Chapter 10

Truncated Autonomy: Neocortical Selves, Reverse Reductionism and End-of-Life Care

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Additional information is available at the end of the chapter

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Abstract

In professional guidelines for palliative sedation in end-of life care, a particular notion of conscious life experience is associated with specific cognitivist notion of frontal lobe autonomy. Drawing on Turner and Fauconnier's work in cognitive linguistics I argue in this chapter that even our most central notions like human subjectivity and autonomy are conceptual blends. This chapter explores the origins and emergence of these concepts and their entailments. It digs deep into the conceptual blending of the ontogenetic development of the individual with the phylogenetic history of life. This hyper-blend of the flesh is contrasted with the hyper-blend of an irreal, non-material deep, inner space that is co-extensive with consciousness and with the rational, operative agent constituting the human subject. The last part of the chapter explores the frictions and problematic entailments of these different hyper-blends for end-of-life care practices concerning brain death, persistent vegetative state and palliative sedation. Despite respect for a patient's autonomy being first among the principles of medical ethics, cognitivist criteria used in the assessment of a patientâ€™s decision-making competence reduce and constrain (truncate) the patient's autonomy in a variety of ways in one of the situations in life where it should matter most, in dying.

Keywords: cognitivist neocortical autonomy, conceptual blending, end-of-life care

1. Introduction

In this chapter, I will develop the analysis of a problematic that cropped up in my previous work on the role of palliative sedation in end-of-life care [1, 2]. Namely, the ways in which professional guidelines constrain the autonomy of patients in one of the situations where it matters most, that is in the process of dying. End-of-life care is an important object of governance. In the

governance of end-of-life care, there are two 'objects of concern'. One is to protect the autonomy and integrity of the dying patient. The other is to maintain public trust in the institution of modern medicine and professional health care. The two are related of course. To maintain public trust in professional health care, constraints are imposed on what assistance-in-dying you can ask for, what will be offered to you or granted when you ask for it. Respect for the patient's autonomy ranks highest among the principles of medical ethics [3]. Yet, when it comes to dying, the patient's right to self-determination is constrained by professional judgment and the health-care professional's right to conscience. A fine line runs between allowing to die and hastening the patient's death. The boundary between the two is diligently monitored and protected. It is a borderland between the prevention and prosecution of illegal, criminal killing and compassionate care, which does not stop when lives can no longer be saved or prolonged. I was struck by the central importance of a notion of 'conscious life experience' in the arguments *against* a more generous availability of palliative sedation in end-of-life care and by a related operationalization of informed consent in terms of higher, neocortical functions of information processing and decision-making. The respect for *a particular form* of *neocortical autonomy* and the almost unbounded respect for the sanctity of life form an unbreakable couple, culminating in the paramount centrality of consciousness in professional guidelines for palliative sedation. It is in a sense peculiar that these principles should stand so strong in end-of-life situations when disease processes erode the capacity for integrated functioning of the brain and body and when death is near. Is it because we cannot let go when it is time?

2. Conceptual blending

To make an inroad into this problematic I will start from the pre-position that all judgments about the world, about human nature and core human values are the products of *cognitive* processes embedded in the bodies, brains and activities of individuals and the interactions among and practices of members of collectives. I will pursue an analysis that draws on recent work in cognitive linguistics. More specifically, I will draw on theories of conceptual blending or conceptual integration in meaning construction as advanced by Fauconnier [4–6] and Turner [6–8]. Conceptual blending theorists do not distinguish between the blending that occurs on the fly in everyday meaning construction through language and dialog [9] and scientific theories and philosophical models [6, 7]. All forms of scientific thought and reasoning can be subsumed under the banner of human cognition, to which perspectives, theories and concepts of embodied and distributed cognitive science may be fruitfully applied. Following Turner we could argue that every theoretical concept is a hyperblend, including the notions that interests us most, namely the notions of human agency and autonomy, *recognizing* them—in the polysemic meanings of both *knowing* and *ac*know*ledging*—as products of contingent, fundamentally biological and social *cognitive* processes.

Let me first explain conceptual blending by example. We usually think of how old we are in terms of chronological age (CA). Measured in years and months, CA measures the time elapsed since we were born. Always living in the present, CA is a point moving along the arrow of time, neither turning back on itself nor speeding up into the future. Biologists of aging have

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introduced the concept of biological age (BA) and search for ways to measure it [10]. In a normalized population, they have measured different sets of features of the body (biomarkers) and how they change with age. Based on these population data, they have construed an alternative aging scale to which an individual's values can be compared. Derived mathematical algorithms are used to calculate the age with which these individual values correlate. In forensic science, such scales based on, for example, development features of the skeleton and dentition are used to estimate the chronological age of a person or body for which that information is missing or disputed. In public health practices, this computed BA is compared (blended) with your chronological age, as a result of which you may be 28-year-old with the body of a 65-year-old. The average life expectancy that has been calculated (blended and compressed) for the men or women who were born around the same time as you were, has turned your lifespan into a limited amount of time that you have been using up at an accelerated speed; destined for a *premature death*? [11] The good news is that BA, contrary to CA, is reversible. The *modifiable risk factors* that have been entered into the etiological model explaining the discrepancy between an individual's CA and BA are within the range of the individual to do something about. By implication, personal health risk management is the individual's responsibility.

Conceptual integration can be schematically presented by the way of a minimal network that comprises at least three mental spaces: at least two input mental spaces and the blending space [8]. The input spaces selectively contribute or project structure and elements to the blended space in which these are integrated. Structure and elements that occupy analogous positions in the two input spaces, which in other words map between domains, may be compressed into identity and human scale. The individual in the CA blend is identical to the individual in the CA blend. However, there may also be vital disanalogies in the blended space: the discrepancy between CA and BA. Following its initial integration structure and elements in the blend can be elaborated, as a result of which new structure and meaning emerges that was not initially available from the input spaces: *premature* death, the idea that you might die ahead of your time, earlier than necessary. In this example, the blended space presents a trajectory of life that is counterfactual compared to the one on which you now are going: a trajectory in which it is possible for you as an individual to reach the average life expectancy of your cohort. This trajectory will remain counterfactual unless you take care and take responsibility for your own health. The point is not that the blend is a 'possible world' or a true representation of the world, but that the blend suggests alternative ways of engaging with the world, and whose primary responsibility that is.

Conceptual integration performs work on its previously entrenched products. New blends are made out of inputs that already are blends. That is, in its advance forms, conceptual integration makes *blends of blends*. Turner calls these "blends of blends"… hyper-blends. "A hyper-blend is a blend that has at least one of its input mental spaces something that is already a blend. Hyper-blends occur routinely" [8].

Models of cause-effect relationships are an important type of blend that enters into hyper-blends that are more complex. In human scale situations, we may observe events in close spatiotemporal proximity and construe one as the cause of the other. In many situations,

however, we only have records of what we take to be effects and try to learn about causes (antecedents) by making inferences from these preserved results (consequences). However, we are particular about what we allow to take the role of a cause. We usually do not allow events that occur after what we take to be an effect to act as a cause. However, we do allow the passage of time to be the cause of death when we say that a person 'died of old age'. We allow features, actions and events that did not happen (counterfactuals) to play the role of contributing causes when we say that an omission of or failure to install a preventative measure causes a disease. We allow private and immaterial human intentions to have effects in the material world or infer unobservable (and difficult to prove) private intentions from recorded effects in the material world. Through blending, we routinely amalgamate the physical and mental, material and immaterial, factual and counterfactual, and is and ought. We blend to create meaning, shape and understand the world we live in.

3. Living in the blend

A theory of conceptual blending is, however, not just a handy tool for conceptual analysis. As a 'space of representation' [12, 13], the blended space envelops, in addition to concepts and logical structure, also data that are produced under the blend's specific epistemic conditions or selectively projected or appropriated into the blend to provide empirical support or foundation. "Of course", Fauconnier [5] writes, "observation and theory are part of the same overall package; a 'phenomenon' requires a theory, even if it is a folk theory, in order to be observed at all. There is no absolute, direct theory-independent observational interpretation of the 'facts'. As a science evolves, there is simultaneous, parallel evolution of the observational procedures and interpretations, and of the explanatory theory itself". Furthermore, conceptual structure, framing logic and produced data are blended with ontoepistemological positions. When blended with a realist or essentialist epistemology, theoretical concepts that were introduced to help order and make sense of disparate data or events reify into real-world processes. Inferred causes are assumed to exist in the world, past or present, and exert their forming power on recordable effects. Human rights and values are assumed to derive from the essential nature of human beings and cannot be alienated from or denied beings who belong to that category. Theoretical notions, produced data and epistemological position thus form, when mutually supportive, a robust package, a *mode of ordering* to use Mol and Law's term [14]. As temporarily stabilized formations, 'modes of ordering', or hyperblends, do not only construe but also represent worlds. Erasing the faint line between epistemology and ontology, one could say that it (the hyperblend) is the world. For scientists, or philosophers, or practitioners with a 'high inclusion in the frame' [15], the set of claims that make up an advanced hyperblend lies too close to the core of their deeply assimilated and largely unconscious beliefs to be challenged, or even overtly recognized as something potentially disputable. They live in the blend. There is recursivity here. Collectively and over time, we construe worlds – through cognitive processes of hyperblending concepts, data and epistemology – and then live in them. However, 'from time to time', Rheinberger [13] writes, "new forms emerge that have something significant about them, something that catalyzes previously present actors,

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things, institutions into a new mode of existence, a new assemblage, an assemblage that not only puts things in a different light, but makes them work in a different manner".

The power a particular hyperblend can hold over people, fueling its own protection and the rejection of alternatives, should not be underestimated. Apparently, this is the case when deeply engrained beliefs about our own human nature are challenged; about what sets us apart from animals; about what is our essence at the end, when our existence as an individual human being is imminent and about what remains after our body has eroded and disintegrated. But neither should the importance be underestimated of recognizing the contingency, multiplicity, diversity and simultaneous coexistence of different modes of ordering life and the world, and how they relate to and interfere with each other. "For", Mol and Law [14] argue, "the various modes of ordering, logics, styles, practices, and the realities they perform do not exist in isolation from one another … They are not islands unto themselves, closed cultures, self-contained paradigms, or bubbles. [T]hey interfere with one another and reveal … partial connections". 'Often', Mol and Law [14] continue, "it is not so much a matter of living in a single mode of ordering or of 'choosing' between them. Rather it is that we find ourselves at places where these modes join together. Somewhere in the interferences something crucial happens … complexity is created, emerging where various modes of ordering (styles, logics) come together and add up comfortably or in tension, or both". The history of the sciences, philosophies and ethics is a history of diversification of modes of ordering, not of the successive replacement of one by the other. It is a history of contended claims about the appropriateness of hyperblends and their entailments.

Blending helps us to compress to human scale and handle, to use Turner's favorite phrase, "vast ideas that span great ranges of time, space, causation and agency, ideas that are not at all restricted to the local scene" [8]. The blended space does not replace the spaces from which it received inputs. In a methodological sense, this implies that the input spaces are accessible and amenable for analysis *through* the blend. However, there is also a diachronic, historical dimension to hyperblends. Powerful hyperblends have evolved over time and can be traced in the history of the sciences and of ideas. To trace the evolution of modern notions of human subjectivity and autonomy we must engage with the history of ideas about the relationship between the development of an individual and the history of life.

4. Blending development of an individual with the history of life

A fault line roughly separates the hyperblends that concern us here, comprising key notions about human nature, consciousness and autonomy. On the one hand we find blends that feature a deity, or other supranatural being, as the creator and giver of life (creationism, intelligent design). On the other hand, we have views of life advanced by sciences that do not allow as causes, entities or processes that are not part of the natural world [16]. Neither do they allow outcomes that emerge temporally after their antecedents (no teleological explanations allowed). I recognize the importance of a spiritual dimension in palliative care and the strength many people derive in dying from their belief in a higher being and an afterlife. However, I

am primarily interested in the power and centrality of an idea of conscious life experience that overrules a person's own direction over the process of dying in a secular, nonreligious context. Therefore, I will leave the former aside and pursue the latter. This hyperblend or view of human life is grafted on a compression into unity of the development of an individual organism and the history of life on earth. On a human scale, we experience individuality as the membrane or skin bound discreteness and uniqueness of organisms. In human reproduction, animal husbandry and plant breeding we experience the birth, growth and decline of individual organisms on a time scale for which the duration of a human life provides the standard. Endeavors to understand the nature of the history of life on earth, stretching back into deep time measured on a geological timescale and utterly inaccessible for present day biologists, have not only received inputs from the study of fossil records [17], but also from the comparative anatomy of now-living species and from embryology. Especially the latter, the idea the one can learn about the history of life from the comparative study of the morphology of embryological development across species has contributed strongly to the blending of ontogeny and phylogeny [18]. Recognizing that all species that rely on sexual reproduction for their procreation pass through a single-cell stage, this fertilized egg maps as the origin of an individual organism onto the origin of life. The 'unfolding' of the individual organism through fetal growth, birth and postnatal maturation maps onto the 'unfolding' (evolution) of life from its humble unicellular origins through higher levels of complexity and perfection in the arrival of man. The themes of differentiation, specialization and maturation of cell lineages and tissues in developing individual embryos map onto the diversification of life forms through speciation and the emergence of excellence in the branching tree of life.

This blend has not only inspired an 'iconography of an expectation' [19], which is the more-than-familiar present day cartoons that represent the evolution of man as a linear march of progress but also inspired the nineteenth century biologist Ernst Haeckel's biogenetic law, better known as the notion of 'recapitulation': the idea that ontogeny recapitulates phylogeny and that embryos during their individual growth and development pass through the adult forms of its ancestors. In Haeckel's view, evolution occurred through the heritable addition of new features to the adult form of ancestors [18]. In other words, "we climb our evolutionary tree in the womb" [20]. Haeckel published a famous plate showing a series of embryos, each aborted in its own development, in a grid along two dimensions: an ontogenetic series comparing stages of an individual's development and an evolutionary series comparing different species. In Haeckel's 'space of representation', in his blend, individual organisms deliberately selected and ordered in a two-dimensional series came to express as new and emergent features in the blend namely development and evolution, history and progress. "Development", Hopwood [20] argues, "is thus not simply the process embryologists study; it is also an effect they have labored to produce". Haeckel's plates gave embryos presented as developmental series a public profile [20]. The idea of ontogeny recapitulating phylogeny endured far into the twentieth century and exerted its influence long after it had fallen from grace and had lost credibility among professional evolutionary biologists [18].

The hyperblend of individual development with the history of life, characterized by directed evolution towards an expected arrival of man at the pinnacle, has been challenged by alter-

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native blends. Darwin displaced the idea that the 'unfolding' of an intrinsic essence was the primary, causal force driving evolution in the history of life. He replaced it with the idea of *natural* selection, itself a blend with input from *artificial* selection as experienced on a human scale in animal husbandry and plant breeding, Natural selection works on undirected, isometric variation (equal likelihood in all directions) in a population. Gould [21] points out that for Darwin natural selection was not just an external negative force weeding out the misfits, but that it was a creative, positive force in and cause of evolution working gradually over vast expanses of time. For Darwin, natural selection worked on the level of organisms struggling for survival. In the twentieth century, Stephen Jay Gould, with Niles Eldredge, worked to recast, through their theory of punctuated equilibrium, the history of life as "a story of massive removal [large extinctions] followed by differentiation within a few surviving stocks" [19]. Gould also worked to expand Darwinian evolutionary theory into a hierarchical theory, allowing natural selection to operate, above the organismal level, on the level of species. In a section called 'The Grand Analogy' in *The Structure of Evolutionary Theory* [21], Gould engages in an extensive and explicit blending operation. Gould maps individual organisms as the units of selection in microevolution to species as the units of selection in macroevolution. He maps the birth and death of individual organisms to the origin and extinction of species. He maps the timescale of the life of an individual to the scale of geological time; the parent–child relationship of organisms to parental and daughter species, the transmission of features from parental generations to offspring to the transmission of formative properties between ancestral and descendant species. Macroevolutionary trends "could be conceptualized as a result of higher order selection upon a pool of speciational events that might occur at random with respect to the direction of the trend. In such a case, the role of species in a trend would become directly comparable with the classical status of organisms as units of change within a population under natural selection" [21]. In this blend, the history of life is not a linear march of progress towards an expected outcome (the arrival of man), but a story that blends ontogeny and phylogeny in a different way.

5. Heterochrony in human development and the brain

Thus far, ontogeny seems to have provided a conceptual structure to phylogeny, the human scale experiences and observations of discrete organisms serving as the source domain of metaphorical projection of structure to the target domain: the utterly inaccessible domain of the history of life. However, Turner [8] emphasizes how structure from the blended space can be projected back to the input spaces. Despite disagreements and controversies among evolutionary biologists about the precise nature, relative frequency and importance of formative, causal processes, the conceptual blends achieved have recast the human species as a species among other species with whom it shares common ancestors. Humans share with other vertebrates the same fundamental 'building plan'. Humans share the basic structure of their brains with other mammals. Our brains are mammalian brains.

It is in our 'expanded' brains, and the 'higher' cognitive functions that they afford, that many scientists and philosophers locate the features through which the human species bootstrapped

itself out of the world of brute animals. Yes, we belong to the animal kingdom, we share ancestors with our companion species, but we also stand above and at a distance from them. Exactly what those features are and what brought them about is a matter of contention.

Today, there seems to be little support among evolutionary biologists for the idea that the expansion of the human brain can be accounted for by the accumulation of mutations in structural genes, that is, in genes that code for proteins. The number of structural genes in the human genome does not far exceed that in other primates. In other words, the differences in genotype are insufficient to account for the marked differences in phenotype. However, in recent years, more emphasis has been put on the regulation of gene expression – both on genes regulating the expression of other genes and molecular non-DNA processes involving histones – the proteins around which strands of DNA are winded to form chromosomes. Interestingly, echoing this shift in emphasis, Gould [18] argues for the relative frequency and factuality (sic!) of heritable changes in the rate of ontogenetic development to account for macroevolutionary trends on the level of species. These changes in the rate of development may be different for different parts of the body and affect developmental processes like teething and the onset of sexual maturation differently.

This 'heterochrony' in ontogenetic development is, when we think about it, a familiar feature. We know from embryology that the cranial parts of the embryo, encompassing the brain, develop and grow faster than its caudal parts. We can observe this feature in common ultrasound images of first-trimester pregnancies. Even at birth the baby's 'hind-limbs' are relatively undeveloped compared to its head, making the newborn infant dependent on maternal and parental care for a long time after birth. The caudal parts of the body catch up during childhood, developing and growing into long and strong legs before the onset of sexual maturation blocks further growth. Contrary to what one might expect, the evolution of the human species and its expanded brain is not the result of a speeding up but rather of a slowing down of developmental processes: *retardation*. This change in the rate of development delays the onset of processes that constrain further growth, allowing for longer growth periods. The slower rate of development and maturation also correlates with a longer lifespan. This relationship seems to hold for the multicellular organism, as well as for the differentiated cell types within the organisms. Slowly maturing nerve cells are the longest living cells of the human body. Fast developing red blood cells, which even discard their nucleus before entering the peripheral blood stream, are among the cells with the shortest lifespan. In humans, newborn infants maintain a fetal growth rate after birth for about a year, much longer than other newborn primates do. Compared with other species humans enjoy the longest juvenile periods before sexual maturation sets in Ref. [18]. The reduced rate of development allows the brain to grow longer and extend its patterns of cell proliferation in time. As a result, humans achieve a markedly higher degree of encephalization. The delay in development also delays the loss of plasticity that is correlated with maturation.

Compared with other species, humans retain for a longer period of time the capacity to form new neuronal connections and to modify existing ones. Jacobson [22] argues that "this reduction [of plasticity] occurs at different times in different classes of neurons, so that those which are generated late in ontogeny and those which mature slowly have the greatest degree

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of modifiability in the mature animal". The long drawn-out growth period, the prolongation of childhood and the retainment into adulthood of neural plasticity under conditions of parental care and instruction, supported by the faculties of memory and language, make 'human' a learning rather than an instinctive animal [18]. It is the embodied activity of the living organism that shapes the pattern of synaptic connections and their firing properties. Hebb [23] argued that "What fires together wires together!"; the principle of what has become known as 'Hebbian learning' that underlies the formation and reformation of neural cell assemblies. Explicitly using Burnet's clonal selection theory of the immune response as an input to the blend, Edelman [24–26] developed a theory of neural group selection to account for the ways in which the pattern of neural connections is shaped through 'differential amplification' in recursive reentrant systems by the activities and experience of the living organism, not by prior programming.

6. Hyperblend of the flesh: self-building brains in evolutionary history and individuals

The ontogeny/phylogeny blend is extended into the morphology of the brain and further blended with inputs from new domains, from the study of consciousness and cognition. This blending process is characterized by a progressive reduction or truncation of the notion of cognition.

Embodied cognition biologists argue that cognition is a fundamental feature of biological life [27–29]. Cognition is coextensive with the recursive sensorimotor loops of the embodied activity of living organisms. In this blend: life = embodied action = cognition. Cognition is a function that emerges with the formation of a living organism. Cognition is not a feature that is confined to the emergence in human brains of self-consciousness. The basic story goes like this. With the formation of a membrane, that envelops an intracellular space and separates it from a now-external environment, any living organism must maintain its functional integrity and organization (homeostasis) in interaction with changes in its environment. This is a recursive relationship. Devices in the membranes (receptors) allow the organism to sense changes in its environment. Internal, or external but membrane bound motor devices (cilia, flagella) allow it to respond to these changes. The repeated, recursive cycles of action and perception constitute an intentional arc. In other words, intentionality conceived as an organism's orientedness towards its environment is a property emergent from the formation of a membrane. Multicellular organisms developed specialized cells and structures for these sensory and motor functions. Only organisms that live free and mobile in their environment have developed a nervous system. A central nervous system and brain developed from the gathering at one side of the body (encephalization) of specialized neurons monitoring and regulating changing conditions inside the body (giving rise to emotions), in close association with sense organs and neurons monitoring changes in the environment. At some point in this evolutionary history, consciousness emerges, at first in prototypical forms that also other animals may have, then blooming into a fully-fledged autobiographical human self-consciousness.

Exactly how body/brains make minds and selves, let alone why, is still a matter of contention. There is dispute with regard to the how and when they emerged in the history of life. There are many theories trying to grasp how brains make mind and usually a single self in the individual body. Nevertheless, the tentative answers to these elusive questions, including the hierarchical relationship that is assumed to exist between humans and animals, between reason and emotions, have been blended with the morphology of the brain. In ascending order, the brainstem encompasses the neural centers that regulate respiration, circulation and temperature. These are the 'vegetative' functions that have to do with the internal conditions of the body. The midbrain is associated with basic positive emotions like care and joy, and with negative emotions like fear and anger [30]. Although brainstem and midbrain emerge during organogenesis in the first trimester of pregnancy, together with the cerebral hemispheres, in a phylogenetic sense they are considered to be the oldest parts of the brain that we share with animals. The two hemispheres with their outer rim, the cortex, are considered to be phylogenetically younger and newer, hence *neocortex*. In addition to visual and motor cortices, that must be assumed we also share with other species, it is here in the neocortex we locate the functions that make us distinctly human: the areas for language perception and language generation, for abstract thinking and reasoning, for imagining alternative counterfactual scenarios and evaluating possible outcomes, yes, for conceptual blending in all its various forms. Especially the frontal lobes, above our eye sockets, stand out as the locus of the most advanced, executive higher brain functions. These functions are not only higher in the sense of more advanced then vegetative functions or emotional functions. They are also phylogenetically higher because they make us distinctly human.

The macroanatomical structure of the individual brain has by evolutionary neuroscientists been overlain (blended) with the emergence through evolutionary time of what Damasio calls a protoself or protoconsciousness, a core self-and-consciousness and the fully-fledged human *autobiographical* selfconsciousness [31–34]. Autobiographical consciousness is the defining feature of what makes us living human beings. It is called autobiographical because it locates the current self in a temporal continuum of a lived past (memory functions) and an anticipated but open future (functions of planning and evaluation of alternative courses of action) [34]. All this miraculous mental and conscious activity, including the sense of unity and continuity over time of an autonomous Self is, in one way or the other, the result of ongoing dynamic biological processes in here-and-now brains in continuous interaction with the body in which it is embedded and of the body's physical and social environment. In this hyper-blend of the flesh, the Self is 'a perpetually recreated neurobiological state' [31].

7. Hyperblend of the immaterial, autonomous, human subject

The modern notion of the autonomous human subject has received inputs from several distinct domains. Rose [35] argues that "the sense of ourselves as "psychological" individuals developed across the twentieth century … we came to understand and act upon ourselves as beings inhabited by a deep internal space shaped by biography and experience, the source of our individuality and the locus of our discontents". We locate psychology's deep internal space

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intuitively inside our skull – above and behind your eye sockets, the space occupied by your frontal lobes? We know from elementary human anatomy that it is the brain that occupies the skull. There is no empty space there. Yet, this deep internal space is the seat of the self-governing subject. This concept underlies the important humanist notion of personhood and human agency. This line of thinking has a long and august pedigree that can be traced back to John Locke and his contemporaries. In his *Essay on Human Understanding*, Locke defines a 'person' as 'a thinking, intelligent Being', that has reason and reflection, and can consider it self as it self, the same thinking thing in different times and places" [36]. We conceive of the deep, internal, private space of the individual mind as being coextensive with consciousness and with the operative agent doing the intending, willing, emoting, conceptualizing and associating of concepts to language that we associate with thinking. It is the thinking that we do in this internal space, and of which we are consciously aware, that we have come to define – in the sense of *delineate* – as human cognition. In the same vain, it is the intentions of which we become consciously aware that we have come to define as human intentionality.

Input to the hyper-blend of the immaterial human subject has also come from a research program in cognitive science that emerged in the 1940s. This program received inputs from mathematical logic, general systems theory, Shannon's statistical information theory of signals and communication channels, and not in the least, from the invention of information-processing machines such as digital computers. An important entailment of this program was that cognition, conceptualized as information processing, storage and retrieval, was *platform independent*: it had been instantiated by Nature in the biological tissues of the brain, but it could also be instantiated by engineers in artificial silicon-based devices. Like the operation of software, cognition was independent of the hard ware on which it ran. Again, conceptual structure and logic was projected back from the blended space to the input space of human cognition. This blend drove a wedge between human cognition and the human body/brain. It displaced the body and disembodied cognition. It also displaced emotions as a form of cognition, that is, as the human body's principal biological valuation system. However, it embraced technologies that now became 'intelligent' and 'smart'. Despite the criticism that has been leveled by embodied cognition theorists [27–29] against this 'cognitivist' program, it has been extremely influential in cognitive science and theories of learning.

As a third input to the blend, Woods [36] argues that the now-commonplace notion of the autonomous self has evolved out of a backdrop of rebellion against traditional sources of authority such as the church and state. 'The contemporary concept of the 'self' and 'person', Woods argues, 'is bound up with a politics of non-interference into the personal life of the individual…' [36]. Autonomy as a right to non-interference is firmly embedded in the now-stronger than ever requirement of informed consent in medical practice and research. In informed consent procedures, cognition is operationalized in 'cognitivist' terms as information processing. Based on valid information provided by health-care professionals the patient weighs, evaluates, judges and makes a decision of consent or approval concerning the medical procedures that are proposed being done to her. The information provided being understood is a prerequisite for the consent to be valid. In other words, the validity of the consent is a function of the information provided. I have called the notion of autonomy embedded in and

performed through these informed consent procedures for *neocortical autonomy* [2]. Perhaps *frontal lobe autonomy* is a better term. Both terms express the *blendedness* of this highly cognitivist concept of autonomy with the parts of the brains anatomy on which it is projected.

8. The *irreality* of the human Self: partial relations, frictions and problematic entailments

Thinking about psychology's deep internal space, in which we locate a cognitivist Self that is the source of motives, intentions and the ability to choose to do what is right – which defines us as moral agents -, I have struggled to find a term to characterize a space that is real in one blend but does not exist in another. How can the human subject, devoid of any form of materialness, exist in human anatomy with its hierarchical spatialization of the brain that is grafted on ideas about the species' phylogenetic history? For want of a better word, I have called it an *irreal* space to indicate that it is the result on an imaginative act of conceptual blending [2]. The modern notion of the human autonomous subject (Self) may also be characterized as *irreal*: to express the ambiguousness in two senses in which we think about ourselves: (1) the sense that we are coextensive with our body, with the entailment that the 'I' or 'Self' ends with the disintegration of the body/brain, and (2) the sense that there is some-thing more, an immaterial entity (soul?) that we perhaps hope will live on after death. I do not want to define the two blends as two essentially distinct and separate ontological domains, Descartes' *res extensa* and *res cogitans*. I want to stress the complex ways in which they are related. As Mol and Law put it, 'If there are different modes of ordering that coexist, what is reduced or effaced in one may be crucial in another so that the question no longer is, Do we simplify or do we accept complexity? It becomes instead a matter of determining which simplification or simplifications we will attend to and create and, as we do this, of attending to what they foreground and draw our attention to, as well as what they relegate to the background' [14].

In everyday life, we routinely, and apparently without too much trouble, amalgamate the immaterial mind with the flesh inside our skull. The lack of trouble, I suggest, is a result of our ability to move between and inhabit them both, depending on the discursive requirements of the situation. Alternating between them helps us to avoid the complexities associated with the places where the different modes of ordering (hyperblends) join together and interfere. However, to use another of Turner's [8] favorite expressions, we are not fooled. We know that consciousness is dependent on the functional integrity of the biological processes of the brain; that lack of oxygen (syncope; ventricular fibrillation), or glucose (diabetic hypoglycemia and coma), the loss of coordination of neural firing (epileptic insult) or the inhibition of certain neurotransmitters (anesthesia), very quickly makes us loose consciousness. The reversibility of these conditions, with the phenomenological reappearance of a sense of Self, suggests *continuity* of the Self even during the period of unconsciousness: an effect that we labor to produce. We also know that psychoactive drugs can provoke hallucinations or modify the quality of our mental state: an effect that we, when positive, may seek or use therapeutically in an attempt to treat or rebalance mental disturbances. However, the frictions between the

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two hyper-blends become inevitable in end-of-life care situations, when the 'brilliant fire of consciousness' [24] is in danger of being extinguished permanently and irreversible.

In the 1950s, when the new resuscitation techniques of external closed-chest compressions in combination with mouth-to-mouth ventilation left the hospital and were taught to lay people, the greater sensitivity of the neocortex to lack of oxygen – compared to midbrain and brain stem structures – produced a new *form*. In some cases resuscitation efforts did succeed in restoring spontaneous heart action and respiration, the regulatory centers of which are located in the brain stem. However, in the same patients the restoration to *animated* conscious life failed. These patients survived an episode of cardiac arrest, but they remained severely brain damaged: dead brains in bodies with hearts again beating. French physicians coined the term *coma dépassé* to describe the state. Today the condition is known as *persistent vegetative state* (PVS). With the widespread use of external cardiac massage and mouth-to-mouth breathing, supplemented with closed-chest defibrillation and supportive drug therapy, their numbers increased during the 1960s and the 1970s. Their undeniable presence triggered a reformulation of the concept, criteria and diagnostics of human death in terms of *brain death* [37, 38]. Definitions of *neocortical death* have been proposed, attributing central importance to the irreversible loss of *higher brain functions* [39, 40]. For these functions, a viable, phylogenetically younger, cerebral neocortex was identified as a necessary, albeit not sufficient *conditio sine qua non*. Proponents of a neocortical definition of death took great care to emphasize that the work of redefining death served to clarify the *real o ntological status* (sic!) of severely brain damaged patients in intensive care arrangements. The distinction between the body that has developed or retained the capacity for higher brain functions - the body that *is* an embodied person -, and the body that has irreversibly lost this capacity - the body that *is* a biological remnant after the person has died-, is not, so they argued, a value-based or moral divide. Yet, neocortical definitions of death have not been translated and embedded into law.

As the question of the status of severely brain damaged patients in intensive care units became more urgent as the need for good quality donor organs increased, most countries settled on a more conservative *whole brain definition of death* that requires that all nerve cells within the skull must be shown to be irreversibly damaged. Only after demonstrating that there has been no blood flow through the brain for 20 min or more can the patient be pronounced dead and organs extirpated. Practices preceded their legal regulation. In the Netherlands, a provisional legal basis for the extirpation of healthy organs for transplantation purposes was found in the *Law on the Disposal of the Dead*. As an input to the new emerging hyperblend of brain death, it was the analogy between autopsy and partial dissection on one hand, and the extirpation of health organs for transplantation purposes on the other, which provided in 1971 the initial legal justification for the latter. The Dutch legislator spent 20 years, and a series of Health Council reports, negotiating public confidence in the new brain-related definition of death before eventually formalizing the new hyperblend in the 1991 bill on the Donation of Organs [38].

Today, PVS-patients still have the ontological status of being alive and deserving of the protection of the law, despite the absence of consciousness. Whereas a stable new hyperblend, or mode of ordering, has emerged around potential heart-beating organ donors with dead

brains, matters are quite different for people still in possession of a fully fledged autobiographical consciousness who wish to maintain control and a certain degree of self-direction over the time and manner of their death. With a few exceptions, physician-assisted suicide and euthanasia are illegal in most countries. Even national and professional guidelines that aim to regulate the use of palliative sedation for terminal, dying patients are quite restrictive. Criteria for this pharmacological reduction of consciousness in dying patients include intense and sustained suffering from physical symptoms that have been shown to be refractory to ordinary treatment. Arguing on the one hand that palliative sedation should be considered to belong to the repertoire of ordinary and legal medical treatments, these guidelines clearly mark, through restrictive safeguards, their distance from illegal practices of assisted suicide and euthanasia [1, 2].

Despite the status of respect for a patient's autonomy as the first among the four principles of medical ethics [3], in texts of law, professional guidelines and codes of ethics, it is the much more restrictive cognitivist, frontal lobe notion of the human subject that has been inscribed. One problematic entailment of this is that it seems as if patients, in the face of death, cannot be trusted to know their own mind. The *competence* to make end-of-life decisions has been formally delegated and assigned to physicians, reducing the patient's autonomy into a right to be heard. Respect for the patient's autonomy has been made conditional upon health-care professionals assessment of a patient's cognitive capacity to give informed consent, applying criteria derived from the same truncated cognitivist frontal lobe notion of human subjectivity and personhood. In practice, critically ill and dying patients in health-care settings are often dependent on the generosity of physicians and other health-care professionals. That is, they depend on health-care professionals' understanding of legal regulations and guidelines in combination with their own understanding of the *discretionary space* and leeway that their *professional autonomy* grants them.

9. Conclusion: autonomy truncated three ways

There is no lack of modern states' desire to govern practices of end-of-life care. There is no lack of intervention in and interference with the hardest thing we all must do, dying. This is also the hardest but perhaps most important thing we ever have to do for our partners in life or for parents, that is to assist them in dying [1]. Although first among the principles of medical ethics, the modern notion of the autonomous subject is truncated in at least three different ways. First, exercising autonomy through the direction of the manner of one's death is constrained by the right to conscientious objection of health-care professionals. This right is rooted in the same principle of autonomy as the patient's right to self-determination and noninterference that is inscribed in the international declaration of human rights. As a patient "You have and absolute autonomous right to determine what happens to you … Unless you don't!" [41].

Second, this style of thought reduces the human person to the cognitive capacities and higher brain functions of the bark (neocortex) of the frontal lobes. It ignores the massive recursive

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connections and interactions throughout life between the neocortex and the deeper, midline structures of the emotional brain and the body that are being gradually elucidated by neuroscience [30, 32]. Natural sciences are often accused of reducing the whole person to molecular-genetic and neurophysiological events in the body and brain. In this cognitive, neocortical version of autonomy and personhood, we may recognize a kind of reversed reductionism. This is not to say that neurosciences shall have the last word, but it may be important, as Rose and Abi-Rached [42] argue, to critically explore the implications of the new sciences of the brain for the human and social sciences.

Third, cognitivist notions of an atomistic, modern autonomous subject displace relations and interactions with other beings as processes that are constitutive of human agency. There is no lack of recognition of the importance of social relations and the ability to communicate, even to the extent that this is the capability that makes us truly human. However, the atomistic, individualized person and human subject located in psychology's deep internal, but irreal space gains priority. Social relations and communication come in the second place. The neocortical Self overrules any other conception of humanness. As the governor that controls the city, its stronghold and inner citadel (conscious life experience) must be protected at all costs, even – or perhaps especially – in the face of death. Simultaneously and recursively, by protecting this idea of the *autonomous subject in the patient*, health-care professionals and the law makers who hold the medical professions in high regard maintain the ethical high-ground of moral accountability.

However, we may invert these arguments and offer an alternative hyperblend for consideration. We can argue that human autonomy and independence is a temporarily stabilized result or outcome of a network of relations of dependence and recursive interactions. It is not an essentialist feature of the individual. When that stability starts to unravel due to critical illness and imminent death, the people closest to you in your network should be the ones prepared to accept some of the burden of care as the network reconfigures. We may reclaim cognition from the cognitivists and appreciate emotions again as our principal embodied value system. Because we have mammalian bodies and brains, we can explore the role of physical intimacy and touch as an important mode of caring for the dying, also for those that are no longer conscious. Thinking along these alternative lines would give access to an alternative set of practices around dying and end-of-life care, redefining the roles of the dying patients, next of kin, health-care professionals and treatment options that should be generously available.

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