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Who is the patient?

Tensions between Advance Care Planning and Shared Decision Making

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Abstract: Shared decision making takes many forms, involving different kinds of agents who share the requirement that they must have sufficient decision making capacity for the decision in question. Advance care planning (ACP) is commonly viewed as a form of shared decision making between carers and patients who anticipate losing decision making capacity. What is unclear in this situation is the identity status of individual who has become mentally incapacitated and how to evaluate their rights and interests. This is known as the identity problem of ACP.

This paper suggests that the identity problem can be most convincingly addressed by understanding ACP based on narrative views of identity. These views, however create a tension in our current medico-legal framework for attributing decision making capacity. Current laws and guidelines favor maximum inclusiveness and hence mandate supported decision making of those with reduced or only focally preserved decision making capacity. Yet, an ACP framework based on narrative identity and the relevant capacities to construct such narratives results in more demanding capacity requirements than current medico-legal practice requires. The law thus espouses conflicting views as to who can be an appropriate decision making authority for patient care. I therefore conclude that the law governing medical care needs to be clearer about how to resolve the identity problem and revisit its position on ACP or supported decision making for those who have only focally preserved decision making capacity.

Keywords: medical ethics, clinical guidelines, person-centered medicine, health policy, philosophy of medicine, metaphysics

Introduction

Patient centered care has become the dominant paradigm in medicine. This has many reasons ranging from the recognition of the rights and interests of persons to pragmatic concerns of economy, which aim to achieve best care with least amount of resource use.¹

Advance care planning (ACP) and shared decision making both fall under the banner of patient centered care. In fact ACP is often seen as a subset of shared decision making. Yet, not much attention has been afforded to the problem that the two notions have potentially different ideas about patient identity and the ethics that should guide decision making. This can result in conflicts in the application of our treatment principles and consequently lead to inconsistent treatment decisions.

This paper aims to show the nature of some significant differences between aspects of ACP and the ideology of shared and supportive decision making. It suggests that the ethics and legal framework of shared decision making need to become clearer about their metaphysical foundations and their ethical priorities. It further indicates a potential need for an attitude revision either towards ACP or some values governing shared decision-making.

Shared decision-making

Shared decision making has been conceived in narrow and wide forms, depending on which stakeholders partake in the decision making process.² The narrow form focuses mainly on the individual patient and a particular treatment decision at a particular time, where sharing usually refers to the fact that the patient reaches a treatment decision in conjunction with a treatment provider. In its most basic form this might be a doctor providing relevant information about a treatment option so that the patient can make an informed decision about accepting the treatment or not. It may also involve shared deliberation about how to reach a decision or the shared formulation of treatment goals. This can take as little as a single encounter or grow into a more prolonged process, which may involve multiple encounters and include ongoing deliberations and revision of plans and goals.

The situation may become broader in scope in different ways. Either more treatment providers partake in the deliberation process or formulation of plans and goals, as is

common practice in multi-disciplinary settings, or the patient wishes (or needs to) involve significant others in the decision making process. This is especially so where the patient has reduced competence to make the relevant decision on their own, because of age, disability or illness. In such cases shared decision making is commonly referred to as supported decision making.

Often a treatment decision may directly concern others rather than only the particular patient, such as families or other care providers. Hence shared decision making may in fact not be restricted to individual patients alone. For example a person may need to be cared for in an acute care facility against her and her doctor's preferences, simply because the non-acute care facility (home or nursing home) does not have the resources to provide adequate care and thus refuse to look after her. Thus a broader notion of shared decision making recognizes that shared decision making is not entirely driven by patient preferences or needs, but can be subject wider social factors.

Lastly, cognitively impaired people have a legal (and moral) requirement for assistance with decision making.³ Decision making impairment however, is usually no longer seen as an all or nothing phenomenon, but it is deemed prudent and morally mandatory to actively involve such patients in the decision making process as much as possible⁴. From a mere pragmatic aspect this is sensible in order to achieve maximum compliance with care, but from a moral perspective it is considered the right thing to do in order to preserve patient dignity, maximize a sense of self and self-esteem, aid independence and respect whatever kernels of self-determination are present (with as much associated responsibility as deemed appropriate). These latter aspects correspond to our underlying values of respecting *all* people's rights to self-determination, privacy and self-expression as well as the right to not be harmed or tortured⁵. These values provide the fabric of our moral and social life and hence also ought to guide medical care.

A special tension can arise in shared decision making, in cases when a competent person wants to engage in sharing her decisions preemptively. She may anticipate situations in which she becomes cognitively impaired, but without losing all capacity for developing preferences and she may wish to override these future preferences. In these cases, what we take to be *one* patient may present with dual preferences, effectively posing as *two* different stakeholders in the decision sharing process. According to the ethical sentiments described above, the now cognitively impaired patient should be supported as much as possible, but our ethical ideas about advance care planning would suggest otherwise. Thus there is an internal conflict surrounding ideas of patient identity in our shared decision

making practices. The nature of this conflict is the focus of this paper. In the first part, I will present the basic ideas of advance care planning, demonstrate the nature of the identity problem for advance care planning in some detail and then make the case that the best way to address this problem is by employing an identity account which involves narrative concerns of the patient. The second part of the paper examines some consequences of such an account and makes the case, that, although it looks promising in many respects, narrative accounts pose a threat to our current legal ideas of what constitutes adequate decision making capacity.

Advance care planning (ACP)

Advance care planning is the practice of leaving verbal or written instructions to direct future medical care. These instructions are to be used at times of illness or disability when a patient cannot give care instructions in person, because of some form of mental incapacity.

ACP has been known in medical practice under different names and forms. It was originally conceived in the late 1960's by the American human rights lawyer, Luis Kutner, who thought that by providing an appropriately formulated '*Advance Directive*' (AD) a patient could firstly, provide legally binding instructions, which would serve to authoritatively state a patient's wishes about treatment options (especially treatment limitations) and secondly, protect treatment providers from charges of negligence in cases where treatment limitations were exercised in response to patient requests⁶. Such directives have also been known under other names, such as *living wills* or *refusal of treatment certificates*, to name but a few. Like shared and supportive decision making their moral legitimacy is supposed to be grounded in notions of dignity, respect for autonomy and self-determination and the right to privacy and freedom from harm or torture.⁷

Since its inception, the idea of ACP has evolved significantly in response to many legal, philosophical and medical problems. Ongoing developments of ACP are particularly connected to aspects of shared decision-making in recognition of the fact that ACP is fundamentally a deeply social practice. Although ACP was initially conceived of as a way of documenting a competent individual's medical will, years of unsuccessful attempts of implementing effective ACP have served to demonstrate that it takes more than one person's documented will to achieve a successful outcome. It takes people who can interpret such a document clearly and accurately, accept the content as the 'right thing to do' and act accordingly in a legal environment that provides clear approval. All of these steps from interpretation to legal approval have been problematic in the past⁸ and attempts

at finding solutions to the various problems have led to a modern ACP practice that is very different from some of the original aspects of Kutner's advance directives⁹.

What has been achieved is that ACP has obtained valid legal status in statutory and common law in many countries. However, at the same time ACP oscillates between its original form as '*contract*' between patient and treatment provider, aimed at settling potential disagreement about treatment options, and being a '*tool for communication*' about the presence or absence of agreement. ACP commonly no longer mandates written documents, but may equally be based on relevant verbal instructions (which may or may not be documented by someone else). ACP is no longer restricted to specific treatments, but can be based on value statements or treatment aims.¹⁰ Many people also view the mere formal appointment of a proxy medical decision maker (e.g. medical power of attorney) as a form of ACP, although the patient then may not necessarily have any further direct input in the decision making process, once the proxy decision maker takes over. It is not mandatory that such an appointed proxy has had a relevant discussion with the patient about their values and treatment preferences, although this is usually considered preferable, strongly advised and commonly assumed to have happened. These assumptions may be correct or not. How much patients talk with their proxy decision makers about their values may vary in itself, but another worry is that there is evidence, which suggests that such discussions between patients and their medical proxies do not necessarily improve patient and proxy decision making congruence.¹¹ Nonetheless, proxy decision makers are instructed by law to make decisions (to the best of their ability) in such a way that it reflects what the patient would have wanted. They must not base their decisions on their own preferences¹². How sincerely and accurately this comes to pass is difficult to judge and even harder to enforce. Some jurisdictions and policies even allow proxy decision-makers to make advance care plans on behalf of the patient. However, it is very dubious, whether such plans can be still be justified in terms of respect for autonomy and self-determination although they may certainly qualify for claims in respect of patient welfare.

Who is the patient? - The problem of duplication

Although not all forms of shared decision making constitute advance care planning, most professionals working in this area see all ACP as an expression of shared decision making and patient centered care. This is a myth which I want to call into question, at least insofar as it is questionable that those who provide the care and who design the relevant governing legislation are clear about who, metaphysically and practically, constitutes 'the patient'.

What happens in ACP is that a person who is deemed competent to make her own life choices creates a kind of metaphysical twin of herself, which exists separately from her physical body. ACP is essentially a tool for recording and preserving mental states that express personal wishes (desires) and preferences at a particular time. It is likely that the person who is doing this, takes these wishes and preferences to be stable, yet she obviously anticipates the possibility that she may lose the ability to communicate these at a later date. Alternatively, she may fear that her desires and preferences will not be stable, but her current competent self abhors the development of certain future preferences and wants to prevent them from becoming authoritative in her care. So either an inability to voice preferences or a desire for blocking future preferences can be a motivation for partaking in ACP.

Both of these motivations harbor problems for the moral authority of advance care planning and demand further exploration. Firstly, how can one be sure that the recorded personal preferences will indeed be stable and secondly, if they aren't stable, what reasons can there be to value the earlier preferences of the competent advance care planning individual, let's call her P_{past} , higher than any later ones of the individual who has impaired decision making capacity, call her P_{future} ? One obvious answer might be that the mere fact that P_{past} 's preferences were issued by a competent individual is precisely what makes these preferences more valuable than the incompetent ones. Such an answer is most likely a reflection of the value that we attribute to aspects rationality, insofar as those aspects of rationality serve as enablers for the pursuit of personal well being or effective preference satisfaction. However, if this were the case we can already glimpse slight tensions with some of the general motivations for shared decision making, which, among other things, aims at preserving the dignity of *all* patients, even those who lack competence or aspects of rationality. For it is recognized that non-competent people can have genuine desires and preferences, the frustration of which may well induce distress. Given that anyone has a right to not be subjected to unwarranted harm, such potential for distress generates a general interest in having preferences respected. Hence, to override someone's preferences, however unreasonable or unwise they may be, we need sufficient reasons to override them. The mere fact that a preference is voiced by someone who lacks decision making capacity cannot be sufficient alone for dismissing the preference. An acceptable reason needs to make reference at least to some kind of harm, which outweighs the distress suffered by the person whose preferences are being denied. Thus, when there are conflicting preferences between those expressed in an ACP by P_{past} and those expressed by P_{future} (who is meant to

be subject to the ACP) we need to show that someone or something would be harmed, if the ACP were not obeyed.

So why does this prompt questioning about the identity of the patient in question?

As I have pointed out above, ACP generates a kind of metaphysical twin, by separating decision making authority from a physical body in a diachronic way. As the body endures and undergoes changes we now have two entities, which can have different, competing interests. The fact that ACP allows the disruption of the synchronic cohesion of an individual creates a troublesome complication for decision sharing. Living wills are like ordinary wills in that they fix certain mental states (preferences) in time and aim to make them authoritative. However, the troubling difference to ordinary wills is that there is a living body which is capable of having ongoing, competing preferences and desires. This body is subject to at least some of the rights and concerns that we afford all life human individuals (irrespective of whether we deem them competent or whether we give them full personhood status).

Our legal apparatus refers to a single individualⁱ, which is meant to be synchronically coherent, yet ACP permits the development of interests of two (somewhat defective) individuals who have been created by diachronic splicing of mental states. Allowing ACP to have authority disrupts the synchronicity of the mental and physical: we have some past mental states (contained in the ACP) that no longer have an actual (concurrent) body and a body that no longer has some (concurrent) mental states, yet can develop mental states that contradict the previous mental states.ⁱⁱ

ACP can only make sense if we have good reasons to discount the rights and interests of the later individual P_{future} otherwise it is redundant or only a means of communication that is to confirm that everyone is in agreement. It becomes a 'feel good tool', but cannot settle conflict about treatment options. So one interesting aspect of ACP as a form of shared decision making is that it introduces a new stakeholder, P_{past} , in the decision making process.

It is clear that any physical care can only be given to the body that has persisted, i.e. P_{future} , however, it is not obviously clear which authority should guide the decisions about the treatment of P_{future} ; or more precisely, it is not obvious why one should be convinced that the past autonomy, should govern the care of the current body that has changed over time.

ⁱusually identified by a name, date of birth, social security number etc.

ⁱⁱboth of these have the same name, date of birth, social security number etc.

When a physician treats an ailment of the body, he treats the current ailment, not one of the past. When a psychiatrist treats mental health problems of a patient, he treats current problems, not those of the past and he treats these in consideration of current mental states, not past ones. So when a decision requires the consideration of patient wishes and preferences, why should this be governed by past wishes, rather than current ones? What is it about past autonomy that seems to convince at least some of us that it should govern current care? Why are past autonomous interests more pressing than current non-autonomous ones?

Insofar as the answers to these questions depend on solving the duplication issue, this is known as the identity problem of ACP, which constitutes a significant metaphysical puzzle whose possible solutions shape our current clinical and medico-legal practices and, as I will argue, ought to inform just what those practices should be.

The personal identity problem

As we have seen above, ACP allows the temporal splicing of mental and physical aspects of a person, resulting in a quasi person duplication that can be difficult to cope with in practice. In order to provide consistent and ethically justified care, we have to find a convincing way of discounting the claims of one of those individuals. This is commonly done by trying to define what constitutes personal identity in order to ascertain which individual is the *bona fide* one.

In defining personal identity we are asking which aspects of an individual are essential to their existence, in other words, the loss of which feature would bring about the individual's extinction? Generally, metaphysical identity questions ask (in one way or another) after persistence conditions. Not surprisingly, definitions of personal identity largely focus on the two fundamental aspects of persons, which we have already identified: the continuity of mental (psychological) and/or continuity of physical (biological) phenomena¹³. Although the personal identity literature suggests a multitude of plausible identity accounts that differ in detail, all accounts can broadly be recognized as either a biological (animalist) or psychological identity account. Some accounts include social phenomena¹⁴ and many accounts try to work with a combination of phenomena¹⁵, but almost all identify with predominantly with one of the sides of this divide.ⁱⁱⁱ

ⁱⁱⁱEven bundle views, such as Schechtman's '*Person Life View*', which denies the idea of essentialism, do acknowledge the **biological**/psychological divide and identify more with one or the other.

In regard to ACP, the identity problem first came to prominence in the literature by Dresser¹⁶ and Dworkin¹⁷ in the 1990's, who disagreed in their intuitions about whether the past competent preferences of patients should override later incompetent ones. Their discussion questioned the moral authority of ACP along the lines discussed in the previous section, which ties the moral authority directly to identity concerns. The central argument has been summarized neatly, more recently, by Furberg as follows:

"(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 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."*¹⁸

Roughly, if ACP is based on a psychological understanding of identity and the patient loses the relevant psychological ties, then the advance care plan is no longer about that patient, but about somebody else (who happens to share the same body). Since one has no moral domain to make decision about someone else, especially when such a decision might result in the successor being's death, then the instructions cannot direct their care.

This is a devastating objection to the ethical foundations of ACP, given that an advance care plan only ever needs to be invoked when there is significant discontinuity of psychological features. Likewise it is also an assault on some ideas of shared decision making, which seek to actively involve patients in their future care. However, unless you want to embrace the conclusion that ACP does not have moral authority (which would mean our efforts of having ACP accepted as legally valid instructions were all misguided) there are two basic ways to address this problem: You can either deny premise (1), that ACP's can only have authority over the self or deny premise (2), that psychological continuity is the basis of personal identity.

Dismissing premise (2) is problematic. Thinking about personal identity based on psychological parameters has historically become increasingly prominent for two reasons. Firstly, with the advent of organ transplantation and the better success of living donor transplants compared to cadaver transplants, there had been an increasing shift to seeing

pure biological persistence as meaningless and hence not as 'proper survival'. Over the years this lead to a prominent review of the definition of death¹⁹ in order to increase living donor rates. Secondly, in similar vein, many argued, that if limitation of treatment leading to biological death is justified on grounds of the reduced value of biological persistence with significant cognitive impairment, then this is tantamount to saying that there is nothing worth keeping alive²⁰, which in turn is equivalent to saying that identity ought to be attached to the continued existence of mental phenomena rather than biology.

In spite of this, some (including relevant aspects of the law) have denied premise (2), and pursued the animalist strategy in order to avoid the identity problem of ACP. On their account a person who writes a directive can be assured the directive is about herself, because the identity of the self is determined by the continued existence of her body, irrespective of any mental states and this preserves her authority to say what happens to her. However, this position has at least two difficulties that worth mentioning here.

Firstly, it does not give a very good answer to the question of what matters about persistence. If continuation of the body is what matters, then why should one condone the creation of directives that aim at treatment limitations because of failing mental sates? If it is the survival of the body that matters, why limit the treatment of a severely demented body?

Secondly, why can a person make such a directive without full knowledge of the particulars? Ordinary consent requirements for administration or withholding of treatment demand that the patient be given, understands and retains adequate information about the treatment in question^{iv}, yet this is hardly possible in regards to advance decisions. Even though the patient may know their current values and preferences, she can only guess future preferences and more importantly she cannot know which particular ailments will befall her or what treatment options will be available at the time. So 'advance consent' will principally always be less accurate than contemporary consent and fall short precisely on provision of adequate information. A rebuttal here could claim that all consent has elements of uncertainty, which cannot be overcome. However, the temporal epistemic disadvantage

^{iv}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, which is similar to the UK Mental Capacity Act that deems a person unable to make a decision for himself if he is unable -

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

of ACP's are easily overcome by a competent proxy decision maker, so it is not clear why one should opt for the more uncertain option, when a better one is available. Subscribers to biological identity views could rightly claim that this is not just an objection exclusive to biological accounts, but rather to ACP outright, so why bring it up here? The reason for this is, that some psychological accounts, such as narrative identity accounts, can counter this objection (as will be shown below) in reference to psychological parameters, whereas biological accounts cannot.

We may think that a competent person knows her own values and wishes more accurately than any third party. However, given that time and circumstances are capable of changing preferences of even competent people, it is not clear what warrants the assumption that the patient's preferences will be stable. In fact, if they were, the incompetent preferences of P_{future} should not be different from the competent ones of P_{past} and there would be no need for the directive (other than overcoming muteness in communicating preferences).

We may feel that a person should have the power to dictate her own future and as such prevent the development of preferences which the competent P_{past} feels are undignified or unpalatable in some other way. But these values are then again based on an ethical claim about what life is valuable, which is a question that is not settled by mere reference to biology. This would only be true if we also believe that body ownership is the lone fact that licenses power over it, to such an extent that we can do with it as we please, including subjecting it or letting it be subjected to all sorts of harm. Such an owner/license principle would be contrary to many of our current treatment principles. We cannot enslave ourselves. We usually take evidence of self harm as an indication for initiating treatment, rather than as a prerogative to acquiescence. Often we even see it as a justification for involuntary treatment. Those who are vulnerable to abuse, because of disability usually require extra protection, even against self. We allow refusal of treatment, but not refusal of basic nourishment. We disallow the sale of our future body for organs or other purposes etc. So deriving personal identity from biological parameters (in combination with mere body ownership) does not imply a *card blanche* in terms of what we can do with that body. Thus invoking a biological account as a foundation of personal identity, although it clarifies who the directions apply to, still stands in need of an account that explains why possible future distress does not matter and why treatment decisions should engage with P_{past} rather than P_{future} . The latter point is especially inconsistent with the aspiration of promoting or engaging with as much residual decision making capacity as is present in the impaired patient.

Given these drawbacks of endorsing a biological account and denying premise (2) it is worthwhile to examine the alternative of endorsing a psychological account of personal identity, but denying premise (1). This requires us to make sense of the claim that one person's directive can have moral authority over another person's care. On first glance this would seem to fly in the face of self-determination, which is a prime motivator for ACP, but further examination can make this come out as a reasonable solution.

Firstly, we should recognize that once someone has sustained severe cognitive decline to the point that their identity is discontinued, they are likely to be in a state that leaves them with reduced decision making capacity. If this were not so, then an ACP would have no authority in the first place. So anyone who is in this situation will need a substitute (or supportive) decision maker, whether they have an ACP or not. The question is who or what should this substitute decision maker be, and what kind of factors should they consider in determining the patient's care?

In determining who can have morally valid substitute decision making authority we usually look for some relevant ties between the proxy decision maker and the patient. These ties could be based either special expertise, such as professional medical knowledge, special duties towards the patient or special close personal ties, which may indicate the likelihood of sincere advocacy for relevant patient concerns or well being. These could derive from special knowledge of patient circumstances, patient values or historical facts. Many of these factors apply to the P_{past} , even if we think a genuine numerical separation of persons has come into effect through the mental decline. So it seems reasonable to claim that P_{past} has a relevant moral kinship to P_{future} which makes P_{past} at least morally eligible to be a candidate as substitute decision maker, even if P_{past} 's chronological remoteness puts her at an epistemic disadvantage about future states of affairs. This eligibility can be grounded in their (partially) shared biology and P_{past} 's narrative concern, which is a special aspect of psychological continuity that may justify special interests in future events.

Narrative concern

At this stage the reader might think that this is just a complicated way of confirming the common sense intuition that one should be able to direct one's future via an ACP, so why should one spend so much effort in spelling out the details? There are multiple reasons for this. Some of these pertain to clarification of what common sense is actually trying to express in detail and to give a coherent answer to the identity problem. More importantly though, the detailed account of how the identity problem is addressed gives rise to other

problems and these can only be understood if sufficient detail is observed about the identity problem. Let's turn to the benefits of accounts of narrative concern first.

Firstly, embracing an account of narrative concern provides a coherent answer to the identity problem.

Secondly, it addresses the shortcoming of any reasoning based purely on biology. As the brief discussion above has hoped to show, mere shared biology of P_{past} and P_{future} is a poor candidate to cement authoritative special relations, whereas narrative concern has a more convincing account to offer about why past concerns ought to be valued highly and it can answer many of the justificatory questions asked above.ⁱ

It should be noted about these two points, that the aim in this paper is not to give a comprehensive account of how narratives play a principal role in a human being's life or whether narrative mental states are solely sufficient for constituting personhood or some such concept (which is perhaps unlikely). The importance of narrative mental elements is that they constitute the specific set of mental states *necessary* to ground moral claims over future events, and this is what is needed for addressing the moral skepticism laid open by the identity problem.

Thirdly, talking about ACP in terms of narrative concern also seems to reflect the way in which many (prominent) people think about the justification of ACP. Ronald Dworkin, for example, formulated the justification for ACP in a narrative way:

*"Death has dominion because it is not only the start of nothing, but the end of everything, and how we think and talk about dying – the emphasis on dying with 'dignity' – shows how important it is that life ends appropriately, that death keeps faith with the way we want to have lived."*²¹

The idea that we want a future that is an appropriate continuation (or end) to the life we have lived so far can only gain purchase if we look at life in a holistic way. A holistic view of life considers our future and our past as a part of our presence, and this can only be achieved through a form of narrative^v. That way, even if my future self cannot remember the past and even if the body which is now mine, becomes the body of someone else (based

^vIt is, of course, not mandatory to see life holistically and to identify as having a narrative. Galen Strawson (*Against Narrativity. Ratio -Oxford-, 17, 2004*) gave a very prominent account of this. However, for the current discussion it is only necessary that we can allow a holistic account of personal identity in relation to make sense of ACP. Presumably episodics like Galen Strawson, who do not conceive of their life as a whole, would find little merit in ACP.

on a psychological identity account) we can make claims about how a future denial of my current wishes can harm me presently. This allows us to answer two of the questions that we have raised in regards to factors that influence decision making:

1 - Who is being harmed by not following an ACP? P_{past} is harmed, because she cannot fulfill her narrative and hence her self determination is obstructed.

2 - What justifies our acceptance of a past person's authority? The justification derives from the harm that would be done to P_{past} 's narrative, should the ACP authority be denied.

The consideration of narrative concerns has a further advantage, in that it perhaps allows a genuine weighing of harm considerations. There is scope to consider the harm done to P_{past} 's narrative in comparison to the harm done to P_{future} 's present condition and interests. Looking at ACP as an expression of a personal narrative and the role that an ACP would thus play in shared decision making could constitute the kind of aspect that many people want it to play: a factor that is to be considered *seriously*, but not *dogmatically* one way or the other.

So far so good. But if we can resolve the tension which results from the metaphysical duplication of patients with a narrative account, then why did I make the claim that ACP as a subset of shared decision making is a problem in terms of leaving us confused about who the patient is?

This remains to be shown in the following section, where I will argue that narrative identity conceptions, although promising in regard to solving the identity problem, are problematic in relation to our consent practices and current ideology of supported decision making.

Narrative identity and Decision Making Competence (Autonomy)

If we base ACP on ideas of narrative identity, we are obliged to spell out in more detail what psychological narrativity amounts to and more importantly, which conditions have to be met in order to construct a life narrative. After all, if your whole life comes to depend on it, then you and those who care for you, need to get it right.

What does it take to create a narrative? Are there procedural or special cognitive demands? Does one need a certain intelligence, certain information, a particular emotional state, a minimum age? Do you need to be aware of your narrative or can you forget it once it is formed? What indicates change? Do you need special self-reflective skills to construct it? If

so, which skills? How much memory do you need to access all the relevant parts of your life in order to construct a narrative? Once a narrative is up and running, can you disregard its origins or do they need to stay accessible?

If someone wishes to leave credible instructions for their future care, one needs to be sure that this person is competent to do so. Although the claim about ACP being about respect for autonomy is usually grounded in a claim about the right to make choices, it is clear, that this right needs to be firmly connected to a competent capacity make such choices. Given that the ethical grounding of ACP, as I have described it here, is rooted in the preservation of a narrative, one can only decide whether someone has the capacity to make an ACP, if one knows what kind of skills and information are needed to construct a narrative. This has not been well explored in the research of ACP, but there are some accounts of personal autonomy that refer to the formation of life plans²². Judging by these accounts, it seems that creating a life narrative is quite a complex task that would require complex reflective skills and a fair amount of memory. Constructing a narrative would require something like 'narrative autonomy', i.e. the capacity to construct and maintain a life narrative.

Determining Narrative Autonomy

Anyone who would wish to create an ACP would have to be deemed competent to do so, just as we require that anyone who partakes in any other medical decision making, perhaps giving consent for surgery, is competent to do so. So, when we claim that ACP is based on continuing a life narrative, then we need to establish whether the person who wants to engage in ACP has the capacity to construct and maintain a narrative. How should we establish that such a capacity is present?

Presumably this should follow a similar path as other capacity assessments for medical decision making: either the capacity is taken to be present as a default capacity at the age of legal maturity (commonly age 18) or, if such a capacity is doubted, we need to test for its presence.

Testing principles for this situation are usually formulated in the legal discourse of the jurisdiction that is applicable for the patient in question. In Australia, which has a similar approach to the UK and many other Western countries, it is the *common law principle* which guides capacity determination for decision making. It says the following:

"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."²³

This formulation resulted from an Australian high court decision in the case *Gibbins vs Wright* (1954) and has since been reflected in statutory law throughout the nation.^{vi}

This does not specify any global or special procedural skills or special memory that one might imagine to be needed for the formation of a narrative, but rather makes the general statement that 'the instrument is relative to a transaction' and that the capacity depends on sufficient understanding of the relevant transaction.

It seems clear that the instrument in this case is the Advance Care Plan, but it is far from clear what constitutes the transaction in ACP. One might argue that the relevant transaction is the procedural aspect of ACP. This would mean the patient has to understand the procedural requirements for drafting a valid ACP and understands the effects of such a plan, i.e. that the ACP comes into action when you lose competence and it may (or may not) mean that the patient knows what constitutes absence of competence. However, if we maintain that ACP is about maintaining a life narrative, this kind understanding of the transaction seems to be too minimalistic. Considering merely the procedural aspect of the ACP transaction would be as if in an ordinary consent situation, say for a surgical procedure, all you had to understand was that by signing the consent form you authorize the 'go ahead' for the procedure. Yet, we know quite clearly that this is not what is meant. In a case of ordinary surgical consent a surgeon has to ascertain that the patient has understood the nature of the procedure, the relevant and significant risks for having and not having it and considerable other detail.

Likewise a significant part of the transaction concerning ACP should be that you are actually aware of your narrative or that you are principally able to construct an advance care plan in light of a good understanding of the relative elements of your life narrative. But how is any treatment provider going to establish that a patient is capable of having and forming a life narrative? There seem to be no factual or substantive elements that can be looked for in order to establish that the patient has understood their narrative, so all one could practically do is to assess the kinds of general skills that a person would need to form such a

^{vi}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.

narrative. This is difficult enough, but perhaps one could agree on a protocol which combines the assessment of memory, basic reasoning or other cognitive skills, which can stand as indicators for sufficient narrative construction. These would have to be fairly global and broad though, since creating a life narrative is just about the most complex, global and holistic task I can think of. So even if we were to demonstrate relevant procedural capacities, these would likely be far more global than is usually aimed for in particular medical decision making. After all, the clause, which relates the competence for a transaction to the particular instrument, is meant to be an inclusive element. It is meant to be a clause that enables local decisions, without reference to global understanding or global cognitive skill. It is specifically aimed at including people who may fall short in global decision making capacity and allow them to make all those decisions, which they can understand.

The conflict between ACP and Supported Shared Decision Making

This is where we return to the competing aspects between ACP and the general creed of supported shared decision making. One of the particular aims of supported decision making is to involve the patient actively in all those decisions they can make, even if certain more global capacities have gone²⁴. Yet if one of the stakeholders in the shared decision making is the ACP (as a proxy for the P_{past}) then the global competence of P_{past} competes with the focal competence of P_{future} about the same decision.

How this can be problematic is perhaps this is best seen in an example. Imagine P_{past} has competently considered her narrative and thinks it befitting that her intellectually well developed life should not be concluded in a state of prolonged dementia. She creates an ACP, which expresses that should she come to suffer advanced dementia, any ailment that could lead to her death should not be treated other than with supportive comfort care to ease her passing. P_{past} develops into P_{future} , who indeed suffers from advanced dementia and develops such an ailment (perhaps pneumonia or urinary sepsis), which, if treated with supportive comfort measures only, would lead to her death. So the case applies. However, P_{future} , even though she has a advanced dementia still understands that she will die if she doesn't get specific treatment and she understands what this treatment entails^{vii} (perhaps

^{vii}Readers might object that the patient cannot have 'advanced dementia' if she understands this much. However, the clinical literature provides many examples, where just such cases are presented. This becomes especially relevant when many indirect signs of communication are accepted as request for life supporting treatment and when one realizes that dementia can present with an amazing mosaic of preserved and lost capacities and interests.

admission to hospital and iv therapy). What she no longer understands is her previous life narrative or any extended life narrative. She just wants to live.

P_{future} passes the common law capacity test and accordingly she should be deemed competent to make the decision. Her ACP either never gets consulted or P_{future} 's interests overrule. We cannot say that P_{future} has revoked the ACP, for on the common law principle she does not have the capacity to do so, as she no longer understands her life narrative or what ACP is about. So she does not have the relevant understanding that the transaction of 'revoking an ACP' would require. So she should not be deemed capable to revoke the plan. Thus, by following the common law principle, ACP does not make it into the decision making process, even though it was specifically created for this situation. ACP has become redundant.

Alternatively, we could claim that in light of the harm that would be done to P_{past} , we ought to follow the ACP. If we do this, we must ignore the common law principle about decision making capacity and we abandon the ethics of supported decision making, which hold that respect for the dignity and self-determination of patients requires us to support and honor whatever residual capacities are present. This option, at the very least, would require a legal ruling which allows the particular exception of ACP from the common law principle of capacity assessment. Such ruling should include an explicit reasoning of why such an exception ought to be made. Presumably this is principally possible, but, as far as I know, not the case in any jurisdiction.

What would be required is the formulation of a clear principle for capacity testing that applies specifically to situations of advance care planning and that includes the acknowledgement that residual partial capacities in regards to individual treatment decisions (as acknowledged in the common law principle) must be ignored once the capacity to appreciate or update one's life narrative has gone. This would also require the official acceptance of a narrative idea of personal identity as the basis for ACP and thus represent an unprecedented clear metaphysical legal position in regard to ACP. It would mean that a patient and their carers must understand that an ACP becomes a firm instrument of self-paternalization, which potentially conflicts with our usual ethical stance on supported decision making and fostering residual capacities. Whether this is something we would want, is another question entirely. Perhaps, the more recent trends in ACP, which focus on mere ongoing communication²⁵ and the appointment of medical guardians, rather than written statements, indicate that a majority would prefer to stick with residual capacities and err on the side of ACP redundancy terms of conflict resolution. Except for cases in which

P_{future} has no discernable residual preferences, ACP then should merely function as a communication tool that makes us feel good about the fact that there is agreement with past preferences. However, if this is the case, one cannot but wonder why so much effort went into getting ACP formally anchored in law, unless perhaps we think that communication in medical practice has suffered so much, that it now must be legally prescribed rather than be simply standard good practice.

Conclusion

I have examined the practice of ACP in light of its position as a tool for shared decision making and drawn attention to the fact that in many circumstances the ethical and metaphysical foundations of ACP are at odds with current practice and ethical ideas in the general understanding of shared and supportive decision making.

By showing that ACP is best understood based on a metaphysical background of narrative identity, I have given a credible solution to the identity problem of advance care planning. At the same time I have drawn attention to the fact that the required corresponding ideas of narrative autonomy do not sit well with current legal practice for capacity assessment and consent. Therefore our legal framework is not well prepared to deal with the patient duplication problem that is a consequence of ACP.

As a result, I have suggested that we either need to aim for a much clearer metaphysical stance of the law in regard to which entity ought to be counted as the authoritative patient in the setting of ACP, globally *capacitated* P_{past} or partially capacitated P_{future} , or that we need to become much less ambitious in our expectations about what ACP can achieve in terms of shared decision making. Whichever path is taken, it should aim at providing a clearer understanding for carers and patients alike, as to where this leaves ACP in the setting of shared decision making.

Author Declaration:

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