects of their life! It seems a fair argument that a person who makes decisions that affect all aspects of their life should also be required to be autonomous regarding all of these aspects of their life. As ACP concerns are global, it might well be argued that any autonomy concept used in reference to ACP should therefore also be global. The current 'particularity of understanding' requirements in the common law discourse are, hence, at least confusing or may be inappropriate for the ACP context.

But even if this latter claim can be refuted, it is still the case that the diverse aims within the law lead to a total legal discourse, which is permissive of contradictory elements, because its notion of autonomy is imprecise and variable. As seen, this leads to problems in practice.

One could suggest solving this problem by improving the precision and clarity about our legal conceptions of personal autonomy. Would ACP fare better if the legal autonomy discourse were simply more explicit about its particular aims and their hierarchical value?

Again, I think the required solution cannot be as easy as that, because it is not only the lack of clarity which is the heart of the problem; lack of clarity only obscures it.

7 – ACP'S CONTRADICTORY NATURE

The intractable conceptual difficulty at the center of ACP is *the contradictory nature of what it wants to do*:

a) ACP wants to ensure diversity, but it depends on unity for its success.
b) It wants to pursue contradictory aims under the same rules of governance, i.e. it wants to refrain from paternalism, but at the same time wants to say,

who or what needs protection. Saying who needs protection is only possible through paternalism.

c) It wants to see autonomy as something that can be extended into a non-autonomous phase of life. This is conceptually difficult as it neglects the diachronic aspects of autonomy, which ensure a person's flexibility in regards to their previous life concerns (i.e. current autonomous wishes override previous ones). Autonomy preserves a person's right to change their mind and values over time. It ensures flexibility, yet ACP sets things in concrete![xcii]

Clarity in the autonomy discourse would be helpful in a lot of places, but what really is needed to make ACP conceptually sound is a solution to its intractable contradictory conceptual nature. In practice it seems that this can only be achieved via a clear uncontested hierarchy of goals, yet a set hierarchy of goals of the autonomy discourse seems in many ways to contravene the specific intent and spirit of ACP.

8 – SUMMARY

This chapter has dealt with the conceptual diversity of the autonomy discourse in ACP. It has argued that the origins of such diversity can be traced back to a lack of shared discourse, which has its roots in the different perspectives of the autonomy discourse participants. This is intimately tied to the various participants' goals, and as these are diverse and in some cases outright contradictory, a non-hierarchical

---

[xcii] Those who argue that ACP does not want to extend autonomy but merely respect it, still have the problem of clearly saying what there is to respect and to justify why certain past statements of a person should be governing this person's life in the future. This latter argument is likely to revolve around concerns of identity and related diachronic future concerns. These will be discussed in chapter 9.

and non-dogmatic solution to discourse unity is unlikely. A hierarchical solution seems however contradictory to ACP's ambition, may threaten the professional or other cultural identity of the participants (such that their support for the idea of ACP falters) and may not be practical in terms of enforcement. I have further pointed out that the idea of ACP in itself contains intractable contradictory elements, which remain problematic even if the discourse problem had a satisfactory solution.

CHAPTER SEVEN – Best Interest

1 – INTRODUCTION

So far this thesis has examined conceptual problems of only one of the main philosophical concepts on which ACP is based, autonomy. However, as I have shown in chapter 1 (p. 36ff), ACP is a complex idea, which does not only rest on concerns of respect for patient autonomy, but may also consider independently whether and why ACP is good for a person or a society as a whole. Thus like any other medical intervention, ACP has to be seen in light of other bioethical principles, such as beneficence and justice, as well. For from the fact that some action respects autonomy, it does not follow that respecting autonomy is what should be done in all cases. Doubts of this kind might especially arise in situations where autonomous choices may harm others or lead to persistently poor outcomes for the individual herself. This may prompt us to ask whether respecting autonomy is necessarily beneficial or at least whether it is in the best interest of a particular person to have their autonomy respected. That this is not a trivial or purely hypothetical question becomes clear when we consider some of the safety laws which have arisen out of these kinds of concerns, such as a law about wearing bike helmets, socially enforced immunisation or bans on smoking.

But even if we are convinced that autonomy should be (predominantly) respected, it is not self evident why the autonomous choices of a past person should govern the life of a current or future person. The answer to this concern is rooted in the kind of metaphysical and moral worries which arise in relation to ideas of personal identity.

For these reasons I think the idea of ACP rests essentially on a total of three significant concepts: autonomy, beneficence and numerical personal identity. If we think it is reasonable to promote ACP in practice, these three ideas must form a coherent idea-network, otherwise ACP is likely to fail to make sense to different people for potentially very different reasons.

This chapter aims to take a look at some of the difficulties which can be found in regards to concerns of best interest. Problems of numerical personal identity and tensions arising from networking all three ideas will follow in the next two chapters.

The central claim of this thesis is that considerable (perhaps even insoluble) problems of ACP are of a conceptual nature, even though they seem to appear as practical failures in clinical life, and that this cannot be remedied by attention to the provision of adequate resources or empirical research. By showing that conceptual problems and inconsistencies are not only prevalent within one of the three foundational concepts for ACP, but in all of them, and that even more constraints arise from the necessity of coherence within the bigger conceptual framework, I want to further this claim and draw attention to the great magnitude of the problem. This should then pave a way for the final part of this thesis, which will concern the conceptual limitations that ACP faces as a coherent idea and how these limitations impact on any expectations we might have for its use and success.

2 – BEST INTEREST [xciii]

In 1928 the Czech–German novelist Franz Werfel published a novella called *'The man who conquered death'*.[118] It describes the fictional story of a man who falls terminally ill just prior to the maturation of a very substantial life insurance, which he had hoped would ensure the security of his retirement and the welfare of his wife and disabled son. At the time of his diagnosis, none of the medical specialists thought that he would live to his 65th birthday, the day of importance for the insurance claim. In the story, the insurance matter remains largely a private concern to the patient and his family, removed from the medical awareness, although some of the doctors have an inkling that the patient must have a ‘secret’ that makes him

---

[xciii] In this thesis the terms ’best interest’ and ‘beneficence’ are used interchangeably.

hang on to life so bitterly, refusing even the small measures of comfort which he might have been afforded despite his dire prognosis. Although already in receipt of his last rites, Herr Fiala, the protagonist, wills himself to live on much longer than expected, much to the astonishment of his treatment team. In great suffering he soldiers on two days past the relevant insurance date. This secures the future provision for his widow and son.

Set in the early twentieth century, his care consisted only of simple measures of comfort, such as the provision of bodily hygiene, properly arranged sheets and oral nourishment as tolerated by the patient. Morphine to alleviate suffering was offered, but refused by the patient by thrashing around whenever the syringe was brought near. Modern palliative measures, advanced life support or ACP (as we know it now) were not available. The patient was expected to die and this is simply what everyone waited for. Although Herr Fiala's exact moral or personal motives are left somewhat open to the interpretation of the reader, the point of the story is that even an inconsequential[xciv] man such as Herr Fiala, through a strong identification with his sense of duty, can will himself to live on and thus 'conquer death'. His life extension, at least in this story, is a celebrated victory.

In some sense, ACP can be understood as the late twentieth century extension of this: a way to will one's way forward according to values and wishes one identifies with. Although Werfel's story is fictional, it shows many interesting facets of the complex concerns which may factor when considering ideas of best interest. Furthermore, in 2010, at the inaugural international conference of Advance Care Planning in Melbourne, Dr Saul presented a non-fictional case, which showed uncanny similarities: a man in the terminal stages of advanced metastatic bone

---

[xciv] The original German title of the story is "*Tod eines Kleinbürgers*"; the term 'Kleinbürger' would be well translated as 'citizen of no consequence'.

cancer presented to hospital in respiratory distress two days before his 60th birthday. It was known that this man had lung metastases[xcv] and that these were the most likely cause of his presentation. The lung complications of his cancer were not treatable and the man would die soon, irrespective of any form of treatment.

It was also known that this man had battled his disease for more than two years with various forms of aggressive treatment and that he had an ACP, which was frequently updated and again confirmed on the night of his admission. His ACP was slightly unusual in that, rather than requesting certain treatment limitations, it repeatedly confirmed the request for any treatment that would prolong his life as long as possible, by whatever means available (including advanced life support) even if it would only buy him a short time of life of poor quality.

Further knowledge about this man included that he had lost his daughter and son-in-law in an accident in recent years and had thus (together with his wife) become the main carer for his young grandchild. The man also had a life insurance policy which would mature on his 60th birthday and although this was not mentioned in the ACP, it did become known to the treatment team.

The fictional literary case and the real life case present many similarities, except that in the literary case the power and will to change the cause of events seems to lie only with the person who is suffering the illness. Unlike in the real case, the doctors had no means to prolong the life, and since the patient was ‘only a Kleinbürger’, they possibly had no particular interest in doing so; at least this is how the story is portrayed. The wife, who had a strong interest in prolonging her husband’s life for many reasons, had no power at all. A big difference between the fictional case and the real case is that the literary imagination which created the

---

[xcv] Cancer spread to the lung.

fiction included the depiction of the large variety of motives which may drive a person’s will to live. This includes a gesture towards the obscure nature these motives may have, such as personal memories from the man’s youth and particular associations of his past identity, which are in no way accessible to an outsider and which may even be distorted or at least influenced by the effects of the illness. The fictional case also conveniently places first and third person perspectives side by side, including a first person perspective which, the closer it gets to death, becomes increasingly troubled by a dreamlike delirium.

In the real case the power to influence some of the outcomes lies with the treating team. Given that strong class differences are not at issue here, one may also credit the doctors with a professional commitment to the benefit of the patient. The wife and grandchild certainly stand to have a strong interest in the man’s survival to his 60th birthday on many levels, but as next of kin (unlike in the fictional case) also have certain powers of influence. What is missing in the real case is an insight into the patient’s experiences and motives that goes beyond the mere instruction 'to have his life extended at all costs’.

At this stage we then might ask, what should be done for this man?

In order to guide our answer we ought to have some principles along which we decide and it seems reasonable to assume that these should be the same widely accepted bioethical principles that I mentioned in the introduction to this chapter. Although concerns for justice will probably play a role in the wider scheme of things, especially as precious public resources are at stake here, this shall not concern us at the moment. What is more important here is to work out what would be best for the man (which has to be addressed prior to working out what could be just anyway).

What would be best for the man might be answered in one of two ways: do what he wanted (as per ACP) or do what would be in his best interest, independently conceived.

If we presupposed a certain hierarchy between the bioethical principles, then the question would be less complicated, we would simply follow the top most regarded bioethical principle. However, firstly, it is not usually assumed that such a hierarchy exists [119], nor have we (just yet) established that autonomy should or can be enshrined in past utterances. Secondly, even if we favoured a particular hierarchy of principles as a standard view (perhaps autonomy above best interest) and we were convinced that past instructions count as valid expression of enduring autonomy, we would still need to be able to give a reason to justify the hierarchy and this requires us to articulate how autonomy concerns relate to best interest. We may wish to claim that autonomy is an objective good in itself or only instrumentally good or we might think that autonomy is only a good for those who want to be autonomous. But since all these justifications make an ethical claim about what is good, it must cohere with our claims about how we determine what is in someone's best interest.

So, what is in Dr Saul's patient's best interest?

And in order to do so we need to be able to establish what the man's best interest is.

Is it in his best interest to receive advanced life support, knowing full well that this will neither cure him nor alleviate his suffering, but may well increase it; knowing full well that the remainder of his life will be spent unconscious, with the support of machines and that it will not be long anyway, but that it will grant his expressed wish? Alternatively, should this man receive just simple measures of care aimed at comfort and not have his life prolonged with advanced measures, which would be against his ACP?

3 – TWO WAYS OF UNDERSTANDING BEST INTEREST

In the beginning of the last section I indicated that I would be using the term best interest and beneficence interchangeably. What I mean by this is that I take the attitude of beneficence to mean to act with a view of promoting the best interests of the person.

However, when considering the question of what is meant by best interest we run into considerable conceptual ambiguities, because we have not specified what kinds of interests are being referred to. This is especially liable to introduce confusion in a health setting. Firstly, do we refer simply to matters of health, as in *absence of diagnosable disease*, or do we refer to a more global aspect of their whole life, such as what the ancient Greeks called eudemonia? Secondly, do we mean to refer to peoples' personal well-being or some greater entity of interests, such as their concern for others, which no doubt influences in some significant way how they feel and act and what they want? Thirdly, how do we think about the internal coherence between a person’s deliberation and action, i.e. do we think it possible for people to act deliberately against their own conception of what is best for them? If we don’t, then we must take their action (or documented decision) to be the direct expression of their idea of their best interest.

Parfit[120] gives a brief outline of basic theories of personal interests, which apply to some of the questions noted above. However, the main point I want to draw on from his discussion of personal interest is the basic separation of theories of best interest in regards to issues of preferences and authority. Parfit distinguishes hedonistic theories, desire fulfillment theories and objective list theories of personal interest. Hedonistic theories ask the question, what would make life happiest? Desire fulfillment theories ask, what would best fulfill this person’s desires? Objective list theories suggest that there are certain things, which make life better or worse for us, independently of whether we want or do not want these things?

Of note is that the objective list theory differs from the other two in that it does not require a subjective stance (by the person affected) on the matter in question? It presupposes that there are matters of fact (that anyone could recognize) about value, whereas theories based on desire fulfillment or hedonism deny this. This difference obviously influences, who can claim to know someone's best interests, and hence also affects the kind of obligations that people have, when they are required to act beneficently. If there are objective facts about the best interest of a person, which are accessible without reference to the preferences of the person, then an obligation to consider patient preferences is not grounded in the principle of beneficence itself (although such obligation may arise from concerns of autonomy), whereas if we view best interests as necessarily including person preferences, then the obligation to consider these is integral to the best interest concept.

The hedonistic question of ‘what would make life happiest?’, does not seem to suit end of life questions well, because it seems inconsistent to affirm the possibility that death could be what makes life happier. One could possibly construe a negative version in terms of absence of pain as increasing net pleasure, but I think this is not worth while, especially as preference base accounts of personal interests seem to offer a better approach to end of life questions, so I will not refer to hedonism in the further discussion. The question of what would fulfill a person’s desires best, can be asked most legitimately in end of life settings, especially, when such a desire has been explicitly documented, as in our case above. Nonetheless, as pointed out before, unless one has accepted a preference based account of best interest, one cannot conclude from the fact that preferences have been expressed that the principle of beneficence includes an obligation to adhere to these preferences.

An objective list approach of personal interest would approach the question of best interests differently, in that it would identify as a matter of fact which goods are best for a person to have or achieve, and, as a result, determine what a person should do or in our case what should be done for the patient.

It can turn out that the practical answers based on different theories might arrive at the same practical conclusion, yet they will do so based on different justifications and resulting in different obligations for others. For example one may regard it as an objective good to have one's preferences or desires satisfied (in other words to have autonomy respected), or it may be considered an objective good not to suffer. One may think further that a rational agent forms her preferences based on her notion of what is good. If this were the case then we might think the theories show no essential difference, however, as Parfit points out, this is not so. One difference is that on the objective list theory what is good is a matter of fact, whereas preference accounts deny this. An objectivist prefers something, because it is good, whereas a preference theorist would think something is good, because one prefers it.

One notable difference in consequence of this distinction is, that it is possible to be wrong about matters of fact, which means that anyone determining best interests, including the patient herself, could be mistaken about the merit of the interest in question. Since a desire based account recognizes no such fact about value and one cannot be wrong about one's preferences, it follows that on purely preference based accounts patients cannot be mistaken about their best interest[xcvi]. Hence a preference based account of best interest is necessarily veridical, a feature that is authority bestowing. On this kind of view a person's expressed preferences would authoritatively, necessarily resemble one's best interest. If these preferences furthermore do not coincide with that person's personal well-being, we would have an account where well-being and a notion of best interest can come apart.

One further feature in regards to preference based accounts is that they may differ in regards to which kind of preferences or desires may be taken as authoritatively informing best interests. There are varying views on whether preferences have to be actually currently desired, or would be desired under certain circumstances of

---

[xcvi] The only way in which a best interest assessment here could go wrong would be a mistaken interpretation of someone's statement about their preferences.

rationality or whether they pertain to especially privileged interests, such as the kind of critical interests, which were suggested by Dworkin[121] or whether they fall within a particular acceptable scope of reference. I will comment on some of these differences further on. For now I want to simply draw on one major distinction between two classes of best interest account:

On the one hand we can understand best interest as an objective measure, independently conceived. This may incorporate the appreciation of certain individually held values, but is obtainable from a third person view and is acknowledged as such a view. It does not require a subjective stance. On the other hand, we can characterize the notion of best interest in a subjective way, which in a traces the question of ‘what would this person do (or want), if they were to choose’. This may also be related by a third person , but the third person's own view is not meant to influence what is expressed. In situations where a patient cannot speak (autonomously) for themselves and their interests have to be ascertained via third parties, this may be referred to as the substituted judgement standard. And although substituted judgement could refer to the application of an objectively conceived best interest in lieu of that person's expressed preference, it is not usually taken as such. Substituted judgement standard, as can be seen from the documents examined further on, is usually taken to refer to a standard that is meant to represent what the incapacitated person would chose, if they weren't incapacitated. The only exception here would be if that person had never been able to form or express any significant preferences.

For the remaining discussion I want to characterize the two views briefly as responding to two different questions:

> Objective view - what is best for the person?
>
> Subjective view: what would the person do?

The two ways can come apart in several ways and give very different ways to account for best interest. This can be demonstrated by various[xcvii] ways in which we can analyse Dr. Saul's case.

a) An objective type of interpretation of Dr. Saul's case above may claim that it cannot be in the man's interest to prolong his suffering. He will not stand to benefit from the proceeds of the life insurance; hence making it to his 60th birthday cannot be of any consideration when considering *his* best interests. Therefore advance life support should not be given.

b) A different *objective* way of arguing may say that the man's best interest could be relational in a similar way to how some dimensions of autonomy are relational, and thus concerns for his immediate family are also part of *his* personal best interest. It is therefore in his best interest to live to his 60th birthday and treatment to get him there, including advanced life support, is therefore treatment in *his* best interest. Hence advanced life support should be administered.

c) A *subjective* way of approaching best interest would simply trust that the man had worked out his best interest himself and that his wishes (as per ACP) expressed just that! He wanted to live as long as possible, even if it meant extra suffering and was only for a short amount of extra time. It is also of importance that this man wants to die in the knowledge that his widow and grandchild are well provided for, therefore advanced life support should be given.

d) Lastly it may be said that the man himself would agree that the aggressive, possibly painful treatment prolonging of his life would not be in his best interest, but that his ACP reflects an autonomous choice against his own best interest.

[xcvii] The number of different interpretations is not meant to be exhaustive, but chosen to illustrate several points

Whether we administer life support or not then depends on whether his best interest is of greater concern than his autonomy or not. He may think so, but others, notably those responsible for his care, might disagree about the importance of honouring autonomy over best interest.

Apart from the difficulty that different ways of reasoning about best interest lead to completely opposite actions, there are other similarities with the conceptual problems which we encountered in the discussion of autonomy: the perspectival issue and the problem of conflation of conceptual content. And just as some commonly used synonyms of autonomy may only refer to part of the concept, so we encounter difficulties with terminology in regards to best interest, because the validity of synonyms depends on the different interpretations just given.

We may for example think that *what is in a person's best interest* is always the same as *what is best for this person*? and that denying this synonymy is committing some sort of fallacy. However, in order to answer this we must ask ourselves whether best interest necessarily aims at the well-being of the individual or whether the individual's well-being only constitutes a partial aspect of her best interest. One may clearly distinguish here between a narrow and a wide view of best interest. It would seem that on the interpretations a) and d) given above, it is clearly the case that individual well-being and best interest refer to the same thing, representing the narrow view. Yet, this is not necessarily so in interpretations b) and c) which have a wider conception of best interest. In interpretation b) it is entirely difficult to say where individual well-being starts and finishes, because the relational concerns make it difficult to demarcate individual from some group concerns. If physical well-being was all that mattered, the demarcation of concerns would not be problematic, but the view contests that physical concerns are too narrow in order to capture an adequate idea of well-being and therefore the issue remains unsettled. Interpretation c) however, clearly could incorporate a notion of well-being which is separate from best-interest, because on this interpretation best interest is understood as the practical instantiation of *the best thing to do, all things* *considered*. If best interest is understood thus widely, it could be that factors independent from one's well-being, such as limitations of options, unusual personal preferences (e.g. masochism) or concern for the well-being of others (e.g. altruism), contribute to the general understanding of best interest. On such an understanding the notion of well-being and best interest come apart in the width of concern. From an external point of view, simply reading the ACP cannot distinguish between interpretations b), c) and d) since they result in the same choice, yet, conceptually they are based on different reasoning about how individual well-being relates to the idea of best interest.

Perspectival differences, similar to those encountered in the discussion on autonomy, may also appear in relation to a of best interest. Considering the question of 'the best thing to do' asked from the patient's perspective is not necessarily the same question as asked from the third person perspective, because someone in the first person perspective may consider different factors to someone in the third person perspective, or they may consider the same factors, but give them different weight. These differences may particularly concern the level of obligation to respect a choice or which kinds of interest (wide or narrow) are to be considered. It may for example be reasonable or even intuitive to expect that patients design their ACPs with respect to all of their life concerns, i.e. in regards to an *all things considered* view, but that medical staff by making recommendations about treatment only feel (or have) an obligation to make a recommendation about personal well-being narrowly construed. A patient may have a strong preference about having their choices respected, but a health carer may have competing obligations, which restrict the ability to assent to the requests made[xcviii]. A patient

---

[xcviii] Note the opposite scenario also exists: a patient may not have a strong preference to have their choices respected, or may not have any preferences, but the health care worker may strongly request the voicing of a preference in order to make a particular treatment recommendation.

may think about treatment choices in terms of eudaimonia, life narratives or critical interests, such as Dworkin[122] suggested or as is discussed by Cullity[123], however to consider such wider concerns may be beyond any carer's ability or obligation to fulfil. A doctor's duty for beneficence can easily be described as obliging her to administer prudent treatment in regards to producing states of health (narrow concern), however it is much harder to sustain that the doctor has a duty to make the patient's life go better (widely construed). Similarly, one might question whether an obligation to promote best interests concerns the notion of simply adding a 'good' to the life or whether it concerns improving life conceived as a whole. An example of the former might be to prevent suffering, such as not commencing painful futile treatment, whereas an example of the latter might be arranging for a suitable end to a life story, such as ending one's life as a reliable provider for the next of kin (as may have happened in Dr. Saul's case).

In addition to the scope question, a major concern is the question about who can have the right authority to determine what a person's best interests are. This is a problem for the objective view as much as for the subjective view. The objectivist approach has to specify who is in the right position to construct the correct list of objective goods, whereas subjectivists struggle to exclude preferences, which one would think ought to be excluded from being authoritative. Furthermore, both accounts need to specify in which way beneficence is a genuinely separate concern from respecting autonomy. Objective accounts seem to do better in this regard. Separating beneficence from autonomy is only problematic for the objectivists, if they favour an account which accepts 'having one's preferences satisfied' as a significant objective good. However, even this can be qualified in such a way that preference satisfaction is good only instrumentally, i.e.as long as it does obstruct some other greater good. Another attempted solution might be to put the patient in charge of the objective goods list. But although this is initially appealing, in view of the fact that patients are the ones to suffer the direct consequences, there can be reasonable opposition to this view on grounds of their limited medical expertise, position of vulnerability and the observation that patients are not the only people who are subject to consequences of treatment decisions. This is especially so in the necessarily inter-dependent setting of ACP. Furthermore, it would not be unreasonable to claim that this is but a poor disguise of a subjective approach, as it does not sufficiently divorce objective interests form patient's preferences.

Subjectivist accounts have trouble keeping the distinction between beneficence and autonomy, because both principles share the same justificatory notion: preference. As seen in the previous chapters, discussions of autonomy are focussed one way or another on personal preferences, but they also involve seeing autonomy as an important benefit to the patient, not only because it is presumed that people prefer to be autonomous, but also because it is construed as an objective good. Hence it is perhaps no great surprise that when viewing the concept of beneficence from an angle of what a person wants, the concept of autonomy significantly intrudes. The question thus arises as to how one can keep the two concepts apart? That we ought to consider them separately is not only suggested widely in the literature, but may be seen from the following example.

Imagine the following scenario: a father takes his 3 year old son up to a snowy mountain hut for a holiday. The 3 year old, excited by the snow in the morning, does not want to wait to be dressed, but runs out naked and plays in an avalanche prone snow area.

Would we say it was in the child’s best interest to be properly dressed and not be allowed to play in a snow area that was dangerous? – Yes!

Would we think the father negligent in his care, if he left his 3 year old son to do just as he wishes? Yes! –Why? Because the father has a duty to look after the best interest of his child and we have no trouble determining what this is, objectively! The child’s best interest objectively is to be safe from physical harm.

Does the father not need to respect what the child wants? Well, it would be nice if the father took into account the child’s wishes as well and provided snow play, appropriately dressed in a safe area. In that sense, we do view the preferences of the child as something like a desirable good. However, the question of best interest, used primarily in order to delineate the father's obligations of care, is clearly focussed on the safety issue (as a risk to well-being) more than on what the child wants. The issue of what the child wants concerns autonomy, and a 3 year old is not autonomous.

Now imagine the same scenario 30 years later. The child has grown into a normal autonomous 33 year old adult. The same thing happens. The son excited by the snow and in memory of his childhood restraints runs out naked into the avalanche prone snow to play.

Is this in his best interest?

If we answer no, our best interest assessment remains consistent and objective, we have separated notions of personal preference from best interest. However, this does not commit us to any verdict about the nature of the father’s action or doubt the autonomy of the son, for the father may have no longer any duty of care (or at least a much lesser duty of care), hence he is not negligent, nor do we have to demand that people always only do what is in their best interest. Although some think that rational agents form rational desires based on an objective conception of the good, and that we can make statements about an agent's rationality based on the formation of the quality of their preferences, this does not equate to a statement about the permissibility of autonomous poor choices. Thus we can say that the son does autonomously do what is not in his best interest. Hence an objective approach to the principle of best interest seems to neither compromise notions of autonomy nor commit us to approve seemingly unsafe or unbeneficial conduct. It does however require clarity about whose judgement is to be followed.

If we answer yes, based on the idea that best interest is subjectively based on the son’s wishes, then how we think about best interest has suddenly changed between the two scenarios. Any reference to the ability of adequately working out what best interest is runs into notions of autonomy, yet autonomy is not what we are inquiring about, we want to know what *best interest* is.

If the 33 year old son was heavily intoxicated, such that we thought his ability to work out best interests was significantly impaired, we would have no trouble identifying his best interests, again, objectively. Hence in this case at least what a person wants (and whether he can work this out for himself) seems a very separate issue from best interests. In terms of ACP we could imagine the case that the son may have stated to the father that he always wished he would be able to run out one day and play naked in this area. Then, when intoxicated, he goes about it. He may even intoxicate himself in order to have the courage to do so; would this alter our assessment of what was in the son's best interest? I don't think so. The questions of autonomy and best interest should remain separate issues.

Unfortunately, comparisons of what is better for a person can be very subtle, and the items on the 'best things to do list' can be outright difficult to compare on a single scale, especially when the concerns of a person are ill defined and it is not clear whether we are operating in a narrow or wide scope of concerns. It is here, where we struggle to maintain an objective assessment and where the conflation of principles of autonomy and best interest happens.

Life seems better than death. Yet a little extra life under a lot of suffering may not be better than death. Under these pressured circumstances the question of 'what is better?' turns into 'who gets to say?' – the question about best interest gets hijacked by autonomy and authority concerns. So should we let autonomy concerns intrude on the best interest principle?

In Werfel's story, the question of whether to go on suffering or shed the mortal coil in comfort was entirely in the hands of the patient, but, as seen in the real case, the increased options for treatment in modern times has moved this question more into the communal domain.

ACP advocates point out that it is in these difficult situations, where objective views are doubtful and that subjective approaches should be used; the choice, they say, should be in the hands of the patient, because it is her life that is at stake. With the heightened attention to advance care planning in recent years, this view has moved increasingly into the public domain and can be found in many prominent legislative instructions[124] such as the British Mental Capacity Act (MCA), which was completely revised in 2005 (see further discussion below).

However, moving to a subjective best interest principle leaves us with a number of significant problems:

1 – We are effectively unable to separate the principle of best interest from ideas of autonomy.

2 – Views which see autonomy as a good only if it is in the best interest of the patient to be autonomous presuppose an objective best interest principle; i.e. one must be able to tell whether autonomy is in the best interest of a person or not, independent of autonomy concerns. Hence subjective views of best interest preclude us from seeing autonomy as a good in terms of being in the best interest of the patient. This removes one of the most important justifications of the value of autonomy from the ethical debate and threatens some substantive accounts of autonomy outright. (It would almost suggest that autonomy becomes more of a duty than a benefit or right.)

3 - As far as best interest concerns for non-autonomous[xcix] people are concerned (e.g. the 3 year old child or a heavily intoxicated person), best interest must be seen as an objective measure, since it seems clear that a minimum cognitive ability (which at least makes up an important part of the autonomy concept) is required

---

[xcix] I am disregarding the variety of definitions of autonomy for the moment.

for working out one's best interest. Therefore we face a problem of conceptual inconsistency (or at least conceptual relativity), as we would be required to change ideas of best interest between objective and subjective views depending on the autonomy of the patient.

4 – Whereas the previous points are problems of general conceptual entanglement, a particular problem arises in the domain of medicine, where the notion of proper treatment indications and notions of medical expertise are dependent on an objective notion of best interest.

This can be demonstrated well in the case presented by Dr Saul. In this case it was very clear that the patient had presented as a result of a terminal illness and that he would not survive long with any kind of treatment. In such cases, advanced life support is deemed futile. Futile treatments are considered to lack a *proper treatment indication* and therefore should not be offered. The notion of futility is essentially based on treatment aims and it is at this point where the tension arises, because treatment aims are covertly linked to notions of best interest. A futile treatment is a treatment which does not achieve its aims. Aims of medical treatment are very difficult to define, but whatever definition is used, it employs some idea of (medical) best interest of the patient, qualitative, quantitative or both[125] These aims are usually construed in the narrow sense of best interest.

Dr Saul's patient did receive advanced life support and did live past his 60th birthday, although he did not remain conscious enough to find out that he did. The man was intubated, ventilated and supported until his birthday. All tests that definitively confirmed the 'strong clinical suspicions' of futility were delayed till after this date. The day after the birthday, treatment was withdrawn based on grounds of futility and he died.[c]

According to Dr Saul's presentation, the provision of intensive care treatment to this patient strongly divided the health care workers involved in his care to the point of not speaking with each other over the decision. Those who argued against advanced life support did so based on grounds of futility, the costliness of such futile treatment and the associated injustice to other health care users, who might have used the intensive care resources to better outcomes. Some thought initiating such treatment was cruel to the patient, prolonging his suffering and it was therefore not in the man's best interest. Even concerns about defrauding the insurance were raised. Those who argued in favour of the provision of advanced life support did so based on a number of different reasons: denying the futility of the treatment, given that it seemed to achieve a well-known personal patient goal; respecting the patient's autonomous choice; compassion for this man's family and their dreadful bad luck; reference to the patient's best interest, perceived as a wider notion, which included care for those who were eminently important to the man.[ci]

One of the problems with widening the aims of treatment to notions of best interest other than objective, medical best interests, such that subjective patient wishes might become *proper* treatment indications, is that this may not only abuse

---

[c] Note, this makes it even debatable that we can say his ACP was followed. If the plan states he wants to make it to his 60th then we can say yes; however if it just stated he wants to live as long as possible, then the answer would have to be no.

[ci] Incidentally, the division of opinions of what should be done was repeated at the case presentation. When Dr Saul asked the large number of conference attendees (approximately 500 people) what they would have done, the audience was equally divided!

resources, but hijack any medical expertise to the point where the patient rather than the doctor determines the appropriateness of treatment.

We can illuminate these worries by imagining slight variations of the real case presentation. For example, Dr Saul’s patient might have easily presented one week or one month before his relevant birthday. He would have been further from his goal. Would he still have received the same care, given that it might still have achieved his aim to live to his 60th? The effort to achieve his aim would have been greater, and may have had some greater chances of failing, but it would not have been impossible. We may also easily imagine the patient presenting with a less definite goal. The ACP only stated that the patient wished to live as long as possible, without specifying a particular event. Should we grant advanced life support for indefinite goals? What would the endpoint of treatment be and how do we get a sense of proportionality of effort and benefit? A patient may also request treatment that shows no scientific evidence of benefit, or a 'benefit' which is disputed by the medical profession, such as certain drug seeking behaviour; should doctors be required to provide this? In order to achieve a stable, sensible notion of expertise, there must be limits outside the patient’s wishes, which curtail what may be requested of treatment providers, and it seems that no other principle than best interest can supply these limitations as satisfactorily. The principle of justice could be invoked, but justice only applies where issues of others competing for resources are concerned. This may not always be the case, e.g. where a patient demands ineffective or cruel treatment, or where a patient is providing the means and resources herself, such that injustice issues do not arise.[cii]

[cii] A famous example of this is that of Nelson Mandela, who at the age of 95 received intensive care treatment and prolonged advanced life support at home for about 6 months (see:

An independent objective medical best interest principle is needed to ensure a sense of appropriate matching of medical treatment and medical outcome, a notion of expertise and sometimes, where the distribution of limited resources are concerned, the insurance of a relevant degree of justice.[126]

4 – CONCEPTUAL AMBIGUITIES OF THE BEST INTEREST PRINCIPLE

A number of points in the discussion above are very reminiscent of aspects which were encountered in the conceptual discussion of autonomy; notably, whether an individual is to be envisaged predominantly as a person of individualistic, independent or relational concerns again seems to influence the conceptual understanding of beneficence. We also face interpretational problems of whether an event is portrayed as loss or gain (e.g. death = loss of life, or death= relief of suffering)

Furthermore, there is a recurrence of questions about the scope and stability of medical expertise. However, whereas this problem appeared in a more limited form under the individual medical perspective in the autonomy debate (see p. 192) the beneficence discussion faces this difficulty on a grander scale, as the notion of valid treatment indication is directly linked to the whole scientific fabric of the profession.

In contrast to the scant specifications of how autonomy is to be conceptually interpreted legally, the instructions about how to interpret or pursue the notion of best interest can be found in greater detail. A very prominent example in this case is the *Code Of Practice* which accompanies the recent British Mental Capacity Act

---

ERASMUS,S.&OTTERMANN,B.2013.Mandela'sHealthHistory,www.health24.com/Lifestyle/Man/Your-life/Mandelas-health-history20130610.)

(MCA). It leaves no doubt that best interest questions are to be investigated along a strongly subjective understanding of what a person would choose, were they in a position to do so. It also makes a very explicit point about the supremacy of autonomy over concerns of best interest as determined by third parties. In article 5.3, the *Code* says:

"the Act's first key principle is that people must be assumed to have capacity to make a decision or act for themselves unless it is established that they lack it. That means that working out a person's best interests ***is only relevant***[ciii] *when that person has been assessed as lacking, or is reasonably believed to lack, capacity to make the decision in question or give consent to an act being done."*[127]

Although this leaves unstated any justification for the key principle, i.e. whether this is due to a conflation of beneficence and autonomy, a subjective understanding of beneficence, or due to a hierarchical understanding of how autonomy is to be valued in relation to the best interest principle, it is clear in its instruction.

The predominant subjective nature of the best interest approach (i.e. the substituted judgment standard) further appears in the summary articles of section 5 of the *Code*, which specify the determination of someone's best interests who is found not to have capacity. This is highly relevant for ACP situation as any ACP falls under these considerations.

The *Code*[128] runs as follows:

[ciii] My emphasis

> *"Encourage participation*
>
> *• do whatever is possible to permit and encourage the person to take part, or to improve their ability to take part, in making the decision*
>
> *Identify all relevant circumstances*
>
> *• try to identify all the things that the person who lacks capacity would take into account if they were making the decision or acting for themselves*
>
> *Find out the person's views*
>
> *• try to find out the views of the person who lacks capacity, including:*
>
> *– the person's past and present wishes and feelings – these may have been expressed verbally, in writing or through behaviour or habits.*
>
> *– any beliefs and values (e.g. religious, cultural, moral or political) that would be likely to influence the decision in question.*
>
> *– any other factors the person themselves would be likely to consider if they were making the decision or acting for themselves.*
>
> *If the decision concerns life-sustaining treatment*
>
> *• not be motivated in any way by a desire to bring about the person's death. They should not make assumptions about the person's quality of life."* [civ]

[civ] It is not at all clear to me how one is supposed to arrive at a judgment of a non-autonomous person's best interest without making some assumptions about their quality of life. However, this lack of clarity is likely to be the result of ambiguous wording of the Act rather than genuine conceptual ambiguity, and as it is not the task of this section to analyze the clarity of the wording, but rather the confusion of concepts, I will not pursue this point here.

If one were to analyse these points in a discussion of autonomy, one would probably come to the conclusion that they represent a scalar, partial view of autonomy and the approach has the intention to be autonomy enabling. However, these recommendations are clearly listed under the section ***best interest***, and therefore they could be taken to express one or more of the three following positions:

1 – They express a view which conflates best interest and autonomy. If this is the case, one would have to wonder why autonomy and best interests are referred to as separate principles or concepts at all.

2 – They weigh personal values and desires higher on the scale of importance than objective outcomes, even if the person who has lost capacity is not able to connect these values and desires to the outcomes themselves. If this is the case, then the capacity question becomes somewhat redundant, given that the mental capacity connection between desires, values and their bearing on outcome is deemed unimportant

3 – They represent the view that knowledge of these desires and values are a necessary ingredient to determining best interests. This would mean that we would have to accept two further assumptions:

a) In all cases where wishes, desires and values are unknown, our best interest assessments are necessarily impoverished, incomplete or lacking in essential information.

For adults, who previously had gained, but now have lost autonomy this may be acceptable, but for those who never had autonomy (e.g. the 3 year old snow player), this may be more difficult to accept. There is no reason to believe a non-autonomous person cannot have desires or some values, but there is good reason to believe that they cannot meaningfully connect these to their choices. This is the precise purpose of the Act! To assume that our best interest judgement here must be lacking in essentials does not seem right. Furthermore, third party (e.g. parental or medical or judicial) ideas about best interest may actually shape the development of a non-autonomous person's idea of what is good and therefore should also not be seen as defective.[cv] An example of this may be the legal overruling of Jehovah's Witness parents' choice of denying their children access to life-saving blood transfusions.

b) A subjective approach to the best interest principle assumes the persistence and stability of prior desires and values. This assumption may be criticised on various grounds, which I will discuss further in chapter 8 and 9, but if the stability assumptions are accepted, one has to also accept that they commit us to 'locking' the non-autonomous person into a prior lifestyle.

It seems unreasonable to think that only some interest are stable, but others are not, although it might be possible to think that a person instructs in an ACP to only oblige some interests (perhaps the critical interests) but not others (such as the experiential interests). However, if our obligation to honour interests simply arises from their stability, we would have no grounds for discriminating between the two kinds of interest. If it arises out of the fact that the person's autonomy is extended to reach past autonomy loss via an ACP, we would have few grounds to override experiential interests, because we are meant to respect the extended autonomy. Thus ACP would have to make the further claim that it only extends autonomous critical interests (such as Dworkin believes), but not autonomous experiential ones and it would have to be amazingly specific about which kinds of interests fall under which category. Despite this, if the autonomous person indulges in certain unhealthy behaviours, although they are not conducive to their own critical

---

[cv] The latter may actually also be true for persons of capacity, too, but it is less enforceable, if we adhere to a notion that autonomy is reached at a particular age or some other point. (i.e. a threshold/ global account of autonomy).

interests, and one is not allowed to interfere with these for reasons of respecting autonomy, then it is not clear why this should change after actual autonomy is lost (but maintained with an ACP).

For example, a person who never valued hygiene or attendance to a beneficial diet or non-smoking habits over health concerns should, according to the assumption of stability of values, be maintained in their lifestyle. A diabetic person who never adhered to a diabetic diet should not be restricted to such a diet when they lose autonomy, as this would be incongruent with their previous values and desires, even though prudent medical treatment would suggest such a diet. If they valued a smoke, we should perhaps supply this, too.

This is obviously tricky territory and leads right back to questions of medical expertise, appropriate treatment and guidance. One way out of this dilemma, would be to attempt calling such ‘medically imprudent’ lifestyles ‘weakness of the will’. One may then further claim that such weakness is lost together with the loss of autonomy, or that it may be justly overridden when autonomy is lost, since the assumption behind weak-willed desires are that they do not ‘really’ represent what the person wants (because the weakness of the will interferes with autonomy).

A subjective desire based approach to best interest might attempt to distinguish between ill and well formed preferences and that only the well formed preferences should count as part of best interest. We might call well formed preferences those that the agent would have if she were sufficiently rational, well informed and her actions would cohere with her well formed preferences. One could then claim that the earlier autonomous person, when smoking, acted on actual desires that were ill formed. If we also hold that only well formed desires are obligating, but ill formed preferences are not, we would have a possible solution to say why an autonomous person may act against her best interest, but why we are not obliged to follow suit. However, this would presuppose that the earlier autonomous person was really in agreement about the bad nature of her smoking, eating preferences, etc., but was simply not resolute enough to overcome her bad habits, meaning she was not rational enough to follow an idea of what was good. I don't think that this presupposition really coheres with a subjective account of preferences, but even if we could construe some cases where we call the healthier life style the kind of life style the person would have wanted to lead subjectively, maybe she had second order desires about not smoking, which were just not strong enough, this would not help us on occasions where the previously autonomous person had a genuine and well formed desire to lead an unhealthy life style. In these cases the obligation to honour those well formed poor health choices would have to hold.

I think, any reference to weakness of the will is at best a pseudo-solution to the obligation of locking people into their previous life styles.

Firstly, it either assumes that the best interest is something separate from what the person wants, then we are back in the territory of an objective best interest account; or it assumes at least that there is a difference between a person's actual and hypothetical preferences (the kind that they *'would want'*, if they were somehow different, perhaps maximally informed, rational and strong willed). This would give us something like a hypothetical preference based best interest account, which would presuppose that our best interests can be based on desires that were *never* actual. This would be akin to saying that my actual desires do not reflect my wishes. Although a subjective account of best interests in the setting of ACP needs to be able to claim that best interests can be about preferences and interests that are no longer actual (because one may have forgotten them in the cause of dementia, such as Dworkin's critical interests[129]) this version of hypothetical interests would be claiming that one's best interests could be based on desires that a person *never actually had, but only would have had under certain conditions, which did not actually obtain.* This is not convincing, since a desire needs to be actually had at least at some time in order to ground an obligation for a carer. If a person fears that in the future she may not have the actual desire to consent to the kind of care, which she now thinks best, it seems that on a preference based account the future obligation to fulfil the preference rests on the actuality of the current autonomous desire. It would not be sufficient to say that if I were different now (e.g. more rational) than I actually am, I would prefer something different for my future than I actually do prefer now, and therefore I want those who care for me in the future to honour want I *would* want now rather than what I actually *do* want now.

Furthermore, these hypothetical preferences would be very difficult to ascertain by a third party in such a way that it is not to be mistaken for an 'objective' best interest. The third party would need to make a claim not only about which values the patient actually held, but which she would have wanted to hold. Ascertaining how these hypothetical values would be different from the current actual ones would be especially difficult when we take people's past actual choices and behaviours as a guidance to our ideas of what they would want now. Yet this is commonly done and recommended. Peoples' actual past actions are commonly taken to be more convincing evidence of what they really wanted than their verbal professions. Thus, on a subjective account it is more reasonable to hold that their past autonomous life style should be taken as informing obligations owed.

Secondly, as mentioned above, I don't see any reason why one should one assume that only some wishes and values survive the loss of autonomy, but that the akratic or weak willed desires do not survive. If we think preferences obtain at least some of their obligation inspiring authority from their veridical nature, akratic or weak willed desires are just as true as other kinds of desire, so there is no difference on account of the truth of the preference. If we think the authority of preferences derives from whether they were formed during an autonomous period of life, this would be equally true for akratic and weak will desires. Even if we think the person may have had a concurrent second order desire (e.g. the desire to give up smoking) to not have a first order desire, as is suggested in Frankfurt[130] style accounts of free will, then it is still not clear why the force of the desires or their order should be reversed or changed in any way, simply because the person has lost autonomy. (If one claims that an ACP may authorize such a change of desire force or hierarchy, then it seems inconsistent not to have such authority before the loss of autonomy.)

Thirdly, delineating weakness of the will from autonomy in itself throws back open the whole question of what constitutes autonomy and we enmesh ourselves in a circular discussion, which does not distinguish between interest and autonomy.

The British MCA *Code Of Practice* does not address issues of conceptual ambiguity, but it makes some attempt at securing the notion of medical expertise and guidance in terms of treatment requests. It makes a sharp distinction between treatment request and treatment denial. This distinction can also be found in commentaries on Australian law.[131] In its section on ACP at point 9.5 the British *Code* states:

"People can only make advance decisions to refuse treatment. Nobody has the legal right to demand specific treatment, either at the time or in advance. So no-one can insist (either at the time or in advance) on being given treatments that healthcare professionals consider to be clinically unnecessary, futile or inappropriate. But people can make a request or state their wishes and preferences in advance. Health care professionals should then consider the request when deciding what is in a patient's best interests (see chapter 5 [cvi]*) if the patient lacks capacity."*[132]

The last sentence however has us come full circle, where again best interests are referred to as an objective third party assessment, not as a wish that has to be obeyed. According to this, doctors are not obliged to provide treatment, but they are meant to consider the best interests of the patient (which is what the patient wishes).

[cvi] My footnote: chapter 5 here refers to the relevant chapter in the *Code of Practice*

A further complication is given by the summary section on ACP where the *Code* says:

"Sometimes healthcare professionals will conclude that an advance decision does not exist, is not valid and/or applicable – but that it is an expression of the person's wishes.[cvii] *The healthcare professional must then consider what is set out in the advance decision as an expression of previous wishes when working out the person's best interests (see chapter 5* [cviii]*)."*[133]

On the one hand, this statement clearly separates wishes from interests, but on the other hand it makes the wishes highly important, the latter, surely, being more a gesture towards autonomy rather than best interests. Thus the embedded ambiguity in these statements becomes obstructive in the process of working out whether to understand best interests according to subjective preferences or to more medical objective outcomes, because they want to affirm both potentially opposing positions. This again is very reminiscent of the difficulties described in the autonomy discussion.

In an attempt to evade this problem of conceptual ambiguity and circularity of reasoning, one sometimes encounters a separation of personal best interest from medical best interest, which is akin to the earlier mentioned separation of wide and narrow interests. But although this may sound appealing and is probably somewhat indicative of what is going on in our deliberations about the best interest concept, it has no real practical purchase in the setting of advance care planning. This is because treatment decisions usually affect the whole person and not just their

---

[cvii] My footnote: Apart from the conceptual delineation problems discussed below, one does have to wonder, why an invalid, non-applicable or non-existent directive should be representative of the patient's wishes? What would be the point of the validity assessment?

[cviii] My footnote: again, the Code's chapter 5 is meant here

personal or their medical affairs. If someone suffers a stroke as a consequence of certain lifestyle choices or trauma, the consequences are not restricted to personal or medical interests, they affect both kinds of interests. Thus this division seems purely academic, not practical. From this point of view then, talking about best interests has to be taken holistically and refer to the sum of all interests. Nonetheless, as we have seen earlier, questions of scope do have a significant impact on the question of obligations owed to patients in terms of their best interest. And the potential conflict of obligations in regards to narrow and wide scope interests may aggravate problems of conceptual consistency rather than alleviate them. These difficulties are heightened in considerations of ACP, compared to perhaps some other medical situations, as ACP seems to presuppose a holistic or narrative element in its justification, as Dworkin[134] suggests, and as I will explore further in chapter 9).

5 – ORIGINS AND CONSEQUENCES OF CONCEPTUAL AMBIGUITIES

As with the concept of autonomy we may ask why the conceptual ambiguities exist, whether they exist necessarily, and in what way they matter. We may also wonder whether the conceptual difficulties are recognized as a problem.

I want to begin with the latter question first. As the British MCA has such explicit sections on best interest and ACP, and since it seems in approach in many ways quite akin to the Australian situation[cix], and is referenced in the prominent legal and philosophical literature[135], I think it adequate to take its insights and reasoning on this point as significantly indicative and representative of current public thought. In point 5.5. the code of practice to the MCA says the following:

[cix] For example Skene notes that the more objective Bolam principle which preceded the MCA in the UK was never generally accepted in Australian common law, thus indicating a more subjective approach to best interest here. (see p. 93 of reference given in endnote 86)

"The term 'best interests' is not actually defined in the Act. This is because so many different types of decisions and actions are covered by the Act, and so many different people and circumstances are affected by it."[136]

The lack of definition of best interest as a term here is justified on situational and circumstantial grounds. This seems to express the view that one cannot define an underlying principle in situations where too many diverse types of decisions, types of people and circumstances are concerned. However, if this were the case, many questions would be significantly underdetermined in much the same way as was the case with the concept of autonomy.

On the one hand, point 5.5 could mean that the term 'best interest' must be understood differently in different contexts, which would then leave us wondering, just how it is to be understood in which context. On the other hand, it could mean that what is considered to be in the best interest of one person in one situation may not be in the best interest of another person in the same situation, because they are different persons, who express different values etc.; it could also mean that the people and values are the same and the contexts differ and therefore the best interests differ. On each interpretation the variables for the consideration of what is meant by referring to best interests are different, and by not attempting a definition or at least a conceptually defining principle, the way in which the term is used may have quite different practical applications.

I think that by putting the difficulty of definition down to contextual variation the Act fails to admit the importance of conceptual congruity and clarity and the problems which arise from this. It may even put the difficulty for a definition in the wrong place, for it may not be the differences in circumstance that make a definition of best interest contestable, but rather the conceptual tensions and ambiguity.

If this thought is correct, then we again have to ask where the conceptual tensions originate and whether these tensions can be addressed satisfactorily.

Refraining from a conceptually explicit definition of the best interest principle is at least as much a problem of conceptual ambiguity as it is a problem of circumstantial variety. Thus this is again the result of wanting to achieve too many potentially opposing things from too many perspectives with the *one principle.* In this case it wants to:

(a) ensure individuality, but from a communal base;

(b) allow medical judgement over personal circumstances and at the same time ban overarching medical conceptions of what is good for people;

(c) to be the adequate support for treatment decisions by which we can determine what to do when the patient cannot tell us, but at the same time it is meant to conjure up the missing autonomy.

(d) be operative as an independent ethical principle, but at the same time is asked to surrender its independence to autonomy.

However, whereas the conflicting aims of the principle of autonomy could to some degree be traced back to the different aims embedded in the integrity of professional identities and therefore seen as necessarily embedded in the cross-disciplinary approach to conceptualising the idea of autonomy, the situation is different in regards to the conceptualisation of the idea of beneficence.

If the principle of beneficence is truly understood as an independent ethical principle, then there is no need to abandon an objective third party view of the concept of best interest, given that people's choices would be preserved under the concept of autonomy, provided that we are prepared to admit that autonomous people are entitled to make non-beneficial choices.

Nor does an objective best interest principle commit anyone of any profession to a particular view in regards to the relational or non-relational aspects of best interests, as could be seen in the various justifications for treating Dr Saul's patient. Only philosophical debate can make a difference on this aspect of beneficence.

Nonetheless, in situations where a person is non-autonomous, we may, from a third party position entertain whether certain personal preferences would give a patient greater benefit than strict medical or physiological aims, and take these into account. However, if we felt this were not the case, from a third party perspective (of whichever professional identity), the principle would demand that we judge accordingly and consistently. It would not require us to provide some kind of proxy-autonomy. Thus the pressures on professional identity are not really operative in the objective conceptualisation of beneficence, because the question as to whose choice is authoritative is clear, and clearly removed from the patient.

This is not the case with a subjective conceptualisation of beneficence, because on such a view there is a strong emphasis on recreating a ‘patient perspective’, which is meant to function as quasi-autonomy (or an autonomy–enabling principle) and this very much blurs the delineation of where the decision making authority can be found. On the subjective beneficence view, the proxy decision maker is seen as a mere execution machine, whose own authority is dubious, and whose own concerns, expertise, autonomy and input are of hazy relevance.

So why don’t we just agree that the objective beneficence principle is clearer, more consistent and less ambiguous and therefore should be adopted? Why do the MCA and many other legal positions clearly favour the substituted judgement standard and the subjective principle?

The answer to these questions, I think, lies in three domains:

Firstly, as I have pointed out above, I do not think there is sufficient awareness about the nature and consequences of conceptual vagueness and given that there is little awareness, there is no recognized pressure to address conceptual confusion. The difficulties in practice are traced to practical, situational roots rather than conceptual vagueness, and hence the pressure is railed into the attempts of finding ‘practical solutions’.

Secondly, the subjective best interest principle seems to connect well with a partial, scalar idea of autonomy and the idea that autonomy can and should be enabled through certain strategies. It also sits well with the idea that autonomy loss is a loss of such importance, overshadowing a person's plight in such a way, that any of their other concerns pale against it, and that hence all possible means at restoring as much autonomy as possible must be highest in priority. Such a partial view of autonomy is therefore implicit in the Act, even though the presumption of 'autonomous until proven otherwise' seems to imply a global approach to autonomy (see above, p. 151).This position is actually highly reminiscent of some of the prominent legal perspectives on autonomy (especially the Australian common law definition of capacity to consent, as given in the chapter 5 of this thesis, p. 147) and it may therefore not be surprising to find it embedded in the Act.

Thirdly, a subjective best interest principle justifies to some degree the notion of advance care planning in that it cements the authority of ACP, in the sense that it recognizes the authority of the wishes of a previous self over all future non-autonomous selves and the stability of values and desires over the time in which a person transitions from an autonomous to a non-autonomous phase.

The subjective best interest principle is slightly less convincing for ACPs which are drawn up by a third person on behalf of the patient (e.g. a next of kin or appointed PoA[cx]), because such proxies have limited access to the patient's wishes and values.[cxi] Nonetheless, the thought is that they have better underlying knowledge of

---

[cx] Power of Attorney.

[cxi] I will actually argue towards the end of this thesis that PoA can only be understood as a weak form of ACP, which does not cohere with Kutner's original idea and can only make extremely limited claims towards respecting autonomy. However, as autonomy is not under question here, the substitute decision-maker form of ACP is included in the discussion for now.

the patient's particular views than any professional. Whether this reflects what actually happens is not entirely settled, as this view has been seriously challenged by several empirical studies, which found that close relatives do not do significantly better in predicting patient's preferences than long–term physicians.[137] Other studies[138] however, supported the view that (especially when informed by ACP) appointed proxies do better than (especially hospital based) physicians.

I will examine the point of personal preference stability in more detail in the next two chapters. However, as a final point to this section on best interest, I may note that we have now on many occasions found instances where a number of different ideas must be networked in a particular way, in order to make sense. Subjective accounts of best interest are more consistent with partial and non-substantive accounts of autonomy; objective best interest accounts work more convincingly in conjunction with global substantive autonomy ideas, because they share similar aims and assumptions. The problem is that all of these ideas are apparent in some aspects of the British MCA (and other laws) at some time and therefore it is difficult to identify any conceptual consistency.

As explained in the introduction of this chapter ACP should be regarded as a complex idea that rest on a number of concepts. Given that the complex idea of ACP is based conjunctly on the concepts of autonomy and beneficence, which are usually regarded as independent ethical domains, we should require these to form a consistent conceptual network, because inconsistent ideas lead to confusion, inconsistency of practice and conflict.

Combining inconsistent ideas, especially ideas which pursue contradictory goals, seems irrational. Hence, the consequence of networking vague or conflicting concepts makes ACP not only vulnerable to the charge of inconsistency, but even to the charge of irrationality. At the very least it significantly constrains the claims ACP can legitimately make, and thus will affect its public acceptance and successful implementation. This problem grows in difficulty the more conceptual variety is to be accommodated. That we have not yet encountered the full magnitude of the conceptual problems for ACP can be seen in the next chapters, which will identify similar difficulties of conceptual diversity in regards to the metaphysical dimensions of ACP.

6 – SUMMARY

This chapter introduced the conceptual problems arising from diverse interpretations of the concept of best interest. I distinguished between two main interpretations of the idea: a subjective (preference based) and an objective view, and illustrated some practical consequences of each view with relevant clinical examples. I further commented on issues which may arise from a disagreement about the scope of relevant interests to be considered, which is reminiscent of the perspectival problems seen in the discussion of autonomy. Although an objective view answering the question ‘what is good for the patient’ seems to offer better conceptual clarity and conceptual independence from notions of autonomy, it is nonetheless not favoured in current thinking on ACP. I suggested that this is because it sits poorly with competing ideas of autonomy, especially partial, scalar accounts and hence poses trouble for an overall coherent ACP framework.

I further noted that the relevant legislation, although more explicit in formulating a preferred conceptual interpretation of the concept as subjective, i.e. answering the question of what a patient would want, seems ignorant and extremely unclear about the conceptual tensions involved in this preference, nor does it apply this kind of interpretation clearly throughout the relevant legislation and recommendations. This can lead to similar practical dilemmas and difficulties of interpretation as encountered with the application of the autonomy concept, and it thus magnifies the problem of finding a conceptually coherent framework in which ACP can operate.

CHAPTER EIGHT – NUMERICAL PERSONAL IDENTITY AND SURVIVAL

1 – INTRODUCTION

The previous sections have dealt with the diverse conceptual interpretations of autonomy and beneficence, and the significant conceptual interweaving that can be found between these two concepts. This chapter will deal with the concept of numerical personal identity, which also has important connections with the other two concepts when used to establish a philosophical framework for ACP.

The idea of personal numerical identity, like the idea of autonomy, is subject to a large volume of philosophical scholarship, which it would be impossible to cover in detail within the span of this thesis. However, some main themes and points from the identity literature are important to consider in a conceptual analysis of ACP, because metaphysical and ethical objections to ACP as a coherent idea can be made based on ideas of numerical identity, and some conceptions of identity can seriously challenge some conceptions of autonomy. Indeed, it is probably within the exploration of questions of identity, rather than beneficence or autonomy, where ACP has had the most direct philosophical attention.

Furthermore, an analysis of some basic accounts of personal numerical identity shows that some conceptions of identity seem to pander to very particular purposes and thus are highly perspectival in nature. This in turn connects to a theme taken up in the last two chapters, which is to identify who is more likely to adhere to what kinds of identity accounts and consequently arrive at particular views about ACP. Given that ACP is meant to make sense across a diverse professional and cultural field, the generation of conceptual perspectives may then again shed light on likely conceptual restrictions of ACP as a holistic idea and may contribute to an explanation of why ACP has limited success.

2 – PERSONAL NUMERICAL IDENTITY

When a person makes an ACP she expects it to apply to herself and not to anyone else. In an important sense she expects to be the same being over time, such that the directive applies undoubtedly to her. She also implicitly assumes that her current values and wishes should govern what happens to her in the future. Likewise, from a third person perspective, if we accept someone's ACP and act on it, we demand that this plan was drawn up by the same person whom it refers to. Where this is not the case, we at least want significant substantiation that the person who provided the instruction stands in the right kind of authoritative relationship to the person to whom the ACP applies, such that she is entitled to give directions of this kind.

Our expectations of persistence over time, such that we refer to an entity as being the same over successive episodes, are captured philosophically in the concept of numerical identity, whereby the term *identity* refers to the attribute of sameness and the term *numerical* adds clarification as to number, given that very alike looking things are sometimes referred to as 'identical'. We may for example talk about identical twins, but by no means wish to say that we are only talking about one person. So when we are talking about things being numerically identical, we particularly want to express that just one object has persisted over time and that it is this object we are referring to. Because we are referring to persons in the context of ACP, the appropriate concept in this discussion is numerical *personal* identity.

In terms of being a foundational concept for ACP, numerical personal identity is important for two reasons: firstly, because it may be needed to ground ACP's moral authority with regards to satisfying our expectations about the correct relations between author and subject of an ACP; and secondly, because the integrity of our concept use must be coherent across our thinking about all aspects of patient care, otherwise we run a risk of being charged with irrationality and confusion. If for example we call someone the same person because they have persistent biological features, but at the same time imply a denial of person-sameness because their mental features have not persisted, then we are unable to say whether or not they are the same person in the relevant sense necessary for ACP. Likewise if we declare someone dead based on the absence of any mental states, we cannot call them alive at the same time based on the persistent functioning of biological systems. Concepts like life and death need to be mutually exclusive, otherwise practical medico-legal and other cultural mayhem ensues; e.g. if we attribute rights to a person based on the fact that they are biologically alive, then we cannot deny these same rights based on the fact that they have mentally died. This chapter therefore seeks to examine whether particular personal and professional commitments about personal numerical identity may incorporate requirements that are in tension with identity requirements for the conceptualization of ACP. Such tensions would be problematic, because they would either beg for a justification of why different identity accounts should be used concurrently or (more likely) expose conceptual incoherence.

3 – NUMERICAL IDENTITY AND AUTONOMY

The relevance of identity questions in the context of advance care planning first received attention in the late 1980s by Buchanan[139], who acknowledged the challenges identity questions posed for ACP. However, it was not until the 1990s that the interdependent conceptual connections between concepts of identity, beneficence and autonomy received some attention in Dworkin's[140] discussion of ACP in regards to the case of 'Margo' published by Firlik[141] in 1991. Margo was a woman with severe dementia, who nonetheless seemed to pass her days very happily with the help of her carers and with such repetitive pursuits as she could manage. She enjoyed reading random pages in the same book over and over, and painting the same picture day in and out. These occupations seemed to give her great satisfaction. In fact Firlik, who had met Margo on a geriatric elective as a medical student, commented specifically that *"despite her illness, or maybe because of it, Margo is undeniably one of the happiest people, I have known."* Dworkin asked us to imagine that Margo may have had in place an advance directive that called for no active treatment in case of such an advanced state of dementia and concurrent illness.

Dworkin then went on to give an account of autonomy which involved the idea of a personal narrative. As part of this account, he suggested that people have basically two different kinds of life interests: experiential life interests and critical life interests. Experiential interests refer to the liking of individual experiences, which are not essential to a life narrative. Having these experiences is pleasurable or good, but life would not be going wrong without them. Critical interests however concern events which apply to life as a whole. They guide life's fundamental decisions and are reflective of the kind of person one is.[cxii] Critical interests are the type of interests which guide an individual's personal narrative and about which the person would feel a strong sense of loss, if they were not respected or achieved. As part of his integrity view of autonomy and supported by claims akin to a subjective view of beneficence, Dworkin proposed that advance care wishes ought to be taken as an expression of critical interests and constitute precedent autonomy. Because a person would ordinarily not feel a loss at the denial of experiential interests and experiential interests are all that remain in advanced dementia, this should ground a reason to believe that the critical interests should be taken as surviving into the time when a person is no longer competent and should therefore be given due respect. For Buchanan[142], as for Dworkin, the survival of certain interests grounded the moral justification of ACP much in the same way as the survival of interests is morally recognized in ordinary wills.

Dworkin explicitly made the point that if we did not understand advance directives as the enforcement of an individual's surviving *critical interests*, we would not have any good reason for why we should respect the content of an advance directive, if

---

[cxii] Some of this was discussed in detail in chapter 3.

its author can no longer speak for himself (say in dementia); i.e. if we believed the content of an advance directive to refer to something like experiential interests, it would not make sense to emphasize the fulfillment of these interests, since the person himself could no longer feel a loss about their neglect.

Although a very plausible argument in framing the intellectual landscape for ACP, this account neglects a number of important points. Firstly, when ordinary wills are concerned, the interests which survive are 'disembodied' such that no competing body remains in place, which could mount a claim to different interests. Hence the comparison of 'living wills' with 'ordinary wills' is difficult in situations where such conflicts exist. Secondly, for people who can no longer appreciate 'their' life narrative, experiential interests may have greater importance and the non-fulfillment of such experiential interests may constitute a bigger proportional loss, much as the loss of a penny means little to a millionaire, but the world to a pauper. In response to Dworkin's publication Dresser[143] questioned the feasibility of his account. As the loss of autonomy does not necessitate the cessation of experiential interests, it may sometimes be reasonable to believe that their relative importance increases in the individual's life at that time and therefore cannot simply be denied on the basis of surviving critical interests. Dresser also pointed out that the very low incidence of ACP amongst the public may be an indication that people care less about their future mode of treatment and mode of death than Dworkin's critical interest account would suggest. However, more importantly, she questioned (as before her Buchanan had done) whether the decline of a psychological state would even allow us to refer to a demented patient as the same person as the non-demented person. But unlike Buchanan whose framing of doubts came before the case of 'Margo' and who basically dismissed the realistic likelihood of such cases of genuine interest competition, Dresser appreciated their realistic possibility and the difficulty resulting from genuinely competing interests between the demented and pre-demented individuals.

Essentially, the problem at hand consists in the fact that different aspects of human life (biology, values, interests, mental states) have different persistence spans. This opens the avenue to disagreement about what kinds of attributes persist and which of the persistent features are essential to the survival of the person as a whole, in such a way that certain rights, responsibilities and moral claims of the person persist also.

In the accounts discussed by Dworkin and Dresser, the disagreement is about the survival of certain interests and their importance in grounding certain rights. Dworkin thought critical interests survive and are important to a certain understanding of autonomy, which grounds the rights of the person in a particular way. Dresser suggested that the survival of significant experiential interests cannot be so easily discounted, nor be reliably predicted and therefore she thought the overall importance of a life narrative and critical interests becomes questionable when designing ACP policy. She seriously challenged the account of precedent autonomy, which presumes the persistence of personhood (in the relevant sense) despite severe psychological decline or change. And although the dispute was conducted in terms of autonomy and interests, the basis for it revolved around questions of numerical personal identity.

Other discussions in the identity literature deny the existence of a life narrative for personal identity concerns altogether, and do not involve concerns for autonomy so directly. They may refer to a variety of other features, such as biological life parameters or the continuity of psychological attributes, as important for personal survival. The following section will give an overview of some salient features of different identity accounts with particular reference to ACP.[cxiii]

4 – DIFFERENT IDENTITY POSITIONS

Philosophically the questions of (a) '*what matters in survival?'* or (b) *'what are we essentially?'* make up the core of the identity debate. Some authors conflate these two questions, arguing that they essentially aim at the same content; others[144] see important differences between the answers to these questions and therefore take pains to keep them apart. This is especially so where numerical survival and structural survival come apart and where the discussion is aimed to distinguish matters of importance. Which position is taken depends, I believe, largely on the context of the discussion and one's wider metaphysical commitments.

The subtle differences between the questions may even map in certain characteristic ways onto different personal and professional approaches of thought. However, for the purpose of the current enquiry about ACP I will treat the above questions (a) and (b) as roughly equivalent for the moment without distinguishing between rival metaphysical views, and only note in passing that the distinction may

---

[cxiii] As the identity literature is vast and occurs in a large variety of settings, the given selection is necessarily wanting in much detail and acknowledgement of many a prominent philosophical figure and/or idea. However, as this thesis is focused on the greater framework of ACP, the following more focused view should suffice.

be of some importance in the coherence of the wider network of beliefs.[cxiv] For matters of ACP, the meaning of 'survival' largely matters in terms of *the unit that will command (or be owed) certain moral treatment* and hence I will for a large part of this discussion conflate essence and survival in the term numerical 'personal identity', before returning to its impact on the conceptualization of ACP at the end of this chapter.

The following section will sketch out three general positions on identity, which will roughly reflect the important differences that matter in the ACP discussion and allow the illustration of the greatest points of tension in the conceptual framework. The three positions try to answer the two questions given above according to different criteria, and they can be grouped accordingly. There are biological views, psychological views,[cxv] and complex, substantive views of personal identity – each has distinct advantages and disadvantages and some manage to capture different moral intuitions better than others, but none succeed in providing entirely satisfactory answers to all aspects of ACP.

[cxiv] One may think for example that a metaphysical realist approach seems more coherent with a scientist's view of the world and may therefore be more common among scientists, who would be more likely to favor identity concerns answering the second question about what we essentially are; metaphysical idealist (or dualist) views seem more coherent with views more common among spiritual and arts communities, who therefore would be more prone to emphasize the first question about what matters about us. And although the examination of a philosophical framework of ACP is a philosophical undertaking, this consideration is by no means restricted to the metaphysical views held by mainstream philosophers, but rather must consider the metaphysical outlook of all who may be involved in ACP. How this might impact on wider belief sets and ACP acceptance as a practice is discussed in chapter 9.

[cxv] As narrative identity views are special cases of psychological accounts, I will not treat them separately in the following section, because they share many of the relevant general psychological account worries. Since narrativity is important to ACP however, I will simply point out the relevant features of narrativity in regards to ACP as they become evident in the ongoing discussion.

A) BIOLOGICAL (ANIMALIST) VIEWS OF IDENTITY AND SURVIVAL

Biological views hold that we are essentially organisms, i.e. particular biological units. The definition of a biological unit varies between different identity accounts, but they all share a number of common criteria:

1 – Disintegration of the biological unit is the cause of death

2 – Death is a biological event and therefore can be objectively determined by science

3 – Questions or phenomena of consciousness are a *mere function* of the unit, which is not essential (non-determinate) to its survival.[cxvi]

Based on these common criteria biological accounts characterize organisms as biological units, which resist physiological disintegration. This has been stated commonly in one of two ways[cxvii]:

[cxvi] Biological accounts formulate identity concerns more along the metaphysical question of 'what we are essentially'. However, in order to have any relevance to the moral concerns of ACP, biological accounts imply that questions of consciousness are not what matter in 'survival'. Note that if the biological view is formulated semantically in terms of existence, this distinction becomes quite hazy. Someone may say that biologists contend that we continue to exist after death; just we exist as dead animals. This would make sense in some ways. However, it would not make sense to say that we survive as dead animals. Given that ACP is not about instructions for the time after death (this is the task of an ordinary will), the claim about existence seems the wrong one to use.

[cxvii] A third common way to characterize biological units is through genetics. A genetic biological account revolves around genetic consistency. Cessation of a being happens upon interruption of genetic make-up. On this account, the death of an organism would presumably be achieved by significant genetic alteration or engineering, but not by direct interruption of physiology in the homeostatic sense. In the current debate about advanced directives and end of life questions, such an account has little to contribute. Yet, it is worth noting that with the advance of genetic

> i) A living organism is one, which maintains the integrated functioning of the organism as a whole. The death of an organism means its "permanent loss of organic integration preventing function as a whole".[145]
>
> 0r
>
> ii) A living organism resists entropy characteristic of inanimate matter by maintaining a system of integrated somatic functions, thereby maintaining a particular form.[146]

Version i) is a characterization which has in mind complex organisms, made up of a number of large independently understandable sub–units (i.e. organs), such as the human body. It aims at emphasizing that even though the complex sub–units may survive independently, the whole of the being's survival cannot be assumed, unless these complex sub–units survive working *together in the right way*.

This kind of definition has the particular objective of legitimizing a diagnosis of brain death[cxviii] as a valid diagnosis of death of the whole organism. It came about historically at a time when organ transplantation became a viable treatment for end-stage organ disease and it was recognized that 'live'–organ transplants had a much higher chance of success and were considered valid treatment options.[147] On current ethical and legal thought, it is only permissible to harvest live organs from dead persons or persons who can give valid consent for organ donation. If the death

---

technology, these accounts may gain increased significance. It might be imagined that in the future advanced directives might need to include statements about which types of genetic curative technology someone finds compatible with their understanding of survival.

[cxviii] This refers to 'whole brain death', where the important feature of the brain is regarded as organic integration of the other organs, notably respiration, circulation and higher brain structures (via the reticular activating system), rather than consciousness.

of the brain constitutes only an organ failure, but not the person's death, live organ harvest would not be allowable under such an ethical and legal framework.

The point of death is of critical importance legally and ethically, because it determines when most human rights and moral obligations towards the individual cease to be effective and this has important implications for ACP. In the debate about when this point is reached, consideration is given mainly to two aspects of the individual:mental life and biological life. It is currently believed that all significant mental phenomena cease with the cessation of higher brain function, which is attributed to the large hemispheres. Thus, mental life stops on cessation of function of the higher brain. However, autonomic biological life persists if the lower brain functions, realised in the brain stem, are intact. A person in such a position is said to be in a persistent vegetative state (PVS). This state is also sometimes called higher brain death. Those who advocate that mental life is really what matters about life and survival, which is the position consistent with most types of ACP[cxix], should claim that a PVS equals the point of personal death. Yet, legally this position has not been accepted as baseline[cxx], indicating that in terms of the law the point of person-death[cxxi] is taken more on biological criteria. The legal position does not accept a diagnosis of brain death as 'person death' unless the brainstem is also lost. This indicates that legally, loss of mental phenomena is not the *crucial* loss in death.[148]

[cxix] I.e. virtually all ACP, which asks for treatment limitation

[cxx] Although one could see ACP as a kind of personal '*opting in*' to a definition of higher brain death (however, then all the problems that psychological accounts face would also apply).

[cxxi] In fact, this is not quite accurate. Legal ideas of death distinguish a biological and a civil death, but for the current discussion of person–death a legal notion of biological death is implied. I will clarify this later on.

However, for those who subscribe to a purely biological view of identity, the challenge of advocating for a legally accepted brain death (as whole organism death) consists in justifying why the brain should have a special function, without reference to any mental phenomena. Such justification has been attempted and legally accepted at least in the death definition: biological account advocates argue that the brain is critical for the survival of the **whole** organism, because they attribute to the brainstem a special **organ-integration function**, which maintains autonomic biological control, independent of machines or invasive techniques. Thus, they believe, they do not have to refer to consciousness criteria of identity in order to maintain a diagnosis of brain death as person–death and hence can accept 'live–donor–organ' transplantation.

Version ii) is aimed at basing the survival of the organism on a cellular level. In this case the relevant functional organic sub–units are much smaller, and therefore greater loss of function and a greater degree of disorganization has to have occurred in order to affirm the death of an organism. Such definitions are the basis of the majority of positions, which deny brain death (or any sub-organic death) as a valid diagnosis of organism death.

The difference between the views is one of scale rather than quality. However, as medical technology successfully achieves meaningful survival (or replacement) of 'organs', but not of sub-cellular organelles, scale makes an enormous clinical difference with respect to organ transplantation, current definitions of death and ideas of sanctity of life.

I believe version i) fails in securing a good argument for a consciousness-independent view of the significance of brain survival, because there is no good reason why we should attribute a *distinct* organ integration function to the brain or why such an organ-integration function should be so special that its loss would constitute death. Although it is true that the brain stem integrates cardiac and respiratory functions, similar organ complexity functions can be ascribed to other organs as well and hence are not unique to the brain. The kidneys for example release hormones which are involved in metabolic and cardiac control. Furthermore, even brain dead individuals can be kept biologically functional for significant amounts of time with artificial means[149], whereby the medical means just have to supply the extra organ integration function as well.[150] If the objection to the level of medical intervention is somehow based on 'naturalist views', which object to the non-organic type of intervention with machines, then this objection should similarly hold for implantable machines such as cardiac pace-makers and defibrillators, or external machines such as dialysis machines or portable ventilators in people who are either conscious or unconscious. As far as I can see, the only thing that is special about the brain up to this point in history is that it generates mental states.

So, if one accepts the idea of brain death as a valid diagnosis of death, which is the current legal position, and believes advance directives should be able to guide treatment limitations under these circumstances, it would be inconsistent to base a notion of numerical personal identity in the sense of 'what matters in survival' on a view of identity which disregards psychological criteria. Thus, the identity criteria which form the current legal bases for brain death are in strong tension with the identity criteria which form the base for ACP.[151]

In general, purely biological identity accounts are hard to bring into accord with *treatment limiting* ACPs, which are by far the majority of ACPs. Since matters of life quality of any sort do not come into the underlying definition of life, a biological account needs to be supplemented by another account, which expresses why certain forms of life would not be worth living, why consciousness is not essential to life and how this compares to our everyday use of language and intuitions in referring to persons. How this may be attempted I will explore in the next chapter. For now, I will only note it as a requirement.

On the other hand, favoring version ii) and denying brain death is highly consistent with the less common form of advance directives, which demand that biological life should be supported to the extreme, independent of 'life quality' or consciousness questions. These views are common within, but not restricted to some religious traditions that adhere in an orthodox way to notions of ‘sanctity of life’.[cxxii]A purely biological identity position of this kind would, for example, have been consistent with Dr Saul’s patient discussed in the last chapter. However, apart from standing in tension with the acceptance of any type of brain death, this position also has the problem that a person would not even be considered dead on cessation of circulation, because resistance of cellular entropy (as per definition ii) continues for quite a while after cessation of circulation and thus death would ensue only on actual body decomposition!

Some positive aspects of biological identity concepts are that they guarantee species consistency and measurability. They allow ease of scientific discourse and are robust against anxieties about premature diagnoses of death. These aspects make a biological view perfect for any scientific perspective and biological views are therefore at home in any science-dominated thought, but they face grave difficulties to justify treatment limitations in advance care planning. One distinct advantage of biological accounts of identity is that they do not face multiple– and split–identity problems, as psychological views do (see below) and these, as we have already noted in the case of Margo, are at the heart of the objection to ACP from identity.

[cxxii] Such a view may be non-sustainable for other ethical reasons, such as limited resources or justice., which have nothing to do with either the biological or mental criteria of identity. However, since these are not traditionally incorporated in the criteria for ACP I will not discuss them here. It might be noted though that even in consideration of economic criteria, i.e. the question of ‘who can we afford to maintain’, may be decided on identity criteria.

B) (PURELY) PSYCHOLOGICAL VIEWS OF IDENTITY AND SURVIVAL

Psychological views propose that the essence of identity lies in the preservation of certain mental capacities and psychological states, which are connected with each other in such a way that enables the perception of some form of unity. This is often described as *psychological continuity*.[cxxiii]

Purely psychological views typically conceive mental unity as independent from any physical manifestation. This independence can have material or immaterial form. Thus, some views do not postulate any physical matter as the necessary bearer of mental states (e.g. a Platonic[152] or Cartesian soul), others see physical manifestations as necessary, but do not require them to be particular organisms (Locke [153]) or organisms at all (e.g. replicas of organic or inorganic varieties as suggested by Parfit[154], or clever machines á la Putnam[155]).

Psychological views seem much more convincing in terms of making sense of what it means to have a personal narrative and why and how this narrative is important. As Dworkin suggested quite plausibly, this is important in the discussion of advance care planning. However, purely psychological accounts face other significant problems: multiple– and split–identity problems, third person recognition problems and some associated problems with the assignment of social roles, rights and responsibilities. These are all highly relevant for ACP, and thus I will turn to them in the order given above.

[cxxiii] A strong form of psychological continuity is psychological connectedness, which demands that there is direct connectedness of mental states (rather than mere continuation) in order to preserve identity. Although this is of some relevance for ACP, I do not particularly distinguish between these views here, as they share qualitatively the same problems, just in different magnitudes.

PROBLEMS WITH PURELY PSYCHOLOGICAL ACCOUNTS

PROBLEM 1) MULTIPLE-IDENTITIES AND ACP

Psychological accounts face the problems of ‘multiple identities’ per body. This is sometimes referred to as ‘the other person problem’ and is essentially what is at the heart of the identity objection to ACP as indicated for example in Margo’s case, but also many others[156]. The idea is that if a certain psychological discontinuity suggests the death of a person or at least indicates the discontinuity of a particular personal identity, then, so far as the physical body persists, it can be a successive ‘home’ to more than one person. This is a severe difficulty for the conceptualization of ACP. We saw it above in the identity and autonomy discussion between Dworkin and Dresser, but it was more recently re-examined in detail and with great clarity by Furberg.[157]

THE OBJECTION ARGUMENT

Furberg, for slightly different reasons[cxxiv] than I have given above rejects biological identity accounts and supports a psychological continuity view of personal identity in her examination of identity concerns in regards to ACP and she sets out the argument against the moral authority of ACP as follows:

[cxxiv] Furberg argues her position in contrast to Olsen and De Grazia, who are both proponents of biological views. They rejected psychological accounts because they supposedly fail to account for what happens to a foetus when ‘a person’ comes into existence through developing psychological states, and because they fail to give a good account of how the psychology is satisfactorily connected to the physical body. Furberg rejects these criticisms and the biological account, because it equally fails on the foetus problem and she believes that a constitutive version of the psychological continuity account can address the other criticisms adequately.

> *"(1) One person's advance directive has no moral authority to determine the care of a different (numerically distinct) individual.*
>
> *(2) Lack of sufficient psychological continuity (due, for example, to advanced dementia) between the person who issued the advance directive and the later incapacitated patient, implies that they are different (numerically distinct) individuals.*
>
> *(3) Thus, when there is lack of sufficient psychological continuity between the person who issued the advance directive and the later patient, the advance directive has no moral authority."*[158]

Premise (1) asserts a claim which captures our intuitions about the moral authority of ACP as given at the very outset of this chapter and which would presumably also be the prime motivation for anyone considering the completion of an ACP[cxxv]. However, if *premise(2)* succeeds also, this very intuition undermines any coherent idea in favor of ACP. Hence we have to either find a significant alternative moral justification for ACP, defeat *premise (2*) or give up on the idea that ACP makes sense (at least in a setting, where mutually exclusive competing personal interests are involved).

*1.1) OBJECTING TO PREMISE (1)–**DRESSER***

I think, like Furberg, that Dresser's account of ongoing interests of the post-dementia individual can be reasonably interpreted as an objection to the position that a severely demented person ceases to be a person (or becomes a lesser person) in a relevant sense for ACP; hence, Dresser must be taken as at least accepting *premise (2),* if not the whole argument. However, if she wanted to save

---

[cxxv] I.e. if I didn't think the directive was about me, why would I bother to make it; why would it have to bear my name and date of birth, etc.

the idea of ACP in the face of the objection from identity, then one must take her to object to *premise (1).* If one takes her to object to *premise (1) also,* she must allow for multiple successive identities and hence, has to negotiate the multiple identities problem, which goes against the intuition that drawing up a directive is done for ourselves.

However, maybe this latter intuition needs revision. One could for example envisage the successor individual as holding a special relation to the predecessor, such as the closest relative. This may address to some extent the moral justification problem. It may allow precedent autonomy and only provide for intervention in cases of actual conflicting competing interest. Yet, how close would we have to view this relationship between body predecessor and survivor, and what exactly matters in this relationship? The mere fact that they inhabit the same body, does not say anything about psychological relationships, so the relationship has to be grounded in psychological overlap (otherwise one would revert to a biological account of identity in which biological survival is what essentially grounds the relation).

So how do we meaningfully characterize the psychological overlap between predecessor and surviving individual? Should we do it quantitatively, similarly to what Parfit[159] suggested for sufficient psychological continuity: say at least 50% of psychological states have to be preserved from day to day in order to count as the same person? Should we do it qualitatively and determine particular kinds of psychological states that have to be preserved? Would surviving interests qualify as psychological states? Would a conflict of surviving interests show that a new individual has emerged? How would we measure psychological states, quantitatively or qualitatively, given that we already have such trouble getting agreement on autonomy assessment? And, disregarding the difficulties of autonomy assessment for the moment, why wouldn't autonomy loss be the most relevant psychological discontinuity in question?

In retracing the significance of psychological change, we seem to be back at the start, i.e. retracing the ground of persistence conditions for personal identity, except this time it would be disguised as specifying the conditions for identifying the closest, most relevant, relation.

If we viewed the body predecessor as the closest relative to the successor individual and compared the predecessor to any other competent concurrent close relative of the successor individual, one would have to ask in what way they differ (independent of biological parameters) and why the predecessor should be favored over a contemporary benevolent carer.

The difference between the two would consist in epistemic access to different aspects about the biological individual. Where another relative may be epistemically remote in terms of the predecessor individual's history of values, she would be synchronically informed about relevant treatment options, chances of treatment success (and other consequences), as well as current interests and maybe even surviving interests; she could compare the two. The advance directive author would be informed only in terms of preceding values and preferences, which may or may not be of significance to the successor individual, who will reside in the future body. If one had to choose which relative would be the more relevant one, a competent person residing in a different body or a historically remote person residing in the same body, which should one choose?

This choice may be informed by looking towards the predominant thinking in the related concepts examined in the previous chapters. For example, if we look to the current preferences in thinking about ideas of beneficence, it seems that recent thinking (as for example. in the MCA, see p. 230) gives a great preference to the 'precedent' person and ideas more related to narrative identity[cxxvi]. If we look to the criteria which are legally applied to determine competence in decision making,

---

[cxxvi] The crux here, of course, is that a pure account of beneficence does not elaborate identity questions, because it tacitly assumes that identity is preserved unless otherwise specified.

narrative features and life plans as well as a greater understanding of (the history of) one's life values are not required at all for decisions about treatment; rather the only criterion applied (as per common law) is whether the person understands what is currently at stake in the most basic terms. This latter approach would have to give preference to whoever is contemporaneously informed, i.e. the concurrent individual in a *different body*, rather than the prior individual in the same body, who is only informed about precedent choices, values and interests, but not concurrent ones.

So it seems that even when viewing the predecessor individual as standing in a special relationship to the survivor individual, we have trouble maintaining a coherent position independent of acknowledging something like precedent autonomy that would overcome the moral objection to ACP from identity.

*1.2) REJECTING PREMISE (2) –**DWORKIN***

Dworkin's narrative account must also be seen as a psychological continuity view, because he affirms that the loss of critical interests (i.e. psychological parameters) mark the end of the person's active narrative creation and it is this narrative that is important for the person's survival. Mere survival of experiential interests do not ground a person's right to their own claims of survival. I think, given that he directly endorses *premise (1)* he must be taken as indirectly discounting *premise (2)*, in the sense that his denial of the significance of experiential interests for personal identity at least counts the demented person as a person of lesser interests and rights, and maybe even not as person at all[cxxvii]. As pointed out before, this position

---

[cxxvii] It might be tempting to object here that because critical interests are understood as 'surviving', these are still the demented person's critical interests, but I do not think such an objection succeeds, for two reasons. Firstly, Dworkin says critical interests are the kind of interests that one would feel a significant loss about if they were frustrated, and a demented person like Margo cannot feel a

captures the initial intuition of persisting personal identity and preserves the motivation for making up an ACP, but it does so at a significant cost, since it leaves the post-dementia individual with very few rights indeed. In fact it almost equates the post dementia person with the status of a dead person[cxxviii]. This seems legally and culturally quite out of step with the normal embodiment of rights; for it seems that on this account, personal rights and responsibilities are embodied in precedent autonomy rather than personhood (or maybe one could say it conflates personhood with precedent autonomy). Apart from being at odds with our usual human rights attribution, it would be in tension with the rights assignment for those who never have precedent autonomy. We would end up with two groups of people, those who have and those who never have precedent autonomy, and it would turn out that the latter would enjoy much greater protection and a different basis on which human rights are attributed than those who are subject to an ACP. At the very least this would make advance care planning a risky business, given that one's

---

significant loss about such interests; hence she cannot have them (this is precisely the reason why we are not obliged to grant her any veto rights over preconceived instructions) Hence, I think we need to think of surviving critical interests as 'disembodied' interests. Secondly, if .we just assume that the surviving critical interests still belong to the demented person all the same, then we have presupposed identity, which is either fallaciously circular, since we have presupposed that which we were meant to establish, or we have presupposed the identity on non-psychological criteria and this does not fit with the narrative account.

[cxxviii] In fact the legal system has employed the term “living dead” on some occasions, although it tends to refer to those in a permanent vegetative state rather than those who are minimally conscious or have some other diminished conscious state; yet, it does not usually strip these of legal personality until formal death is declared, which happens according to biological definitions. Nonetheless, it has occurred in some of these cases that the law recognizes reduced duties to treat on behalf of the medical profession, when the best interest of the patient is deemed to be at stake; but as with the objection to *premise (1)* we have here a direct link to the difficult questions of best interest. See also Stewart, endnote 193

instructions are necessarily epistemically and diachronically remote from the time at which treatment decisions need to be made. If this position were true[cxxix], as Dresser hinted, it might even be a very good reason for why ACP is not very prevalent in the community.

1.3) DISCREDITING PREMISE (2) MORE EXPLICITLY – ***BUCHANAN***

A more direct way of approaching the objection from personal identity comes from Buchanan[160] in his original discussion of this problem. His position seems to sit 'in between' Dworkin and Dresser in that he takes the identity objection seriously, but explicitly attempts to discredit *premise (2)*. Buchanan's basic points were that the significant loss of psychological state, seen as disruption of psychological continuity, does not so much result in the creation of a new personal identity, but rather constitutes a simple loss of any personal identity (without creating a new one). Identity just fades out. Gone!

He suggests that in the process of severe dementia, for example, we do not become a different person, we become a non-person and therefore any ACP is not threatened by the objection from identity, since it does not 'enslave a different person' to the will of another; it simply gives instructions about what to do with the non-person.

Buchanan bases his non-person account on criteria taken from what he takes to be a reasonable consensus in the philosophical literature, which see the following as necessary conditions for personhood:

> *"(a) the ability to be conscious of oneself as existing over time – as having a past and a future, as well as a present;*

[cxxix] And it seems to appear that this position is the best match to a number of recent legal decisions.

> *(b) the ability to appreciate reasons for or against acting; being (sometimes) able to inhibit impulses or inclinations when one judges that it would be better not to act on them;*
>
> *(c) the ability to engage in purposive sequences of actions."*[161]

On his account then, the body of the non-person is to be regarded as the property of the prior individual, who retains a right of disposal, the details of which may be specified in an ACP.

Apart from doubts about whether we should accept an account of non-personhood in the first place, Buchanan's argument hinges on the degree to which we, firstly, accept that ACP can apply to non-persons and secondly to what extent non-persons can command any moral obligations. Thirdly, it also still requires us to establish at which point a person turns into a non-person.

So let's examine each of these points:

1) - Can we accept that ACP's apply to non-persons?

Although it may not be quite as intuitive as the idea that an ACP is for oneself, the idea that it deals with one's remains is probably not a particular problem. It might be taken in a similar vein as instructions about one's funeral, e.g. cremation versus burial. This may actually have been operational in the coining of Kutner's term 'living will'. It may also coincide with many people's attitude of feeling responsible for their affairs and the idea that one's deposition is just one of those affairs. So maybe this issue is not so controversial.

2) - Do non-persons command moral obligations?

Buchanan answers this in the affirmative. Although he sees non-persons as individuals of "radically truncated interests", he does not think that they are completely devoid of rights and moral respect. However, like Dworkin he thinks that respect for the surviving interests of the prior person outweighs the non-person's rights, with the exception of basic palliative measures (relief of pain and suffering). Non-persons on this account do not have the right to life. Buchanan compares the status of a non-person to that of a non-human animal or anencephalic individual. He does not really consider people like Margo directly, but instead debates at which point people become non-persons.

3) - At what level do persons become non-persons?

Buchanan suggests that this is an arbitrary choice, mainly made for pragmatic reasons, but advocates, that the threshold for non-personhood should be at a low level of psychological continuity, levels that are closer to a vegetative state than significant non-autonomous function. He advocates this position for two reasons:

> (i) so that moral obligations felt towards the non-person will not become a significant issue;
>
> (ii), so that we do not over-populate the world with non-persons, who would then be children, siblings or spouses of no one, and who do not have property or debts or any other responsibilities.

There are a number of problems with Buchanan's suggestion, which make them unviable in a framework of ACP. Some of these were pointed out by Furberg[162] in her recent review of the identity objection to ACP:

Firstly, if non-persons can command a certain moral tribute, the question that was given by the Margo case (and others like it) is not really answered, but rather side-stepped or ignored as an unlikely event. On Buchanan's necessary conditions for personhood (as cited above) Margo fails to satisfy criteria (a) and (b), but she can still engage and enjoy in purposeful actions (c), however trivial. So, if Margo were considered a non-person, it seems that concerns like Margo's experiential happiness are discounted as negligible, as they were by Dworkin in his precedent autonomy account, favoring the surviving interests of the prior person. It would put the threshold rather high, which is against Buchanan's recommendations. Secondly, if Margo were still a person, we would have to explain why her differing interests to the prior Margo do not make her a different person (independent of biology). It may also be noted here that any very young child would do equally badly or worse on these criteria.

The fact that according to these qualitative personhood criteria some individuals fall somewhere on a spectrum of personhood supports Furberg's[163] view, that personal identity may very well behave in the similar sliding scale fashion as is commonly proposed about autonomy; personal identity, she claims, often does not behave in an all or nothing fashion in many cases. This then poses problems for ACP in the form of making the identity objection valid. If Margo is not a non-person, but an individual with radically[cxxx] different interests from the prior individual inhabiting her body, she must be a different person and hence cannot be dealt with by the ACP of the prior Margo.

On a conceptual level we have here a similar difficulty to that which we encountered in the discussion of autonomy: it will be remembered from chapter 3 (p. 94) that autonomy can also be seen as a discrete or continuous parameter, depending on one's perspective. And although Furberg[164] is right that competence is commonly viewed as a continuous parameter, this is by no means uncontroversial or universal. It is also a rather recent development. Furthermore, even though we do have attempts to contextualize questions of autonomy, cut–off thresholds are in place invariably in order to respond to pragmatic constraints.

[cxxx] Radical is meant here in the strong sense of mutually exclusive, i.e. to have the right to life–saving treatment or not. It may be noted here that people commonly encounter choices between pursuing mutually exclusive interests, which are both in 'their' interests; however, due to the lapse of time and autonomy in the setting of ACP, the comparison of these two situations is dubious; in the end one could very well see the difficulty of ACP reduced to a question of whether we think ACP can overcome the lapse of time and autonomy.

In general, global discrete parameters allow for easy inclusion into groups and enable clear, dichotomous decision making, which is desirable in a clinical setting, where pro or contra treatment decisions have to be made. Nonetheless, global discrete decisions are insensitive to situational subtleties and lack flexibility to cope with contextual diversity; yet this is also desirable in clinical life, where a multitude of phenomena arise over a variety of situations, which have to be taken into account and addressed. The problem with active end of life decisions is that here all perspectives must funnel into one decision; hence some perspectives must submit to others, for we can never actively satisfy mutually exclusive conceptual demands concurrently. Again, a practical need for hierarchy appears as a result of conflicting aims. In this sense, borderline cases like Margo present more than a clinical difficulty, they show the tensions in our web of concepts and question our need and capacity for consistency.

The question of whether identity should be viewed as a continuous parameter was also discussed by Parfit[165], who, in relation to the numerical aspect of identity, thought that a non-discrete view was nonsensical. Instead he proposed to divorce the notion of survival from notions of numerical identity and went on to claim that what mattered was not maintenance of number, but maintenance of psychological continuity.

However, Parfit’s discussion is only obliquely relevant to ACP, because it was primarily associated with the problem of split identities (discussed below), rather than multiple identities. The problem with Parfit’s approach of divorcing ideas of survival from number is that its emphasis on psychological connectedness effectively relies on a first person perspective, which is not immediately applicable to the situation of ACP. For the question in ACP is not primarily ‘will the future demented Margo think she has survived? (as evidenced by her maintenance of sufficient psychological connectedness[cxxxi]), but that of 'does ACP author Margo survive?'; and furthermore, since both Margos command different consequences (of which only one can be instantiated) the question of maintenance of number becomes imperative. Whether Margo in fact would survive on Parfit's account remains unsettled, I think. If we go by the 50% daily overlap of mental states (if such a thing could even be measured), it could very well be that we would end up with a succession of several Margos, not just pre- and post-dementia Margo; a situation not in any practical way helpful to ACP. Both, Furberg and Parfit, make valid points about the gradual nature of identity, but in terms of the practical needs of ACP it must be emphasized that any attempt to side-step the issue of maintaining number are ultimately not executable, and Buchanan is right that we do need to determine a threshold that identifies loss of numerical identity. The question about our degree of consistency of criteria across contexts, and the required considerations relevant in terms of delineating a context, will be discussed in the next chapter.

Buchanan's other reason in favor of a low threshold for non-personhood concerned the practical and cultural difficulties that would arise in consequence of producing a population of non-persons. This Furberg addresses also, and quite rightly observes that his reasoning about the nature and consequences of creating a 'population of non-persons', who are not relatives of anyone nor owners or debtors of anything, does not hold up to scrutiny: for if it were true that non-persons could not be relatives, owners etc. (because of the loss of their mental states), we would not be entitled to use the funds of these non-people to care for them or approach the kin of the 'previous person' for advice or matters of responsibility about the non-person. Buchanan's ideas about what commands a person's role in society cannot be traced only to their personal identity or personhood as given by their continued

---

[cxxxi] The connection to the first person perspective is given because no–one but the person in question can confirm or deny connectedness of mental states.

mental states. The reason why we do not regard individuals as relatives or owners, Furberg[166] argues, is more likely to be that, as far as kinship and ownership are concerned, we tend to rely on biological parameters and not psychological continuity. This certainly seems to be in line with the current law and general social practice, where forgetting or unawareness about a debt, or other legal obligations or matters of kinship, does not count at all in terms of not being regarded as holding the positions of debtor, owner or relative. Thus a more accurate appraisal of this situation would be that a purely psychological account of personal identity just does not seem to do justice to our social practices.

In the same text, Furberg also examines the issue of whether individuals with radically truncated interests (non-persons or otherwise), could be thought of as not being harmed by death, as was proposed by Kuhse[167], and which might serve to strengthen Buchanan's position (although he did not suggest this himself). Furberg concludes that this line of argument does not hold up to scrutiny either, because it is based on too narrow a conception of harm and would have to include for example 'non-persons' at the other extreme of life, such as very young children.

In addition to Furberg's valid criticisms of Buchanan's non-person account, I think, it faces some further difficulties, in that it must restrict ACP to cases of irreversible mental state discontinuity (or decline). This would mean that ACP would not be possible for people who want to plan ahead for certain psychiatric episodes, as Kutner had envisaged and as has been advocated widely.[168] Such psychiatric episodes, may well qualify as severe disruption of psychological continuity, but couldn't be reasonably said to create non-persons.

I also think Buchanan's position would face trouble in other common scenarios. We would for example want to include directives about the refusal of blood products under ACP, but it is not clear how Buchanan could satisfactorily exclude states like deep sleep, narcosis or any recoverable biological coma from the psychological discontinuity view, which relies on a non-person status. Would we become non-person's during these episodes, merely on the loss of psychological continuity? How else would we justify ACP about blood product refusal? Say someone becomes unconscious from severe acute anaemia curable by blood transfusion. On Buchanan's account one would have to say that the unconscious individual is a non-person, such that the surviving interest of the ACP author retains their authoritative status. He could not claim that the individual is the same person, for unconsciousness constitutes psychological discontinuity, at least if left untreated (as per directive). He could not refer to biological parameters, for that would make redundant his entire non-person threshold discussion. So it seems he would either have to restrict his ACP to irreversible conditions, which would exclude denial of blood products and other unpalatable life-saving treatments[cxxxii] or he would have to admit that even reversible unconsciousness results in a non-person status; but then the non-person status could not do much moral work at all.

Thus, it seems that Buchanan's account fails for one other highly important reason: it does not cover a lot of the cases which the background ideology of ACP wishes to cover. If it would not already fall short on the other points discussed above, it must be seen as far too narrow in scope for the kind of ACP that is meant to respect autonomy as it was first described by Kutner.

Buchanan's narrower scope seems to reflect a different perspective of ACP, which he declares at the start of his paper, where he says: "*By issuing an appropriate advance directive one can* ***do good to others.***[cxxxiii] *Viewing advance directives in this broader way can be liberating. Instead of being simply as directives for protecting the patient or exercising autonomy for its own sake, they might in addition become vehicles for new forms of altruism, new forms of exercising the virtue of charity.*"[169]

[cxxxii] E.g. Mrs. T's treatment in chapter 2

[cxxxiii] An explanatory footnote of Buchanan's is omitted in this quote here; it relates to relational concerns and surviving interests of the patient – for full quote see reference in endnote.

By broadening the scope of motivations for ACP, Buchanan has at the same time drastically reduced the kind of people to whom it may apply, and this in itself may betray a marked difference of attitude towards ACP as a whole, which could be the result of professional or at least interpersonal perspectivalism. Whereas Kutner's (a human rights lawyer) ideas about ACP are strongly rooted in an understanding of individual rights, especially the individual's right to autonomy, Buchanan's (a philosopher and ethicist) ideas do not reflect such emphasis. His views might be more compatible with more relational ideas of autonomy and the acknowledgement of the importance of social structures. But in the end, for all the reasons given above, Buchanan's attempt to overcome the objection from identity seems to be quite inadequate.

Apart from overcoming the multiple-person problem all psychological views, in so far as they are purely psychological accounts, suffer from two further problems: the phenomenon of split personal identities and the problem of 3rd person recognition.

PROBLEM 2) SPLIT PERSONAL IDENTITIES

The split identity problem is not currently directly relevant to ACP in practice. The split identity problem arises from thought experiments that compared survival in terms of continuity with survival in terms of number. Parfit[170], in discussion of one of Wiggins' cases, observed that the two can come apart and that survival in terms of continuity was not dependent on survival of number, if it did not depend entirely on the number-constituting entity.

As Parfit's observations were based mostly on thought experiments the current relevance to ACP is limited. Parfit and Wiggins discussed cases in which one had to imagine that part of one's psychology could continue in an alternative 'body' via some mechanism of transplantation or teleportation (or the like), or where the entire organism can split. However, as the idea was inspired by clinical neuro–surgical cases and may become relevant with future developments in medicine, it is worth a brief discussion. In the neurosurgical procedure which Parfit referred to[cxxxiv], the communicating anatomical structures between the two brain hemispheres are severed; as a result both hemispheres operate independently as if they were two brains. Parfit quoted the surgeon as saying the operation creates “two separate spheres of consciousness”[171], each of which control one half of the patient’s body. From this Parfit extrapolated how we should think about such cases, if they were slightly simplified with respect to the real surgical cases provided.

His point was that if each half of a brain could continue in half a body or in another vessel which could support the mental states (memories, intentions etc.), then each progeny would remember these and hence count as psychologically continuous with the person, who existed prior to the commissurotomy and would have to be counted as a survivor. Such a case would somehow represent the opposite to the problem above: here we have to battle person creation rather than person annihilation.

As indicated a little earlier, Parfit in his famous paper then claimed that what really *mattered* was survival and not numerical identity, hinting to some degree at the tension between the question of ‘what matters in survival’ and ‘what we are essentially’. With regard to the case of multiple identities, I have already made the point that number does matter in terms of moral consequences. I suspect that similar situations of moral consequence could arise in the area of ‘person fission’. However, as these cases are hypothetical as yet, current ACP does not quite have to accommodate this problem now. It would not be too outlandish though, to see it as a problem on the horizon; for we might conceive it as quite possible that in the

---

[cxxxiv] Parfit called this procedure lobotomy in his text, but it is clear from the description that he meant a procedure which is more accurately known as commissurotomy. It is a rare procedure today, but was once used more commonly in the attempt to cure or improve certain forms of epilepsy.

foreseeable future the successful separation of Siamese twins joined at the level of the brain could provide a case in question, or that brain transplantation (complete or partial) might become successful.

For the current state of ACP, however, the more important problem of psychological identity accounts is that in a pure form, i.e. without specification of where or how mental states are ‘at home’, they are insufficient to account for our social practices and therefore they cannot provide a base for a successful framework of ACP. The various criticisms of Buchanan’s account pointed somewhat in this direction, but the simple problem of how anyone can recognize anyone else from a third person point of view drives the point home more bluntly.

PROBLEM 3) THIRD PERSON RECOGNITION

Purely psychological views face considerable opposition from the strong common intuition that our physical body is an important and vital part of our identity. This is one of the main criticisms made by proponents of biological views, such as Olsen and De Grazia, but it is also connected to very practical aspects of our daily life: one could not identify anyone from a third person perspective, if they did not have continuing physical features by which one can recognize them![cxxxv] It is impossible to distinguish people on the basis of their mental states alone and we would most likely not wish to accept person–discontinuity based simply on certain changes of their mental states: e.g. we would not like to release someone from a promise, because they ‘changed their mind, attitude, intention’ or simply forgot about it. Furthermore, it is impossible to maintain, how a particular mind (the presumed site of our psychology) can be seen as *’some**one**’s’* mind at all if it does not attach to one particular and clearly identifiable object or body.[172] To secure identification of

---

[cxxxv] In fact it is not entirely clear that one could identify oneself, if one didn’t also have a body to go by, but this point, I suppose, can neither be proven nor disproven.

precedent authority, for example, a mere general notion of embodiment is not enough; the embodiment needs to be *specifically* identity-preserving and identity-indicating.

A response to these requirements of embodiment and psychological continuity is the generation of a substantive (complex) view of personal identity, which makes up the third group of personal identity positions.

C) SUBSTANTIVE VIEWS

Substantive views recognize as essential to survival both the physical and the mental aspects of identity, and they attempt to give accounts of how the physical and mental are related in various ways. Relations suggested in the literature include supervenience (Wiggins[173]), constitution (Baker[174], Lizza[175]) and predication (Strawson[176]).

Although complex accounts perform well on body and mind continuity, and intuitions about their shared importance to identity, they all suffer from various difficulties in accounting for how exactly, when and why the body and mind are connected, and which dimension should actually be the predominant factor influencing our ideas about the content of advance directives.

Lizza, for example points out that on Wiggins' supervenience view "the individuation and identity of the human being (the supervenience base) does not necessarily entail the individuation and identity of a person (supervening entity)"[177], thus leading to problems of relative identities.

Lizza,[178] Baker[179] and Furberg[180] each favor a constitutional view, which understands persons (mental beings) as beings made of biological human organisms, in such a way as we understand Michaelangelo's "David" as being made of marble or rivers as being made of water. This view sees persons as substance primitive and therefore complies with Strawson's[181] demands, for identifying particular minds with particular bodies and it asserts that we cease to be persons as soon as we lose either psychological or physical dimension. It also seems to sit well with initial common intuitions about personhood, and justify ideas about treatment limitations.

However, as DeGrazia points out, Baker's constitutional view, which characterizes the psychological component in terms of a persistent first person perspective, has trouble in accounting for the existence of personhood at the extreme ages of life[182], which is of significance when considering the authority of advance directives and 'the other person problem'.[183] Some of these criticisms have been addressed and rejected by Furberg, mainly by pointing out that DeGrazia's and Olson's biological views suffer from similar problems about accounting for the existence of animalism at the beginning and end of life. In fact, many important and interesting points can be made in the discussion of various forms of substantive views; however, there is no room to pursue them here.

What matters is that as far as ACP is concerned, even the adoption of a substantive view of personal identity cannot solve decisively and uncontroversially the moral justification difficulties for ACP associated with identity concerns. This is because the incorporation of the psychological continuity requirement as a necessary ingredient into a view of identity carries its problems along, and any moral justification difficulties persist even in a constitutive view. As long as psychological and biological criteria have to both be present for the continuation of identity, the morally relevant other person problem persists. In a constitutional view, biology provides bodily recognizable persistence, and psychological continuity provides moral persistence, and when one of the parts goes missing, we cannot claim that the whole persists.

Furberg suggested that in practice we seem to have a contextual use of identity criteria; e.g. we use biological criteria for family relations, but psychological criteria for self-identification and narrative. One might think that a view like this is operative in ACP, such that the biological dimension of identity provides third person recognition and determination of the end of life, and the psychological aspect of identity gives the moral relevance; however, I doubt the coherence of such an approach. It would seem to me that this would not adequately represent the additive nature of any substantive view. A substantive view claims that identity is a whole, where both biology and psychology have to be present as necessary constituents of identity. If we (contextually) cherry pick, and only pay attention to one of these domains as it suits our other conceptual constraints, we effectively treat the parts of the whole as disjunctive and not additive and this would not be true to the concept of a substantive view; i.e. when we consider either biology or psychology as sufficient for the preservation of identity, we have converted necessary conditions into sufficient conditions and left behind the idea of the substantive nature of the dual dimension.

The problem in ACP is that the value and the definition of identity are not independent from each other. Because treatment limiting ACPs derive their moral justification for subject limitation and the definition of their subject from the same identity criterion, we have to grapple with the paradoxical claim that ACPs apply to that which has gone out of existence, because it has gone out of existence.

Because we are faced with this paradox, we have to either find an identity account which can deliver a coherent justification for ACP from within the identity account, or we have to assume an identity account which places the moral justification of ACP well outside the domain of identity (e.g. a biological account).

5 – Essence and value: animal essentialism versus person essentialism

It might, at this point, be important to return to the possible distinction that one can make between essence and survival, and some may think that this can deal successfully with the objection to ACP from identity concerns.

It could, for example, be claimed that a person can think of herself in the following way:

> (ϕ) 'I am essentially an animal, but the value of the animal that is me resides in the fact that it can mentally do x, y and z. Therefore, when the animal that I am essentially can no longer do these things x, y and z mentally, the value of the animal vanishes and it should no longer receive any treatment to prolong its biological life, for although the life continues, its value does not.'

The benefit of such a formulation is that the continuity relation in terms of numerical identity is divorced from the value of the person and it might be said that this defeats the objection from multiple identities, without destroying the force of ACP.

Whether we can accept such a position as credible depends on whether we think ‘essence’ and ‘value’ enquire after the same relevant thing or not. Our position here might depend on whether the term ‘what matters’ is cashed out in terms of moral value or some other form of essential (most likely material) thing. If one thinks that the essence of a thing is constituted by ‘what matters about that thing’ then the question of ‘essence’ and ‘what matters’ cannot be separated and the above position (ϕ) would not make sense, because it would assert the contradiction that something can survive despite losing its essence. This is what I take to be behind Buchanan’s position, who denies the thesis that metaphysical and moral personhood can be clearly distinguished in the framework of ACP.[184]

However, if one believed that the essence question asks about a material substance, but the value question asked about a moral dimension which this substance has, the above position (ϕ) may be a more promising solution. This would be akin to De Grazia’s thought on human identity. These two positions are separated in the literature under the terms of ‘*person essentialism*’ and ‘*animal essentialism*’ and the question most important for ACP is, in what way such a distinction could be helpful or important. ‘Person essentialism’ proves to be a severe problem for ACP, because of '*the other person*' problem, so it is not helpful. Does ‘animal essentialism’ fare any better?

In order to assess this we must briefly revisit some points made regarding the biological accounts. We observed there that any animalist position, which wanted to support treatment limiting ACP, would need an extra justification that would make a good case for why the value of an animal devoid of certain mental abilities would be reduced to the point of justifying the limitation of survival treatment. Could '*animal essentialism*' achieve this?

The problem with animalism is that the information about what one essentially is (namely an animal) does not carry any moral force; it is merely descriptive; it is a thing to be discovered, but nothing follows from the discovery. An animalist identity account only entitles us to the claim that the animal survives, but so what? Unless there is a separate (maybe animal intrinsic) moral code that assigns a value to survival as such, the notion of survival remains empty for ACP. However, any such moral code would then directly compete with and limit the moral scope within which ACP can operate. In this way the animal essentialist position is actually remarkably similar to Buchanan's 'non-person' account, as the moral difference between 'non-person' and 'animal' seems largely nominal (when metaphysical differences are excluded) and it carries with it most of the criticisms raised there; i.e. it also carries the problem that ACP cannot apply in a range of situations that we would want to include, based on beliefs of the value of autonomy. Thus, although the animal essentialist has a sound continuity claim as to number, the mere descriptive quality of this claim cannot secure a sound moral base for the significance of the self in relation to treatment limitation instructions. The animal essentialist thus needs a kind of Dworkinesque narrative or critical interest account of autonomy in order to sustain a moral claim of treatment limitation based on patient choice.

There have been some attempts to ground the moral base of autonomy outside of person essentialist concerns, such as McMahan's[185] time relative interest account, but this is not without problems.[186] Essentially, McMahan's account concerns attempts to evaluate an individual's interest at various stages of their biological life.

These interests might be actual or potential and the account relies on a number of intuitions about the correct assessment of these values; intuitions, about which people may vary significantly in opinion.

The details of this debate again are too extensive as to be included here, as are further details about ways in which one might supplement an animal essentialist position, but this is not important. What matters are the two following insights:

> Firstly, identity account considerations impact in an important way on the kinds of autonomy accounts which are feasible in a conceptual framework for ACP.
>
> Secondly, our overall web of beliefs significantly constrains the way in which we can convincingly conceptualize ACP.

Furthermore, different views bring different constraints, such that coherent conceptualization can fail for a multitude of different reasons that originate in a variety of beliefs, held on basic foundational levels. Embedded within this insight is the recognition that some more general core beliefs about the world, such as questions about deep metaphysical beliefs concerning essence and value, may pre-determine conceptions of ACP in ways that we do not ordinarily recognize when looking at particular questions within treatment contexts. Many of these core beliefs are shaped through our existence as social beings and they influence our social, cultural and professional views.

6 – Social and relational aspects of identity

In recent times, just as relational aspects of autonomy have been observed in the autonomy literature, similar aspects have come to the fore in the discussion of identity. Lizza[187] (a person essentialist), who is partial to Baker's constitutional view of identity has explored what would be necessary to count as a person, and observes (in contrast to Baker) that a strong first person perspective would not be enough, as it neglects the significant social aspects of identity. He cites especially cases of advanced senile dementia, and he observes that a significant aspect of our ongoing sense of someone commanding a sense of personhood is our third person reaction towards them; our memory of their past, even if they have lost it, and our perception of them and their affairs. The fact that we have different responses towards a living individual and a corpse should serve as an indication that a significant amount of numerical personal identity is embedded in a person's social existence.[188] Furthermore, Lizza makes the point that *"a person's subjective identity over time is dependent on self-conceptions, which in turn are dependent on social factors of recognition and re-enforcement. […] A person may not correctly identify himself with certain traits unless this identification is reinforced and recognized by others*"[189].He goes on to claim that *"personal identity is, at least in part, a matter of social and cultural interpretation and practice and not purely an empirical fact to be discovered"*[190] and therefore it is significant for the problem of defining and determining death.[191]

This aspect of identity can be substantiated with a number of convincing examples of different cultural practices that define death along quite different parameters. These parameters are based on culturally different metaphysical beliefs (about body, soul and essences)[192], on the one hand, and on social forces, on the other.

Another example of the social aspects of identity and social aspects of life and death definitions can be found in common law.[cxxxvi] Stewart in his examination of the history of legal constructions of life and death makes the point that "*the concepts of life and death in the common law have depended not only on the practice of medicine and the interests of science, but on social factors such as crime, property, religious values and economics. The law has created its own versions of life*

[cxxxvi] Given that common law to a large extent governs ACP, common law ideas about legal personality and its persistence conditions are relevant here.

and death which are divorced from biological meanings and are centered on concepts of legal personality."[193]

The law makes distinctions between 'biological death' and 'civil death'. Biological death follows the (medical) definitions of biological death. Civil death refers to a person who is stripped of legal personality (for various possible reasons). Legal personality is a social construct and refers to an entity which is recognized by the law as a person with appropriate personal rights. Such an entity may be biological or not.[cxxxvii] Personality here sits in direct opposition to property. This is an important legal distinction, as common law is traditionally divided into law about persons and law about property.

As Stewart points out, there are various entities which the law finds difficult to treat as either property or person, in response to various social pressures. For example, since the abolishment of slavery, the law is quite categorical about the fact that a human being cannot be property;[cxxxviii] this extends to corpses and body parts, the latter originating historically from the social needs for dissection and research. Such social needs persist today, where rulings about body parts, tissue cells, frozen embryos and gametes, etc., influence how we think about ownership rules in these cases. At the same time, the law does not bestow person rights on inanimate objects. Thus corpses and body parts fall into a legal space somewhere in between property and personhood. A similar thing can be said for foetuses and the 'living dead', which are not quite inanimate, but because of their lack of consciousness are not considered fully alive. Whereas conceptualization of ACP might be a social force, which would favor an 'ownership'-model of the body, other opposing social

---

[cxxxvii] E.g. it could be a corporation.

[cxxxviii] We note here the direct opposition to Dworkin's and Buchanan's idea of ownership of one's future self and the right of disposal of one's body.

forces, such as transplantation and research needs, are against such a conception. As was the case in the analysis of autonomy, we note here, that due to the fact that the same body of law has to accommodate conflicting social demands, it struggles with consistent conceptualization.

However, what is more important here is the observation that different social issues influence definitions of life and death, and that our beliefs about life and death may change in turn with these influences.

Although we may note that this point is directly opposing the characterization of death according to the biological view, which says 'death is a biological event and therefore can be objectively determined by science' (see p. 255), it serves at the same time as a good explanation of why individuals and communities might arrive at very different views and perspectives about this matter.

Given that ACP is meant to work across cultural and professional contexts, and that its liberal subtext aspires to overcoming differences, this point seems of particular relevance in the question of an ACP framework. This is so, because it does not only affect the kind of content an ACP might contain in terms of choices voiced by the author, but because it may fundamentally explain why (under what circumstances) ACP does or does not make sense to the potential individuals involved as individuals, as members of a community or of a profession. This in turn is of significance when we contemplate why ACP may fail, irrespective of increased attention to issues of resources and practical shortcomings.

7 – SUMMARY

This chapter has looked at ideas of personal numerical identity, the last of the three big concepts needed in the construction of a conceptual framework of advanced care planning.

It has given a brief overview of the three types of identity accounts: biological, purely psychological and substantive, and tried to identify their most relevant insights for ACP, including significant social and relational aspects. The two main challenges for ACP from identity concerns are the justification of treatment limitation for biological accounts and the justification of moral authority for psychological accounts.

Furthermore, this chapter has drawn out further the significant interplay between the concepts of identity and the two other concepts, autonomy and beneficence, in order to highlight the conceptual limitations one faces in the formation of a coherent ACP framework.

This has led to the insight that various perspectives and limitations can arise from a multitude of ideological sources and therefore can be quite varied in appearance and nature, illustrating more than one way in which ACP can fail to make sense conceptually. Some of these conceptual difficulties may arise from quite abstract core ideas in the web of beliefs which each potential ACP participant may hold and thus be far from obvious; others may originate from social pressures quite unrelated to ACP.

In the next chapter, I will try to identify which conceptual versions of autonomy, beneficence and identity work best together as a unified framework and which parameters for coherence we should demand. This will then lead to an attempt of assembling a picture of who could realistically be expected to gain from ACP, an assessment of which goals and successes ACP can claim under various circumstances, and which kinds of criticisms would remain valid under all circumstances.

CHAPTER NINE – Piecing together the conceptual framework of ACP

1 – INTRODUCTION

After having examined the conceptual ingredients for a framework of ACP as somewhat separate entities in the previous chapters, this chapter aims to examine how these concepts can be fused best in order to produce a coherent picture of ACP as a whole.

Whereas the first half of this thesis could not really settle the question of what kind of autonomy concept is employed in the practical aspects of ACP, I will attempt in this section to provide a conceptual answer; i.e. I will try to give an idea of what kind of autonomy concept should be employed in ACP, based on the particular conceptual dynamics of the idea of ACP as a whole, respecting all its immediate conceptual restraints. This will then lead to a discussion of how such concept of autonomy compares to the current ACP situation and issues of scepticism about ACP as an enterprise.

2 – TAKING STOCK OF THE PREVIOUS INSIGHTS

In order to put together the larger picture of the conceptual framework for ACP, it will be helpful to revisit the main insights from the previous chapters and then see how they best fit together to create a coherent whole. This will make it easier to assess what kind of claims can reasonably be made about ACP, and it will provide a base from which to assess current practices and set expectations about what might reasonably be achieved by ACP (provided that it can also overcome a myriad of practical obstacles).

One of the main points we gleaned from chapter 1 was Kutner's original idea about ACP. From these we could derive the concepts which had to be included in providing a framework for ACP: as ACP is meant to be the extension of the right to self-determination and the right to not excessively suffer, autonomy turns out to be the most central concept; as ACP is meant to benefit the patient, ideas of beneficence are also important; and because Kutner rightly claimed that autonomous ACP can only be achieved by planning for oneself, numerical personal identity becomes a third vital requirement within the ACP framework, although maybe a less obvious one. A further point Kutner envisaged was that an ACP should achieve the status of a binding contract, which could be used as evidence in any court, and thus function as protection against claims of negligence or other kinds of foul play, which might be brought against a carer.

Subsequent chapters made the points that these framework concepts are subject to considerable conceptual interpretation, which, when put into practice, can lead to remarkably different outcomes. Chapter 2 provided the case of $Mrs\ T$ where the effect of conceptual diversity in regards to autonomy was shown in greater detail, in order to defend the claim that the cause of treatment outcome differences can be traced directly to conceptual differences (as opposed to some other medical cause).

Chapters 3 – 5 showed that these conceptual differences with regard to autonomy are an inter- as well as intra-disciplinary phenomenon and that this complicates any attempt of consistent concept interpretation within the community of advanced care planners. Points of variance were ideas about whether autonomy is individual or relational, procedural or substantive, global or partial, scalar or discrete, risk relative or not, and whether it concerns notions of life plans, narratives or critical interests. An attempt at gleaning an insight into which features of autonomy currently prevail in medico–legal practice suggested that over the last 30 years trends seemed to steer towards scalar, partial autonomy models, with some attention to risk relativity and only minimalist requirements for procedural capacities in situations where autonomy is under question, but that in situations where autonomy is not under question (the default position for every adult), a global individualist model of autonomy prevails.

Chapter 6 suggested that the idea of autonomy should be taken as a cluster concept, in which a variety of related ideas (authorship, rational capacity, right to choose, individuality, non-interference) group together under the same name.

Conceptual diversity then arises from paying increased attention to some aspects more than to other aspects. I further argued that the existing conceptual diversity is not only observable, but to a certain degree to be expected and even necessarily present, because it results from the pursuit of different, sometimes mutually exclusive, aims, which are integral to the world views of various participants of the ACP endeavor. I further suggested that in so far as these various aims are mutually exclusive, and in so far as they are tied to the personal or professional integrity of the ACP participants, they pose an intractable problem for ACP that has a paradoxical nature. This paradox includes the desire of ACP to be simultaneously non-paternalist, but protective; being maximally inclusive, but enforcing certain minimum standards, and being non-normative, within a normative framework. I further observed that the operational basis of the professions involved in regulating and applying ACP are similarly paradoxical, with law pursuing rights and insurance, whereas medicine is based on care and trust.

Chapter 7 showed how beneficence as a concept is also subject to conceptual interpretation. The main point of contention here is the distinction between an objective or subjective perspective of the concept. I showed that the different positions are in tension with various important aspects of ACP and other necessary health and social concepts. I argued that a subjective concept of best interest largely collapses into conceptual concerns of autonomy and therefore becomes redundant as an independent concept for as long as advance care plans exist or that, if beneficence is seen as an objective concept, it largely competes with advance care planning and may make ACP essentially redundant.

Finally, chapter 8 drew out concerns about personal numerical identity, which like the other two concepts is also subject to different philosophical interpretations. I showed how these interpretations have direct consequences for the kind of moral justification one can provide for ACP and gestured towards the point that details of one's identity account constrain the notions of autonomy which may reasonably be employed in the conceptual framework of ACP. Furthermore, ideas of numerical identity tie directly to a variety of underlying metaphysical beliefs, which constrain the validity of ACP as part of a coherent set of beliefs even more.

3 - DETAILS OF CONCEPTUAL TENSIONS WITHIN THE IDEA OF ACP

After having recalled the main points of this thesis so far, I now want to pay some closer attention to the inter-conceptual tensions. In analyzing how the various conceptual interpretations affect the total ACP framework, I hope then to ascertain which ideas fit best together to produce a coherent picture.

A) BENEFICENCE AND AUTONOMY AND ACP

A subjective understanding of beneficence views this concept in the form of an answer to the question 'what would the patient do?', whereas an objective understanding views beneficence concerns as an answer to the question 'what is best for the patient?'. In a coherent framework for ACP, best interest and autonomy concepts need to work together; hence a subjective beneficence concept seems to fit best, but this does essentially reduce beneficence to autonomy concerns.

A subjective understanding significantly reduces any claims about objectively determinable patient care and thereby threatens the therapeutic position, in particular, any notions of futility, determined independently from patient concerns. As such a subjective notion of beneficence threatens the medical position as holding definitive expertise on forms of well-being and best care, but it is also in direct tension with ideas of distributive justice where ideas of futility play a significant role in determining whether resources should be allocated or not.

A subjective idea of beneficence also prevents one from making objective claims about the benefit of ACP. If we hold ideas of best interest to be patient subjective, ACP can only be seen as being of benefit to the patient, if the patient herself thinks so. Although intuitively appealing, this limits the objective claims one can make about ACP as a benefit, for I think it restricts (on the pain of coherence) the acceptance of ACP to only those people, who accept *all* the various conceptual constraints which apply to ACP as a whole. So the best objective claim one could make about ACP is that it is only best for a person, insofar as the person herself accepts it as good. At the very least the patient must find ACP, despite its rational conceptual constraints, better than any of the rival options.

An objective conception of best interest competes outright with notions of autonomy and thus sits ill with any ACP content which departs from any objectively arrived care recommendation. Thus, objective notions of best interest perceived as an answer to the question of 'what is the best care for the patient?' make ACP in a sense superfluous; at best an ACP would become a mere tool of communication, but it would not ‘contractually’ settle disputes about care in favor of patient ideas. Under these conditions, an ACP would stand up poorly as evidence in court about the patient's autonomous will (as Kutner suggested it should).

It may be objected that autonomy, as a matter of fact, is the best way of promoting a person's 'objective good', since they are in a better position than others to ascertain such a good. However, it seems to me that on a practical level this seems to deny the possibility of any objective care expertise, since although one may agree on an 'objective list of possible good things', epistemic access to the best of these is only to be had by the patient. This seems to effectively collapse the objective view into the subjective view, and it would effectively deny that any genuine disagreement in terms of best care is possible, for best care would always be determined by the patient.

For similar reasons, an objective idea of patient best interest could also not really support the claim that ACP is objectively beneficial for the patient. This is because its claim to the beneficence of ACP is based on the assertion of patient autonomy and not best medical outcome or care, unless best medical outcome and autonomy assertion were held to always coincide. But if we held them to coincide at all times, we would again collapse the objective and subjective perspective. We would have to think either that disagreement about objective best interest could not happen, or that in the cases where it does happen, the ‘non-patient’ idea about best care was the one more likely to be wrong. This again would put in severe doubt the idea of objective medical expertise on questions of best care.

It might be thought that we could affirm ideas of independent medical expertise in a more abstract way, claiming that medical knowledge is the equivalent of the objective scientific contribution to the overall assessment of patient well-being, which could be affirmed by a formula like this:

> (i) Treatment x is the best treatment, for any patient y, if they want to be well[cxxxix] (but the patient is under no obligation to wish to be well).

But unfortunately, under the subjective best interest notion this is not enough, for the subjective notion requires that in any particular case the patient idea is to be incorporated. The patient idea may agree with the medical recommendation or not, however it may be, but the upshot is that even a general formulation of best interest (in terms of best care) must incorporate the patient-centered idea of well-being, because any case of medical expertise never stays in the general realm; it eventually becomes particular in its instantiation. So the general best interest formula needs to be something like this:

> (ii): Treatment x is the best treatment, for any patient y, if the patient wants to be well and *if the patient accepts that this is the best treatment for being well.*

It is the latter italicized condition which significantly unhinges medical expertise from its objective footing. I think from these observations on best interest one can conclude at least one of two things and maybe both:

[cxxxix] ‘Well’ could be substituted by 'have the best outcome'.

1 – ACP cannot objectively be in the best interest of the patient (i.e. ACP is only in the best interest of the patient, ***if the patient thinks it is***)
and/or
2 –A framework of ACP must include a subjective idea of beneficence; even though this is still in tension with ideas of medical expertise on best care and renders notions of futility subject to patient agreement.[cxl]

B) IDENTITY AND AUTONOMY AND ACP

If one accepts Kutner's constraint that genuine ACP can only be made validly for oneself and not for another person, then the section on identity will have made clear that the foundation of ACP's moral justification rests to a large degree on identity concerns. Irrespective of which version of identity conceptualization one subscribes to, the identity concept must give criteria for the persistence of the individual, such that we can insure that the person drafting an ACP is the same person to which it must apply in the future. In cases where an ACP incorporates treatment limitations, moral justification must then also be supplied as to why the values and notions of a person at time(x), as per ACP, should govern the treatment circumstances of this individual at time(x^f).[cxli] As we have seen, identity concepts which incorporate persistence of certain mental states may have such value persistence conditions incorporated within the identity account. This is the case for some psychological accounts; however, they suffer difficulties in terms of third person recognition and person continuity claims, and therefore do not cohere very well with the idea of ACP. Biological accounts may do better in this area. They also

---

[cxl] Where futility concerns compete with issues of distributive justice, one would still have the option of using an objective idea of futility and agree that this is not in the patient's best interest. One could just not claim that the idea of futility is based on ideas of best interest.

[cxli] ($X^{f)}$ denoting a time in the future.

seem to be the basis for most current practical legal identity conceptions. However, since mere bodily continuation leaves any normative claims about treatment untouched, they must supply a separate account of normative continuity. What could such a normative continuity claim look like?

Given that it establishes the care conditions for the *post-autonomy loss* phase of the patient, such an account must incorporate some idea of value stability and some idea of why these stable values should govern an individual, who can no longer recognize or identify with these values at the time they are being put into practice; as was seen in the case of Margo, it must also justify why these *pre-autonomy loss* values should override existing interests.

In the last chapter I also mentioned that such an account must postulate the existence of a 'Dworkinesque' type of critical interest account. If the ACP did not have the power to overrule the existing interests of the non-autonomous person with critical interests, one would not need the ACP, one could just ask the incompetent person, or, if they could not communicate, assess their current existential interests at the time they come under question. An ACP of 'truncated authority' that could not overrule future interests would be reduced to be a mere communication device, with little authoritative force. Yet, this is not what ACP usually professes to achieve. The point of an ACP is precisely to enforce authority about future care, irrespective of who doubts its wisdom (future non-autonomous patient or carer).[cxlii]

Therefore, the account must hold that some kind of personal narrative becomes so important for the patient that it should persist past autonomy loss, and the

---

[cxlii] So even if the future incompetent patient were to agree (non-autonomously) with what is suggested in an ACP, this has no bearing on the ACP authority (although it may make treatment choices somewhat easier to achieve).

justification for its applicability must rest on the fact that it was generated by the same biological entity who then stands to suffer its effects.

Such an account can be achieved by formulating a slightly alternative way of what it means to be autonomous in the setting of ACP, which one could call the narrative autonomy principle:

Autonomy in the setting of ACP is the ability to update one's active life narrative

(or one's critical personal values).

From the point of properly morally justified ACP, it would thus seem reasonable to assume that a valid ACP can only be drawn up by a person who retains such an ability, i.e. the ability to validate or appropriately update her critical values; conversely, any ACP should be consulted and acted upon as soon as this ability ceases to be present.

At this stage, two argument clusters present as immediately relevant: firstly, a number of sceptical points can be made about such a conception of autonomy, and, secondly, quite a few critical points result from such a conception of autonomy in respect to current medico-legal practice.

I – SCEPTICISM ABOUT A NARRATIVE AUTONOMY ACCOUNT

As we saw in chapter 3, the notion of life plans is well considered at least within the philosophical debate about autonomy, although they are not uniformly acknowledged. Some more detailed critical points and general difficulties about life plans were explored by Meyers in response to Rawls account of life plans (p.89),but the idea of life narratives have also been discussed directly in reference to ACP, by people like Dworkin[194], Dresser[195], DeGrazia[196] and others. However, in chapter 5, I showed that life narrative accounts don't seem to feature at all in the current legal autonomy concept application, although some references in the British code of practice of the Mental Capacity Act seem to allude to it indirectly, as observed in chapter 7.

I do not know that one can decisively settle whether we should accept versions of narrative accounts. Whatever value stability one obtains, one cannot help but wonder about the kind of factors which are actually responsible for their stability. Some factors might be person-internal[cxliii], but it seems just as likely that value stability is also related to external factors such as 'life changing events'. It would seem that the loss of autonomy and the progression of mental decline (for whatever reason) may well go hand in hand, at least sometimes, with significant changes in person external circumstances. Things like change in physical abilities, place of residence, level of personal interactions, comfort, etc. may well qualify as life changing events in terms of what one values or would value, and it is not clear to me that within a setting of such change one can justly or confidently make a case for the likely persistence of value stability.

Life narrative accounts, which claim stability of critical interests, suppose a trajectory from a multitude of unstable values in youth to a stable critical value set in adulthood. But why should this be so? Why should not the value set naturally decline in stability, just as it was unstable in childhood; or why should one suppose that one should wish to hold it at a certain stable point, fixed by means of a plan? Maybe one could say that there is a distinct difference between a narrative and critical interests. It would seem that a narrative implies some form of stability or at least a trajectory, but it is not clear that critical interests do so. If we go by Dworkin's description, critical interests refer to interests about which one would feel a loss if they were not fulfilled. Now, it is true, that one seems to need something like critical interests (or critical values) in order to construct a narrative,

---

[cxliii] And thus may be queried in terms of procedural requirements for autonomy, as was done by Meyers (see chapter 3).

but it is not clear that the critical interests themselves need to be stable[cxliv]; in fact, it seems that the degree of stability of these interests is precisely what shapes the narrative. The interesting question is then whether we aim at a narrative first and the criticality of our interests is revealed as a consequence of our narrative, or whether we have critical interests first, i.e. we feel a particular loss first, and this feeling of loss reveals our narrative. It would seem that the trajectory nature of ACP would presuppose the former, rather than the latter idea, i.e. having an ACP presupposes that people construe a narrative, which then extends into the future.

Yet, it is not clear that all people should be alike in this respect. It could well be the case that some people have relatively fixed narratives and some do not. Galen Strawson[197], for example, denies that he experiences his life as a narrative and proposed that people psychologically and perhaps even genetically differed in this regard. He also denied that narrativity was ethically necessary or desirable in order to lead a valuable life. It may also be that some people have a relatively stable set of values, but see no particular reason for why this set should remain stable. In childhood there is no narrative or stable value set, and paternalism is a natural consequence. Admittedly, old age affected by dementia, or other causes of diminished autonomy, differs from childhood in that the individual has some kind of 'moral history', which a child does not have, but I am not convinced that one can argue from the mere existence of a personal moral history to the conclusion that such moral history should necessarily determine the future. As I said, I do not think one can decisively settle this point one way or another, and therefore I believe the most reasonable conclusion is to adhere to what I take to be Dworkin's insight:

[cxliv] I take it to be the case that the criticality of our interests (or values) is not derived from their stability, but rather from the severity of loss one would feel about their frustration. If criticality were construed as 'stability' then the point which follows in the main text would simply apply to the variation of stability of interests that people may have.

those who do not believe in critical interests or the stability of such critical interests (based on stable values) or do not see themselves as wanting to have such interests extended, have no reason to engage in ACP; for them ACP has no moral authority.[cxlv]

A proponent of ACP might contend that all people have critical interests, but may not be aware of them. To this one may rightly object that one cannot plan on the basis of values or interests of which one is unaware. Here the ACP planning counselor might propose that part of a good planning process would involve identifying such stable values. Such an argument seems to come very close to a position of viewing ACP as *objectively* beneficial, either based on an assumption that ACP is objectively beneficial for all patients (they just need the help of the counselor to see so) or on the assumption that people generally have stable values along a certain trajectory and that such values only need to be uncovered in order to be implemented. The 'objective beneficence claim' for ACP I have already dismissed as being incongruent with the idea of ACP (see p. 153) and the 'stability of value' approach can at least be seriously doubted and needs a separate justification or at least needs to be endorsed by the patient. The latter also jumps from the existence of stable values at time(x) to the need for enforcement of value stability to time ($x^{f)}$, but as I suggested above, this need not be the case.

In cases where the initiative for ACP does not come from the patient herself, the worry is that one may not be able to tell in what sense a person owns these ideas herself or simply accepts them in a somewhat uncritical manner as part of a recommended calculus of 'what should be done' or even as 'what is required to be done'. This is especially so when ACP is not presented as only beneficial for those

---

[cxlv] At least no moral authority based on autonomy; there may be other moral justifications, such as economic ones, but these are not relevant here.

people who take themselves to have stable values. These points very much relate to procedural aspects of ACP in general, but also to the necessary procedural requirements of autonomy and aspects of coercion. If ACP is portrayed as 'recommended treatment', this would be misleading in so far as it does not stress that the patient's ideas about the stability and narrative projection of values are crucial (based on the subjective idea of beneficence). However, if there are only minimal procedural requirements (as suggested by the current legal framework) in order to fulfill the required decision making constraints, such aspects may never come into consideration, and care planning may go ahead irrespective of the patient's own ideas on these matters. This may especially be the case, where those who counsel about ACP are themselves unaware of these conceptual ties to the role of stable, planned narratives. This leaves ACP open to (probably unintended) abuse!

II – CRITIQUE OF CURRENT MEDICO–LEGAL PRACTICE

In chapters 4 and 5 I tried to ascertain which of the diverse autonomy accounts are currently employed in practice and found that uniformity was absent. As the decision about patient autonomy depends not only on patient circumstance but also on the autonomy concept applied in the assessment, we saw that the lack of concept uniformity was directly involved in justifiable treatment inconsistencies, through lack of precision in guidance. This, it would seem, is undesirable and we therefore have a need for a greater consistency of ideas. Such consistency is difficult to achieve, for the reasons given in chapter 6. Even if we put legal concerns at the top of the hierarchy and within the legal context also hierarchize the legal goals, the autonomy concept may still be left wanting, if it does not fit within the overall conceptual framework of ACP.[cxlvi]

Thus, it is now appropriate to inquire which autonomy concept fits best within the overall framework of ACP. If we acknowledge the relevant constraints suggested by the requirements of identity and beneficence concepts, it will become clear that the number of autonomy concerns eligible for consideration is considerably reduced. Especially the need of a biological identity account has significant restraining force, because its consequence is that one needs to rely on a narrative idea of autonomy, such that value continuity into post autonomous times (which is not justifiable on the basis of a biological identity account) can be justified for any values.

If the relevant autonomy concept for advance care planning thus is *the ability to update one's personal narrative or one's critical interests*, then this is what needs to be established, each time a plan is drawn up, altered or a situation is assessed as to whether an ACP should 'kick in', i.e. each time any treatment considerations are under discussion in conjunction with an ACP.

This could be a very laborious process, for it would potentially require frequent autonomy assessments; if nothing else, it will be unpractical. In view of the difficulties we currently have to even reliably test for certain partial competencies (refer to p. 110ff), one might also wonder whether we actually possess tests, which could reliably, and with sufficient practical feasibility, answer the question of whether a person has the ability to update their life narrative. This is especially

---

[cxlvi] This point is quite separate from the fact that legal ideas of autonomy often practically do not prevail, because the law, although in governance, is actually fairly removed from the advance care action, both in time and in execution. The number of cases, whose outcomes are actually decided by a particular legal ruling is very small, so for practical reasons alone the law can never be more than a guide; nonetheless, it would be good if it was a clear and consistent guide.

curious, as we have not convincingly established that all people have such a life narrative or stable critical interests. These tests would also need to confirm whether this ability is clearly present or absent, i.e. they need to supply a discrete definitive threshold for narrative autonomy, because otherwise one cannot clearly identify the consent giving authority.

If ACP is about maintaining one's narrative (as beneficence and identity constraints demand), it is also clear that this limits to some extent the type of content an ACP may have, for narrative and critical interests are distinctly separate from any experiential comforts or preferences, whereby experiential comforts are understood as such comforts about which one would feel no great loss.[cxlvii] Although these kinds of comforts may not stand in contradiction to the personal narrative, they cannot be the sole purpose of ACP [cxlviii] and they cannot be respected on occasions when they come into conflict with one's narrative.

[cxlvii] I use the term ’experiential’ here in the way Dworkin distinguished between critical and experiential interests. If a person was a decided hedonist, experiential comforts may play the role of critical interests in that they are the aim of one's narrative. However, such a hedonistic outlook provides a special case in which critical interests consist of experiential 'pleasures'. Any non-hedonistic narrative would find a sharp distinction between the two, unless we granted Dresser's point (see chapter 8, p.249 that with increasing mental decline experiential interests become more important than critical interests. However, if that were the case the compellingness of a personal narrative as authority over the future would vanish and ACP would lose its binding force morally and legally .

[cxlviii] One might think that a very truncated version of ACP, which simply documents experiential interests could still be of merit for those situations, where post autonomous preferences and pre-autonomous preferences do not conflict, but this again would make an ACP a mere (non-forceful) communication tool, rather than a legally binding document and is thus not true to the aims proposed by ACP proponents.

More importantly, it seems that autonomy as *a life narrative updating ability* could mean trouble for our current common law consent standard, because the capacity or ability to give consent to a particular treatment, may be quite different from the capacity or ability to genuinely update one's narrative. A patient may well legitimately consent to antibiotic treatment, because she understands that without it she would become gravely ill and die, and she may well understand that she wants to go on living; however at the same time she may well *not understand* that this is contrary to her previous instruction and her previously fixed narrative. This is Margo all over again! However, it is also an illustration of how the application of the 'particular transaction standard', as given by the Australian common law definition (p. 147) of 'competence to give consent', fails to cohere with a coherent idea-framework of ACP.

For as long as there is an ACP in place, the question of whether it is applicable to the patient or not must rest on the patient's ability to genuinely update her narrative and her critical life interests. Because any clarification of authority to make a choice must come prior to any treatment decisions, this question must be asked every time, when an ACP is in place. For once the person has lost this ability to update their narrative, the ACP should apply and should become the authority for all further treatment choices! I am not clear whether the existence of an ACP puts extra pressure on the default assumption of autonomy for adults[cxlix], but it certainly complicates matters when autonomy is doubted and it complicates the question of what kinds of things should cause us to doubt someone's autonomy.

As observed above, the ability to update one's narrative and critical interests, cannot be risk relative, since ACPs are usually meant to apply bindingly, even if it

---

[cxlix] From my own practice there is certainly at least anecdotal evidence that some staff imply (falsely) a lack of capacity from the mere existence of an ACP.

leads to the death of the patient. It also seems to me that narrative autonomy also cannot involve a partial notion of autonomy, because life narratives concern all areas of life and clearly all areas of life are threatened by life limiting decisions. At best one could have low procedural requirements for determining who counts as 'narratively' autonomous. Given that it must allow for the event of death as a result of any treatment limitations, the narrative autonomy concept also cannot be substantive, or at least suffers significant limitations in what way it could be substantive, for it must not prohibit such particular ideas as the idea of favoring death over unpalatable alternatives of life![cl]

From these considerations I infer that most coherent autonomy concept for an ACP framework is a global, procedural account that is risk independent in so far as it must not restrict ACP capacity to certain treatment decisions only. It could however incorporate a certain risk awareness in terms of procedural requirements, i.e. we may require the patient to demonstrate certain reasoning abilities. Alternatively, it could aim at maximal inclusiveness through setting a low procedural threshold, however, it cannot be maximally inclusive and risk averse at the same time; whether it should be relational or individual remains to be determined from other considerations. Turoldo[198] suggested that relational autonomy concepts cope better with demands of multiculturalism and one may also see the decidedly social nature of ACP as a reason to favor a relational account, but there seems to be no compelling feature within the total ACP framework, which would make the adoption of a relational or an individual account more coherent. Relational accounts tend to be able to specify to a greater degree in what way someone may fail to have global autonomy, and therefore commonly cohere very well with scalar autonomy accounts, but these concerns could be incorporated into a global account: for

---

[cl] This latter idea would be akin to the Millian prohibition of selling oneself into slavery.

example, one could raise or lower the global autonomy threshold via procedural requirements for narrative autonomy (as long as legal rules aiming at maximal inclusion do not prevent us from doing so).

Furthermore, when it is to be established whether a person has sufficient autonomy to draw up an ACP, or when an ACP is in place, the common law standard of competence to make a treatment decision should take as the *transaction to be considered*, the ability to understand one's life narrative and critical interests, and not any focal circumstances of the treatment transactions, which might have prompted ACP. Additionally, all treatment decisions which fall after this ability to understand one's narrative has been lost must refer to the ACP as consent-giving authority, irrespective of any residual focal understanding (or residual interests) of the individual to whom it applies.

To illustrate this latter point, it might be instructive to return to the case of *Mrs T*. If my autonomy analysis in regards to ACP is correct, then the first thing to establish is, whether deciding *Mrs T*'s treatment course (for or against tracheostomy) is a matter of consent to treatment, or a matter of drawing up an ACP. If it were a matter of consent to treatment, the common law standard should apply and we should question whether she understood the relevant concerns of the treatment, its alternatives etc. However if we understand this to be an instance of ACP, we should assess whether *Mrs T* has stable critical interests and perceives herself as living according to a personal narrative and whether she is currently able to competently update or maintain such a narrative. According to my analysis, the treatment decision would require partial autonomy only, the ACP decision would require global autonomy. It thus seems that we have an intrusion of double standards![cli]

One might object here that different standards are not objectionable per se, because we can tell the situations apart clearly according to context. As the case of *Mrs T* has shown, however, this does not hold true, because ACP is so indeterminate about the timing of treatment decisions that clear contextualization fails, for it is often very difficult (or near impossible) to tell apart, whether we are advance care planning or treating, practically and conceptually. *Mrs T* was not asked at the time to consent to tracheostomy, but whether she would consent to it, if her condition became a lot worse over the next few hours or days. And she was asked this now, because her medical deterioration would necessarily further decrease her autonomy. So even if she were partially autonomous enough to withhold consent for a contemporary decision, her contemporary decision would also be the best that could form the basis for an ACP decision in terms of near immediate deterioration. If her concurrent refusal of consent was not good enough to inform any planning about a near future deterioration, because this would be considered advance care planning for which she would have to be narratively globally autonomous, ACP would not be possible in such a situation. Furthermore, the recent refusal of consent to a contemporary treatment decision, based on partial autonomy, could not inform the treatment decisions which would have to be made on her behalf if she did critically deteriorate, because they did not involve the relevant narrative concept of autonomy (the case of *Mrs T* also illustrated that all of these concerns are made more difficult by the fact that many different people have

---

[cli] If it was thought that double standards could simply be prioritized according to a hierarchy, say, contemporary partial autonomy outranks diachronically remote global autonomy, one would seriously undermine any ACP enterprise.

to contemplate them). So dual standards cause practical and conceptual havoc, because the contextual difference is unclear.

One might see this simply as a limitation of ACP in the setting of acute illness. One might say, that, as it is not clear whether we are dealing with true ACP or a (contemporary) simple treatment decision, maybe we should go for the treatment decision option, for it seems to have less stringent autonomy requirements and therefore is more inclusive. The acute illness may prompt the patient to think about future goals and values and perhaps formulate these in an ACP under less acute circumstances later: 'if in doubt, presume autonomy', might be the thought here.

Such an approach would throw considerable doubt on the not uncommon current practice whereby treatment limitations are established as an ACP during a critical illness. This is a practice which makes at least some ACP programs indistinguishable from medical treatment limitation orders (such as NFR[clii] orders, DNR order, or the like), and one would seriously have to doubt in what sense these genuinely represent a considered extension of the patient's narrative. This would require us to further specify whether any ACP drawn up during an acute phase illness is valid, which again would have to engage the questions of what kind of autonomy was needed and the double standards issue would recur.

In the case of *Mrs T* this may play out the following way: she would either die as a result of her treatment decision (should she be found competent to make the treatment decision) and thus never get a chance to make a considered ACP, or she

---

[clii] NFR = not for resuscitation, DNR = do not resuscitate; these are commonly used abbreviations for medically formulated treatment restrictions, which are used in medical communication. The practice of these limitation orders varies greatly amongst institutions. They may include a patient consent to or acknowledgement of the treatment limitation, or they may simply be an expression of medical opinion on the futility of certain treatments.

would survive. If she later were to go on to make an ACP (when well) based on a considered life narrative that substantiates her choice against possible future tracheostomies, then any future treatment decisions have to include whether she can competently update her life narrative at that time. This, as suggested above, requires global autonomy. If she passes the 'update the life narrative' autonomy standard, she will probably also satisfy any partial autonomy requirements for individual treatment concerns, as they are likely to be lower. However, if she doesn't qualify as globally autonomous in terms of having the ability to competently update her narrative, her ACP will become operative in order to maintain her narrative, and any partial autonomy that she may have will not be relevant! Hence, as soon as ACP is in play, scalar autonomy accounts are no longer relevant for medical decision making. So overall, a coherent ACP framework, which includes relevant identity concerns (and therefore an account of narrative autonomy), seems to raise the bar for medical decision making to a global autonomy level[cliii] (after an ACP has been made).

It might be said that the idea that an ACP raises the bar of medical decision making to a global autonomy level is not really an objection to ACP, if that is what one intends by making an ACP. True, if ACP really intended that, this point would not be very troublesome. However, it seems to me that this is not what most people really intend, when they engage in ACP. The reasons for thinking this is that a global autonomy concept does not seem to be the autonomy level applied legally in

---

[cliii] None of this has established that we can actually reliably test for an ability to update one's narrative, but for the sake of this argument I will assume that the community could, in principle, agree on practices which are deemed sufficient. What would not be acceptable, would be the reasoning that we cannot demand global autonomy as a requirement for ACP, because we have no satisfactory test for it; for it would not do to make the ACP framework incoherent based on test fallibility.

regards to ACP, for the predominantly quoted standard in reference to ACP is the common law standard. And as far as I can determine no one has ever portrayed ACP as lifting the autonomy threshold or as it having such intentions.

ACP is also commonly forwarded as a guard against paternalism and as a way of increasing participation in one's future concerns. Such a picture does not usually involve ideas of 'self-paternalization' or ideas of overriding future partial capacities. I think ACP is more broadly viewed as providing information for the future in the setting of outright autonomy failures, not partial failures. Thus claiming that by being involved in ACP one *intends* to raise the autonomy threshold by which one's autonomy is assessed seems to be a misinterpretation of ACP. An ACP does not want to raise autonomy thresholds; it is just meant to step in when thresholds are not reached. However, the problem is that the threshold for autonomy failure in terms of concurrent decision making and narrative autonomy affirmation in regards to ACP are different.

An important practical point is further given by the fact that questions about the existence of an ACP only arise, if the patient appears to not be competent to make a treatment or care decision, but this is of course only the case when 'common law autonomy' (i.e. relevant partial autonomy) fails. However, if the ACP exists as a kind of 'narrative autonomy shadow', one should really consider the question of whether an ACP exists with *every* patient encounter (with an ACP-eligible patient), adjudicate whether it should apply and only then proceed with determining care questions. This is not what happens in current practice, nor what is suggested by current medico-legal guidelines.

Hence, I think, it cannot really be sustained that the intention of ACP is to lift the autonomy threshold level to an account of 'global autonomy'. It should rather be seen as a problematic conceptual consequence of the idea of ACP, which is in tension with current views on assisted decision making.

Finally, any individual, whom we do not think capable of establishing a life narrative, or stable critical interests or the like, cannot be eligible to draw up an ACP at all, because they would never fulfill the identity criteria necessary in order to morally ground the claim that the future individual should be subject to the previous individual's critical moral values. Similarly any individual who does not believe they have a particular projective narrative would not qualify for ACP, for the same reasons. By promoting ACP, we thus necessarily generate a double standard in autonomy requirements for medical decision making, a global standard for those with ACP and a scalar one for those without, unless we return to generally global standards, which is against the aim of inclusiveness and the trends in medical decision making over the last few decades.

From what was found in chapters 2, 4 and 5, global, narrative ACP autonomy requirements seem to be quite at variance with current practice or even with what seems to be aimed for in current practice. This kind of autonomy conception is certainly also at variance with recent trends to be more inclusive and allow increased participation in decision making through risk stratifications and via recognizing partial competencies.[199] As far as increased participation in decision making for ACP is concerned, this would only be coherent if the strategies involved were aimed at enabling the patient to form a stable narrative. However, this would presume a normative position which claims objectively that everyone should have a narrative. As Strawson[200] pointed out, such a position is questionable by itself, but, as I have suggested, it is also in tension with the subjective best interest principle.

4 – WIDER CONCEPTUAL CONSTRAINTS RELEVANT FOR ACP

The examination of the beneficence and identity concepts in chapters 7 and 8 revealed some other, wider, conceptual connections, which I have not yet addressed in this summary of conceptual tensions. However, I think they deserve inclusion, as they seem to constrain the ways in which ACP can make sense to a person in an important manner. Since my primary starting point was to pursue in what way conceptual constraints may prevent ACP from being successful, this seems relevant. The thought here is that, apart from having framework constraints as a result of the direct inter-conceptual dynamics of the three main concepts, ACP also faces limitations from conceptual dynamics, which may prevent someone from accepting one of the particular forms of autonomy, beneficence or autonomy in the way in which they are required for ACP. Although this may not be a failure of ACP itself, it may help to explain, why ACP has a low prevalence in the community, which was one of my original observations in chapter 1. It is commonly an observation which is attributed to some practical failure in the administration of ACP, which could in principle be remedied. However, if the explanation of ACP's low incidence was based on such conceptual grounds as illustrated in the following section, then such remedy is not apparent.[cliv]

For example, a person's overall belief system may make it impossible for them to accept a subjective form of the beneficence principle. If that were the case, the most coherent form of ACP, as expounded above, could not make sense to them; if they did accept ACP then they would have to be prepared to admit (and psychologically accommodate) incoherence.

Why would someone not be able to incorporate a subjective best interest principle? One might simply be convinced that best interest is best determined by objective measures in the sense that it answers the question 'what is best for this person?' as

---

[cliv] Any 'remedy' here would involve a change of people's wider conceptual beliefs and would first have to address the question of why such remedy was felt necessary. It would seem odd to base such need for change of conceptual beliefs on a notion of respect for autonomy. It could be justified on other moral frameworks, such as utilitarianism, which looks for maximal communal benefit. Maybe utilitarianism could make a case for reducing the community treatment burden through treatment limitations, but if this were the case any reference to autonomy seems misguided, and we would not need the entire ACP framework, but rather a community framework for limitations of treatment.

opposed to answering 'what would this person choose?'. Such a conviction may be present in a patient, who might have an experiential track record of having made frequent poor choices, or who simply trusts that the health practitioner has better epistemic access to the kinds of things which are important to the making the best choice. And even though the question of what a person's best interest is and the question of best epistemic access to finding the answer are conceptually distinct, the practical outcome will be the same, such that the patient rather surrenders his choice to what he deems to be the better informed party to make this choice. In this case the patient's basic attitude towards his carers becomes an expression of his underlying philosophy.[clv] Alternatively, a person who is in the business of giving professional medical advice, and whose professional integrity involves holding an objective best interest account as central to their operation, may feel equal coherence tensions, if they are meant to assert a subjective and an objective best interest account at the same time. This may be especially difficult, the more we take concepts to have concrete truth values. A person who thinks best interest just ***is*** objective, where the ***is*** denotes some sort of context-independent truth, will feel especially conflicted when they are meant to entertain at the same time that beneficence ***is*** not objective. People who have a more contextualized approach to truth values, such as philosophical relativists, may feel less tension in this respect. However, when they have to specify distinct contextual boundaries, which can equally present as a question about concrete truth values, their position may become just as problematic.

Other co-conceptual constraints might apply to the other principles. In chapter 8, I noted that certain metaphysical convictions lead to the preference for certain

---

[clv] This also demonstrates that not all philosophies need an 'academic' representation in order to be effective.

identity accounts over others. It may be that these basic metaphysical convictions are also in direct conflict with ACP.

If I hold a belief that people do not essentially have a persistent identity, such as many Buddhists do, or that people can have (or do have) multiple identities per body (such as would be suggested by Parfit), then ACP is not an option, for it demands a single persistent identity. Similar constraints apply to person essentialists: if I hold that people are essentially persons, and that with the loss of autonomy (or some other such severe event of mental decline) my personhood essentially stops, then ACP may make limited sense, because I would not plan for *me*, but for some sort of 'essentially non-me' entity.

If I do not take myself as living according to a personal narrative, ACP makes no sense.

If I hold idealist metaphysical beliefs, e.g. I hold that my world is entirely made up of mental events (even those parts, which conventionally are taken to be material or real), then ACP will not cohere with my underlying metaphysics. It is probably true that amongst mainstream philosophers, metaphysical idealists are rare these days, however, that does not mean that this is the case for the general public. Buddhism, for example, can be understood as a form of such idealism. There are many Buddhists in the world. Even if this were not the case, the point here is that certain metaphysical outlooks do not cohere with the idea of ACP, idealism being one of them. Some metaphysical dualists may struggle in a similar way, depending on how the person's particular ideas of the persistence of the soul affect their conceived ideas of identity persistence and death.

In the first chapter, I raised the hypothetical case of how Socrates would fare with ACP. His idea of the persistence of the soul being an essentially important consideration seems to have led to his position of having little concern for his bodily remains. If he had held that the departure of his soul would be indicated by a loss of autonomy, then he may have had little interest in any directions about what should happen to his body (and associated mental remnants). However, if he thought that his soul could only depart if his body was treated in a very particular way, then such planning might mean the world to him.

Furthermore a person may not believe herself to be autonomous. Someone who holds a fatalistic or deterministic view about free will may fall into this category. The reasons for such limitations may be many-fold. They could be epistemic, such that a person thinks she cannot know enough about all the relevant circumstances in order to see herself as truly autonomous. The perception of lack of autonomy can be the result of lack of sufficient valid choices: e.g. a choice between only bad options. One may not perceive this as any choice at all (death or horrible dementia or painful existence).[201] Some particular pious beliefs as part of certain religious convictions about how or in which ways one may plan for one's life may be incoherent with the autonomy demands necessary for ACP ('the Lord giveth and he taketh away' or 'it's not up to me to say'). Some relational concerns such as altruistic choices may be taken as sufficiently contrary to a perception of autonomy. A strong concern about being a burden may be conceived as prevention of a self-realization of autonomy. People may simply not value autonomy as sufficiently significant to warrant ACP. On a communal basis this would be consistent with utilitarian concerns, e.g. someone may hold that communal demands should outweigh individual interests. This is true even if autonomy as a right to self-determination is enshrined legally, for the mere provision of legal right that does not mean that a person must 'subscribe' to such a right personally; the way to express this might be simply through abstaining from personal ACP. However, it need also not be part of a utilitarian attitude; it could be purely in reference to personal circumstance. There are many other explanations, some of which can be found in the examination of cultural differences in the attitude towards autonomy, such as are explored by Turoldo[202] or Lock.[203]

In so far as these wider conceptual considerations do not say anything about the conceptual coherence of ACP, they do not threaten the idea of ACP itself. They do, however, contribute to an understanding of how ACP may feature in the wider conceptual network of ideas of any particular person who considers the merit or sense of ACP. Such understanding is needed to consider whether any particular person is likely to wish to plan for themselves or whether they are likely to endorse or even promote the idea within the care setting. As noted above, this seems to be significant for the overall importance that we may attribute to the idea of ACP, as it may contribute to explanations of why the prevalence of ACP is generally not high and what kind of conclusions we can take from such low incidence and maybe its resistance to significant promotional efforts.

5 – NEED FOR ANTHROPOLOGICAL INFORMATION

To what degree we find these wider conceptual concerns present and expressed within a relevant community is perhaps a matter of cultural anthropological [clvi] research, at which my examples could only gesture. Without particular anthropological information in this area very few points may be convincingly made, except perhaps for the following general intuitions.

Firstly, the more diverse a community, the more likely it seems that said community will involve people for whom ACP does not make sense for one reason or another (given that the reasons for rejecting the idea of ACP can be so various). This thought is substantiated by empirical research which found the highest prevalence of ACP in very homogenous communities.[204] And although the same study has shown that comprehensive advance care planning programs can raise ACP rates in ethnic minorities, ACP rates remain lower in such minorities.

[clvi] I take 'cultural anthropology' to be the study of how people make sense of the world, whereas sociology is an investigation of socio–cultural behaviors. Since this analysis is more concerned with the thought component rather than with behaviors, I take anthropology to be the discipline relevant here, although both disciplines, no doubt, would have valid contributions to make.

Thus it would seem that in communities which are very culturally diverse, especially those communities which have a significant proportion of recent migrants, as I take the Australian community to be, one needs to take extra care to evaluate cultural conceptual constraints, which seem inconsistent with the idea of ACP. This seems important in so far as we should not wish to impose certain conceptual demands on patients who would not of their own conceive of their ideas thus. One must therefore take care to not push a vulnerable community into what it does not choose, or if one does, one cannot do it legitimately under the banner of respect for autonomy. There may be independent reasons why one would wish for more explicit long term plans for individual care, but these cannot run under a banner of 'respect for autonomy', if they are not driven by patient ideas about the planning need.

Secondly, it would seem that the more homogenous a community, the more homogenous will be its values about treatment considerations and the less will be the potential for disagreeing about appropriate treatments in a given situation. This, however, reduces the need for ACP as a tool for overcoming differences. So ACP will work best where it is least needed. It may be simply rendered a tool for communication, rather than evidence to sway or enforce divergent choices.

Thirdly, where wider conceptual concerns threaten the professional integrity of the parties who are ***necessarily*** involved in ACP (especially people working in law and the care professions), we do have to seriously wonder whether these wider concerns have to count as threatening even the possibility of practically coherent ACP. In what sense these professional communities feel threatened might also only be established through a relevant anthropological investigation, but I think it should be noted as one of the potential threats to important practical aspects of ACP.[clvii] Furthermore, if we just saw the emergence of conceptual tensions as a psychological dilemma, we might think it to be only the problem of some individuals. But if we view conceptual incoherence as a failure of rationality, a much more sceptical charge may apply to the entire project of ACP, for it would cast a serious doubt on the professionalism of the efforts of anyone involved in the ACP enterprise. To me the latter seems to be a significant worry, which must be taken seriously. Professions who in all other respects praise rationality and profess to adhere to the highest standards should display high standards of coherence in this domain also.

6 – SCEPTICISM ABOUT THE 'REALITY' OF CONCEPTS

In what way the professional communities see the relevant concepts as concrete, real foundational entities, or as contextually flexible entities may be of significance here. This, too, may be influenced by their professional culture. E.g. someone working in science, who may be more used to viewing the world in the dichotomous forms of data collection, where phenomena are either verified or not, in a particular way, may see concepts as more concretely existent and concretely real. Someone who does not subscribe to such clear dichotomies may feel no such concrete obligations towards conceptual rigidity. So what on the one hand may appear as a psychological trait may actually be the result of a professional metaphysical

---

[clvii] I think, it would be important to consider that the culturally important background is the particular *professional* culture and not the cultural background of the individuals who are part of the professions; i.e. although the comparison of the cultural diversity of the professional individuals in comparison to the cultural diversity of the patients may have important consequences for the appropriate execution of ACP, this is not what is at issue here, where the question involves the conceptual coherence based on conflicting aims of the professions.

commitment, and these seem to differ significantly between the professions of science and law, for example.[clviii]

How this can play out in our appraisal of ACP as a whole may be ascertained from the degree of scepticism we derive from the conceptual variations and tensions in terms of their 'reality'. Thus our sense of conceptual reality may play an important part of ACP acceptance and interpretation.

Someone who observes great interpretational variation may resort to a broadly sceptical outlook along the lines of the following argument: 'if autonomy can mean so many different things, then it really means nothing in particular and therefore does not really exist; ergo, ACP is an illusion'.

Someone who was less concrete about the 'reality' of the concepts may acknowledge the different aspects as part of a cluster and prefer a more subtle clarification of particular limits to broad scepticism. We may call him the particularist.

Yet another approach is a pragmatic one: people who observe forms of ACP in practice may deduce from their practice that their particular conceptions of autonomy influence their actions, and therefore, they conclude that their idea must be the instantiation of a distinct reality ('if we use it, it must exist'). One could call this approach 'activity realism' or pragmatism.

Whereas the sceptic will probably give up on the idea of ACP (as some have[205]), the particularist and the pragmatist must then embark on the clarification of coherence and limitations and determine what would count as successful ACP.

[clviii] Such fundamental differences in professional commitment are reminiscent of the nature of the professional rift between the importance of issues of trust as a basis for the medical profession and the importance of rights ensurance as a basis of the law, which I pointed out in chapter 6.

Thus we can see that even at this basic level, our particular network of beliefs guides and constrains the way in which we think about and engage with ACP. This is true for carers, practitioners, and theorizers alike. We are uniform in that we are limited, however, we differ in our limitations, practically and conceptually.

7 – SUMMARY

This chapter has attempted to draw together the conceptual elements discussed in the earlier parts of the thesis. I have suggested that because professional and ethnic cultural commitments limit the context in which we may think about the individual conceptual elements needed for a framework of ACP, the context for these conceptual elements should come from within the idea of ACP itself, in such a way that we at least achieve a coherent idea.

My examination leads me to think that the most coherent set of concepts as the basis for an ACP framework uses a *subjective* idea of beneficence in combination with a *biological* account of identity, which are then combined with a *'narrative' account of autonomy*. The latter would ensure the moral justification of extending a person's current concerns of self-determination into the future, overriding the interests of the future individual that the ACP subject will become. I have suggested that such a narrative autonomy concept would deal best with the conceptual problems arising from concerns of identity. Although the idea of narrative identity is well known, the idea of *narrative autonomy*, as I have provisionally called it, has not been mentioned explicitly in the literature; nonetheless I have noted that its contents will in some respects draw heavily on Dworkin's account of critical interests and will relate to some ideas of 'life plans' mentioned by Meyers and Rawls.

My idea of what a detailed account of narrative autonomy should look like is only a sketch so far, but I have noted some features which seem to me to be highly likely requirements, such as autonomy as global rather than partial capacity, and the absence of risk relativity. The comparison of these features to the relevant elements noted in the previous discussion of autonomy seems to put considerable pressure on our current use of autonomy in relation to ACP (especially in comparison to the common law formulations of capacity to give consent). This, together with other wider conceptual constraints, severely limits whether we can view ACP as a coherent and good idea.

In the final chapter I will thus explore in what sense we may accept ACP (as currently practiced and promoted) as successful, how we can assess its claims about respecting autonomy and what kind of outlook in terms of conceptual integrity we can have.

CHAPTER 10 – CONCLUSION AND OUTLOOK

1 – INTRODUCTION

A starting point for this thesis was the question whether ACP is or can be successful, especially in reference to claims of respecting autonomy. This final chapter aims to return to this question and to explore how one might formulate ideas of ACP success and how they compare to the ideological outset of modern ACP as given by Luis Kutner in the 1960s. I will look at what kind of implications and dangers these ideas of success include, how the original aims and ideas may be subject to ongoing change, in what way my conceptual analysis has any bearing on expectations of success and how this compares to current practices.

This will then lead to a conclusion about the conceptual integrity of ACP as an idea, allow me to formulate my thoughts about what could reasonably be expected of ACP and to put forward an outlook towards further research that would be important in order to situate ACP in an appropriate place within the community.

2 – SUCCESS OF ACP

A – GENREAL FEATURES

Ideas of successful ACP can be quite variable, because there is considerable room for disagreement on a number of parameters which are important for an appraisal of success.

Firstly, one needs to agree on who ACP is for, i.e. who is meant to benefit from it. And although respect for patient autonomy has probably been the most prominent factor driving ACP, it is by no means the only factor involved. Even Kutner in his original proposal mentioned the aim of protecting carers from accusations of wrong-doing. Other benefits, such as lower community burden or economic gains may also play a role. So, even though the patient is clearly a central figure in the ACP project, ACP is not only about the patient.

ACP is about how a community determines how to care for its mentally infirm.

As I have shown, this is an enterprise which involves the consideration of many different perspectives and a major difficulty arises from the fact that all these different perspectives have to lead to one unified action in terms of patient care.

Secondly, ideas of success have to specify a *proper patient target group*, i.e. whatever the other markers of success may be, we have to be clear to whom they have to apply. Should they apply to the whole population, only to those who have a life threatening illness, to certain age groups or to groups of people who express agreement with the idea of ACP? If we measure participation rates, for example, this makes a huge difference, because the denominator for the calculation will be vastly different between, say the whole population and a particular age group, say people aged greater than 80.

Thirdly, ideas of success have to incorporate an agreement on *outcome markers*. This means we have to specify success indicators, e.g. patient satisfaction with the planning process, participation rates, adherence to ACP contents at the time of application, to name but a few common ones. A complicating factor here is that the central figure in ACP, the patient, usually is not available to give an appraisal of the outcome (at least in terms of treatment outcome), which necessitates the use of a number of *substitute success markers*, each of which have their limitations. We also need agreement on who is in an appropriate position to judge success.

Finally one has to agree on *what counts as ACP*. This is increasingly important as the ideas of ACP have evolved since Kutner's proposal of the living will. His idea involved an appropriately witnessed written statement that could only apply to the patient and not to anyone else. However, current ACP literature commonly includes other forms of ACP, such as verbal statements, not-formally witnessed written documents or medical powers of attorney (PoA). Some even include DNR orders, where it often is not clear how much patient input contributed to the drawing up of such an order. This certainly makes appraisal of success very difficult and one has to be cautious to compare and analyze data which is sufficiently alike or demonstrative of the idea under question.

As this thesis focuses on an appraisal of how ACP can live up to the claim of respecting patient autonomy and to aims of enforcing the right to patient self-determination, the following analysis of success markers will be especially critical about what kinds of ACP can live up to this claim. Hence, I will discount as valid ACP those measures which cannot be convincingly seen as affirming patient autonomy and discuss in what sense some ACP measures, such as the PoA, may fall significantly short of the original ACP ambitions voiced by Kutner.

B – ACP – PARTICIPATION RATES

In chapter 1 my initial inquiry about the merit of ACP as an idea was partly fuelled by the observation that ACP rates do not seem to be very high, locally and world-wide. However, since I first made this observation a number of significant developments have taken place locally [206] and internationally[clix], which warrant a closer look at what can be said about ACP participation rates.

As pointed out above, ACP rates depend greatly on the target population taken as denominator and what kind of measure is included as ACP. In 2008 the Wisconsin ACP initiative, called Respecting Choices® pioneered a comprehensive ACP education and management program in a relative homogenous American

---

[clix] E.g. In 2010 the international society for advance care planning was founded at the inaugural international conference for ACP in Melbourne, which has since run annual international conferences and promoted significant international collaboration. Since 2008 significant funding and promotion of the Respecting Choices ACP program has occurred in Victoria and other Australian states, and government funded research continues to investigate ACP measures. In Victoria this included for example an inquiry into ACP by the Victorian Health Care association (VHA) in 2012.(see endnote 206)

population. It has been much lauded as the first to report very high ACP participation rates, claiming that 85% of the population in their county had an ACP at the time of death.[207] This is commonly cited alongside an American national ACP-completion rate, quoted to be somewhere between 18% and 36%, and an Australian national advance directive prevalence of 14% (with a significant inter-state variation ranging from 7.5 % in WA to 21% in QLD.)[208] However, the Wisconsin data have as a denominator 'number of patients died' and included PoA and community DNR-orders as possible forms of ACP, whereas the American and Australian national survey has as denominator 'number of general population', while the Australian survey did not include PoAs or community DNR orders. It can thus be seen that the mere comparison of numbers says little about success itself, and that a lack of uniformity in what should be seen as success can at least be inferred from the kinds of differences that appear in the empirical data generation.[clx]

The Australian authors judged the prevalence of 14% as low prevalence, but only gave limited reasons for why this figure was deemed to be something that needed improvement: their reasoning seemed to be based on an assumption that makes reference to a 'general benefit' of ACP, very reminiscent of an objective idea of ACP beneficence. I have rejected such a best interest approach as inconsistent with a coherent framework of ACP in the last chapter and will not revisit the issue here; however it serves to demonstrate the difficulties that one may encounter with using advance directive completion rates as a marker of success. Another reason why these authors may have felt the Australian national rate was low might be because it is significantly lower than other similar population groups (they cite a comparative Canadian prevalence figure of 30%). They do acknowledge the difficulties in

---

[clx] When researchers design their study they have to make a judgment as to what the appropriate target group is, and these investigators clearly differed in their opinion here.

comparison and generalization between populations and jurisdictions, but give no idea of what a successful ACP prevalence for Australia would be. The assumption simply seems to be: higher is better.

The difficulty is to know whether there is a particular figure that should be aimed for and what such a figure would represent. Likewise we may wonder what state of affairs the current figures represent. Given my prior discussions in this thesis, I think these figures could indicate a number of things, some of which may not be appreciated by those who advocate ACP or operate on the understanding that ACP is 'objectively' good.

Low ACP participation rates may be due to ignorance (on behalf of the public) that ACP options exist; they also may be due to other practical obstacles, which make ACP difficult. These are commonly the target of current efforts to improve ACP planning and are based on the assumption that ACP is beneficial and that current rates are too low. However, the current level of participation rates could also be due to a variety of wider conceptual concerns which result in scepticism about the merit of ACP, especially in regards to written documents of the 'living will' kind. This seems to be consistent with the greater preference of patients for appointing a substitute decision maker in favor of producing a written advance directive; for example, more than 80% of ACP in a recent Wisconsin study consisted of PoAs only.[209] This trend could reflect the not unreasonable[clxi] worry that the existence of a written document may in fact reduce actual patient interaction and participation and become the 'new' benchmark for decision making.

The ignorance problem can potentially be overcome with promotion and information, although we have to acknowledge that such promotion would need to

---

[clxi] Not unreasonable, because time for adequate personal communication is increasingly under threat in health institutions which operate under severe budget constraints.

be aware and sensitive to the conceptual constraints expounded previously. To some degree, this has been attempted on an increasingly large scale nationally and internationally. However, the scepticism problem is different and more difficult to deal with.

Scepticism about ACP might present individually merely as a choice not to take up the ACP option, which is a fairly benign consequence. Yet, it may also present (again individually) as an inability to complete a plan that is consistent with one's beliefs or with the kind of treatment options available. In this case, what seemed like a good idea does not eventuate. This might explain, for example, why some studies[210] show that people generally think that ACP is a good idea, but on closer inspection do not have one or do not produce one that is of any merit. ACP generally seems to become more complicated the more one engages with it, and what is often initially embraced, doesn't stand up to scrutiny later on. If such initial positive responses simply fail to become an advance care plan, there is not really a problem either, just a moment of realization of one's position. However, a problem might arise in a situation where the planning process starts and difficulties in developing coherent ideas about one's future develop into a *non-representative ACP* for the sake of task completion, thus producing a misrepresentation of a person's ideas. This is the main worry with overzealous promotion efforts that are insensitive to a person's conceptual outlook and its consequences, especially when this person is in a vulnerable position of acute illness. In regards to concerns of autonomy, one has to worry in these circumstances that a particular drive to improve ACP participation rates may act as coercive force, especially when ACP policies may include insensitive performance indicators[clxii] or when there is scope for imposing a sense of obligation on the patient.

Local Victorian[211] research has noted that people were more likely to engage in ACP in the presence of family members, but it is not clear what this represents, given that this research did not particularly query in which way ACP actually reflects autonomy. The presence of family could either be indicative of a less vulnerable position in which the patient feels empowered to make decisions for herself, it could represent a more effective way of achieving relevant understanding or improved channels of communication, or it could reflect an extra level of effective coercion. A sense of obligation to family members may be greater than to an institution, and a patient may well feel obliged to complete documents when everyone has ‘gone to the trouble' of getting involved on one's behalf. The former two positions may be consistent with a relational interpretation of autonomy, whereas the latter may look at autonomy from an individual perspective, which (if this were representative of coercion) fails to assert itself.

Recent Australian research further demonstrated that higher advance directive rates are associated with 'not being in a significant relationship' and in association with other 'planning type' behavior, such as will making or appointment of a non-medical PoA.[212] This suggests a kind of pragmatic self-selection process of the appropriate ACP target population. However, the same authors believe that ACP would be appropriate also for the wider population outside these groups. This attitude correlates well with the prominent cases which originally forced the way

---

[clxii] Although I am not aware of current performance indicators operative in advance care planning programs, I could easily imagine that under ever pressing health budgets, the rate of ACP completions, per dollar spent or per staff hour expended, could easily lead to problems in this regard.

for the ACP movement; they were almost exclusively young, healthy people (e.g. Karen Quinlon, Anthony Bland or Nancy Cruzon), who had no particular prior health or personal history that would have made ACP especially pressing. Yet the reluctance of the general population to issue written advance directive documents seems to oppose this view, certainly within the general population, but arguably also within the more focused target group of the ill and aged; at least this is what the definite preference for the appointment of a substitute decision-maker to a written directive-type document would suggest. As such the question of who would be the appropriate target group for ACP seems very much unsettled.

An interesting observation derived by the Australian study cited above[213] was that ethnic background did not seem to be a particular predictor for ACP activity, although the study quotes that 40% participants were either born overseas themselves or had one parent born overseas. On the face of it, this would speak against my suggestion that cultural diversity significantly influences ACP participation. However, I would contend that the more important cultural divide here must be sought in diversity of thought and not diversity of geographical ethnicity, which do not necessarily match.[clxiii] Furthermore, I think that one could assume a certain amount of assimilation of values throughout the generations, such that children of migrants, who were born in Australia and grew up here, may think quite differently to their parents. As such the 40% ethnicity figure given in the study may overestimate the amount of intellectual ethnic diversity represented, as it included people who were born in Australia and only had one parent born overseas. Furthermore, this phone survey was conducted in English and thus would have been biased in favor of English speakers.

[clxiii] My observations about differences in professional cultures may, for example, serve as a point of illustration here.

Lastly, one may rightly wonder which kind of measure we should accept as a valid advance care planning activity, such that it should be included in the participation rates and counted as 'success'. As I am pursuing the question of autonomy assertion, I think it would be highly dubious to include DNR orders, which may have little patient input. As far as I am aware this is usually not done in Australia, but certainly seems to be the practice in the United States. It is harder to say in what sense the appointment of a substitute decision maker (PoA) can claim to represent patient autonomy.

The problem, as mentioned in the first chapter, is that apart from the actual 'appointment decision' all other decisions are removed from the actual personal input of the patent; i.e. the substitute decision maker is always second guessing what the patient would choose. Arguably[clxiv] the guess is better informed than anyone else's, but nonetheless it remains a guess. Likewise, the patient has to 'guess' who would make the best choices on their behalf and this may be a difficult decision if one does not even know exactly what kind of choices will have to be made. Furthermore, the patient may have quite limited options of choice, which are often restricted by geographical or other pragmatic[clxv] constraints, that have nothing at all to do with one's values or treatment preferences. And even though medical PoAs are ultimately the only possible way to make treatment decisions on behalf of an incompetent patient, they cannot really qualify as proper autonomy representation, although they may be the patient's best remaining option to be somewhat adequately represented.

[clxiv] Studies, which argue against this better knowledge are discussed a little further on.

[clxv] In Victoria the office of the public advocate offers advice on how to choose a medical PoA. Their module 'You decide who decides' includes, for example, contemplating attributes like 'ability to communicate with doctors' and geographical considerations, reliability, availability and many other attributes – only one of the consideration is 'will know what I want'.

At this point I think one may justly say that the activity of advance care planning and the provision of an advance directive become quite distinct projects. On the one hand, ACP can be seen as a 'weak' project, which may simply be about good communication and ease of decision making under pragmatically best possible considerations. This may well involve appointing a PoA. However, the writing and adequate updating of a personal directive, which is meant to represent one's ongoing personal narrative, is more ambitious in terms of autonomy; it wants more than communication, it aims at asserting oneself against potentially differing opinions. This is difficult to achieve, but if we want to take the claims about respect for autonomy seriously, it is this stronger sense of ACP that needs to be examined. The weak sense of ACP is merely good medical practice; the stronger sense is what Kutner suggested and what I think should be evaluated in terms of success.

With these concerns in mind, I think one is somewhat justified in being suspicious of very high ACP participation rates, especially in very diverse communities, and one has to wonder what high participation rates really represent and whether they are achieved by what we should consider appropriate means.

Thus, ACP participation rates may indicate various different things: high rates could either be reflective of a 'very good ACP program' or they could be reflective of significant indoctrination or a feeling of obligation. Low rates could be indicative of respect for diversity or of poor ACP efforts and structures. Overall, participation rates do not necessarily reflect respect for autonomy.

C – PARTICIPANT’S SATISFACTION

The gold standard for ACP (in terms of outcome) would obviously be to ask the patient to rate success; however, this is usually unobtainable, for we cannot ask the dead or those who are severely mentally incapacitated for a meaningful outcome satisfaction rating. This excludes the small percentage of people who may elect to give an ACP for a temporary mental illness (or physical illness which temporarily affects their mental well-being) and who regain their autonomy at a later stage. As the numbers of this cohort are very small and comprehensive research in this regard is lacking, not much can be said in terms of success here. But even if these directives could claim success, the overall proportion of such ACPs in the total pool of ACPs is tiny and distinct enough that it would warrant a separate appraisal. Nevertheless, some observations in regards to success in this cohort, have been made by Atkinson,[214] and these are not dissimilar from mine, especially in terms of their perspectival aspects[clxvi] (such as I flagged in chapters 6 and 7).

Apart from the 'gold standard', there are other substitute satisfaction markers: some studies have engaged in comparing hypothetical patient wishes to next of kin (NoK) choices, or doctors' choices. However, these studies have epistemic limitations, in so far as the patient could only imagine the relevant realities, but did not experience them. Furthermore, these studies were not really aimed at substantiating patient satisfaction with the care process, but rather with establishing whether we can take NoK choices as satisfactory substitutes for what the patient would choose. This relates to my discussion of the adequacy of substitute decision making as autonomy assertion and would support my view that the adequacy is not especially convincing.[215] Interestingly enough, these studies have also suggested that the provision of an advance directive or advance care planning process does not improve the substitute decision making ability of a NoK or PoAs. They suggest instead that the only improvement in substitute decision making could be found when the patient's choice was compared to that made by complete strangers[216], such as an emergency doctor. Family physicians did just as well (or badly) as the NoK.

[clxvi] Her appreciation of perspectival aspects however, seems to be restricted to ideas of success and does not extend to ideas of autonomy. Despite this, she makes the observation that the success of ACP very much depends on the mutual acceptance of the elements involved in ACP, which would support my observations of the divisive power of professional culture.

Other studies[217] have simply assessed, how satisfied patients were with the planning process, rather that the plan outcome, and there seem to be some very favorable data sets there. However, since this does not concern treatment outcome, one cannot be sure what it reflects. A patient may simply be happy about the increased level of engagement and communication. And although this is a good in itself, it is not something particular to ACP. In fact, it rather emphasizes a lack of what should be good standard care and it may serve as a possible explanation for why some patients may lack trust in their treating practitioners. Some studies have suggested that in places where good communication practices were in place, the need for ACP was much lower.[218] If patients need ACP simply in order to achieve adequate communication, this seems to reflect poor practice more than any respect for autonomy and should be viewed with suspicion.

If we rate success by NoK satisfaction, we obviously have the limitation that it is based on second–hand information, and that it may reflect more the NoK perspective, rather than an appraisal of how they thought things were for the patient. It would seem impossible to overcome this level of entanglement. Furthermore, if we get the autonomy appraisal wrong, the NoK may falsely believe that autonomy was respected, and base their satisfaction rating on a false assumption.[clxvii] A similar thing can be said for an appraisal by a professional[219] carer, who will also only have their individual point of view, which may further be biased by their personal level of professional effort within the ACP environment and their convictions about ACP benefits.

One way in which ACP has been lauded as successful is that it has been shown to improve the bereavement process[220] of the remaining NoK. Although this is obviously also an independent benefit of ACP, this is not one that can be claimed

---

[clxvii] A worry of this kind have been voiced by Fagerlin et.al (see endnote 30).

under the banner of respecting patient autonomy. At best it is a lucky side effect, for one would not wish to claim that ACP was aimed at the benefit of the NoK. Furthermore, where autonomy questions are on shaky grounds, critics have claimed that the improved bereavement process may be based on false reassurance and as such be a supreme case of 'self-deception'.[221]

A professional may also compare the ACP standard of care to ordinary care and arrive at a professional 'objective' success of care rating. Whatever one may make of such an appraisal, it can also not be claimed under respect for patient autonomy, and although it may make for an independent moral defense of some kind of ACP, it cannot be claimed as success here.

D ECONOMIC BENEFITS

Under ever straining health budgets, the economic benefits of ACP have received increasing attention over time. Although initial data did not suggest economic benefits[222], this seems to have changed. At least some studies now seem to indicate some economic benefits in relation to ACP.[223] The calculations in this respect are very difficult, for the boundaries of which costs and savings should be included in the calculations are somewhat hazy. However, unless the economic success is directly tied to personal patient interests, such as was the case with Dr Saul's patient, such concerns can also not be construed under the respect for autonomy.

E – IDEOLOGICAL APPRAISAL

Success can also be questioned in a more generic way. We could simply ask whether ACP achieved what it set out to do. In order to answer this, we then need to specify what we set out to do. Given that I started with Kutner's original formulation of the living will, it seems reasonable to return to his starting points.[clxviii]

Kutner wanted to preserve the right of self-determination, protect the patient from undue suffering and reliably protect the carers from accusations of 'foul play'. He also insisted that this could be done only on the basis of the patient determining her own future care.

Unfortunately, it seems that Kutner was too confident in assuming that these parameters (self-determination, undue suffering, etc.) could be clearly established in fairly uncontroversial ways; or rather, he too easily accepted that the normative elements of these parameters could be satisfactorily established by the professions involved.[clxix] It turned out instead that in the half century that has passed since his first formulation of the living will idea, the diversity of conceptualizations within and

---

[clxviii] A number of sceptical views have appeared in this respect in the literature already and recommend that ACP has to be seen as a failure on Kutner kind of criteria. Outstanding in this respect is Fagerlin and Schneider's paper from 2004 (see endnote30) They have recommended a move towards patient appointed substitute decision maker in favour of living wills. However, since my evaluation is based on conceptual grounds and in several aspects quite different from Fagerlin and Schneider's appraisal, I think my re-evaluation of Kutner's initial approach is relevant in a different kind of way. Furthermore, although the role of patient appointed substitute decision makers within an ACP context is not part of the examination of this thesis, some of what is behind the idea of valid ACP may nonetheless be conceptually relevant in this context also, as it can be related to Kutner's original ideas.

[clxix] That this is not the case can be seen easily by comparing internationally the normative influence of the professions. Skene for example comments that the Bolam standard, which accepts the medical profession's appraisal as normatively valid in Britain, is not accepted in Australia. This is indicative of the considerable disagreement that can persist at very high professional legal levels about the adequacy of normative authority.

across disciplines seems to have contributed as much to confusion as to satisfactory achievement of his aims.

We aim to respect the right of self-determination, but have failed to clearly articulate what this consists of in ACP. We aim to protect from undue suffering, but cannot confidently say what undue suffering consists of, or who has the right authority to say so. We want to claim the patient's authority in addressing this question, but at the same time do not allow a patient to deny basic palliative measures such as pain relief or allow her to have the last word on what therapies are appropriate.

Some of this is the result of the fact that the aims Kutner set can be contradictory from the outset, i.e. protection of carers from accusations of wrong-doing may involve some ‘undue’ suffering on behalf of the patient; or protection from undue suffering might involve infringement on the right of self-determination. Kutner (as well as many other ACP proponents), I think, underestimated the degree to which ACP must be a community venture, rather than a patient action. The community surrounding the patient needs to make available structures for ACP expressions and the community must accept these structures and what is expressed within them. The practical aspects[clxx] of the history of ACP alone have shown that this poses very difficult hurdles. One large scale example of this is the Patient Self-Determination Act (PSDA) in the USA. It linked public funding to the provision of ACP structures. However, this was under-supported in terms of funding and education and left ample room for contradictory statements and uninterpretable ACP documents and it essentially failed to ensure, that sensible ACP were implemented and adhered to.[224] Other examples of this kind could be pointed to within Australia and world-wide.

[clxx] This is well documented elsewhere and not the topic of this thesis.

Yet, as this thesis suggests, some of these failures are not only due to practical constraints, but a result of the conceptual constraints of the underlying ideas. They are therefore not likely to find remedy in attention to funding, or education or any other practical matters, but would rather involve the acceptance of some forms of conceptual dogma. This, I suggest, is itself against the spirit of ACP and therefore difficult to accept.

Kutner also accepted too readily that the right to self-determination could be extended to future (physical) bodies, without considering in detail what kind of entities in terms of personhood status and right holders these future bodies would be, and that their interests could genuinely compete with the interests of the planning patient. Hence, his moral justification of basing ACP on planning for a future self was too simplistic.

Complicating features of his account are that, because it is formulated in the terminology of human rights, we get the subtle inclusion of other aims which are commonly connected to rights issues, but which are somewhat foreign to questions of quality of care. Examples are the desire for inclusion of maximum numbers of people or questions of relating such rights to duties and responsibilities. Desires for maximum inclusion may lead to an inappropriate lowering of autonomy thresholds and ideas of duty may lead to the intrusion of other concerns; e.g. Buchanan's[225] observation that through ACP someone may have the opportunity for altruistic choice (see p. 275), may be extended to considerations of social justice and worries about social burden. In this context one may even consider ACP not only an individual right, but a duty, aiming at the protection of carers from the burden of treatment decisions and certain elements of care, or the protection of society from the burden of having to provide 'futile treatments'. Although Kutner himself was far from suggesting such duties, evidence of these trends might be suspected in the increased attention ACP has achieved from health economic aspects, as well as the push to achieve high ACP rates.[clxxi]

One explanation for the attention to economic concerns may be the attempt to show that ACP cannot only be asserting the patient's will, but can *also* be economically sound, because it prevents the establishment of expensive treatments, which nobody wants. This would then provide additional (rather than substitute) moral grounding for ACP, a strategy employed by ACP advocates to secure funding, for what they think is a good idea. However, if it was true that ACP shows that treatments are not wanted, then one seriously needs to wonder why any such treatments are offered or discussed in the first place. If nobody wanted them or saw them as indicated they should not be offered as part of care. Again, if there was agreement on these matters, it would seem that ACP is unnecessary.[clxxii]

Given that, according to Kutner, ACP is meant to protect the carer from accusations of wrong-doing and it is meant to settle potential disputes, ACP should not need any positive economic back-up and we must acknowledge that people are sometimes genuinely in disagreement about the appropriateness of certain forms

---

[clxxi] Some authors, such as Hammes, who is prominently associated with the Wisconsin initiative, have stressed that ACP is not necessarily about withholding treatment; however, the vast majority of plans seem to work this way, and all studies about economic benefits look at costs saved from 'acute hospital transfers' or 'place of death' with particular interest in avoiding expensive acute care provision.

[clxxii] A related worry is also that, if large numbers of ACPs showed that a particular form of care is not wanted by a majority of patients who participate in ACP, this would promote a case of making these treatments generally less available and thus the preference of the advance care planners would also lead to the direction of care of the non-planners also. Evidence of this has been found; e.g. in an American study, the rate of transfers of elderly patients from nursing homes to acute care hospitals dropped in the non ACP portion of patients to similar levels as the rate for ACP patients, after ACP was introduced (for reference: see endnote 223).

of care. One should be very careful that the original aims of asserting a patient's right to self-determination does not get hijacked by other concerns and turned into a civic duty.

Another complication of the formulation of Kuntner's account in the language of human rights is that it is unable to accommodate the 'flexibility aspect' of autonomy. Although a *right* to self-determination can be rigid and extended over time, the practical aspects of what it means to *be* autonomous, which involve a contemporary responsiveness to concurrent situations, cannot be so. In this sense the *right* of self-determination differs markedly from the *ability* to self-determine.

A further question is, whether ACPs are really that different and better from the previous lack of 'due process' that Kutner lamented in the publication[226] that first suggested the living will idea. In some sense there is a greatly heightened awareness about the problem now, and there certainly seems to be a somewhat better recognized formal legal process in trying to address these problems.[clxxiii] However, whether this really has achieved the main aim of patient self-determination is at least open to doubt, for it is not clear in what sense the mere introduction of some formal process has actually achieved its underlying goals. It is not clear whether these goals are actually achievable, and whether, upon further reflection, these are really the kind of goals we were aiming for.

For example, if I am right in my appraisal that ACP needs to be based on a concept of narrative autonomy and thus would increase the level of autonomy that a person needs in order to participate in decision making, then this may not be what we would want. Perhaps we would be better off sticking with concepts of partial autonomies and the kind of soft paternalism which aims at enabling the patient's

---

[clxxiii] Although many argue that the inconsistency and multiplicity of jurisdictions provides many obstacles to effective ACP.

participation in decision making for as long as possible, independently of any predetermined narrative, or at least not accepting the pre-determined narrative as dogma to be followed.

Even if I am wrong in my intuition that the relevant narrative autonomy needed for ACP is a global form of autonomy, I think I am still justified in the weaker claim that the current medical–legal system does not assess patient autonomy in terms of life narratives. It has poor testing procedures available to establish such narratives, nor does it seem to recognize that these narratives (whatever kind of autonomy they represent) are essential to a coherent understanding of ACP (in the strong sense of ACP). As such, the current medico–legal system is falling significantly short of achieving the kind of self-determination Kutner envisaged and it is completely ambiguous about what the predominant goals for care are, in circumstances of compromised patient autonomy. Alternatively, if we accept the status quo as the best we can do, i.e. a medico-legal system that is in many respects either incoherent or too vague in its specifications, then we are no better off in terms of being at the mercy of the interpretations of our social surroundings than those past patients and carers in the 1960s, whom Kutner wanted to protect by means of an ACP.

Apart from these concerns, Kutner neglected to appreciate the difficulties associated with epistemic access to future possibilities. This has considerable impact on questions of adequate self-government, but also on the level of adequate detail one can give in one’s ACP instructions. From a practical point of view, this has not only led to questions about adequate autonomy in terms of the patient possessing appropriate understanding, but has also led to difficulties in determining when and how ACPs should be formulated. How long can there be between the formulation of an ACP and its implementation? How frequently does it need to be updated? How stable should we suppose narratives to be? Can treatment decisions and ACPs be the same or are they necessarily different ventures? Should ACPs give a range of patient values, which the carer has to implement, or should they be specific about treatments? If ACPs formulate patient values, there are likely to be complications as a result of interpretive differences about how such values are best instantiated and there is yet greater room for disagreement. If ACPs are treatment specific, like Jehovah's Witness instructions about blood products, or decisions against CPR, they may be too narrow in terms of allowing for achievement of possible patient aims, and re-evaluation of one's aims in times of distress. They may also pre-conceive an illness context inappropriately. There is a lot of room for error in predicting the future: for example CPR for treatment in the acute setting of anaphylaxis may be quite indicated and beneficial within the patient's value parameters, even in someone with advanced chronic disease, who might have imagined the application of CPR under a different clinical indication. Blood-products, currently perceived as particular extracts from the full blood of a stranger, may become available in synthetic form (or as re-infusion from the patient's own blood) and it is then not clear how the newer product is to be interpreted within the patient's value system. Such events would for example preclude ACPs which were too distant in time from their implementation. But even the same treatment in the setting of different illnesses may be experienced quite differently (as may have been the case with *Mrs T's* tracheostomy), and thus past experience may be doubted to give appropriate epistemic warrant. If the patient is at death's door, should one not question how such an event would shape their values and their perceived narrative, and how this event would actually compare to what the patient might have imagined things to be like?

ACP has been attempted in both forms, as values history and as specific treatment instructions. The Refusal of Treatment Certificate (RTC) in the state of Victoria is an example of the latter and various forms of the Respecting Choices program[227], currently running in Victoria and other Australian states, exemplify the former. Both versions of ACP have problems. The documentation of patient values does not ensure that the patient contemplates the right kind of medical situation and therefore allows greater room for misinterpretation of treatment appropriateness when the time of crises comes. Value histories are commonly too vague. Treatment prescriptions are specific, but run risks of misjudging the relevant contexts and thus fail to achieve the patient's goals. They are commonly too narrow in scope, either failing to get an outcome that the patient wants, or failing to match the specifics of the situation. They are also prone to being inconsistent with other concurrent instructions.

Out of all ACP situations, Jehovah's Witness instructions against blood products seem to be the most robust in terms of achieving values and specificity, but, as evidenced by some Australian cases[228], even those are problematic in interpretation in the setting of medical advances in available therapies and against questions of patient value stability.

Overall, Kutner certainly initiated a more recognized formal process for ACP. However, there is much room for doubt as to what this process actually represents: Is it really an improvement on past circumstances? Is it in line with what we really want in the setting of impaired autonomy? Is it really a tool to settle disagreements or merely an attempt of ensuring adequate communication in the modern setting of rushed medical consultations, frequent change of care providers and multi-disciplinary care input in ever sub-specializing institutions? If it were the latter, then Kutner's idea cannot be taken as having succeeded.

F – THE FAILURE OF THE LIVING WILL

In 2004 Fagerlin and Schneider claimed that the living will is dead. They made this claim based on a systematic review of empirical evidence which looked at whether five basic steps necessary for ACP are fulfilled.

These steps were:

1- People must have an ACP
2- They must decide what they would want , if incompetent
3- They must be able to lucidly and accurately state their preferences
4- The living will must be available at the right time to the people making decisions for the patient
5- Those people have to "grasp and heed the living will's instruction".[229]

Their review then examined each of these steps, and found them all wanting. They concluded from this that the living will pursued on public policy level is not beneficial and potentially damaging, and should be abandoned in favor of appointing substitute decision makers.

Nonetheless, since the publication of their review, ACP efforts have increased world-wide with some modest claims rebutting some of their criticisms. For example the POLST-program[230] and Wisconsin[231] projects have made inroads on document availability at the right time and place. Both the Wisconsin and Victoria Respecting Choices programs similarly report favorable rates of practitioner's adherence to ACP instructions. Furthermore, economic benefits, which did not seem apparent in 2004, have since been suggested by some studies. So where does this leave ACP now?

Part of the difficulty in judging this is the fact that Fagerlin and Schneider's and my criticisms largely address ACP in the 'strong sense', i.e. advance directives as proposed by Kutner; yet ACP as policy and practice, which claim some of the more recent successes, does not distinguish between the strong and the weaker sense of ACP. Furthermore, some of the ACP benefits claimed in the more recent publications (e.g. economic benefits or improved NoK bereavement) cannot be claimed as autonomy assertions and hence blatantly ignore a central aspect of ACP in their appraisal. It is difficult to say whether this is mere inattention to conceptual detail or as, Fagerlin and Schneider put it, the result of a fairly defiant attitude expressing “triumph of dogma over inquiry and hope over experience”.[232]

I am generally sympathetic to Fagerlin and Schneider’s comprehensive review, because their empirical evidence is thorough and fairly compelling and their worries are legitimate. I also share their view that the appointment of a substitute decision maker is often the best option a patient has from a pragmatic point of view. However, I see this as a pragmatic solution, which can meet only extremely limited or sometimes no claims about respecting patient autonomy. More importantly, although I agree with their extended claim that the five conditions stated above are in principle *unmeetable,* I do so for slightly different reasons. They offer little more than assertions for this claim, but showing empirical evidence about what has happened so far, does not show that these problems are not in principle resolvable. My thesis however has tried to offer some conceptual reasons for why one might think that Fagerlin and Schneider’s claim about the unmeetability of these criteria is warranted. Since my argument rests on conceptual grounds and the importance of the communal nature of ACP, my list of necessary requirements for ACP would be formulated slightly differently. I would put it in the following way:

1- people must have a prospective narrative conception of their life
2- people must believe ACP can appropriately communicate and extend this narrative, and that this is beneficial for them
3- people must decide what they want, for when they are no longer autonomous
4- they must be able to accurately and lucidly state their preferences and update these at regular intervals
5- the information needs to be available, interpreted with reasonable accuracy, and accepted by the relevant decision makers at the time of the decision
6- all participants in the ACP process need to share a mutually acceptable and relevant concept of autonomy and personal identity

My analysis suggests that, although this is not principally an unmeetable set of requirements from within a conceptual framework of ACP, it seems unmeetable in at least two other aspects: Firstly a coherent ACP framework would require a considerable re-working of our understanding of the idea of autonomy relevant for ACP towards an idea of ‘narrative autonomy'. This however seems to pose more problems than it would solve; the idea of narrative autonomy seems unlikely to be acceptable within the legal system, because it seems too demanding (and thus fairly exclusive) and would introduce a second standard in competition to current legal ideas of autonomy and consent. It is also not clear how one would test for narrative autonomy and distinguish the various contexts in which one or the other version of autonomy should apply.

Secondly, this set of requirements seems to be impossible to meet from the cross-disciplinary points of view that are a necessary aspect of the communal nature of ACP. In particular, my thesis suggests that the different professional perspectives, which result from the pursuit of divergent aims integral to the professional identities of the people involved, seem to be an insurmountable hurdle for meeting all these requirements. Furthermore, I propose that this set of requirements does not necessarily cohere well with a significant number of other cross-cultural differences between individuals and therefore cannot be promoted unreflectively and unreservedly as a general benefit to the community.

Current advance care planning practice does not work within a coherent conceptual framework; it is therefore permissive of inconsistent practice and at times can seem as incoherent as the framework itself. This is an intractable problem, not because it would be impossible to generate a reasonably coherent framework, but because the cure would be worse than the disease, insofar as the coherence conditions would leave us with a seemingly undesirable practice. Hence, I agree with Fagerlin and Schneider, that it would be better to abandon the idea of strong (Kutneresque) ACP in favor of something less ambitious, such as shared decision making and forms of soft paternalism. Essentially the right of self-determination can only go so far;

when the ability to self-determine has gone, it has gone, and even those with the best intentions can do nothing, but guess and rely on their own ideas of what is good.

Appointing a substitute decision maker makes fewer claims to extending autonomy (in any of its guises); although it may have the feeling of having contributed something to one's future, just how good that something is, is questionable. Is it better than luck? Depending on the circumstances, it is likely to be better than luck only in situations where the patient is not too badly off anyway; i.e. where he is socially well supported and has reasonable options as to who might accept the job of 'decision maker' and do it well. Yet, such a patient would probably do fairly well anyway, so the need for ACP is smallest.

Those who would need ACP most (even weak versions) can have it least; these are the people who have poor social networks or who find themselves in a foreign environment, where their ideas are not shared. They need the good fortune of an uncomplicated quick demise or finding themselves among the like-minded at the right time or, like Socrates, keep their wits until the last moment.

3 – THESIS CONCLUSION

This thesis set out to demonstrate that the idea of ACP has significant conceptual problems which appear in the clinical setting as problems of inconsistent and poorly predictable practice. This is undesirable and cannot be remedied by attention to practical problems.

I argued that the root of these difficulties lies to a significant extent in the diversity of the philosophical interpretation of the idea of autonomy, which presents as a conceptual cluster of ideas, rather than a clear concept. The problems are complicated further by the fact that philosophical diversity also applies to the other two essential concepts, beneficence and numerical identity, in such a way that the three concepts do not easily form a coherent framework within which ACP can operate clearly. This penetrates even into diagnostic questions, which, although ordinarily held to be the domain of science, must nonetheless rely on an agreed underlying philosophy. On the bases of actual clinical and legal cases, I showed in detail how these difficulties can present in practice in acute and non-acute situations, and therefore present a dilemma for ACP generally.

I further advanced the claim that conceptual agreement can be hindered by the wider necessary network of beliefs a person has to accommodate intellectually, which poses particular limits on how professionals and individuals are free to conceptualize the ideas of autonomy, beneficence and identity. This restricts coherent ACP framework options further. Each working within a set of particular goals and ideas, patients and professionals involved in ACP execution and governance commonly face contradictory dilemmas through the pursuit of divergent aims, which may often hinder unified action.

Overcoming these dilemmas would only seem possible through the imposition of a hierarchical structure. But this would mean the kind of dogmatic intervention that ACP seems to wish to avoid and thus contradicts the idea of patient autonomy as a central theme of ACP. Such dogmatic imposition also threatens the professional integrity and identity of those involved and thus threatens the cohesion of an idea, which must necessarily be communal in application. Furthermore, as conceptual consistency is lacking even within the same professions, especially the law, it would not even be clear why any *particular* hierarchy should prevail.

An alternative approach to pursuing conceptual consistency for ACP in order to allow consistent practice could be via devising a coherent philosophical framework independent of particular professional or individual aims. This is theoretically possible by combining a subjective notion of beneficence with a biological concept of numerical personal identity and a prospective narrative idea of autonomy. However, it would seem that such a framework imposes just a different kind of dogma, which may be even less appealing to the many people involved. Such a philosophical framework would lead to an understanding of ACP that would seem at least unattractive in the current health care setting, seems impractical within the current medico–legal practice, and could not claim to be universally beneficial for all patients.

Finally, I have distinguished between 'strong' advance care planning options according to Kutner's idea of the living will, and the 'weak' ACP practice of appointing a substitute decision-maker. The strong version, I argued, cannot claim success, because the effects of conceptual diversity lead to variable, unpredictable and therefore unreliable practice and the weak version cannot claim success, because it fails to live up to any serious claims of respecting autonomy. Although the weak version may ultimately be the best practical solution available for care decisions regarding those who lack autonomy, and may at least promote ongoing communication, it suffers from the added weakness that it supports best those who least need it and that it is least successful for those who are most in want.

Thus the idea of advance care planning cannot alter the fact that under increasingly common circumstances, we lose control over our affairs and even the best intentions of everyone involved in the advance care planning community, patient, carer and legislator alike, cannot ensure that we get it right. This is especially so as long as there is no clear agreement regarding what 'getting it right' actually means and the more people are involved in the matter. Hopes for any kind of contractual assurance thus seem slim.

4 – OUTLOOK

The need for ACP has commonly been seen as a consequence of modern medical technology, which enables people to continue biological life in the absence of mental abilities. Ventilators, dialysis machines, defibrillators, advanced interventions and medications all have contributed to this development. These interventions have not only enabled people to biologically outlive their mental capacities, they have also changed the emphasis of the meaning of care. Whereas prior to these technologies the care emphasis was on personal provisions and communication, much of the time and resources spent in medicine now focuses on interaction with these technologies, rather than the interaction with the patient. As time and resources are limited, this is often to the detriment of personal engagement with the patient's particular affairs and circumstances.

The nature of care has changed and the development of the advance care planning movement exemplifies this. What is needed for good care, after all, is engagement with the patient's individual affairs. Despite all the criticisms made about ACP, the modest successes that the ACP project can claim are all in areas where successful and ongoing communication has been demonstrated with the patient and her NoK. Independent of whether this can claim success as *respect for* or *assertion of* autonomy, the most convincing claim for the ACP idea is that it involves genuine care, based on engagement and empathy with the patient. As this is constantly under threat in modern practice, the promise of communication and personal engagement is what holds the real attraction in the ACP idea, much more so than the idea of advanced timing or planning. The latter, I think, are less important and certainly more troubling in ever so many aspects.

Thus the idea of narration is important in other aspects than for assertion of autonomy (in whatever guise). When people are ill and vulnerable they do not only wish to be cured (especially when curing is no longer an option), but at least they wish to be heard – irrespective of whether this asserts anything for the future. This need cannot be met with a legally witnessed document. Thus legalistic and bureaucratic versions of ACP fail miserably. The most attractive versions of ACP efforts all want to ensure the provision of resources for basic human interactions, that is conversation about and regular updating of a patient's particular circumstances. The more isolated people get, the harder this is to achieve with or without modern advance care planning. ACP is yet another attempt at people asserting non-technical needs in a technologized understanding of health and well being, and should be seen as that. As such, care planning is as important as it always has been, just how much in advance it can be made seems highly dubious.

Nonetheless providing adequate resources for care planning is vital to good healthcare.

Patients who do feel strongly, that their life has a particular narrative, and who wish to assert such a narrative, should have provisions to do so. However, as care planning is a communal activity, such narratives must be examined not only in terms of their viability within realistic medical and social options, they must also be examined in the context of competing professional identity constraints, such that boundaries and expectations are clear for the patient and the professionals involved. As such philosophical research into what a concept of narrative autonomy would be like might be helpful alongside a clarification of the needs and limits of professional integrity and identity through anthropological research in this area.

Furthermore, although adequate resources for care planning are needed, it must also be clear that advance care planning has its due limits, conceptually as well as practically and it must not be pushed beyond these. The last thing ACP should wish to be is dogma.

BIBLIOGRAPHY

1988. Medical Treatment Act.

2010. Advance directives have evolved. *Hospice Management Advisor,* 15**,** 93.

ASHCROFT, R. E., DAWSON, ASHCROFT, R. E. & GILLON, R. 2007. *Principles of Health Care Ethics, 2nd edition*.

ATKINSON, J. M. 2007. *Advance directives in mental health. [electronic resource] : theory, practice and ethics*, London : Jessica Kingsley, 2007.

BAKER, L. R. 2000. *Persons and bodies : a constitution view*, Cambridge : Cambridge University Press, 2000.

BEAUCHAMP, T. L. & CHILDRESS, J. F. 2001. *Principles of biomedical ethics*, New York, N.Y. : Oxford University Press, 2001.5th ed.

BEAUCHAMP, T. L. & CHILDRESS, J. F. 2009. *Principles of biomedical ethics*, New York : Oxford University Press, 2009.6th ed.

BROCK, D. W. 1991. Decisionmaking competence and risk. *Bioethics,* 5**,** 105-112.

BROWN, B. A. 2003. The history of advance directives. A literature review. *Journal Of Gerontological Nursing,* 29**,** 4-14.

BUCHANAN, A. 1988. Advance Directives and the Personal Identity Problem. Princeton University Press.

BUCHANAN, A. E. & BROCK, D. W. 1989. *Deciding for others : the ethics of surrogate decision making*, Cambridge [England] ; New York : Cambridge University Press, 1989.

CHAYTOR, N. & SCHMITTER-EDGECOMBE, M. 2003. The ecological validity of neuropsychological tests: A review of the literature on everyday cognitive skills. *Neuropsychology review,* 13**,** 181-197.

CHRISTMAN, J. P. 1989. *The Inner citadel : essays on individual autonomy*, New York : Oxford University Press, 1989.

CLEMENTS, N., CLAPTON, J. & CHENOWETH, L. 2010. Indigenous Australians and Impaired Decision-Making Capacity. *Australian journal of social issues,* 45**,** 383-393.

COPPOLA, K. M., DITTO, P. H., DANKS, J. H. & SMUCKER, W. D. 2001. Accuracy of primary care and hospital-based physicians' predictions of elderly outpatients' treatment preferences with and without advance directives. *Archives Of Internal Medicine,* 161**,** 431-440.

COYNE, C., SULLIVAN, K. & COLLIER, B. 2005. *Mental capacity : powers of attorney and advance health directives,* Annandale, N.S.W., Federation Press.

CRAIGIE, J., MACKENZIE, C. & ROGERS, W. 2013. Autonomy, vulnerability and capacity: a philosophical appraisal of the Mental Capacity Act. *International Journal of Law in Context,* 9**,** 37.

DEGRAZIA, D. 2005. *Human identity and bioethics,* Cambridge ; New York, Cambridge University Press.

DETERING, K. M., HANCOCK, A. D., READE, M. C. & SILVESTER, W. 2010. The impact of advance care planning on end of life care in elderly patients: randomized controlled trial. *British Medical Association*.

DRESSER, R. 1995. Dworkin on dementia: elegant theory, questionable policy. *The Hastings Center Report***,** p32.

DUKE, G., YARBROUGH, S. & PANG, K. 2009. The Patient Self-Determination Act: 20 years revisited. *Journal of Nursing Law,* 13**,** 114-123.

DWORKIN, R. M. 1995. *Life's dominion : an argument about abortion and euthanasia,* London, HarperCollins.

FAGERLIN, A. & SCHNEIDER, C. E. 2004. Enough: The Failure of the Living Will. *The Hastings Center Report***,** 30.

FEIGL, H. 1958. *Concepts, theories and the mind-body problem, edited by Herbert Feigl, Michael Scriven and Grover Maxwell*, Minneapolis, University of Minnesota Press [c1958].

FEINBERG, J. 1989. *Feinberg, Joel: The moral limits of the criminal law.. 3. Harm to self*, Oxford Univ. Press.

FIRLIK, A. D. 1991. Margo's Logo. *JAMA: Journal of the American Medical Association,* 265**,** 201.

FRANKFURT, H. G. 1971. Freedom of the Will and the Concept of a Person. The Journal of Philosophy, Inc.

FRANKFURT, H. G. 1988. *The importance of what we care about : philosoph. essays*, Cambridge Univ. Pr.

FURBERG, E. 2012. *Advance Directives and Personal Identity* [Online]. Available: https://ezp.lib.unimelb.edu.au/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edsswe&AN=edsswe.oai.DiVA.org.su.80513&scope=site [Accessed].

GRUBB, A. & KENNEDY, I. 1998. *Principles of medical law,* Oxford ; New York, Oxford University Press.

HALPERN, J. 2012. When concretized emotion-belief complexes derail decision-making capacity. *Bioethics,* 26**,** 108-116.

HASAN, M. K. & BAKER, D. G. 1993. Competency assessment in the elderly. *W V Med J,* 89**,** 386-8.

HEPBURN, K. & REED, R. 1995. Ethical and clinical issues with native-american elders - end-of-life decision-making. *Clinics in geriatric medicine,* 11**,** 97-111.

HOLTUG, N. 2011. Killing and the Time-relative Interest Account. Springer.

HOMERUS 1996. *The Iliad and the Odyssey of Homer : transl. by Richmond Lattimore*, Encyclopaedia Britannica.

JOHNSON, C. E., SINGER, R., MASSO, M., SELLARS, M. & SILVESTER, W. 2015. Palliative care health professionals' experiences of caring for patients with advance care directives. *Australian Health Review,* 39**,** 154-159.

KERRIDGE, I. H., MCPHEE, J. & LOWE, M. 1998. *Ethics and law for the health professions,* Katoomba, N.S.W., Social Science Press.

KOLARIK, R. C., ARNOLD, R. M., FISCHER, G. S. & TULSKY, J. A. 2002. Objectives for Advance Care Planning. *Journal of Palliative Medicine,* 5**,** 697-704.

KORSGAARD, C. M. 2009. *Self-constitution. [electronic resource] : agency, identity, and integrity*, Oxford : Oxford University Press, 2009.

KUHSE, H. 1999. Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity. *Kennedy Institute of Ethics Journal***,** 347.

KUTNER, L. 1969. Due process of euthanasia: the living will, a proposal. *Indiana Law Journal Bloomington,* 44**,** 539-554.

LIZZA, J. P. 2006. *Persons, humanity, and the definition of death,* Baltimore, Md., Johns Hopkins University Press.

LOBO, B. & THOMAS, K. 2011. *Advance care planning in end of life care / edited by Keri Thomas, Ben Lobo*, Oxford : Oxford University Press, c2011.

LOCK, M. M. 2002. *Twice dead : organ transplants and the reinvention of death,* Berkeley, University of California Press.

LOCKE, J. 2001. *An essay concerning human understanding. [electronic resource]*, [Blacksburg, VA] : Virginia Tech, 2001.

MACKENZIE, C. 2008. Relational Autonomy, Normative Authority and Perfectionism. *Journal of social philosophy,* 39**,** 512-533.

MACKENZIE, C. & STOLJAR, N. 2000. *Relational autonomy : feminist perspectives on automony, agency, and the social self / edited by Catriona Mackenzie and Natalie Stoljar*, New York : Oxford University Press, 2000.

MCMAHAN, J. 2001. *The ethics of killing : killing at the margins of life,* New York, Oxford University Press.

MEYERS, D. T. 1989. *Self, society, and personal choice*, New York : Columbia University Press, c1989.

MILL, J. S. 1998. *On liberty and other essays*, Oxford Univ. Press.

MOLLOY, D. W., GUYATT, G. H., RUSSO, R., GOEREE, R., O'BRIEN, B. J., BEDARD, M., WILLAN, A., WATSON, J., PATTERSON, C., HARISON, C., STANDISH, T., STRANG, D., DARZINS, P. J., SMITH, S. & DUBOIS, S. 2000. Systematic implementation of an advance directive program in nursing homes - A randomized controlled trial. *Jama-journal of the american medical association,* 283**,** 1437-1444.

MOLLOY, D. W., SILBERFELD, M., DARZINS, P., GUYATT, G. H., SINGER, P. A., RUSH, B., BEDARD, M. & STRANG, D. 1996. Measuring capacity to complete an advance directive. *Journal of the American Geriatrics Society,* 44**,** 660-664.

MOORE, G. E. 1903. *Principia ethica*, Cambridge, At the University press, 1903.

MULLALY, E., KINSELLA, G., BERBEROVIC, N., COHEN, Y., DEDDA, K., FROUD, B., LEACH, K. & NEATH, J. 2007. Assessment of decision-making capacity: Exploration of common practices among neuropsychologists. *Australian psychologist,* 42**,** 178-186.

MUNN, N. 2014. Capacity-testing as a means of increasing political inclusion. *Democratization,* 21**,** 1134-1152.

OSHANA, M. 2003. How Much Should We Value Autonomy? *Social philosophy and policy,* 20**,** 99-126.

PARFIT, D. 1971. Personal Identity. Sage School of Philosophy of Cornell University.

PARFIT, D. 1984. *Reasons and persons,* Oxford [Oxfordshire], Clarendon Press.

PECANAC, K. E., REPENSHEK, M. F., TENNENBAUM, D. & HAMMES, B. J. 2014. Respecting Choices® and Advance Directives in a Diverse Community. *Journal of Palliative Medicine,* 17**,** 282-287.

PERKINS, H. S. 2007. Controlling Death: The False Promise of Advance Directives. *Annals of Internal Medicine,* 147**,** 51-W9.

PLATO *Phaedo*.

PLATO *Phaedrus*.

PLATO 1996. *The dialogues of Plato*, Encyclopaedia Britannica.

RAWLS, J. 1972. *A theory of justice*, Oxford : Oxford University Press, 1972, c1971.

SCHNEIDERMAN, L. J., JECKER, N. S. & JONSEN, A. R. 1990. Medical futility: its meaning and ethical implications. American College of Physicians.

SCHNEIDERMAN, L. J., KRONICK, R., KAPLAN, R. M., ANDERSON, J. P. & LANGER, R. D. 1992. Effects of Offering Advance Directives on Medical Treatments and Costs. *Annals of Internal Medicine,* 117**,** 599-606.

SKENE, L. 2005. The Schiavo and Korp cases: Conceptualising end-of-life decision-making. *Journal of law and medicine,* 13**,** 223-229.

SKENE, L. 2008. *Law and medical practice : rights, duties, claims and defences,* Chatswood, N.S.W., LexisNexis Butterworths.

SOMMERVILLE, A. 1996. Are advanced directives really the answer? And what was the question? *In:* A.M.MCLEAN, S. (ed.) *Death, Dying and the Law.* Dartmouth Publishing.

STEWART, C. 1999. Advanced directives, the right to die and the common law: recent problems with blood transfusions. *Melbourne University Law Review,* 23**,** 161-183.

STEWART, C. 2002. Legal Constructions of Life and Death in the Common Law [article].

STEWART, C. & BIEGLER, P. 2004. A primer on the law of competence to refuse medical treatment. *Australian law journal,* 78**,** 325-342.

STEWART, C. & LYNCH, A. 2003. Undue influence, consent and medical treatment. *Journal of the royal society of medicine,* 96**,** 598-601.

STRAWSON, G. 2004. Against Narrativity. *Ratio -Oxford-,* 17**,** 428-452.

TAYLOR, D. M., UGONI, A. M., CAMERON, P. A. & MCNEIL, J. J. 2003. Advance directives and emergency department patients: ownership rates and perceptions of use. *Internal medicine journal,* 33**,** 586-592.

TONELLI, M. R. 1996. Pulling the plug on living wills. A critical analysis of advance directives. *Chest,* 110**,** 816-822.

TUROLDO, F. 2010. Relational Autonomy and Multiculturalism. *Cambridge Quarterly of Healthcare Ethics,* 19**,** 542-549.

UK-GOVERNMENT. 2005. Mental Capacity Act 2005 Code of Practice. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf.

WERFEL, F., FADIMAN, C. & DRAKE, W. A. 1927. *The man who conquered death / by Franz Werfel*, New York : Simon & Schuster, 1927.

WHITE, B., TILSE, C., WILSON, J., ROSENMAN, L., STRUB, T., FEENEY, R. & SILVESTER, W. 2014. Prevalence and predictors of advance directives in Australia. *Internal Medicine Journal,* 44**,** 975-980.

WIGGINS, D. 1980. *Sameness and substance*, Oxford : Blackwell, 1980.

WILKINSON, A. M. 2010. *Advance directives and Advance Care Planning: the US experience*, Oxford University Press.

WITTGENSTEIN, L. 1958. *Philosophical investigations,* Oxford, Blackwell.

ENDNOTES

---

[1] PLATO *Phaedo*, PLATO 1996. The dialogues of Plato, *Encyclopaedia Britannica*.[118]

[2] HOMERUS 1996. The Iliad and the Odyssey of Homer *: transl. by Richmond Lattimore*, *Encyclopaedia Britannica*. p. 422 (verse 190)

[3] FEINBERG, J. 1989. *Feinberg, Joel: The moral limits of the criminal law.. 3. Harm to self*, Oxford Univ. Press., p. 83

[4] LOCK, M. M. 2002. *Twice dead : organ transplants and the reinvention of death,* Berkeley, University of California Press. p. 66

[5] KUTNER, L. 1969. Due process of euthanasia: the living will, a proposal. *Indiana Law Journal Bloomington,* 44**,** 539-554.

[6] Ibid. p. 540.

[7] Ibid. p. 542.

[8] BROWN, B. A. 2003. The history of advance directives. A literature review. *Journal Of Gerontological Nursing,* 29**,** 4-14.

[9] KUTNER, L. 1969. Due process of euthanasia: the living will, a proposal. *Indiana Law Journal Bloomington,* 44**,** 539-554. p. 550.

[10] Ibid. p. 551.

[11] Ibid. p. 553.

[12] Ibid.

[13] Ibid.

[14] Ibid.

[15] Ibid. p. 549–550.

[16] Ibid. p. 552.

[17] Ibid. p.545.

[18] PLATO 1996. The dialogues of Plato, *Encyclopaedia Britannica*.Plato, Crito [48].

[19] WILKINSON, A. M. 2010. *Advance directives and Advance Care Planning: the US experience*, Oxford University Press.

[20] DUKE, G., YARBROUGH, S. & PANG, K. 2009. The Patient Self-Determination Act: 20 years revisited. *Journal of Nursing Law,* 13**,** 114-123.

[21] SKENE, L. 2005. The Schiavo and Korp cases: Conceptualising end-of-life decision-making. *Journal of law and medicine,* 13**,** 223-229.

[22] Ibid.

[23] LOBO, B. & THOMAS, K. 2011. *Advance care planning in end of life care / edited by Keri Thomas, Ben Lobo*, Oxford : Oxford University Press, c2011., p. 19.

[24] DUKE, G., YARBROUGH, S. & PANG, K. 2009. The Patient Self-Determination Act: 20 years revisited. *Journal of Nursing Law,* 13**,** 114-123. p. 117.

[25] Ibid. p. 114.

[26] LOBO, B. & THOMAS, K. 2011. *Advance care planning in end of life care / edited by Keri Thomas, Ben Lobo*, Oxford : Oxford University Press, c2011. pp 231–235.

[27] KOLARIK, R. C., ARNOLD, R. M., FISCHER, G. S. & TULSKY, J. A. 2002. Objectives for Advance Care Planning. *Journal of Palliative Medicine,* 5**,** 697-704.

[28] DUKE, G., YARBROUGH, S. & PANG, K. 2009. The Patient Self-Determination Act: 20 years revisited. *Journal of Nursing Law,* 13**,** 114-123.

[29] BROWN, B. A. 2003. The history of advance directives. A literature review. *Journal Of Gerontological Nursing,* 29**,** 4-14.

---

[30] FAGERLIN, A. & SCHNEIDER, C. E. 2004. Enough: The Failure of the Living Will. *The Hastings Center Report***,** 30.

[31] Ibid.

[32] For a fairly comprehensive review of criticisms see: Ibid.

Also for detailed example of some conceptual criticisms: PERKINS, H. S. 2007. Controlling Death: The False Promise of Advance Directives. *Annals of Internal Medicine,* 147**,** 51-W9.

[33] PLATO *Phaedo*. [117].

[34] PLATO *Phaedrus*. [249].

[35] KERRIDGE, I. H., MCPHEE, J. & LOWE, M. 1998. *Ethics and law for the health professions,* Katoomba, N.S.W., Social Science Press., p. 162.

[36] COYNE, C., SULLIVAN, K. & COLLIER, B. 2005. *Mental capacity : powers of attorney and advance health directives,* Annandale, N.S.W., Federation Press., p. 61.

[37] MEYERS, D. T. 1989. *Self, society, and personal choice*, New York : Columbia University Press, c1989., part I.

[38] Ibid. p. 10–12.

[39] Ibid. p. 16.

[40] MILL, J. S. 1998. *On liberty and other essays*, Oxford Univ. Press., p. 14.

[41] Ibid. p. 91ff.

[42] MILL, J. S. 1998. *On liberty and other essays*, Oxford Univ. Press., chapter 1 paragraph 10.

[43] RAWLS, J. 1972. *A theory of justice*, Oxford : Oxford University Press, 1972, c1971., p. 516–517

---

[44] Ibid. p. 20.

[45]MACKENZIE, C. & STOLJAR, N. 2000. *Relational autonomy : feminist perspectives on automony, agency, and the social self / edited by Catriona Mackenzie and Natalie Stoljar*, New York : Oxford University Press, 2000., p. 4 ff.

[46] Ibid. p. 4.

[47]MACKENZIE, C. 2008. Relational Autonomy, Normative Authority and Perfectionism. *Journal of social philosophy,* 39**,** 512-533., p. 513.

[48]MEYERS, D. T. 1989. *Self, society, and personal choice*, New York : Columbia University Press, c1989., p. 76.

[49]Ibid. p. 86.

[50]RAWLS, J. 1972. *A theory of justice*, Oxford : Oxford University Press, 1972, c1971., p. 409.

[51] Ibid.

[52]DWORKIN, R. M. 1995. *Life's dominion : an argument about abortion and euthanasia,* London, HarperCollins., p. 199.

[53]ibid. p. 204.

[54]MEYERS, D. T. 1989. *Self, society, and personal choice*, New York : Columbia University Press, c1989., p. 79.

[55]MACKENZIE, C. & STOLJAR, N. 2000. *Relational autonomy : feminist perspectives on automony, agency, and the social self / edited by Catriona Mackenzie and Natalie Stoljar*, New York : Oxford University Press, 2000., p. 79.

[56] Ibid.

[57]MOORE, G. E. 1903. *Principia ethica*, Cambridge, At the University press, 1903.

---

[58] KORSGAARD, C. M. 2009. *Self-constitution. [electronic resource] : agency, identity, and integrity*, Oxford : Oxford University Press, 2009.

[59] FRANKFURT, H. G. 1971. Freedom of the Will and the Concept of a Person. The Journal of Philosophy, Inc.

[60] MEYERS, D. T. 1989. *Self, society, and personal choice*, New York : Columbia University Press, c1989.

[61] MILL, J. S. 1998. *On liberty and other essays*, Oxford Univ. Press., p. 114.

[62] OSHANA, M. 2003. How Much Should We Value Autonomy? *Social philosophy and policy,* 20**,** 99-126.

[63] See: Feinberg, J. , Autonomy in: CHRISTMAN, J. P. 1989. *The Inner citadel : essays on individual autonomy*, New York : Oxford University Press, 1989., p. 30.

[64] BUCHANAN, A. E. & BROCK, D. W. 1989. *Deciding for others : the ethics of surrogate decision making*, Cambridge [England] ; New York : Cambridge University Press, 1989., pp.52-55. For further elaboration and defense see also: BROCK, D. W. 1991. Decisionmaking competence and risk. *BIOETHICS,* 5**,** 105-112.

[65] BEAUCHAMP, T. L. & CHILDRESS, J. F. 2001. *Principles of biomedical ethics*, New York, N.Y. : Oxford University Press, 2001.

5th ed., p. 76.

[66] MACKENZIE, C. 2008. Relational Autonomy, Normative Authority and Perfectionism. *Journal of social philosophy,* 39**,** 512-533., p. 515 referring to Kim Atkins’ account of epistemic humility

[67] HASAN, M. K. & BAKER, D. G. 1993. Competency assessment in the elderly. *W V Med J,* 89**,** 386-8. and VICTORIAN GUARDIANSHIP AN ADMINISTRATION ACT 1986, Part 4A, Division 42A – Emergency medical or dental treatment

---

[68] COYNE, C., SULLIVAN, K. & COLLIER, B. 2005. *Mental capacity : powers of attorney and advance health directives,* Annandale, N.S.W., Federation Press., p. 101.

[69] HEPBURN, K. & REED, R. 1995. Ethical and clinical issues with native-american elders - end-of-life decision-making. *Clinics in geriatric medicine,* 11**,** 97-111. (especially page 101: indirect Communication) as well as CLEMENTS, N., CLAPTON, J. & CHENOWETH, L. 2010. Indigenous Australians and Impaired Decision-Making Capacity. *Australian journal of social issues,* 45**,** 383-393.

[70] COYNE, C., SULLIVAN, K. & COLLIER, B. 2005. *Mental capacity : powers of attorney and advance health directives,* Annandale, N.S.W., Federation Press., p. 94.

[71] Ibid. p.103 (Measuring mental capacity)

[72] For a list of commonly employed neuro–psychological tests in Australia see MULLALY, E., KINSELLA, G., BERBEROVIC, N., COHEN, Y., DEDDA, K., FROUD, B., LEACH, K. & NEATH, J. 2007. Assessment of decision-making capacity: Exploration of common practices among neuropsychologists. *Australian psychologist,* 42**,** 178-186.

[73] Ibid. p.179.

[74] Ibid. p. 184.

[75] COYNE, C., SULLIVAN, K. & COLLIER, B. 2005. *Mental capacity : powers of attorney and advance health directives,* Annandale, N.S.W., Federation Press., p. 116.

[76] MOLLOY, D. W., SILBERFELD, M., DARZINS, P., GUYATT, G. H., SINGER, P. A., RUSH, B., BEDARD, M. & STRANG, D. 1996. Measuring capacity to complete an advance directive. *Journal of the American Geriatrics Society,* 44**,** 660-664.

---

[77] CHAYTOR, N. & SCHMITTER-EDGECOMBE, M. 2003. The ecological validity of neuropsychological tests: A review of the literature on everyday cognitive skills. *Neuropsychology review,* 13**,** 181-197.

[78] MULLALY, E., KINSELLA, G., BERBEROVIC, N., COHEN, Y., DEDDA, K., FROUD, B., LEACH, K. & NEATH, J. 2007. Assessment of decision-making capacity: Exploration of common practices among neuropsychologists. *Australian psychologist,* 42**,** 178-186., p. 183.

[79] For a striking example of emotional interference in decision making capacity see: HALPERN, J. 2012. When concretized emotion-belief complexes derail decision-making capacity. *Bioethics,* 26**,** 108-116.

[80] MULLALY, E., KINSELLA, G., BERBEROVIC, N., COHEN, Y., DEDDA, K., FROUD, B., LEACH, K. & NEATH, J. 2007. Assessment of decision-making capacity: Exploration of common practices among neuropsychologists. *Australian psychologist,* 42**,** 178-186., p. 197. And: Victorian guardianship review report 2012, Chapter 7 : Capacity and incapacity – point 7.22 assessing capacity " there are no definitive, scientific tests for use when assessing whether a person meets a particular capacity standard.

[81] Ibid. p. 185.

[82] Ibid.

[83] Ibid

[84] COYNE, C., SULLIVAN, K. & COLLIER, B. 2005. *Mental capacity : powers of attorney and advance health directives,* Annandale, N.S.W., Federation Press., p. 62.

[85] Ibid.

[86] SKENE, L. 2008. *Law and medical practice : rights, duties, claims and defences,* Chatswood, N.S.W., LexisNexis Butterworths., p. 82.

---

[87] COYNE, C., SULLIVAN, K. & COLLIER, B. 2005. *Mental capacity : powers of attorney and advance health directives,* Annandale, N.S.W., Federation Press., p. 68.

[88] Ibid.

[89] STEWART, C. 1999. Advanced directives, the right to die and the common law: recent problems with blood transfusions. *Melbourne university law review,* 23**,** 161-183.

[90] STEWART, C. & BIEGLER, P. 2004. A primer on the law of competence to refuse medical treatment. *Australian law journal,* 78**,** 325-342.

[91] COYNE, C., SULLIVAN, K. & COLLIER, B. 2005. *Mental capacity : powers of attorney and advance health directives,* Annandale, N.S.W., Federation Press., p. 66.

[92] SKENE, L. 2008. *Law and medical practice : rights, duties, claims and defences,* Chatswood, N.S.W., LexisNexis Butterworths., p. 101.

[93] MUNN, N. 2014. Capacity-testing as a means of increasing political inclusion. *Democratization,* 21**,** 1134-1152.

[94] 1988. Medical Treatment Act., http://www.health.vic.gov.au/mta

[95] SKENE, L. 2008. *Law and medical practice : rights, duties, claims and defences,* Chatswood, N.S.W., LexisNexis Butterworths., p. 155.

[96] Ibid.

[97] Ibid. p. 156.

[98] STEWART, C. & BIEGLER, P. 2004. A primer on the law of competence to refuse medical treatment. *Australian law journal,* 78**,** 325-342.

[99] Ibid.

---

[100] GRUBB, A. & KENNEDY, I. 1998. *Principles of medical law,* Oxford ; New York, Oxford University Press., p. 138

[101] STEWART, C. & BIEGLER, P. 2004. A primer on the law of competence to refuse medical treatment. *Australian law journal,* 78**,** 325-342.

[102] STEWART, C. & LYNCH, A. 2003. Undue influence, consent and medical treatment. *Journal of the royal society of medicine,* 96**,** 598-601.

[103] Ibid.

[104] Ibid.

[105] Ibid. p. 601.

[106] Ibid.

[107] Ibid.

[108] Ibid.

[109] HALPERN, J. 2012. When concretized emotion-belief complexes derail decision-making capacity. *Bioethics,* 26**,** 108-116.

[110] Mackenzie, Catriona, opening address at AAP conference July 2014, ANU Canberra : “The dimensions of Autonomy”

[111] WITTGENSTEIN, L. 1958. *Philosophical investigations,* Oxford, Blackwell.

[112] Ibid.

[113] Ibid.

[114] CRAIGIE, J., MACKENZIE, C. & ROGERS, W. 2013. Autonomy, vulnerability and capacity: a philosophical appraisal of the mental capacity act. *International journal of law in context,* 9**,** 37.

---

[115] STEWART, C. 2002. Legal Constructions of Life and Death in the Common Law [article]., *oxford university commonwealth law journal*, Vol. 2, Issue 1 (Summer 2002), pp. 67–92.

[116] COYNE, C., SULLIVAN, K. & COLLIER, B. 2005. *Mental capacity : powers of attorney and advance health directives,* Annandale, N.S.W., Federation Press., p. 61.

[117117] See case of Mrs. Q in: STEWART, C. 1999. Advanced directives, the right to die and the common law: recent problems with blood transfusions. *Melbourne university law review,* 23**,** 161-183.

[118] WERFEL, F., FADIMAN, C. & DRAKE, W. A. 1927. *The man who conquered death / by Franz Werfel*, New York : Simon & Schuster, 1927.

[119] BEAUCHAMP, T. L. & CHILDRESS, J. F. 2009. *Principles of biomedical ethics*, New York : Oxford University Press, 2009.

6th ed.

[120] PARFIT, D. 1984. *Reasons and persons,* Oxford [Oxfordshire], Clarendon Press., Appendix I, p. 493-499

[121] DWORKIN, R. M. 1995. *Life's dominion : an argument about abortion and euthanasia,* London, HarperCollins., p 201

[122] Ibid.

[123] CULLITY, G., *Beneficence*, in ASHCROFT, R. E., DAWSON, ASHCROFT, R. E. & GILLON, R. 2007. *Principles of Health Care Ethics, 2nd edition*., p. 22-23

[124] TONELLI, M. R. 1996. Pulling the plug on living wills. A critical analysis of advance directives. *CHEST,* 110**,** 816-822. p. 818.

[125] SCHNEIDERMAN, L. J., JECKER, N. S. & JONSEN, A. R. 1990. Medical futility: its meaning and ethical implications. *American College of Physicians*.

[126] Ibid.

[127] UK-GOVERNMENT. 2005. Mental Capacity Act 2005 Code of Practice. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf.

[128] Ibid. p. 65.

[129] DWORKIN, R. M. 1995. *Life's dominion : an argument about abortion and euthanasia,* London, HarperCollins. p 201

[130] FRANKFURT, H. G. 1988. *The importance of what we care about : philosoph. essays*, Cambridge Univ. Pr. p. 12

[131] SKENE, L. 2008. *Law and medical practice : rights, duties, claims and defences,* Chatswood, N.S.W., LexisNexis Butterworths., p. 157.

[132] UK-GOVERNMENT. 2005. Mental Capacity Act 2005 Code of Practice. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf.

[133] Ibid.

[134] DWORKIN, R. M. 1995. *Life's dominion : an argument about abortion and euthanasia,* London, HarperCollins.

[135] CRAIGIE, J., MACKENZIE, C. & ROGERS, W. 2013. Autonomy, vulnerability and capacity: a philosophical appraisal of the mental capacity act. *International journal of law in context,* 9**,** 37.

[136] UK-GOVERNMENT. 2005. Mental Capacity Act 2005 Code of Practice. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf.

---

[137] TONELLI, M. R. 1996. Pulling the plug on living wills. A critical analysis of advance directives. *Chest,* 110**,** 816-822.

[138] COPPOLA, K. M., DITTO, P. H., DANKS, J. H. & SMUCKER, W. D. 2001. Accuracy of primary care and hospital-based physicians' predictions of elderly outpatients' treatment preferences with and without advance directives. *Archives of internal medicine,* 161**,** 431-440.

[139] BUCHANAN, A. 1988. Advance Directives and the Personal Identity Problem. Princeton University Press.

[140] DWORKIN, R. M. 1995. *Life's dominion : an argument about abortion and euthanasia,* London, HarperCollins., chapter 8.

[141] FIRLIK, A. D. 1991. Margo's Logo. *Jama: journal of the american medical association,* 265**,** 201.

[142] BUCHANAN, A. 1988. Advance Directives and the Personal Identity Problem. Princeton University Press.

[143] DRESSER, R. 1995. Dworkin on dementia: elegant theory, questionable policy. *The hastings center report***,** P32.

[144] PARFIT, D. 1984. *Reasons and persons,* Oxford [Oxfordshire], Clarendon Press.

[145] LIZZA, J. P. 2006. *Persons, humanity, and the definition of death,* Baltimore, Md., Johns Hopkins University Press., p. 10.

[146] DEGRAZIA, D. 2005. *Human identity and bioethics,* Cambridge ; New York, Cambridge University Press.*,* p. 56 (A similar definition was given by .BECKER in 1975, and quoted by LIZZA in *Persons, Humanity, and the Definition of Death*, John Hopkins University Press, Baltimore, 2006, p.25).

---

[147] STEWART, C. 2002. Legal Constructions of Life and Death in the Common Law [article]. *Oxford University Commonwealth Law Journal*, Vol. 2, Issue 1 (Summer 2002), pp. 67–92, p. 81.

[148] Ibid. p. 82.

[149] Ibid.

[150] LIZZA, J. P. 2006. *Persons, humanity, and the definition of death,* Baltimore, Md., Johns Hopkins University Press., p. 11.

[151] STEWART, C. 2002. Legal Constructions of Life and Death in the Common Law [article]. *Oxford university commonwealth law journal*, Vol. 2, Issue 1 (Summer 2002), pp. 67–92, p. 83.

[152] PLATO *Phaedo*. 64c

[153] LOCKE, J. 2001. *An essay concerning human understanding. [electronic resource],* [Blacksburg, VA] : Virginia Tech, 2001., book II, ch. XXVII, sect.6 ff.

[154] PARFIT, D. 1984. *Reasons and persons,* Oxford [Oxfordshire], Clarendon Press.

[155] LIZZA, J. P. 2006. *Persons, humanity, and the definition of death,* Baltimore, Md., Johns Hopkins University Press., p. 40.

[156] DEGRAZIA, D. 2005. *Human identity and bioethics,* Cambridge ; New York, Cambridge University Press., p. 159.

[157] FURBERG, E. 2012. *Advance Directives and Personal Identity* [Online]. Available: https://ezp.lib.unimelb.edu.au/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edsswe&AN=edsswe.oai.DiVA.org.su.80513&scope=site [Accessed].

[158] Ibid. p. 14.

[159]PARFIT, D. 1984. *Reasons and persons,* Oxford [Oxfordshire], Clarendon Press., p. 206.

[160]BUCHANAN, A. 1988. Advance Directives and the Personal Identity Problem. Princeton University Press.

[161]Ibid.

[162]FURBERG, E. 2012. *Advance Directives and Personal Identity* [Online]. Available: https://ezp.lib.unimelb.edu.au/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edsswe&AN=edsswe.oai.DiVA.org.su.80513&scope=site [Accessed]., chapter 5

[163]Ibid.

[164] Ibid. p. 70.

[165]PARFIT, D. 1971. Personal Identity. Sage School of Philosophy of Cornell University.

[166] FURBERG, E. 2012. *Advance Directives and Personal Identity* [Online]. Available: https://ezp.lib.unimelb.edu.au/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edsswe&AN=edsswe.oai.DiVA.org.su.80513&scope=site [Accessed]., p. 70.

[167]KUHSE, H. 1999. Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity. *Kennedy institute of ethics journal*, 347.

[168]ATKINSON, J. M. 2007. *Advance directives in mental health. [electronic resource] : theory, practice and ethics*, London : Jessica Kingsley, 2007.

[169]BUCHANAN, A. 1988. Advance Directives and the Personal Identity Problem. Princeton University Press., p. 278.

---

[170] PARFIT, D. 1971. Personal Identity. Sage School of Philosophy of Cornell University.

[171] Ibid. p. 6.

[172] P.F. Strawson,[1958] *Persons*; in H. Feigle, M. Scriven and G. Maxwell (editors), *Concepts, Theories, and the Body-Mind problem* (Minnesota Studies in the Philosophy of Science, vol.2) Minneapolis: University of Minnesota Press; *reprinted* in D.M. Rosenthal (ed.) *The Nature of Mind*, New York: Oxford University Press 1991, p. 107.

also: Lizza, *op.cit.*, p. 54

[173] WIGGINS, D. 1980. *Sameness and substance*, Oxford : Blackwell, 1980.

[174] BAKER, L. R. 2000. *Persons and bodies : a constitution view*, Cambridge : Cambridge University Press, 2000.

[175] LIZZA, J. P. 2006. *Persons, humanity, and the definition of death,* Baltimore, Md., Johns Hopkins University Press.

[176] Ibid. p. 41.

[177] Ibid. p. 60.

[178] ibid. p. 78.

[179] BAKER, L. R. 2000. *Persons and bodies : a constitution view*, Cambridge : Cambridge University Press, 2000.

[180] FURBERG, E. 2012. *Advance Directives and Personal Identity* [Online]. Available: https://ezp.lib.unimelb.edu.au/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edsswe&AN=edsswe.oai.DiVA.org.su.80513&scope=site [Accessed].

[181] FEIGL, H. 1958. *Concepts, theories and the mind-body problem, edited by Herbert Feigl, Michael Scriven and Grover Maxwell*, Minneapolis, University of Minnesota Press [c1958].; reprinted in D.M. Rosenthal (ed.) The Nature of Mind, New York: Oxford University Press 19911991, p. 107.

See also: LIZZA, J. P. 2006. *Persons, humanity, and the definition of death,* Baltimore, Md., Johns Hopkins University Press., p. 54

[182] DEGRAZIA, D. 2005. *Human identity and bioethics,* Cambridge ; New York, Cambridge University Press.*,* p. 45.

[183] Ibid. p. 167 ff.

[184] BUCHANAN, A. 1988. Advance Directives and the Personal Identity Problem. Princeton University Press., p. 284.

[185] DEGRAZIA, D. 2005. *Human identity and bioethics,* Cambridge ; New York, Cambridge University Press., p 189 ff. Also MCMAHAN, J. 2001. *The ethics of killing : killing at the margins of life,* New York, Oxford University Press.

[186] HOLTUG, N. 2011. Killing and the Time-relative Interest Account. Springer.

[187] LIZZA, J. P. 2006. *Persons, humanity, and the definition of death,* Baltimore, Md., Johns Hopkins University Press., p. 86 ff.

[188] Ibid. p 91.

[189] Ibid. p. 85–86

[190] Ibid. p. 90.

[191] This also seems to be supported by the Lock's appraisal of the Japanese situation, in which the recognition of certain family and ancestry ties plays a significant role in the understanding of an individual's identity. See: LOCK, M. M. 2002. *Twice dead : organ transplants and the reinvention of death,* Berkeley, University of California

---

Press.

[192] LIZZA, J. P. 2006. *Persons, humanity, and the definition of death,* Baltimore, Md., Johns Hopkins University Press., p 91.

[193] STEWART, C. 2002. Legal Constructions of Life and Death in the Common Law [article]. *Oxford University Commonwealth Law Journal*, Vol. 2, Issue 1 (Summer 2002), pp. 67–92, p. 68.

[194] DWORKIN, R. M. 1995. *Life's dominion : an argument about abortion and euthanasia,* London, HarperCollins.

[195] DRESSER, R. 1995. Dworkin on dementia: elegant theory, questionable policy. *The hastings center report*, P32.

[196] DEGRAZIA, D. 2005. *Human identity and bioethics,* Cambridge ; New York, Cambridge University Press.

[197] STRAWSON, G. 2004. Against Narrativity. *Ratio -Oxford-,* 17**,** 428-452.

[198] TUROLDO, F. 2010. Relational Autonomy and Multiculturalism. *Cambridge Quarterly of Healthcare Ethics,* 19**,** 542-549.

[199] CRAIGIE, J., MACKENZIE, C. & ROGERS, W. 2013. Autonomy, vulnerability and capacity: a philosophical appraisal of the Mental Capacity Act. *International Journal of Law in Context,* 9**,** 37.

[200] STRAWSON, G. 2004. Against Narrativity. *RATIO -OXFORD-,* 17**,** 428-452.

[201] SOMMERVILLE, A. 1996. Are advanced directives really the answer? And what was the question? *In:* A.M.MCLEAN, S. (ed.) *Death, Dying and the Law.* Dartmouth Publishing., p. 34.

[202] TUROLDO, F. 2010. Relational Autonomy and Multiculturalism. *Cambridge Quarterly of Healthcare Ethics,* 19**,** 542-549.

---

[203] LOCK, M. M. 2002. *Twice dead : organ transplants and the reinvention of death,* Berkeley, University of California Press.

[204] PECANAC, K. E., REPENSHEK, M. F., TENNENBAUM, D. & HAMMES, B. J. 2014. Respecting Choices® and Advance Directives in a Diverse Community. *Journal of Palliative Medicine,* 17**,** 282-287.

[205] FAGERLIN, A. & SCHNEIDER, C. E. 2004. Enough: The Failure of the Living Will. *The Hastings Center Report***,** 30.

[206] http://www.vha.org.au/docs/20120913--position-statement--advance-care-planning.pdf

[207] PECANAC, K. E., REPENSHEK, M. F., TENNENBAUM, D. & HAMMES, B. J. 2014. Respecting Choices® and Advance Directives in a Diverse Community. *Journal of Palliative Medicine,* 17**,** 282-287.

[208] WHITE, B., TILSE, C., WILSON, J., ROSENMAN, L., STRUB, T., FEENEY, R. & SILVESTER, W. 2014. Prevalence and predictors of advance directives in Australia. *Internal Medicine Journal,* 44**,** 975-980.

[209] PECANAC, K. E., REPENSHEK, M. F., TENNENBAUM, D. & HAMMES, B. J. 2014. Respecting Choices® and Advance Directives in a Diverse Community. *Journal of Palliative Medicine,* 17**,** 282-287.

[210] E.g. TAYLOR, D. M., UGONI, A. M., CAMERON, P. A. & MCNEIL, J. J. 2003. Advance directives and emergency department patients: ownership rates and perceptions of use. *Internal medicine journal,* 33**,** 586-592.

[211] DETERING, K. M., HANCOCK, A. D., READE, M. C. & SILVESTER, W. 2010. The impact of advance care planning on end of life care in elderly patients: randomized controlled trial. *British Medical Association*.

---

[212] WHITE, B., TILSE, C., WILSON, J., ROSENMAN, L., STRUB, T., FEENEY, R. & SILVESTER, W. 2014. Prevalence and predictors of advance directives in Australia. *Internal Medicine Journal,* 44**,** 975-980.

[213] Ibid.

[214] ATKINSON, J. M. 2007. *Advance directives in mental health. [electronic resource] : theory, practice and ethics*, London : Jessica Kingsley, 2007.

[215] FAGERLIN, A. & SCHNEIDER, C. E. 2004. Enough: The Failure of the Living Will. *The Hastings Center Report***,** 30.

[216] COPPOLA, K. M., DITTO, P. H., DANKS, J. H. & SMUCKER, W. D. 2001. Accuracy of primary care and hospital-based physicians' predictions of elderly outpatients' treatment preferences with and without advance directives. *Archives Of Internal Medicine,* 161**,** 431-440.

[217] DETERING, K. M., HANCOCK, A. D., READE, M. C. & SILVESTER, W. 2010. The impact of advance care planning on end of life care in elderly patients: randomized controlled trial. *British Medical Association*.

[218] SCHNEIDERMAN, L. J., KRONICK, R., KAPLAN, R. M., ANDERSON, J. P. & LANGER, R. D. 1992. Effects of Offering Advance Directives on Medical Treatments and Costs. *Annals of Internal Medicine,* 117**,** 599-606.

[219] JOHNSON, C. E., SINGER, R., MASSO, M., SELLARS, M. & SILVESTER, W. 2015. Palliative care health professionals' experiences of caring for patients with advance care directives. *Australian Health Review,* 39**,** 154-159.

[220] DETERING, K. M., HANCOCK, A. D., READE, M. C. & SILVESTER, W. 2010. The impact of advance care planning on end of life care in elderly patients: randomized controlled trial. *British Medical Association*.

---

[221] FAGERLIN, A. & SCHNEIDER, C. E. 2004. Enough: The Failure of the Living Will. *The Hastings Center Report*, 30.

[222] SCHNEIDERMAN, L. J., KRONICK, R., KAPLAN, R. M., ANDERSON, J. P. & LANGER, R. D. 1992. Effects of Offering Advance Directives on Medical Treatments and Costs. *Annals of Internal Medicine,* 117**,** 599-606.

[223] MOLLOY, D. W., GUYATT, G. H., RUSSO, R., GOEREE, R., O'BRIEN, B. J., BEDARD, M., WILLAN, A., WATSON, J., PATTERSON, C., HARISON, C., STANDISH, T., STRANG, D., DARZINS, P. J., SMITH, S. & DUBOIS, S. 2000. Systematic implementation of an advance directive program in nursing homes - A randomized controlled trial. *Jama-journal of the american medical association,* 283**,** 1437-1444.

[224] DUKE, G., YARBROUGH, S. & PANG, K. 2009. The Patient Self-Determination Act: 20 years revisited. *Journal of Nursing Law,* 13**,** 114-123.

[225] BUCHANAN, A. 1988. Advance Directives and the Personal Identity Problem. Princeton University Press.

[226] KUTNER, L. 1969. Due process of euthanasia: the living will, a proposal. *Indiana Law Journal Bloomington,* 44**,** 539-554.

[227] DETERING, K. M., HANCOCK, A. D., READE, M. C. & SILVESTER, W. 2010. The impact of advance care planning on end of life care in elderly patients: randomized controlled trial. British Medical Association. and http://www.nevdgp.org.au/info/division/respecting_choices.htm

[228] STEWART, C. 1999. Advanced directives, the right to die and the common law: recent problems with blood transfusions. *Melbourne University Law Review,* 23**,** 161-183.

[229] FAGERLIN, A. & SCHNEIDER, C. E. 2004. Enough: The Failure of the Living Will. *The Hastings Center Report*, 30.

---

[230] 2010. Advance directives have evolved. *Hospice Management Advisor,* 15**,** 93.

[231] PECANAC, K. E., REPENSHEK, M. F., TENNENBAUM, D. & HAMMES, B. J. 2014. Respecting Choices® and Advance Directives in a Diverse Community. *Journal of Palliative Medicine,* 17**,** 282-287.

[232] FAGERLIN, A. & SCHNEIDER, C. E. 2004. Enough: The Failure of the Living Will. *The Hastings Center Report***,** 30.