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Personhood and Disorders of Consciousness: Finding Room in Person-Centered Healthcare

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Abstract

Advocates of the Person-Centered Healthcare (PCH) approach say that PCH is a response to a failure of caring for patients as persons. Nevertheless, there are many human subjects falling to fulfill the requirements of a traditional philosophical definition of personhood. Hence, if we take, PCH seriously, a greater clarification of the key terminology of PCH is urgently needed. It seems necessary, for instance, that the concept of the person should be extended in order to include those individuals with insipient or immature levels of consciousness, as well as those who are severely and permanently mentally handicapped. In this article, we will depart from some well-known philosophical concepts of what it means to be a person and try to offer a broader and more inclusive meaning. We suggest that persons are human beings with a socially recognized biography, which implies to recognize as persons individuals with necessities, but also with narratives about their interests and claims, expressed sometimes by other people related to them. This is particularly the case of individuals that suffer from severe disorders of consciousness. For those, is not only care that matters; respect matters too. Caregivers should therefore not only sympathetically care for the well-being of these people; they should also be concerned to respect their interests and claims by interpreting them empathetically, in the light of their biographical story. Our conclusion is that, in order to be coherent, PCH must consider individuals with severe disorders of consciousness as persons and we think that our revised concept of personhood fits with this requirement.

Keywords

Biography, disorders of consciousness, narratives, ontology of personhood, personal identity, person-centered healthcare, personhood

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Introduction

“[Person] is a forensic term, appropriating actions and their merit; and so belongs only to intelligent agents, capable of a law, and happiness, and misery. This personality extends itself beyond the present existence to what is past, only by consciousness - whereby it becomes concerned and accountable.” (Locke, Essay, Book II, §26 [1]).

“What is most important in the survival of a person are a number of psychological relations. Most of these relations hold, over time, to varying degrees. So the identity of a person over time is only in its logic all-or-nothing; in its nature, it is a matter of degree.” (Derek Parfit [2]).

“Each human being traces a unique autobiographical route through the world, and the combination of genetic endowment, variable responsiveness to individual experience, and memory gives each human being a personality (...). Our consciousness of our past itself

typically incorporates an awareness of our family and social group, and of the form of life that contributes to the generation of our social identity and plays a crucial role in our conception of ourselves.” (Peter Hacker [3]).

Many advocates of Person-Centered Healthcare (PCH) say that it is “a new way of ‘thinking and doing’ in clinical practice” and a response to a failure of “caring for patients as individuals, which is to say as *persons*” [4]. Miles and Mezzich, for instance, see PCH as a humanistic framework of care, in which science is applied in a manner that respects “the patient as a whole person” [5]. Nevertheless, as Loughlin has argued, the meaning of “person” (besides other related concepts) deserves to be settled. Maybe we can never attain a consensus about what is meant by this word (as we can about practical issues, as guidelines for good practices), but philosophically it certainly matters to reflect deeply about what practitioners could mean by their discourse that “persons” should be at the center of healthcare [6].

“Patient-centeredness” is sometimes used as an ecumenical expression. Entwistle and Watt, for instance, maintain that “person-centeredness” is near synonymous to other qualifications like “patient-centered”, “client-centered”, “family-centered” and “relationship-centered”, since all of them remark on the importance of shifting medicine and healthcare from a practice that is “too disease-centered” or “too system or staff-centered”, to one that improves patients’ experiences of healthcare. A general concern behind this is ethical. The tenet that patients should be “treated as persons” [7] seems to be made for the sake of emphasizing the principle that healthcare must be respectful and responsive to individuals’ preferences, needs and values [8,9].

But the ethical requirement to treat patients “as persons” raises hard ontological issues: what are persons? If we cannot give a clear, philosophically defensible account of the nature of personhood, then we cannot explain what we mean by “persons” when arguing for a person-centered approach. Philosophers consider ontology as a branch of metaphysics [10]. Nevertheless, it can be rightly argued that practitioners do not need an appropriate metaphysics to be good professionals. It is also arguable that we also do not need any metaphysics in order to supply the practice of PCH with a coherent *theoretical* approach. So, why should we bother with ontological issues? Ontological issues are quite contentious in that they affect our confidence in a theory of healthcare. In spite of those skeptical questionings, we think it is at least *prima facie* reasonable that we do need an appropriate metaphysics in order to build a cogent, sound and comprehensive theoretical approach to the field.

Taking the topic seriously, we invite the reader to consider whether we need to be bothered by those “abstruse” issues, as philosopher David Hume calls them (we will return to this point at the end of this chapter). Assuming that we do have to deal with those issues in order to build a coherent philosophical account for PCH, one salient problem we have is this: since PCH is focused in persons, if we follow philosophers’ traditional accounts (see below), one bitter conclusion is that, since not all human beings can be considered (in this very strict sense) as “persons”, not all patients are at the center of a humanized approach to healthcare - a conclusion, let us say, that is quite repugnant. Certainly, this is not what proponents of PCH have in mind when they demand that persons should be at the center of care. As Loughlin has commented, since there are many human subjects falling short of the requisites of traditional philosophical definitions of personhood, and assuming that proponents of PCH do not recommend relegating them to the margins of medical concern, a greater clarification of the key terminology of PCH is urgently needed [6].

In order to see how deep the problem is, let us pay attention to the three quotations in the epigraph of this chapter. Here we have three distinct philosophers, whom we have not quoted at random (John Locke is the main advocate of one of the most persuasive accounts on personhood in modern philosophy; Derek Parfit is one of the most influential contemporary philosophers dealing with this same issue; and Peter Hacker is a proponent of an insightful and critical new approach to the topic, mainly

influenced by late Wittgenstein). All of them emphasize the importance of self-consciousness (and also self-narratives) to personhood. Assuming that our personal identity must extend beyond our present existence to some beginning in the past, Locke concludes that present consciousness should be capable of retrieving and accounting for a unique chain of past memories and that this is what constitutes personhood. The problem is that this is not something that plausibly happens in our own lives. We not only lose memories, we also sometimes break the entire chain (as happens in the elderly with dementia). Apart from this, in our childhood we do not maintain a plain conscious account of what we were and are. Parfit’s and Hacker’s views are more realistic at this juncture. Parfit points out that our “psychological” relations come into various degrees in our life, and Hacker marks the social character of the self-conceptions of who we are. Below, we will discuss these views in the necessary detail. For now, let us remark that if self-consciousness should be considered necessary for any account of what we mean by “personhood,” then if persons should be our prime concern in PCH, the conclusion would be that a huge number of patients would be excluded from the center of care.

Nevertheless, if PCH is interested in persons, and if persons are truly all that matters, then we need to rethink these traditional accounts of the ontology of *personhood*. After all, in PCH it is not solely individuals with mature rational selves that demand care from health practitioners. Newborns, toddlers, children, the mentally handicapped, and the elderly with chronic or progressive conscious disorders, as well as people endowed with severe disorders of consciousness (SDC), are certainly also persons with rights to healthcare. So, in taking PCH seriously, it seems necessary that the concept of the person be extended in order to include those individuals with insipient or immature levels of consciousness, as well as those who are severely and permanently mentally handicapped. It seems plainly acceptable that, in clinical practice, those individuals also need appropriate care, and so there is a point that they should be cared for and respected in the same way we care for and respect all non-mentally disabled individuals.

Patients, *persons* and claims

If we assume the view that consciousness is *necessary* for being a “person”, we should as a consequence accept that many people we actually care about in healthcare are not persons. One dictionary definition of “patient” is “an individual awaiting or under medical care and treatment” [11]. The word “patient”, derives from the Latin *patientem*, meaning “bearing, supporting, suffering, enduring, permitting”, but its use to make reference to individuals under medical care occurs from the mid 14th Century. It seems obvious that to regard people under medical assistance as *persons* is not a necessary consequence of regarding those same people as *patients*. The difference can be subtle but, regarding an individual as a patient involves an attitude that is different from regarding this

very same individual as a person. The attitudes are nevertheless not necessarily opposite. Patients are individuals with care needs; persons can be patients sometimes, but caring about them as persons implies more than only caring about them as patients.

Now, if the people we care about in healthcare are, by definition, always *patients*, what could be meant by saying that healthcare should have such patients, at their center? So, why not a *patient-centered* healthcare (PtCH)? Let us then, examine the differences between a conceptual PCH approach and a conceptual PtCH approach.

Consider the 2015 *Montgomery versus Lanarkshire Health Board Judgement*.¹ In the UK, the long-held position about what information should be disclosed by healers to their patients when obtaining consent was that this should be determined on the basis of what a reasonable body of medical opinion would agree to disclose under those circumstances.² The rationale appears to be that the judgment about which information is relevant to disclose for consent is a matter of physicians' discretion; clinical information was seen as purely technical knowledge that is instrumental for medical judgment. Given that, only an expert can decide which information is relevant for consent and how this should be disclosed, including in order to not cause any iatrogenic harm to the patient. Patients are laypeople and, since they are not medical experts, they are not able to discern accurately and without misunderstanding what is at stake regarding their own clinical condition. Following this rationale, clinical decisions are taken by medical experts only. As stated by Judge McNair in *Bolam versus Friern Hospital Management Committee*, "the test for negligence is not the test of the man on the Clapham omnibus, because he has not got this special skill" [14]. The view was that it is a privilege of physicians to decide which is the best medical option for each case and the test for an expert diligence is not what a reasonable ordinary person would think about the case, but what a reasonable expert would do. We will call this the traditional view.

The traditional view does not in fact state that patients have no rights at all, as it sees them as individuals endowed with rights - they certainly have a right to consent, even to *informed* consent. Consent is an act by means of which one gives another an authorization (or a license) to do something that they are otherwise not

authorized to do. So, it is in one's power to give or not to give another person the authorization in question. In the case of medicine, the right to consent implies that patients have an autonomous power to change physicians' legal and moral positions of not being (*prima facie*) authorized to do something (a medical procedure, for instance), unless they afford their physicians this privilege. But, following the traditional view, the authorization given by patients to their physicians is a licence to perform what physicians have already decided to offer to them as appropriate treatments. In this interpretation, the right that patients actually have is simply the right to say "no". This privilege is a consequence of the right not to be submitted to a treatment they do not accept (by reasons that are not under medical expert scrutiny) by force, a specification of a general right to not be forced to do what one does not want (a right of liberty). Grounds for this view can be found in John Stuart Mill's account of what has been called by Feinberg "the harm principle" [15,16].

The *Montgomery* judgment changed the rationale for decisions about appropriate informed consent in the UK. The judges unanimously opted for a view that information should be disclosed to the patient if "a reasonable person in the patient's position would attach significance to the risk," or "the doctor is or should be reasonably aware that the particular patient would be likely to attach significance to it" [12]. This disjunctive statement implies a different approach to consent than the traditional view. Doctors have a broader duty to evaluate the clinical information available, in terms which could be considered by a person in the patients' position as relevant to their own decision to consent to their doctor's options about procedures and treatments. Since patients' decisions could be made for non-technical reasons, doctors have to put themselves into their patients' shoes in order to grasp their beliefs about their circumstances as well as the expert's options. Dunn *et al.* argue that the *Montgomery* judgment marks a "more patient-centric approach" about consent in medical practice. We think, making a proposed distinction between a patient-centered approach and a person-centered one, that the *Montgomery* judgment interprets that the patient-doctor relationship has changed in a way that patients now demand a more active role in the process of clinical decision-making and that physicians must take their patients' beliefs, values and even prejudices into account in their clinical reasoning, disclosing whatever they reasonably think could be in the interest of their patients or that could affect their decisions about consent. Doctors, hence, must see their patients not only as patients in need, but as agents whose beliefs, values and commitments should be fully understood, respected and considered in their clinical reasoning [17]. This is not new; indeed, it is something that has been required to be taken seriously for decades worldwide.

What we are suggesting is that what we call PtCH does not imply (at least not conceptually) that an individual with healthcare needs *should* actively participate in medical decisions. Following the traditional view, the patient's own perceptions about what constitutes their needs could be seen only as additional subjective information that physicians should (propaedeutically) consider in their

1 Here we will not present nor discuss the particularities of the juridical controversy of this case. About that, see Dunn *et al.* [12].

2 Sidaway's ratio [13] states: "The only effect that mention of risks can have on the patient's mind, if it has any at all, can be in the direction of deterring the patient from undergoing the treatment which in the expert opinion of the doctor is in the patient's interest to undergo. To decide what risks the existence of which a patient should be voluntarily warned and the terms in which such warning, if any, should be given, having regard to the effect that the warning may have, is as much an exercise of professional skill and judgment as any other part of the doctor's comprehensive duty of care to the individual patient and expert medical evidence on this matter should be treated in just the same way" (our emphasis).

evaluations (anamnesis). Consent (or merely “assent”) could be seen as implying only a right not to be forced to accept a treatment or procedure that patients (subjectively) do not desire. Our claim is that this kind of respect only partially takes patients as persons seriously, for patients’ personhood in this traditional view is seen as something somewhat “exterior” in medical practice. In PCH, personhood is seen as not exterior but rather at the center of medical practice.

In saying that, we are not arguing that a right to assent is not a legitimate right at all. A right to assent in clinical care is, of course, also an essential part of what constitutes respect for persons. Both a right to assent and the broader right to consent are indeed rights in a full sense. In order to understand this, let us see what we mean by a right in a proper and very strict sense.

A claim-right is a (legally or morally) justified claim [18]. Claims are not mere requests. Claims are *demand*s, that is expressions of someone’s will directed mandatorily to someone else, conveyed by imperative speech acts, made either personally or by means of a surrogate.³ Claim-rights, in turn, are legal or moral statements. They express that someone (the claimant) is in a justified (morally) or legitimate (legal) position to claim something from someone else.⁴ Justified claims directed to specified persons represent what is referred to by legal theorists as *rights in personam*, and justified claims made against a large indefinite class of people are called *in rem* (at least following Wesley Newcomb Hohfeld’s canonical approach) [23]. Rights *in rem* (“multital rights”, in Hohfeld’s parlance) are claims “against the world at large”; rights *in personam* (“paucital rights” for Hohfeld) are claims “against certain persons” ([24] p. 24). A contract right is *paucital* because it can be enforced only

against the parties specified by the contract. A property right is *multital* because it is directed to anyone at large. A property right, for example, is multital also because it includes not only the right the landowner has against the intrusion of other people from the land, as it includes the power to authorize them to enter or use the land (under specified conditions *in personam*). Patients’ rights are *multital* rights. However, the difference between a patient’s right, as a right of a patient understood as a person, depends on a distinction of what is implied by the content of the correlated duty.

Assuming the correlativity thesis [18], all claim-rights are correlated to duties. Seeing rights as correlative to duties implies seeing the duty-bearers as bound to their respective right-holders. In this sense, we respect the other person when we fulfil our duties to them; so, by an act of respect, we discharge ourselves from a subjective burden. Respect, hence, is a kind of liberation.

One consequence of the correlativity thesis is that claim-rights represent legal or moral normative bounds between two individuals (the claimant, or the obligee and the obligor). Claim-rights, as Judith Thomson [25] says, have two “hats”: an individuated right-holder, and an individuated duty-bearer. Stephen Darwall, in a similar guise, calls claim-rights “bipolar” [26].⁵ Claim-rights, hence, are not impersonal or agent-neutral requirements for action; they are, as Darwall stresses, agent-relative requirements [28]. A requirement for action is said to be agent-neutral if it is indifferent to its beneficiary that any other person accomplish the action. Beneficence is said to be agent-neutral in this sense - it is indifferent which person actually does the good deed for the benefited individual. Claims are not like that, since they are directed to specified individuals.

Following these semantics, it is also clear that we can respect different rights under the same general broad name. Language usage can disguise essential differences. This is the case of “consent”. A right to consent can be seen as a mere claim-right to assent to a prescription (even preceded by appropriate information). But a right to consent can also be seen as the claim-right to truly participate in the decision-process. Hence, respecting persons in healthcare can be viewed differently, depending on the meaning of the claim at stake.

It is clear now why respecting a claim to assent is not what is required by the tenet of placing persons at the center of healthcare; for the claim to be respected in a PCH

3 Claims are imperative utterances directed to persons endowed with the capability to take them, when justified or legitimate, as giving agent-relative reasons to submit their will to that of the claimant. In this rough sense, claims are types of “commands”. Claims and commands are illocutionary speech-acts [19,20]. Nevertheless, there is a striking difference between these two kinds of performative speech-acts. A command is an authoritative directive made from someone endowed with (legal) authority over others; yet a claim is not an order or an instruction of some authority, but a demand for something thought to be rightful or due. Commands are hence issued from a “superior” to an “inferior”; claims, otherwise, presuppose *equality* (even an “inferior” can be in a position to claim something from the “superior” - consider a soldier who demands of his sergeant not to be treated in a degrading way; when claiming that, he obviously is not issuing any order to the sergeant). Another salient difference between commands and claims is that claims are *always* made for the sake of the claimant; in the legal sphere, claims are made for the sake of the person legally or morally warranted as its proper right-holder. Commands, on the contrary, can be made in a third-party interest [21].

4 Claims are illocutionary speech-acts. Claim-rights, by turn, are legal (or moral) statements; H.L.A. Hart classified legal rights as primary legal rules [22]. In this interpretation, a claim is justified or warranted by a claim-right. Right-holders, hence, are individuals in a rightful or legitimate position to claim something (and act or maintain the state of affairs) against other persons.

5 Darwall tells us about two kinds of “obligations”: *bipolar* and *period*. He says that “[t]he existence of an obligee is part of the concept of a bipolar obligation, though it isn’t of the moral obligation period” ([26] p.334). Claims (and claim-rights) imply bipolar obligations and being such that the obligor is said to have a subjective normative reason to do something. In the case of obligations period, the agent is also said to be obliged to do something, and that it is wrong to not do it. But this is “insufficient, however, for a bipolar (...) obligation. For a bipolar obligation to exist, some action must *wrong an obligee*, it must constitute a *wronging* and not just a *wrong period*” ([26] p.334). Maybe it is inappropriate to call those “obligations period” obligations as such [27] and are instead things an agent ought to do for some impartial or neutral *moral* reasons.

approach includes the claim to participate in medical decisions, in order that persons' own preferences be considered in the decision-making processes about appropriate procedures and treatments. Perhaps what is demanded is that medical decisions should be taken by a cooperative process between two agents: the ill and the healer.⁶ If we take this account seriously, one conclusion is that persons in healthcare can demand (as a right) that they should be considered not only as *patients*, but also as *agents*, even considering all well-known restrictions and limitations (maybe this request cannot be fully or extensively demanded in all circumstances and domains, for example in emergencies) [17].

Now, this is the problem we will deal with here. If what PCH rightly requires is a cooperative process between healer and patients, how would this be feasible with patients whose selves are not mature, or with patients in a coma, or patients with severe disorders of consciousness, particularly if we regard them not only as "patients" but full agents, that is persons? After all, individuals with mature selves are only a part (in fact a small part) of the whole universe of patients. In placing persons at the center of care we certainly do not mean that only rational people should be cared for and respected as persons; and we are also not arguing for different stances to care for different kinds of people - a care that is appropriate for those people that act as persons (that is, for those people endowed with rational autonomous selves), and a different kind of care for those who are not yet persons (newborns, infants, and children), immature people, and the mentally handicapped ("patients" but not "persons")? So, if we are not simply using "person" in order to distinguish kinds of people,⁷ nor as a mere synonym for "patient" (or a noun that simply marks the condition of a person susceptible to healthcare),

6 Take Manson & O'Neill's distinction between two models of communication, the "conduit/container model" and the "agency model" [29]. If consent in clinical practice were only a matter of assent, then there would not be any problem in the way of thinking and talking about information and communication backed in the conduit/container model. But, as Manson & O'Neill argued, informed consent in clinical practice depends on communicative transactions between *agents*, and not only between an agent (the doctor) and a *patient*. We agree with them that we need a "framework for a transactional model of informed consent, which emphasises what is said and what is done both by those who request consent, and by those who respond by giving or refusing their consent" ([29] p.69).

7 Harry Frankfurt, for instance, uses the word "person" to make reference to a different kind of people he distinguishes from mere "wantons" [30,31]. Persons are individuals that have second-order volitions; wantons have only first-order volitions. Frankfurt's approach to the problem of free will makes profitable use of this ontological distinction. We think Frankfurt's use of "person" is perfectly legitimate and is in fact very insightful. It seems nevertheless obvious that this is not the sense employed by the advocates of a person-centered approach in healthcare. Frankfurtian persons are not the kind of individuals we recognize as being at the center of healthcare, even though they are the persons that can conclude after reflection that it is desirable or preferable to want their practice to be centered on persons and want that this second-order preference to guide their practice in general.

what we need is another conceptual approach to personhood that can be applied to any sort of human patient in need of care.

Defining "person": do we need a broader and more inclusive meaning?

Logicians usually present definitions as conjunctive statements of necessary and sufficient clauses. Albeit useful, a perverse consequence of following this recipe without much scrutiny is becoming trapped by the language game of "all or nothing". Definitions aim for clarity; nevertheless, sometimes reality departs from clarity. Some concepts seem to have fuzzy boundaries. This seems to be the case with the concept of "person." "Person" is taken as an example of a vague notion ([32], p. 54). Nevertheless, if "person" is conceptually vague in an epistemic sense, its meaningfulness depends on its being sufficiently informative about the reality it purports to characterize.⁸

Are the well-known philosophical concepts of "personhood" empirically informative? Do they correspond with what we mean when we employ the term "persons" in our common everyday usage? Do they also capture what we mean by "person" in the context of healthcare? As a starting point, let us take Kant's view of "person" (given Kant's influence on philosophy and bioethics in addition):

"A person is a subject whose actions can be imputed to him. Moral personality [moralische Persönlichkeit] is therefore nothing other than the freedom of a rational being under moral laws (whereas psychological personality is merely the ability to be conscious of one's identity in different conditions of one's existence). From this it follows that a person is subject to no other laws than those he gives to himself (either alone or at least along with others)." ([33, p.50], §223)

Let us call Kant's definition above the Kantian Literal View of Personhood (KLV). If we take KLV as a definition of what it means to be a person, then one could not be a person if one is incapable of acting intentionally. Such people do not have "moral personality". For Kant, moral personality implies a distinct psychological personality. Imputability requires the consciousness of one's identity over time. This seems to be a necessary

8 There is no consensus on whether vagueness is merely an epistemic notion or if it exists in the things themselves. Is "baldness" vague only *de dicto* or is it also vague *de re*? Is our difficulty in classifying some individuals as "persons" part of the things themselves or is it only an epistemic problem? In any case, if the people themselves are entities with unclear boundaries, or if the concept of personality is what is vague, the main epistemological problem is whether or not our preferred philosophical concepts of personality fit into our common conceptual practices. Concepts are appropriate if they, at least in most cases, fit into our common use of the word.

condition; hence, if one permanently ceases to be conscious of one's own identity, then one ceases to be a person. Of course, moral personhood, Kant says, is the "freedom of a rational being under moral laws"; this is a "transcendental" quality, not an empirical attribute such as "psychological personhood", the Lockean conscious ability of being conscious of one's identity from the stretch of the time of one's own existence. But if we sum up those claims, what we have is that persons are individuals endowed with psychological personhood (a necessary condition), that are rationally capable of giving laws to themselves (a sufficient condition), and whose actions can be imputed to them. That is, they are individuals endowed with that Kantian transcendental quality and who display empirically the Lockean psychological ability of being conscious of being the same rational entity over time. They are, using a Sellarsian expression, individuals who can play the game of giving and following reasons [34]. If one of these ceases to be fully capable of playing this mature game, or if they are simply incapable of doing so at all, the consequence is that they are not a person. In Kantian jargon, they are a "thing" (*res corporalis*).⁹

It seems to us plain that these literal interpretations of the Kantian view on what it means to be a person are not even close to what we call "persons" in bioethics and healthcare contexts. In healthcare, even human individuals that do not fully display rational abilities (infants and children, for instance) are also considered as persons and are not, surely, to be considered "things". The same applies to individuals who have lost their rational capabilities. It seems, hence, that a sufficient clause for being a "person" in the healthcare domain is to be an individual of the human species that can benefit in a defined way from medicine and healthcare, so that the ability to play the game of giving reasons is not a necessary clause. In this sense, being a *patient* is a sufficient condition for being a person in healthcare and patients can sometimes be individuals who lack the rational abilities that permit them to reason and behave as autonomous beings.

KLV, therefore, does not fit with our common use of "person" in healthcare. Accordingly, we will put it aside for the moment, as the fact is that every human being that can be an object of care (a patient) is a person. It could be contended that even human beings not yet born are persons in this sense, for it is arguable that Fetal Medicine, for example, aims not only at the wellbeing of pregnant women, but also that of the fetus. Thus, should we say that even human fetuses are persons, since they can also benefit from medical care? And what about human embryos?

What, then, really counts as a person? Some readers may find it difficult to consider an anencephalic baby a person, but even stillborn babies can be recognized by their parents as being endowed with some form of "personality", as evidenced by the custom of giving them names (and registering them) after delivery. The fact that a baby is

stillborn or is born alive but dies following a serious brain defect such as anencephaly, for example, does not seem to give reasons to parents for not giving the baby a name if it is their choice to do so. So, there is a sense that not only the actual capability to reason, but even the potentiality to develop it further, are not necessary conditions for recognizing someone as a person, even more so if we consider the "forensic" sense of being a person (as stated by Locke in the epigraph above).

Let us assume that the boundaries of personhood are fuzzy and vague (and maybe *de re*, and not only *de dicto*). In this case, it is possible that although we cannot establish precisely when an unborn person becomes a person and when they cease to exist, it is incontrovertible that all the human individuals we care for in our health practices are not only patients but also persons in a relevant sense. It seems, then, that even if some ill human beings lack some attributes that are necessary for the full exercise or development of personhood, this does not preclude us from recognizing them as persons "socially".

However, this should not lead us to conclude that it is enough to be human to be a person. Persons seem to be individuals who are deeply attached to social bonds. One could argue, nevertheless, that there could be persons who are unattached to any human social bonds. It is rather undisputable that even a Robinson Crusoe is still a person. To develop our reasoning we posit an alternative tale of Tarzan. In Edgar Rice Burroughs's fictional story, "Tarzan" is the name given to a child born in the jungle and nurtured by a tribe of apes after the death of his parents when still a baby. When he is found, he comes to be recognized as the heir of his parents, who are, in fact, English nobility. A name is given to him and his story as a feral man is incorporated as part of the story life of John Clayton, the Viscount of Greystoke. Consider, now, a different scenario. Suppose that this child has lived all his life with this tribe of apes and suppose that nobody knew or came to know about his birth or existence. Of course, this feral man is actually a human being, but is he also a person? It may be plausible that in this case it would be inappropriate to say that this feral man is also (and necessarily) a person (see Figure 1). So, it seems then that being a person depends upon social recognition. This explains why it can be argued that the feral man cannot be considered as a person, but why the child born with anencephalic conditions usually is.

Let us now consider again Burroughs's story. What kind of "life" does John Clayton have before he is found in the jungle? In one sense, Clayton's life is that of a feral man, not a person. But there is also a sense in which that life is the kind that Clayton, *a person*, has before being found by his relatives and countrymen. Of course, he has a life before being found, but it cannot be possible that in that time he could contemplate himself as a person (see Figure 2). He has nothing to compare himself to and is part of no society that could grant him this status. When Tarzan is found, though, this status begins to be built. First, by the people who find him - they can, at this point, trace Tarzan's life story back to childhood, recognizing who he is and who he was, somewhere in time. After that, a light shines upon Tarzan's life story and this timeline becomes that of a person in its whole. So, something actually

9 Let us admit that maybe KLV is a too literal interpretation of Kant's own views. It is arguable that this is not what Kant actually meant. If we interpret personhood diachronically (see below about our own view) and accept that surrogates can represent persons, even human beings without a psychological personhood could be regarded as persons.

happens with Tarzan himself after he learns language skills and develops cognition of his “psychological personality”. Once he gains it, he comes to see himself as a person - his whole life, even the part in which he has no means of knowing what kind of being he actually is, is now part of his own story (see Figure 3). Now he is capable of rebuilding his story in a contemplative way.

Figure 1 *Tarzan-never-found* lifetime

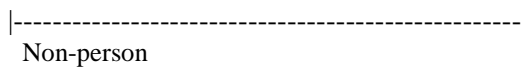


Figure 2 Tarzan's lifetime soon after he is found

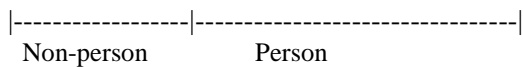
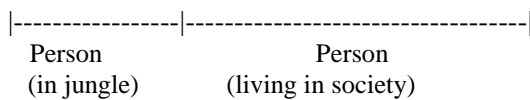


Figure 3 Tarzan's whole story



Persons as primary substances

We return now to KLV, as certainly it has some aspects that are essential to our common conception of what it means to be a person in healthcare. It is not without reason that Kant's view has achieved substantial prominence in considerations of personhood. We believe that one reason why the Kantian view on personhood is so attractive is that they put autonomy at the center of our idea of personhood. Praising personal autonomy in healthcare has a semantical connection with respecting patients. When caregivers fully respect their patients, they are, so it seems, not only caring about them, that is taking them as individuals with healthcare needs and answering to them, but are treating them as persons [35, p.77].¹⁰ The problem is that this image of human beings as self-directed creatures - so attractive as it seems to be to members of our liberal societies, as Marina Oshana remarks, as it captures an ideal of personal freedom and self-definition that we valorize - nevertheless reserves the term “autonomous agent” for

entities that bear little resemblance to actual human beings, that is “to the actual process of making the [human] self” [36, p.145]. This view is especially problematic in healthcare as, if patients are persons, KLV does not capture the sense of personhood that is required by a PCH approach, since many patients are not Kantian persons (some “still” or “anymore”, but others “never”). So, if we do not want to abandon PHC, we should put aside KLV.¹¹

Consider another approach. According to Peter Strawson, if we think of the world as containing particular things, among these are certainly persons [37]. Strawson claims that the concept of a person is “logically prior to that of an individual consciousness”, so it should not be analyzed as equivalent to an animated body or an embodied anima [37, p.103]. The concept of individual consciousness is, following Strawson, a secondary existence that presupposes the primary existence of persons. Persons, hence, are not transcendental entities; they are empirical entities and substantially primary relative to any other qualities (or secondary substances) we can predicate to them.

On the issue of personhood, Strawson's view is similar to those of philosophers such as Aristotle and Thomas Reid, for whom persons are individuated primary substances that occupy a place in the observable world. Although there are criticisms of Strawson's theory, his view has proved influential. Paul Ricouer is one who recognizes Strawson's influence, saying that “the person is, to begin with, one of the things that we distinguish by means of identifying reference” [38, p.27]. In this act of identifying reference, we are able to classify objects of different kinds or sorts. Persons are one kind of individual. Against Descartes, Strawson claims that one is not able to identify oneself as an individual of some kind without being able to discern whether other individuals are of the same type or not [37, p. 104]. But which predicates do these individuals we identify as persons share? Strawson suggests two classes: predicates ascribing corporeal characteristics (M-predicates, the “M” from “material bodies”), and predicates ascribing “all the other predicates we apply to persons” (the P-predicates).¹² So a person is, in Strawson's view, “the concept of a type of entity such that both predicates ascribing states of consciousness and predicates ascribing corporeal characteristics, a physical situation, etc. are equally applicable to an individual entity of that type” [37, p.104]. This view is quite simple and seems persuasive. Nevertheless, this view is of course too simplistic for solving the problem we are dealing with. After all, what kind of P-predicates do persons share? For there are several states of consciousness we share with other animal beings we ordinarily do not classify as

10 We are in strong agreement with Darlei Dall'Agnol when he says that, traditionally, in the history of medicine and healthcare, “caring was the very purpose of medicine and respect for the patient's will was almost absent; modernity reversed that: respect for the patient's autonomy came to be, at least, as equal as - if not more important - than caring”. Arguably, Kant's philosophy contributed greatly to that historical change. Now, says Dall'Agnol, “what we need then is to reconcile care and respect into a single morality, a common and sharable one, based on *respectful care*” ([35], p.77). A respectful care account in Clinical Bioethics, as Dall'Agnol supports, is one that takes patients as *persons* seriously and puts them at the center of medicine and all healthcare practices.

11 Putting the KLV of persons aside does not imply that we should dispense with all the Kantian views on the subject. A version of the Kantian principle that states that one ought to act in such a way as to treat “humanity in oneself and in others, never as a means only, but always also as an end” fits perfectly with a PCH approach that takes persons (all persons) seriously.

12 It seems that the “P” in the expression “P-predicate” is intentionally ambiguous (is it from “person” or from “psychological attributes”?).

persons, and in healthcare we deal with individuals we classify as persons that do not share some states of consciousness that Strawson mentions. It seems obvious that the kind of person Strawson has in mind is the same kind that Kant and others have - mature human beings endowed with rational capacities of seeing themselves as an answerable self (a duty-bearer individual). Nonetheless, in his criticism of the dualist view, he states that the word "I" cannot refer to any "pure subject" of experiences (as Hume notes), but against Humean skepticism he concludes that it cannot be true that the "I" does not refer at all, since *it refers* indeed, as, says Strawson, "I am a person among others". Which others? The other whom we apply P-predicates to successfully, including myself. Which P-predicates? "P-predicates", says Strawson, are "of course very various", and "include things like 'is smiling', 'is going for a walk', as well as things like 'is in pain', 'is thinking hard', 'believes in God', and so on" [37, p.104]. We agree, but we add some other things such as "is ill", "is in a coma", or "is seriously cognitively damaged"? Or things such as "was born and named", "was nurtured by another person", or "is crying"? P-predicates certainly include what we could specifically call psychological predicates, but also other predicates: cultural, social and the like.

A better alternative: the social nature of personhood

Let us suggest a more plausible view. Strawson's approach is a good point of departure for that, but it must be refined. We need a view that fits our common-sense experience of personhood in human affairs, but especially in healthcare, and more especially in healthcare viewed from the point of view of PHC. We need an approach like Strawson's that does not see persons as either animated bodies or embodied animas, but we also need an approach that sees persons as individuals with a "human" history, with successes and accidents. We need, hence, an approach that sees persons as beings individuated in an "externalist" fashion, one that does not take the rational capacities we can develop if we are not subject to bad luck as the sole characteristic of what we mean by a person (even so, we can agree that this characteristic is in some sense "central" for our self-conception of what we mean by a person). In order to do that, let us return to one of the most problematic cases for any view that aims to take any human patient as a person in the fullest sense of the word - that of persons with SDC.

Tom Kitwood, in his approach to the study of dementia, complains about the traditional philosophical view that emphasizes rationality and individual autonomy as the essential attributes of personhood [39]. His main complaint is that personhood should be conceptualized more broadly and that relationships and solidarity should be included as constituents of what we understand by a person. This view is shared by many other scholars. Marina Oshana, for example, claims that the traditional view of personhood is a "picture that ignores the social nature of persons and discounts the importance of

interpersonal relationships" [40, p.196]. She cites Joel Feinberg's [16, p.34] thinking as support for her view. This omission of the social nature of personhood is salient in the case of persons with SDC. This is somewhat curious, since persons with SDC are clear cases in which our social bonds are vitally manifest. As Juliette Brown remarks, SDC "reminds us of the vital importance of relatedness" [41, p.1007]. "Perhaps", Brown says, "the adaptive and experiential selves described by Kitwood can unite in the minds of others and generate a new identity. In all forms of dementia, the adaptive, socially constructed self-diminishes through the disease; the second, experiential self, comes to prominence".

There is indeed a peculiar characteristic of that social nature of human personhood that is so clearly manifested in persons with SDC. All the individuals we identify as persons (the individuals identified with P-predicates) are rational but socially-dependent animals [42]. We live with each other by natural necessity, but our way of living socially is peculiarly different from the rest of the animal kingdom [3, p.310]. So, going forward, we will firstly delineate some aspects that make human societies unique and separate from any other form of communality of the animal kingdom; then, we will present our view that being a person is to be an individual endowed with a biographical story (and since this is peculiar to us, as persons, we will suggest calling the Strawsonian M and P predicates by another name, i.e. Z and B predicates). In the end, we will return to the problem of persons with SDC and the tenets of PCH.

The uniqueness of the societal form of living

"But there is one species, *Homo sapiens*, that has made cultural transmission its information superhighway, generating great ramifying families of families of families of cultural entities and transforming its members by the culturally transmitted habit of vigorously installing as much culture as possible in the young, as soon as they can absorb it. This innovation in horizontal transmission is so revolutionary that the primates that are its hosts deserve a new name. We could call them euprimates - superprimates - to use the technical term. Or we can employ the vernacular and call them *persons*. A person is a hominid with an infected brain, host to millions of cultural symbionts and the chief enablers of these are the symbiont systems known as languages." Daniel Dennett [43, p.173].

It is said by some naturalists that "sociality" is not a distinctively human trait. Non-human animals are also "social" in a sense. But persons, nevertheless, are not mere "social animals" in this pure biological sense, because interpersonal relationships are substantially different from the mutual bonds that we observe in the animal kingdom. Primatologists, notwithstanding, have shown striking similarities between human social behavior and the collective behavior of some species of apes. Frans de Waal and Sarah Brosnan have shown that Capuchin monkeys display other-regarding behaviors that seem to depend on a

sense of fairness. In one experiment, these monkeys voluntarily shared better food - pieces of apple - with a partner in a separate cell, to whom scientists only fed cucumber [44, p.147-150]. In another famous experiment, a Capuchin reacted angrily in the face of unfair treatment (receiving cucumber while the other monkey received grapes) [45]. Economists labelled this unexpected reaction “inequity aversion”. Monkeys behaved as though moved by a sense of unfairness and were capable of behaving in a way that could easily be called a demand for equal treatment. So why do we still think we are worlds apart from them? In fact, there *is* something that sets us apart from other mammals - our distinct social behavior depends on the possibility of having individuals that can take responsibility for their own behavior and also assume the responsibility for taking care of others. This special form of responsibility is qualitatively different from anything we can observe in the animal kingdom, since it depends on a form of socially guided living, as David Hume claims, with artificial virtues, including justice.¹³

Some sociologists emphasize the difference between two distinct forms of social living: communities and societies. In 1887, Ferdinand Tönnies suggested the *Gemeinschaft-Gesellschaft* dichotomy, a distinction between those small-scale, kinship and neighborhood-based social organizations and the large-scale competitive market societies. Tönnies also took human beings as an animal species, so his problem was also about what makes us socially different from the other animals. In communities, social bonds reflect a “real organic life”, in spite of the fact that in societies the relationships between individuals reflect a “purely mechanical construction” that only “exists in the minds” of the individuals [47, p.17]. Tönnies claims that animals (that is, social non-human animals) can (by necessity of their nature) live in communities (albeit not “rational” communities like humans). “Community in general”, Tönnies says, “exists among all organic beings”, but “rational ... Community [only] among human beings” [47, p.38]. Hence, the most salient difference between human social life and other animals is that it is only humans that live in societies.

But since animals also engage in political struggles, coalitions and power relations within their groups, colonies, or communities, the conclusion is that what marks human moral behavior from that of animals is the ubiquitous fact that human social behavior is normatively backed by positive norms, that is legal or legal-like norms. This explains why promises are the preferred institution studied by almost all genealogists of morality (Nietzsche is perhaps the main figure in this). Promises are legal-like conventional practices and rooted in common-law practices. Contracts seem to be special human social instruments and in turn are fully juridical. It is implausible that this capacity to make promises and contracts could evolve independently of any legal or juridical-like social practices. Moreover, promises and contracts depend on an ability to take responsibility for one’s future behavior. This obviously explains why animals cannot develop societies with legal systems, for this necessarily involves attributing

responsibility to representatives and authorities (as Tönnies recognized).

This novelty seems also to depend on more complex symbolic linguistic devices, such as human language. Several thinkers emphasize the importance of language in the separation of the human species from the natural kingdom.¹⁴ Language was (and is) certainly instrumentally important for the development of our distinct sense of justice. Communication made some natural virtues and vices apt to become artificially reinforced, for instance, the case of ingratitude. Hume famously said that ingratitude is the worst of vices, but perhaps this is only a part of the history. In fact, if someone simply does you a favor, the benefactor may be seen as deserving a good return, by reciprocity. This is primitive; animals also expect reciprocity, even without the convention of promises. What makes the convention of promises special is the fact that promises create rights. Hence, if you have promised to do something for another’s benefit then they have taken a claim-right from you; so, if before receiving a favor you in fact promise to pay for the benefit, the benefactor has taken a right from you and this strengthens your reasons to pay them. Promises are instrumental devices by means of which a new form of reciprocity developed. Through this institution, the interactions between human beings evolved into a more complex form of normativity; from animals able to follow simple and direct commands, human beings evolved into a new form of reciprocity characterized by the emergence of positive duties correlated to claim-rights. Persons (with their societal form of living), in our genealogical hypothesis, emerged within the human groupings as a consequence of this new form of cultural environment.¹⁵

This new creation would never be raised if human beings were not endowed with some complex cerebral capacities (Dennett’s “infected brain”).¹⁶ The capability to use “language games” such as promising could not be a mere consequence of the artificial emergence of language; this cultural invention has arisen given some appropriated neurological backgrounds, including the evolved capacity that Uta and Christopher Frith [49] call “mentalizing”, a capability that others call “theory of mind” (ToM) or “mindreading”, or, in broad terms, the mental ability to attribute and explain others’ behavior by their beliefs, desires, thoughts and feelings, so taking them as having different mental states to one’s own [50]. It is plausible that human beings, endowed with language capabilities and the capacity to mentalize, became able to develop a mature way of assuming an empathetic perspective of others. Stephen Darwall calls this a second-person standpoint [28]; contracts, rights and duties, and surrogate

14 This claim could seem as quite trivial, but since animals are also capable of communication, it is a statement that deserves warranted explanations. The school of thought that is widely known to have supported this idea is the sociologist school that follows Georg Herbert Mead “social behaviorism” [48], or as is nowadays called, the school of “symbolic interactionism”. Thanks to Carlos Gadea by this remark to us.

15 In a rather different version, this is Daniel Dennett’s genealogical version of humanity in *Freedom Evolves* [43].

16 See also Mead [48].

13 For an extended approach on this topic see Azevedo [46].

representations depend on the possibility of the existence of those individuals that can fully display this ability of assuming second-personal attitudes.

Nevertheless, this should not lead us to conclude that only these individuals are persons, given that only they can display those mature cognitive abilities. It may be true that humanity would never have developed its present form of living socially unless some of its members had developed this distinct kind of cognitive ability. This new form of social living depends, hence, on the interactive behavior of those imaginative and empathetic beings capable of putting themselves into another's shoes. In spite of that, all the beings that live with each other in societies are persons and not only those that bear the burdens of care and responsibility. A "person" is, then, the name of this peculiar type of social being, whose life exhibits different patterns of mutual dependence during its lifetime, on the basis of which bonds of solidarity and mutual responsibility are emulated, in favor of the most vulnerable or worse-off; requests and claims are therefore made from those in their periods or moments of vulnerability and dependence on others who are more rationally autonomous. It is in this lifetime - which begins with birth (and perhaps even before it, in gestation within a woman's body) and develops in stages of least to greatest dependence on each other, a lifetime subject to misfortunes and illnesses, of temporary or permanent losses and disabilities, and that culminates with old age and death, or even earlier, with the premature interruption of life due to some unforeseen but unfortunate incident - that each individual gains and develops their unique life history, that is to say their personal and unique biography.

Zoographical and biographical stories of human beings

"The self is something which has a development; it is not initially there, at birth, but arises in the process of social experience and activity, that is, develops in the given individual as a result of his relations to that process as a whole and to other individuals within that process. (...) We can [hence] distinguish very definitely between the self and the body. [For t]he body can be there and can operate in a very intelligent fashion without there being a self involved in the experience." G. H. Mead [48, p.135].

What we need, then, is an approach by means of which we can see personhood as a socially-dependent phenomenon. Departing from KLV, we consider Strawson's approach. Strawson describes persons as individuals we identify primitively by means of attributing to them two different kinds of predicates: M-predicates (that describe them as material entities) and P-predicates (those in which only this kind of entity, namely persons, partake). Nevertheless, some insufficiencies in this view can be detected. One of these is that the scope of P-predicates seems to be vague and unable to include all the individuals we recognize as persons (it does not seem to include newborns, infants, the mentally handicapped, and people with SDC, since they do not have the states of consciousness mentioned by

Strawson, or have them but in different or immature forms). It is quite trivial, anyway, that persons are entities that exhibit P-predicates. Let us therefore try to offer an alternative view.

According to Giorgio Agamben [51], the Greeks had two semantically and morphologically distinct terms to express what we mean by "life": *zoe*, expressing the bare fact of living common to all living beings (humans, animals, and even gods), and *bios*, referencing the particular but different human ways of living. Agamben begins his book with this remark about the Greeks in order to introduce his approach to what he calls, following Foucault, a "biopolitical model of power". What matters for us is this distinction between two different stories that can be told about an individual human being - let us call them the *zoetical* (or the *zoographical*) and the *biographical* stories. This distinction can be present in the example Agamben also mentions - the case of Karen Quinlan:

"We enter the hospital room where the body of Karen Quinlan or the overcomatose person is lying, or where the neomort is waiting for his organs to be transplanted. Here, biological life - which the machines are keeping functional by artificial respiration, pumping blood into the arteries, and regulating the blood temperature - has been entirely separated from the form of life that bore the name Karen Quinlan: here life becomes (or at least seems to become) pure *zoe*. (...) Karen Quinlan's body is (...) only anatomy in motion, a set of functions whose purpose is no longer the life of an organism. Her life is maintained only by means of life-support technology and by virtue of a legal decision. It is no longer life, but rather death in motion. And yet since life and death are now merely biopolitical concepts, (...) Karen Quinlan's body - which wavers between life and death according to the progress of medicine and the changes in legal decisions - is a legal being as much as it is a biological being. A law that seeks to decide on life is embodied in a life that coincides with death" [51, p.186].

For someone who witnesses cases like those of Karen Quinlan up close, as a doctor or nurse concerned with giving attention and respectful care to the people in question, there is something wrong in Agamben's grasp of the case. For the difficulty faced by the parents' decision to withdraw the ventilator is that it is not easy for them to separate the bare life of Karen, as zoetically described by her physicians, from the life of the person of their daughter. And what Karen's story in fact has shown us is that they indeed did not do that. The parents' decisions during the years that Karen lived in Persistent Vegetative State (a name that describes her condition zoetically) could be thought by many to be contradictory; they approved withdrawing her from the ventilator, but they did not approve withdrawing her from food and water and this kept her alive in that unfortunate condition for almost ten years. Was Karen alive in a purely zoetical way? It is arguable that Karen indeed lived for all this time, not only her *bare* body. That long part of her life was indeed part of her biography (so much so that we are telling and retelling this story in bioethical circles), even though she could not (could we say fortunately?) have experienced or noticed that at all, given her unconscious condition. Maybe the

wrongness of taking care of her so long in that unfortunate condition is justly the mistake of giving her only a zoetical life, since she could not have any way to live her own life by herself. Given her condition, she could not be the master of her own biography anymore.

Let us make use of this binomial description of a human life in order to introduce the claim that to be a person is to have one's entire life described not only in a zoetical but in a biographical way. Strawson, as we saw above, claimed that persons are individuated by us by means of two different kinds of predicates: M-predicates and P-predicates. Now we can introduce two distinct kinds of predicates by means of which we can identify a singular person: Z-predicates and B-predicates. The first are predicates by means of which a singular individual can be described as having a biological life - a life that is characteristic of that kind of living being as a specimen of some kind of animal, but also a life that can be described by any of those sciences that try to understand the physiology as well as the pathologies typical of those kinds of living beings. The second are in fact more substantial, for they are the predicates by means of which we compound and tell the life story of some individual as a person that lives *with us* as well as our own.¹⁷

In telling our own life story, we vindicate an individual and distinct biography. Combining this particular biography (of individuals essentially identified by B-predicates) with relevant particular descriptions of ourselves (by means of Z-predicates, that can be "objectively" applied to us), we reach what could be called a "complete description of ourselves". Peter Hacker suggests something along these lines:

"Each human being traces a unique autobiographical route through the world, and the combination of genetic endowment, variable responsiveness to individual experience, and memory gives each human being a personality - with a unique combination of character traits, behavioural tendencies, an awareness of a unique past (pertaining both to inner and outer life) and of projects for the future" [3, p.311].

Nevertheless, our "unique autobiographical route" is not in fact only "autobiographical", for there cannot be any biographical route of ourselves that we could give to us "autonomously". Our personality is biographical indeed, but any autobiography that we can tell about ourselves is only a dependent part of this whole. In spite of that, several thinkers claim, rightly, that only persons can raise questions about who they are. Nevertheless, as DeGrazia

says, even though "only a person will raise the characterization question with regard to herself, her inner story can include episodes that took place or will take place at times when the protagonist is not a person." Statements such as, "I was born at such-and-such hospital," and requests such as, "If I permanently lose the ability to remember my life history, don't keep me on life support" are typical of persons. DeGrazia concludes that, "It doesn't matter that one can't remember being born and might have trouble anticipating a state of severe dementia", but that they *could* know or think about that "on the basis of others' testimony and everyday biological and medical knowledge that one was born and might someday become demented" ([53] p.83).

So even our autobiographies are not purely *self-made*. This is true, since we do not autonomously create the rules that settle the paths by means of which our own stories are made, and we cannot pave all the ways we actually live in our life [54]. As Feinberg says, we live our lives under practices, defined by well-understood conventions, settled long before we were born [16].¹⁸

The biography of persons living with dementia and their multiple selves: who should we respect?

A medical treatment is said to be palliative if there is no curative aim attainable by medical means. Nevertheless, in this broad sense, there are several treatments that are not curative, but that can offer to the patient almost the same expectancy of living without misfortunes as a patient without the disease. In one sense of what physicians mean by the term "health", this implies that even the incurable patient under treatment and the non-diseased individual can live under an almost similar state of health [55]. "Palliative", however, has a narrower concept, applied to the domain of what is called "palliative medicine" [56, p.11]. In this narrow sense, a treatment is palliative if its aim is almost only to protect wellbeing from pain and suffering and to alleviate as much as possible all the circumstances that could worsen a patient's wellbeing. In this narrower sense, palliative treatments do not aim at health promotion or offer a better likelihood of survival, but only offer a better likelihood of surviving with at least the best attainable state of wellbeing in spite of the course of a progressive and highly lethal disease.¹⁹

17 Wilfrid Sellars tells us about the two images we nowadays make of ourselves, the *scientific* and the *manifest* [52]. There is an obvious parallel here - the scientific image we make of ourselves as a human collective is to the zoographic story we make of each of us, just as the manifest image we have of ourselves as human beings is for the biographical story we can tell about our own life (*bios*). It is indeed a part of our present condition that our manifest image is more complex and scientifically informed than ever. This seems to be especially salient in the healthcare domain, in which the cultural environment involves what we could call the "scientification" of personhood.

18 Feinberg quotes Gerald Dworkin, who remarked that, "It makes no more sense to suppose we invent the moral law for ourselves than to suppose that we invent the language we speak for ourselves" [16, p.38].

19 Ahmedzai *et al.* propose the following definition for palliative care: "Palliative care is the person-centred attention to symptoms, psychological, social and existential distress in patients with limited prognosis, in order to optimize the quality of life of patients and their families or close friends" [57].

Consider the case of dementia [39,58]. How should these palliative notions be applied to individuals with dementia? Individuals with a diagnosis of dementia are unhealthy because they live with a mental disease that reduces their wellbeing and autonomy, shortening their lives to expectancies lower than persons without this condition. They are also unhealthy because we cannot offer treatments that could put them at the same likelihood of disease, death, or disability of individuals at the same age but without this malady. Nevertheless, dementia is not necessarily lethal and is not progressively or terminally lethal (as are, for example, typically terminal diseases such as cancer). The life expectancy of some people with dementia is indeed not very different from people without dementia. Morbidity (and its associated suffering) is arguably the main problem. Nonetheless, in the final phases of Alzheimer's disease, for example, some people do not suffer (psychologically) more than people without dementia. Actually, sometimes the inverse is true. A person living with dementia who does not suffer from serious comorbidities is sometimes less vulnerable to mental suffering than an elderly person without dementia who nevertheless suffers serious and painful comorbidities. So, dementia seems to present a paradox, as sometimes it both is and is not a condition which inflicts suffering.

So, what is the problem, so to speak, with dementia? If one looks at patients with dementia trying to grasp their misfortunes only in terms of pain and suffering, one could perhaps conclude that it is preferable to live under the conditions of SDC than to live consciously with an incurable illness with persistent and unbearable bodily and mental suffering. Perhaps one could even think that an elderly person living with dementia is happier than one without this condition. We can only grasp the problem of dementia if we see the misfortune of those persons by assuming a second-personal stance. We must put ourselves into their shoes and think about what they could think about regarding their own condition. But who are "they"? If we think about them only as episodic individuals and not as diachronic persons,²⁰ that is, if we do not think about what those persons would think about their own condition, but only about what those *patients* feel and suffer now, we would never understand why living with dementia can be a misfortune for someone else. Nevertheless, the second-personal empathetic stance is not the stance by means of which we can feel the uneasiness of living as a person with dementia. By this sympathetic stance (in fact a third-personal stance) we can of course be concerned with the actual suffering of those individuals, but by means of which it is also possible to conclude that sometimes it is not so painful and distressing to live without being conscious of the way we are actually living. The empathetic stance otherwise consists in putting ourselves into another personality (so not only the present, but the whole character). It is by assuming this empathetic stance that we can understand others' claims and then understand which are or could be their demands on us. This is what makes us capable of assuming a position of respect, and so care for those patients in healthcare respectfully.

One philosophical problem faced by the care of people living with dementia is that of our future selves - who should we respect: the past (non-demented) or present (demented) self? (see the debate between Rebecca Dresser and Dena Davis on the problem of preemptive suicide choices [59,60]. Dresser's criticism of the view that we should prioritize past decisions is allegedly anchored in Derek Parfit's "Complex View" of personhood. Dresser claims that the past non-demented self and the present demented self cannot be the *same* self, and if this is true this "suggests that a legal standard based on respect for incompetent patients would exclude the notion that a past person's statements and behavior should control her future treatment and that other parties should be obliged to effectuate the formerly expressed preferences" [59, p.381].

Dresser's view seems to be focused on granting patient's benefits: "Why should a patient who is now a different person be burdened by a treatment decision consistent with the former person's preferences?" True, if our focus in healthcare is only in the *patient's* best interest, conclusions about what matters *now* are reached by what we call, following Darwall, a third-person description of the individual's (that is, the patient's) best interest. Since, following the Complex View, the same patient can at different times be different "persons", our object of respect cannot be an individual that does not exist anymore, but the actual suffering individual. In fact, the idea that one is a different person at different times is something we can attain just by assuming a third-personal point of view respecting the present interests of the individual we are sympathizing with now.

But it is an essential characteristic of the behavior of caregivers regarding persons at the center of healthcare that not only taking care of them is what matters, but we must also *respect* them. In the case of persons with disorders of consciousness, this means that caretakers should empathetically interpret what their interests and claims could be and, since their biographical story is connected with the persons with whom they live or lived, in order to understand what they would prefer, one must interpret their interests as consistent with their life stories.

A respectful friend or relative would be one that puts themselves into the patient's shoes. In order to respect a demented person, it is important to take this individual as being endowed with a coherent story about their own previous recognized self. Davis's account of the problem of advanced directives aims to be respectful to this biographical being - we should have the right not to authorize anyone in the future to take our "future self" (what Dresser calls an "alien self") as the basis for making decisions on our behalf. The same account that supports the respect for our advanced directives coheres with an account that supports the view that, in circumstances in which we cannot know with certainty what a person would approve, what we should do is take decisions that fit the best way with what we know about their previous desires, preferences, and values. In caring about demented persons individuals with SDC, decisions about mere palliative care

²⁰ This seems to be the mistake of Galen Strawson when he criticizes what he calls the "Narrativity Thesis" [61].

versus treatments of acute diseases that threaten life should be taken by assuming this point of view.²¹

Conclusion

As we argued, in order to be coherent, PCH must consider individuals with SDC as persons and this requires an appropriate revised concept of personhood. Paul Higgs and Chris Gilleard object to this: “People with dementia are and should be objects of moral concern, as indeed should all human beings whatever their disabilities.” Nevertheless, “we [should] also recognize that many people with dementia lack some of the capabilities deemed to constitute metaphysical personhood such as self-awareness, reflexivity, second-order volition and narrative unity and that such deficits increase with time” [58, p.779]. Surely, if people with dementia are not persons anymore, they can still be patients; but in this case, what we should recommend is only PtCH as an alternative to PCH. Nevertheless, within the framework of PCH, all kinds of persons matter. Persons should be viewed not as rational self-conscious beings, but as biographical social beings (persons, hence, cannot be described in a mere zoographical way). In order to understand their patients as persons, caregivers should adopt not only a third-personal stance toward them (the stance of persons that take care of them), but also a second-personal attitude (that is, they should assume the standpoint by means of which one is able to respect the other as another person, as a distinct individual with a life story of their own, endowed as such with personal interests, values, and claims).

Acknowledgements and Conflicts of Interest

This paper reproduces Chapter 28 [a] of a forthcoming volume which is being serialised in the *Journal* in advance of the publication of the book itself in late 2020. For details see [b]. [a] Andrade, B. & Azevedo, M. (2020). Personhood and Disorders of Consciousness: Finding Room in Person-Centered Healthcare. In: Person Centered

²¹ The same applies to advanced directives in circumstances in which the person can previously decide not to be let alive, authorizing her active euthanasia. Nevertheless, in the absence of an advanced directive, decisions of “putting others down” taken by others may always have as their grounds the person’s biography. We agree with Dame Warnock that this also applies to demented persons, considering the burdens of caring for them to the relatives and even to society (see [62]). But, in this case, the decision is of course burdensome for the relatives and friends still alive, people, as we argued above, that are also part of the life story of those that they loved so much. Thus, in the absence of a formal or even “informal” advanced directive, respecting people is a hard and risky decision, and we should not therefore take as a wrong preference (much less as contrary to duty) a decision to continue to care for the demented person, assuming that what they have in mind is to respect her by supporting her living biography.

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