

CONGENITALLY DECORTICATE CHILDREN'S POTENTIAL AND RIGHTS

Abstract: This article is the first in-depth ethical analysis of empirical studies that support the claim that children born without major parts of their cerebral cortex are capable of conscious experiences and have a rudimentary capacity for agency. Congenitally decorticate children have commonly been classified as persistently vegetative, with serious consequences for their well-being and opportunities to flourish. The paper begins with an explication of the rights based normative framework of the argument, including conceptual analysis of the terms “agency,” “potentiality for agency,” and “gradual approach of agency.” It critically examines Alan Gewirth’s account of the criteria for being a rights bearer and principles for settling rights conflicts between agents and potential agents. It then applies the rights based normative framework to the ethical challenges associated with care for congenitally decorticate children. It argues that recent empirical studies support the claim that the concepts “potential for agency” and “capacity for rudimentary agency” apply to children who are born without major parts of their cerebral cortex. The article finally discusses important medical-ethical implications of these results. It specifically focuses on congenitally decorticate children’s preparatory rights to a stimulating intellectual and social environment.

1. INTRODUCTION

The question of how different parts of the human brain interact to generate consciousness is the subject of an ongoing debate. The generation of consciousness is the result of complex interaction between different brain structures, including the upper brain stem and the cerebral cortex.

However, documentation of cognitive capacities of children born without major parts of their cerebral cortex, examined by paediatric neurologists in these children’s homes,[1] a survey with 108 caretakers of such children,[2] and research within the field of neuroscience[3] provide reasons to re-evaluate assessments of congenitally decorticate

children as incapable of consciousness and agency. Shewmon et.al[1] and Merker[3] advance proposals regarding the neurological structure sufficient for consciousness, agency, and potentiality for agency. Despite the significant medical ethical implications of their proposals, these implications have never been thoroughly examined. This article introduces such examination.

Capacity for agency and potentiality for agency are intensively discussed candidates for properties that characterize holders of moral rights. Alan Gewirth's pivotal book *Reason and Morality* still significantly impacts this debate. It discusses the Principle of Proportionality (PP) which, according to Gewirth, implies that beings who do not possess capacities to exercise agency at a certain threshold level hold moral rights in "proportion" to their sub-threshold capacities to exercise agency.

Section 2 of this article discusses Gewirth's proposal. Section 3 discusses empirical studies that support the claim that humans born without major parts of cerebral cortex can have potential for agency in at least a rudimentary sense. It then outlines Shewmon's and Merker's explanations of these individuals' capacities. Their explanations focus on the possibility of neurological reorganization of the brain and new insights into the functioning of the upper brainstem.

Section 4 examines select medical ethical implications of the previous discussion. It focuses on congenitally decorticate children's preparatory rights to social and intellectual enrichment. A noteworthy number of congenitally decorticate children ought to be regarded as potential agents in a rudimentary sense, and as approaching a capacity for agency in a rudimentary sense. These potential agents have preparatory rights to the means necessary to develop their capacity for rudimentary agency. They might develop a capacity for agency along different routes: through neurological reorganization, or normal upper brainstem functioning. Predictions of chronic incapacity for conscious experiences might impact

decisions to choose institutionalised care over home-based care for congenitally decorticate children. Shewmon et al suggest that predictions of chronic incapacity for conscious experiences might become self-fulfilling prophecies. I also explore related ethical challenges raised by adults in a vegetative state, preterm and asphyxiatic infants with severe brain-damage, and the possibility of so-called “islands of awareness,” brains of conscious individuals who are unable to receive input from the external world, or who are unable to interact with the external world.

This article is, to wit, the first to thoroughly discuss the possible relevance of upper brainstem functioning, and neurological reorganization of the upper brainstem, for congenitally decorticate children’s preparatory rights to intellectual and social enrichment.

2. CLAIM-RIGHTS AND THE PRINCIPLE OF PROPORTIONALITY

As the concept of a moral claim-right plays an essential role in the normative framework of my argument, we must explicate the characteristics and moral significance of claim-rights. A claim-right is a claim that correlates with a duty. The claim – duty correlation does not by itself *imply* that rights have any specific moral weight.[4] However, rights are commonly but not un-controversially *regarded* as being particularly morally weighty. This is one reason for the urgency of determining what individuals classify as rights bearers. Detecting a property that characterizes holders of moral rights is particularly imposing when it involves humans with compromised agential capacities.

All rights theorists agree that beings who are capable of exercising agency are uncontroversial examples of rights bearers. Alan Gewirth’s work includes some of the most influential contributions to the scholarly body of works that examines agency as a property that characterizes moral rights bearers. He argues in his book *Reason and Morality* that all

individuals who possess a capacity for agency at a certain threshold have claim-rights against all other agents to the extent that all agents *at least* abstain from interfering with the rights bearer's "freedom" and "well being" (very broadly construed) and also support rights bearers' freedom and well being when rights bearers are unable to secure their own freedom and well being. Gewirth stipulates that agents, per definition, are capable of voluntary and purposeful behaviour to a certain degree. Voluntariness and purposiveness are the "generic" properties of agency. Individuals who possess these generic properties of agency have generic rights to freedom and well being because freedom and well being are necessary for maintaining one's capacity to engage in voluntary and purposeful behaviour. Gewirth carefully emphasizes that a capacity for voluntary and purposive behaviour at a certain threshold is a binary property: an individual is either capable or incapable of voluntary and purposive behaviour at the threshold. He insists that differences in ability *above* the threshold are irrelevant for a being's status as a rights holder. The claim that individuals with capacities at a certain threshold are uncontroversial examples of rights bearers is unchallenged by moral philosophers. But moral philosophers disagree regarding the criteria for including other beings in the class of rights bearers. Gewirth claims that individuals with agential capacities *below* the threshold acquire rights to freedom and well being in proportion to their "approach" towards a capacity for voluntary and purposive behaviour at the threshold. A capacity for purposive and voluntary behaviour at the threshold gives a being rights to freedom and well being. Individuals allegedly acquire rights in "proportion" to how closely they approach possession of the property that gives agents these rights.[5] Gewirth labels these individuals "marginal" agents and describes this proposal as an application of the more general "Principle of Proportionality" (PP): "When some quality Q justifies having certain rights R, and the possession of Q varies in degree in the respect that is relevant to Q's justifying the having of

R, the degree to which R is had is proportional to or varies with the degree to which Q is had.”[5:121]

I have argued in other places that “approaching agency” can be interpreted in two different ways. The first interpretation holds that a being approaches agency in the sense that she gradually develops the sheer physical properties necessary to exercise agency. According to this interpretation, she can “approach” agency even before she is rudimentary conscious. This goes at least for “normal” human fetuses during early stages of the pregnancy. I have argued that we may question the moral relevance of sheer physical differences between potential agents; we will not repeat that argument here.

The other interpretation holds that a being approaches agency in the sense that she also has reached a developmental stage where she is conscious in a rudimentary sense, and gradually develops her mental capacities. I have argued that the moral relevance of such “approach” is somewhat more convincing. This goes at least for “normal” sufficiently mature human beings. The latter being displays, in some sense, varying degrees of actual capacity for mental activity in some rudimentary sense; the former does not.

The claim that beings who do not possess capacities for agency at the threshold acquire rights in “proportion” to their “approach” towards capacities for agency at the threshold remains the subject of debate: for instance, in order to compare the morally relevant properties of agents and potential agents, we need some common measure of comparison. The importance and medical ethical implications of this debate justify continued scrutiny of Gewirth’s discussion of the PP.

Gewirth notes that some individuals who lack capacities for agency at the threshold, such as “normal” human fetuses, infants, and very young children, nevertheless have potential for developing agency at the threshold, in the sense that they will, under “normal” circumstances, mature into agents. Although the definition of “normal” is disputed,

there are un-controversial examples of human fetuses, infants, and young children who develop normally. Gewirth claims that potential agents have “preparatory” rights to the means necessary to *develop* a capacity for agency. Although all “marginal” agents have rights to freedom and well being in proportion to their level of agency capacity, marginal agents who are also potential agents also have “preparatory” rights: Potential agents “have rights that are preparatory for their taking on the generic rights pertaining full fledged agency.”[5:141]

Gewirth holds that we should ensure that “efforts be made to effect whatever improvements may be possible in the direction of normal agency.” “The preparatory rights include as much respect for freedom and well-being as is consistent with this goal of agency.”[5:141]

Possessing the property of being a potential agent is sufficient for holding preparatory rights. [5:141-142]

Gewirth holds that if the rights of agents to freedom and well being conflict with the preparatory rights of potential agents who merely approach a capacity for agency, the rights of agents should be given priority. The relative weight of a potential agent’s rights is affected by her level of approach towards agency, and the severity of the threat to the agent’s freedom and well being. Gewirth holds that the PP can justify prioritisation of the rights of agents over the rights of potential agents in cases of conflicts: “The Principle of Proportionality ... makes clear why this is so. The justifying criterion for having the generic rights is that one is a prospective agent who has purposes he wants to fulfil. When someone is less than a full-fledged prospective agent, his generic rights are proportional to the degree to which he approaches having the generic abilities constitutive of such agency and the reason for this proportionality is found in the relation between having the rights and having the generic abilities required for acting with a view to purpose fulfilment.”[5:142] Although Gewirth writes that “generic” rights are proportional to the degree the individual holds the generic abilities, Gewirth holds that this goes for *preparatory* rights as well. Again, this

argument faces the challenge of finding a common measurement of comparison between the morally relevant properties of agents and potential agents.

Having explicated the normative framework of my argument, we will now examine its application to an important but underexplored medical ethical topic: the morally defensible care options for congenitally decorticate children. We will argue that a noteworthy number of congenitally decorticate children possess the binary property “potentiality for developing *rudimentary* agential capacities,” and discuss two explanations of their potentiality. We will then discuss what implications classification of congenitally decorticate children as potential rudimentary agents has for these children’s preparatory rights to intellectual and social enrichment.

3. CONGENITALLY DECORTICATE HUMANS CAN BE POTENTIAL AGENTS IN A RUDIMENTARY SENSE AND APPROACH AGENCY IN A RUDIMENTARY SENSE

An influential theory of consciousness is the global neuronal workspace theory.[6] This theory claims that consciousness occurs due to “the integration of multiple sensory inputs into a single conscious experience.” This integration progresses throughout the maturation of the human organism, resulting in a “unified consciousness.”[7] In a “normal” human fetus, the central nervous system that is necessary for subsequent development of all senses is grounded approximately on the fifth day from the first cellular duplication, when the core of the brain stem begins to develop, soon followed by the primitive cerebral cortex.[8] The hemispheres of the brain develop after the neural tube has formed.[9] The fetus can register exposure to light from the 10th week of pregnancy.[8] The fetus changes its position in response to being touched from approximately the 10th week,[9] and is able to hear between the 16th and 18th week.[10] The fetus is probably able to react to sound from about the 20th week.[9] The fetus

reacts with “withdrawal reflexes” to noxious stimuli at the 19th week.[10] The fetus is likely able to smell from about the 20th week. Fetuses have demonstrated short term memory from the 25th week.[9] After the 24th week the thalamocortical axons have reached the auditory, visual, and frontal cortex, as well as the system of neurons that enable the sense of touch, temperature, and position, and the fetus “might be able to process input from the sensory organs at a cortical level.”[9:887] It has been suggested that the fetus is able to experience pain around the 29th-30th week.[10]

In some fetuses, the cerebral cortex never develops fully, or never develops at all. When congenital decortication results from a stroke in the fetus’ brain, and the damaged brain tissue is replaced with fluid in the skull, the condition is classified as hydranencephaly. Medical professionals have often assessed that even rudimentary consciousness is impossible in cases of such massive loss of cortical tissue. Our discussion of this claim requires clarification of the concept “consciousness”. It has been described as a “mongrel” or “hybrid” concept: A being can be conscious in several different senses.[11] Lagercrantz and Padilla propose that “a simple definition of consciousness is sensory awareness of the body, the self, and the world.”[9:883] The being can be conscious in the generic sense of being sentient. Sentience is a property that occurs in degrees. The least demanding understanding of sentience merely requires that the being is *capable* of some sensory perception, although she might not currently perceive anything. A more demanding understanding of “sentience” would be that the being actually *has* sensory perceptions; i.e., is *currently* alert and aware. These two senses of “sentience” are equivalent to what I call “rudimentary consciousness.” An even more demanding requirement is that the being is not only aware but that she is also aware that she is aware; i.e., self-conscious. “Self-consciousness” can also be interpreted in a number of ways. It could be interpreted as explicit conceptual self-awareness. According to this interpretation, many non-human animals and even young children might not be regarded

as self-conscious. If only more rudimentary self-awareness is required, a wide range of creatures could be regarded self-conscious. A more subjective understanding of consciousness is Thomas Nagel's well known "what it is like" interpretation. According to this interpretation, a being is conscious if there is some way the external world appears to the being, from that being's subjective point of view.[12] Ned Block introduced an influential distinction between phenomenal consciousness and access consciousness. Phenomenal consciousness is "what it is like" to be in that state. It includes hearing, smelling, tasting, and having pains. Access consciousness means that the being's perceptual information is available for use and guidance in speech and action by the being. It includes thoughts, beliefs, and desires. It is characterized by representational content. Phenomenal and access consciousness can occur independently but they generally interact.[11]

Should the claim that congenitally decorticate humans are incapable of conscious experiences be accurate, humans who are severely congenitally decorticate would unquestionably lack potentiality for agency even in a rudimentary sense and would definitively not approach a capacity for agency even in a rudimentary sense. According to the normative framework outlined above, such beings would unquestionably lack preparatory rights. A being's capacity for conscious experiences has relevance for her capacity for agency in the following way. Agents, per definition, are capable of voluntary and purposeful behavior to a certain degree. Consciousness in some sense is a *prerequisite* for voluntary and purposive behavior. At the very least, the individual must be aware in some sense, and capable of intentionally responding to the external world in some sense. This would require more than mere wakefulness and awareness of some sensual impressions, but not necessarily self-consciousness.

The core moral question is how one should treat congenitally decorticate children given this uncertainty regarding their capacity for consciousness and agency.

Thought-provoking scientific contributions suggest, however, that congenitally decorticate humans can be included in the class of beings with potential for rudimentary agency. These individuals should at least be considered candidates for being carriers of rights to the means necessary to develop a capacity for rudimentary agency. We could plausibly suggest that individuals have preparatory rights to the means necessary to develop *rudimentary* agency, placing the “threshold” level a bit lower than Gewirth would. The normative account outlined above would be applicable to these individuals; we would simply place the level of “threshold” capacities for agency a bit lower than Gewirth would. As these individuals might have potentiality for agency below the threshold level stipulated by Gewirth, he would likely label them “marginal” agents rather than “potential” agents.

The view that severely congenitally decorticate humans cannot even be conscious, and that they lack potential for even a rudimentary capacity for agency, has been challenged by paediatric neurologists David Alan Shewmon, Gregory L. Holmes, and Paul A. Byrne in their 1999 article “Consciousness in Congenitally Decorticate Children: Developmental Vegetative State as a Self-Fulfilling Prophecy.” The authors describe four congenitally decorticate patients who were between 5-17 years of age at the time of the authors’ observations. These children were diagnosed with hydranencephaly and deemed chronically vegetative with absolute certainty by examining neurologists and neurosurgeons. The children had remnants of cortex to varying degrees, but according to all examining specialists, these were not sufficient for the children to be capable of consciousness. The authors specify to what extent these children had remnants of cerebral cortex:

Child 1: Hydranencephaly was confirmed by CT, which showed no cerebral tissue in front of the thalamus, “except for small mesial temporal-lobe remnants.” “A thin crescent of tissue extended from the left middle fossa.” “EEGs showed no electrocerebral activity over the entire head except for some 50 to 60 mV theta plus low-amplitude beta in the left parietal

region, corresponding to the tissue on CT scan; some tracings also revealed epileptiform discharges in the same area.”[1:364]

Child 2: The only subpial tissue found was a thin fibrous membrane entirely lacking neurons.[1]

Child 3: “MRI revealed a gross brain malformation mainly resembling hydranencephaly. A “thin slab of frontal lobe” was detected.[1:368]

Child 4: “Three EEGs, at ages 4 years, 4 years 6 months, and 9 years 6 months all showed no activity in frontal, central, and temporal leads.”[1:369]

The authors comment on these findings:

“Even if [child 1 and 2] were not decorticate absolutely, they were enough so that physicians, including neurologists, predicted a vegetative outcome absolutely.”[1:371] “Primarily, these children’s consciousness can be inferred to be mediated subcortically, not because there were absolute zero cortical neurons, but because the few that were present could not possibly subserve the totality of their conscious behavior. Experienced neurologists, to whom the authors have shown the CT and the MRI scans also typically predicted vegetative state.”[1:371]

For detailed descriptions of these children’s conditions, EEG’s, and relevant CT and MRI images, see Shewmon and colleagues’ 1999 article.[1] Their article is the first published piece of documentation of the capacities of congenitally decorticate children

examined by their physicians in the children's homes. Two of the children were adopted by the same caretaker after initial institutionalisation and foster-home placement. They were initially not responsive to interaction. Examining specialists predicted that the children would remain vegetative and predicted that one of the children would die within a few months. In one of these cases, specialists explicitly recommended institutionalisation. All four received stimulating and nurturing care and subsequently demonstrated rudimentary purposive and voluntary behaviour. The authors document how each of the children demonstrated one or several of the following abilities: social interaction evidenced by imitative playing and vocalizing, associative learning evidenced by ability to look at some persons and objects named by a caretaker, person discrimination evidenced by facial expression, vocalization, and body movements, ability to visually follow a target, interest in their mirror image, ability to scoot around the house and visually avoid physical obstacles, and responsiveness to light and visual threat. They also showed subtle preference for different kinds of music evidenced by different reactions to different pieces, live music, and recordings.[1] These abilities support the claim that these children are capable of consciousness and rudimentary purposive and voluntary behaviour. However, if one would deny that this behaviour indicates that the children are conscious, could they still be regarded as potential agents? There is a *possibility* that the behaviour of these children is reflexive, unconscious response to external stimuli. If so, they would not be potential agents. A core question is what treatment of the children would be morally defensible in the light of such inevitable uncertainty. The moral gravity of treating the children as if they were not potential agents, if they actually are potential agents, is severe. I will argue further in the final section that this should motivate us to possibly err on the side of caution and treat the children as potential agents.

Observations similar to several of Shewmon et al's observations are documented in Barb Aleman's and Björn Merker's survey[2] which documents the behaviour of hydranencephalic children of 108 primary caretakers.

Survey responders were recruited from Hydranencephaly@YahooGroups.com, a mailing-list forum and online parent support-group for caregivers of children with hydranencephaly, and from the website Hydranencephaly.com. Results of the survey include caregivers' responses to questions regarding those of their children's abilities that indirectly indicate a capacity for consciousness, and rudimentary voluntary and purposive behaviour. Let us consider a selection of these questions, the documented responses, and clarifying comments from the survey, published in Aleman and Merker's article.[2]

First, the general question "Is your child aware of his/her surroundings?" Out of 97 responses, 81% responded "yes;" 18% responded "no." 70 responders specified how the children showed awareness. The responses included descriptions such as: "Bright eyes, smiles, moves head from side to side;" and descriptions of the children's reactions to certain situations: "He seems to be more relaxed whenever he comes home after being out. He looks around the room and smiles (as if to say he's happy to be home)" or "She mostly knows if we are near her. She gets upset if we aren't;" "Looks to people talking to her, looks to TV or sounds, coos, vocalises; smiles when approached, gets startled, wants to be picked up, fusses if left alone and turn towards sounds." [2]

To the question " Does your child turn his/her head to sound?" 96 responded, 86% responded "yes," 14% responded "no." [2]

The following cluster of questions generated helpful indications of person discrimination: "Does your child show that he/she recognises certain voices?" 91 responded, 88% responded "yes," 12% responded "no."

“ Does your child indicate if he/she recognises something or someone?” 94 responded; 77% responded ”yes,” 23% responded ”no.”

“ Does your child know you and your immediate family members?” 94 responded, 91% responded ”yes,” 9% responded ”no.”

“Does your child know the difference between a family member and a stranger?” 94 responded; 83% responded ”yes,” 17% responded ”no.”

“ Can your child be comforted more by one person than another?” 96 responded; 89% responded ”yes,” 11% responded ”no.”[2]

“Will your child take turns with you in play activities?” 88 responded; 16% responded “yes,” 84% responded “no.”

“Will your child echo or imitate you?” 90% responded; 29% responded “yes,” 71% responded “no.”[2]

In addition to the “yes/no” answers, 298 clarifying comments to this cluster of questions were documented. According to responders, differentiation between familiar people and strangers was often indicated by the child by smiling and turning the head towards the voices of familiar people, and stiffening, ”shutting down,” or crying in the presence of strangers: ”When strangers speak or touch her, she either screams or turns in on herself, as if asleep;” ”Quiet when picked up by family, cries when even touched by strangers. Would only take bottle from Mom at first, but now takes bottles from familiar people;” “Arms waving, smile, pushes body like she want to jump into their hands;” “Seemed very fascinated with my husband’s voice, would turn to look at him, seemed drawn to him” or “He smiles with me (his grandma), laughs out loud for his mom, searches with his eyes for his teacher.”[2]

Questions regarding the children's ability to enjoy positive experiences included: "Does your child smile?" 95 responded; 89% responded "yes," 11% responded "no." [2]

These results, even interpreted with significant caution, are consistent with Shewmon and colleagues' assessment of hydranencephalic children as conscious, and capable of rudimentary purposive behaviour, although probably below Gewirth's relatively demanding "threshold" level. Aleman and Merker acknowledge the limitations due to the informal context of the observations, but note that the responses are unlikely to be unduly influenced by parental bias: other questions regarding whether the child ever showed affection through hugs and kisses, or ever had been seen peaking around an obstacle to view an object, or rubbing a body part that hurt, resulted in a majority of negative responses, although parents who might be prone to exaggeration of the child's ability easily could have misinterpreted the child's behaviour and could have responded affirmatively to such questions.

We will consider two explanations of how consciousness and rudimentary voluntary and purposive behavior might have occurred in these cases.

(1) Vertical neurological re-organization

Shewmon et al suggest that "vertical" plasticity in the brain stem and related structures might explain the capacities of some congenitally decorticate children. [1] If I understand Shewmon and colleagues correctly, by "vertical plasticity" they mean that a "lower" brain structure, upon the loss of the "higher" brain structure, would begin to assume some of the functions of the lost structure. The function would, as it were, "migrate downwards" after the loss, hence vertical plasticity.¹

¹ This section has benefitted greatly from the expertise of (omitted).

While “horizontal” plasticity *within* the brain stem *or* the cortex has been documented,[13-15] vertical plasticity *between* brain stem and cortex has not previously been suggested, except briefly in Shewmon 1992,[16] in Shewmon and Holmes 1990,[17] and Shewmon et al 1999.[1] The authors argue that, in their documented cases of congenital brain deformation, neurons of the children’s brain stem might have reorganized to take over some functions that normally require a functioning cortex. Notably, the children who had some sight lacked the relevant parts of their cortex, while the children who had no sight had some remnants of the relevant parts of the cortex. The authors suggest that this might be explained by vertical plasticity in the brains of the children with some sight: if hydranencephaly occurs *before* development of cortical functions relevant for vision, neurological re-organization might give the child some vision. They also suggest that if vertical plasticity can explain the children’s vision, it might explain their cognitive capacities as well: the hydranencephaly literature describes subcortical mediation of some senses and abilities. The authors point out that commentators in the hydranencephaly literature suggest that “visual tracking, consolability, associative learning, conditioning,” amongst other mental capacities, might be subcortically mediated.[1] Shewmon et al are careful to caution, however, that vertical plasticity must be “less robust” than horizontal plasticity.[1] They are also open for the possibility that the brain might have a greater capacity for transmodal reorganization than previously thought, as supported by animal studies.[1]

(2) Is the brainstem sufficient for a capacity for consciousness?²

Björn Merker introduces a novel theory of the neurological basis of consciousness, arguing that the human upper brainstem is both necessary and sufficient for consciousness in a rudimentary sense.[3] Consciousness in such a rudimentary sense allows one “to see, to hear,

² These sections have benefitted greatly from the expertise of (omitted).

to feel, or otherwise to experience something.” This “is to be conscious, irrespective of whether in addition one is aware that one is seeing, hearing, and so forth.”[3:64] This kind of consciousness is the “medium” for more sophisticated content: “reflective awareness is thus more akin to a luxury of consciousness on the part of certain big brained species.”[3:64] His theory provides a possible explanation of the consciousness of “normal” potential and actual agents, as well as of congenitally decorticate children. His explanation does not refer to horizontal or vertical plasticity. Merker argues that an action coordination function, located in the upper brainstem, allows vertebrates to efficiently process sensory inputs and select amongst a wide range of available actions, and to assess the relative priority of these options, i.e., *exercise very rudimentary agency*. Although the cortex developed on top of the brain stem, it is not necessary for consciousness in a rudimentary sense. It is, however, crucial for the contents and sophistication of the conscious experience. This theory of labour division of the vertebrate brain would, provided it is accurate, explain the capabilities of congenitally decorticate children with a sufficiently intact brainstem. The role of subcortical brain structures for consciousness requires further clarification. First, it is essential to note that Merker’s theory of the neural organization of consciousness holds that although the cortex is essential for certain *contents* of consciousness, it is not necessary to maintain consciousness *per se*. Penfield and Jasper noticed that cortical removal even as radical as hemispherectomy does not deprive a patient of consciousness *per se*, but rather of certain abilities. Penfield and Jasper noted, while performing surgery on epileptic patients, that removal of significant parts of the cortex leaves consciousness undisturbed, although certain capacities are lost.[18, 19] The phenomenal consciousness Merker has in mind is “the state or condition presupposed by any experience whatsoever.”[3:63] Merker points out that bilateral cortical damage can cause a persistent vegetative state, but he argues that this is not a reason to equate between cortical

function and consciousness, because “cortical damage disrupts numerous brainstem mechanisms normally in receipt of cortical input.”[3:65] He points out that “Adding a small amount of damage in the brainstem to existing cortical damage “cures” what appears to be a behavioral effect of massive cortical damage.”[3:67] Merker is careful to emphasize that the midbrain has a higher function in control terms, not in terms of cognitive sophistication. The essence of the proposal is the “selection triangle” which is “a proposed key to conscious function.”[3:70] All vertebrates, including human beings, have needs. The fulfilment of needs depends on available opportunities to fulfil these needs. These “targets” must be identified, and choices must be made regarding what targets to pursue. Actions connect needs with opportunities. The selection triangle “relates target selection, action selection, and motivation as a means to optimize integration for action in real time.”[3:109] Needs, opportunities and actions work in a tripartite interaction and creates a “neural reality” that constitutes phenomenal consciousness. “An upper brainstem system organized for conscious function performs a penultimate step in action control.”[3:63] According to Merker, this integrative function of the upper brainstem originally evolved to solve problems facing vertebrates that developed mobile eyes capable of scanning the environment.[3] Merker supports his theory by referring to surgery on epileptic patients where the patients remained conscious throughout the procedure of removing large parts of their cerebral cortex, as well as his own documentation of behavior of congenitally decorticate children such as the ones described by Shewmon et al, and decorticate animals.

Neural plasticity in subcortical areas of the brain was investigated by the time of the publication of Shewmon and colleagues article.[20, 21] Brain plasticity and the brain’s ability to compensate for injury by means of plasticity continues to receive significant attention,[22, 23] as does the relevance of the brainstem for the capacity for conscious experiences.[24] Notably, recent research involving ultrasound stimulation of the thalamus in

people with brain damage from external trauma indicates that such stimulation might have at least short term positive effects.[25]

These points could arguably also help explain the observed cognitive capacities of congenitally decorticate humans. Obviously, this discussion does not aim at any scientific assessment of the accuracy of these theories. I have merely argued that Merker's and Shewmon and colleague's observations have significant implications for our application of the concepts of "potentiality for agency," and "gradual approach to agency" to congenitally decorticate humans. Their proposed explanations of these children's capacities can also help us understand why they have these capacities. Individuals with massive cortical loss could be classified as potential agents in a rudimentary sense in virtue of possessing an intact upper brainstem, or because of vertical plasticity.

4. THE PREPARATORY RIGHTS OF HYDRANENCEPHALIC CHILDREN

These observations and explanations of the capacities of hydranencephalic children have important implications for their preparatory rights to social and intellectual enrichment necessary to develop a rudimentary capacity for agency.

The possibility of neurological plasticity makes the identification of an individual as a potential agent a much more open question than previously thought. Until we have mapped all the ways in which neurological plasticity might evolve, we should *always* err on the side of caution and assume that hydranencephalic children are potential agents in a rudimentary sense. Heather Berlin has rightly pointed out that we might commit "moralistic fallacy" in the sense that we are inclined to assume that these children are conscious.[26] I agree with Berlin. It is possible that hydranencephalic children might have developed very sophisticated reflexive responses to certain stimuli. I suggest,

however, that committing moralistic fallacy is better than risk treating conscious beings as if they were unconscious. Potentiality for rudimentary agency might occur along different routes. We are morally required to be very cautious in our exclusion of an individual from the class of moral rights bearers. Add to this the possibility that a functioning upper brain stem *might* co-exist with some vertical neurological plasticity. The classification of bearers of preparatory rights appears significantly more complex than Gewirth realized.

Institutionalized hydranencephalic children are typically un-responsive, while a noteworthy number of children who have been raised in stimulating home environments interact socially. Shewmon et al suggest that assumptions that these children are chronically incapable of consciousness could be self-fulfilling prophecies. Placements of children that significantly reduce their opportunities for social interaction and intellectual stimulation will likely prevent these children from ever developing any visible agential capacities. Individualized care and stimulation are imperative to provide them opportunities to feel sufficiently secure to show any signs of responsiveness. They might show no signs of responsiveness to people or environment for extended periods of time yet benefit from enriched environments. Eye movements, facial expression, and vocalization might be their only means of communication. They have preparatory rights regardless of demonstration of any visible “gradual approach” towards agency. Institutions are often sub-optimal alternatives for these highly sensitive children, but homebased care might be unfeasible. Predictions of chronic incapacity for conscious experiences have sometimes affected placement decisions and are arguably one of the weightiest factors in placement decisions regarding congenitally decorticate children. A child’s potentiality, not her current developmental stage, is relevant for decisions. Home-based care by an exclusive group of people who develop close, lasting relationships with the child optimizes the child’s opportunities to develop her potentiality for

exercising rudimentary agency and should be regarded as the default alternative. This is not a conclusive argument for the claim that home-based care is preferable in *all* circumstances. But we have arguably rebutted *one* of the weightiest arguments for institutionalised care that does not provide individualised social and intellectual enrichment. These children's sensitivity to sudden changes in their care setting adds weight to this conclusion.

Homebased care for a congenitally decorticate child might require full time engagement by the primary caretaker. In some cases, the circumstances might not allow for both the primary caretaker's generic rights to freedom and well being and the preparatory rights of the child to be fulfilled. In such cases, there is a conflict between the generic rights of the primary caretaker and the preparatory rights of the child. Moral philosophers disagree regarding the moral weight of agents' rights to freedom and well being versus potential agents' preparatory rights. There might be several defensible ways of arguing that primary caretakers' rights to freedom and well being are more or less morally weighty than the preparatory rights of a congenitally decorticate child.

Let us extend the discussion to adults in a vegetative state. Patients in vegetative states suffer from severe damage to the cortex, while the brainstem is relatively spared. A patient in a vegetative state is awake but unaware of herself and the environment. Patients in a vegetative state have motor responses to external stimuli that are limited or inconsistent. This makes evaluations of consciousness challenging.[27]

The patient is regarded as being in a permanent vegetative state if the condition has not improved by 12 months after brain injury due to trauma, and 3 months after brain injury due to causes other than trauma.[27]

The diagnosis should be questioned when there is "sustained visual pursuit, consistent reproducible visual fixation, and response to threatening gesture." [27:164] It is crucial to

“establish formal absence of any sign of conscious perception or deliberate action” before making diagnosis.[27:164]

Patients can have stereotyped responses to external stimuli such as “grimacing, crying, and occasional vocalization.”[27:165] This does not necessarily indicate conscious experiences. However, patients fulfilling all criteria for vegetative state has sometimes retained ability to respond to spoken commands. This discovery is possible due to improved methods for identifying cerebral activity.[27]

Functional neuroimaging is used to identify cognitive functioning. Conscious awareness has been detected by magnetic resonance imaging. This is a very useful tool for detecting cognitive activity in presumed vegetative patients, but it can only be used to assess cognitive activity in patients with enough cortical tissue to generate measurable activity.[27]

What similarities and differences between presumed vegetative adults and presumed vegetative hydranencephalic children can be detected, and what is the moral relevance of these similarities and differences?

One major difference is that adults in presumed vegetative states have a cerebral cortex which can be examined to detect possible activity that could indicate consciousness. Although some hydranencephalic children have cortical residue, such examinations cannot be used to detect brain activity that could indicate consciousness.

The argument can also be extended to cases of infants with severe brain damages due to extreme prematurity and asphyxia.

A birth is premature if it occurs before 37 weeks of gestation. “Premature infants are further classified as ‘very preterm’ and ‘extremely preterm’ because the complications associated with preterm birth vary based on the infant’s gestational age.”[28:183] 22-24 weeks are considered threshold for viability.

The causes of premature births are somewhat unclear, but infection plays an important role. The major complications from premature birth are respiratory distress symptoms and neurodevelopmental disability.[28] We will focus on the latter. Although the survival rate of premature infants has increased, the rate of neurodevelopmental disability remains “stable.”[28]

Perinatal asphyxia is caused by interruption in blood flow to the fetus, for instance from umbilical cord compression, “rupture of the uterus, a sudden separation of the placenta from the uterus (abruption), or maternal cardiovascular compromise.”[28:189] The fetus’ brain is deprived of oxygen.[28, 29] Metabolical changes in the brain subsequently cause cell death; so called reperfusion injury despite restoration of blood flow.[28]

What similarities and differences between such children and hydranencephalic children can be detected, and what is the ethical relevance of such similarities and differences? Again, preterm children and children whose brain have been damaged by asphyxia typically have a cerebral cortex, although it may be no more functional than the cortical residue of some hydranencephalic children. They are similar in the sense that prognosis regarding their future cognitive capacities is very uncertain at times when decisions regarding their care arrangements need to be made. A major decision is whether to proceed with invasive treatments that may be futile, or whether to focus on comfort and palliative care of these children. This ethical challenge applies to preterm children and children whose brain have been damaged by asphyxia, as well as to hydranencephalic children. Even if all available life-saving treatment is offered and the child survives, there may be significant remaining uncertainty regarding the child’s level of consciousness.

Could some decorticate children who have been diagnosed as “persistently vegetative” have so-called “islands of awareness”?

Islands of awareness “are instances of complete or partial disconnection between the brain and the body” and stimuli from the external world: the disconnection can occur in the input of impressions from the external world, or in the individual’s motor responses to impressions from the external world.[30] Some congenitally decorticate children could arguably be examples of both types of disconnection: some might be conscious without perceiving the external world, and some might perceive the external world and be incapable of motor responses to impressions from the external world. Hence, even if a congenitally decorticate child is unable to respond to external stimuli, they might still be conscious. These cases require much more ethical examination than this article could provide. I suggest, however, that morally responsible treatment of such children requires us to attend to them as if they were conscious. This article has not covered medical ethical topics such as requirements for pain relief for congenitally decorticate children. However, the argument advanced in this article obviously indicate that congenitally decorticate children should be assumed capable of experiencing pain, and that pain relief, and anaesthetics during invasive medical procedures such as surgery are required.

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