

Human dignity and researcher conduct in emergency care research with incapacitated adults

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Emergency care research sometimes involves incapacitated adults as research participants. The ethical principle of respect for autonomy may not necessarily apply to an incapacitated person unable to act in an autonomous manner, although it can be argued that researchers still have a duty of respect towards such people because they have moral status despite being incapacitated. Sharing some common ground with theories of moral status based on 'humanness' and the ability for rational thought is the notion of human dignity, which features in arguments regarding researcher conduct with incapacitated patients. However, human dignity premised upon the unique ability of humans for rational thought and moral self-regulation is contingent upon these capabilities – a limitation that possibly makes dignity a less useful framework for research conduct in emergency care research. In this article, I will discuss the different conceptions of human dignity – as equality, status and virtue – and then draw on more recent literature that explains human dignity as a social constraint and as a factor influencing the conduct of healthcare professionals and researchers. I will address questions of whether dignity as a principle ought to apply only to those who have the ability to think rationally, or to all humans regardless of their condition or mental status. I will argue that, in relation to offering protection to research participants in emergency conditions, it is immaterial which view is taken.

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Health research in the field of emergency care, both in the hospital and pre-hospital environment, sometimes involves adult patients who lack capacity to provide informed consent. This may be for a number of reasons, ranging from significant alterations in consciousness caused by a wide variety of injuries or disorders to other factors such as acute or severe pain, anxiety or the effects of analgesic and sedative medications. As a requirement for participation in health research, informed consent is considered mandatory in South Africa (SA), as specified in section 12 of the Bill of Rights of the Constitution^[1] and section 71(1) of the National Health Act No. 61 of 2003.^[2] Although it may not always be possible to obtain informed consent in such situations, several alternative approaches, such as proxy consent and delayed consent, have been suggested.^[3]

Underlying the legal requirement for informed consent is the ethical principle of respect for autonomy.^[4] This principle, originally expressed as respect for persons in the Belmont Report but reformulated as respect for autonomy by Beauchamp and Childress,^[5] is built upon the liberty and agency of the individual and their ability to protect their own interests. While the principle of respect for autonomy is considered obligatory for researchers, it is unclear to what extent this holds true when the capacity for independent decision-making is impeded. Beauchamp and Childress^[5] are of the view that there is no obligation to respect the autonomy of any individual not capable of acting in an autonomous manner. However, they point out that this does not mean such individuals are not owed moral respect. To the contrary, Beauchamp and Childress claim that researchers have a duty to protect the interests of incapacitated adults because, despite their inability to act autonomously, they still have moral status.^[5]

Considerations of moral status are considerations of who should be safeguarded by moral norms, to whom moral obligations are owed and why. Several theories of moral status exist, each putting forward an idea about what it is, in essence, that determines moral status. Many of these theories rest on characteristics or properties that might entitle a being who possesses them to moral status. Among these are theories claiming that human properties ('humanness'), cognitive properties and moral agency constitute the foundation of moral status.^[6]

While it is true that a theory positing moral status upon some notion of humanness is broadly inclusive and deals with the problem of incapacitation outlined above, such a theory might be accused of being too vague in its determination of precisely what counts as humanness or personhood.^[6] Related to this are criticisms that such a theory is no more than a form of speciesism, and does not constitute any valid claim for the moral status of humans by itself.^[7] The other two theories of moral status suffer from a similar problem – they rest upon the ability to think rationally, and seem not to apply in cases where individuals are not able to do so, including those who are incapacitated in emergencies.^[6] Limitations in application of the three theories above, particularly those contingent upon cognition, raise questions about the moral status of incapacitated research participants, and what principles should guide the conduct of researchers under such circumstances.

Inherent in any consideration of moral respect is the notion of human dignity. While notoriously difficult to define, and dismissed by some as nothing more than a synonym for the principle of autonomy,^[8] dignity is appealing in relation to this problem because it

may be thought of as operating at a societal and not just an individual level. That is, an appeal to dignity can be seen as a constraint on behaviours towards others who society views as abhorrent or undignified. Moreover, there is also a view that considerations of dignity and the respect owed to others because of it persist beyond the realm of normal cognition and even life itself. Thus, consideration of the dignity of incapacitated adults may serve as a useful framework for researcher conduct in such situations.

In this article, I will discuss the different conceptions of human dignity, firstly in a more general sense and then specifically in relation to the context of emergency care research with incapacitated adults. I will address questions of whether dignity as a principle ought to apply only to those who have the ability to think rationally, or to all humans regardless of their condition or mental status. I will argue that, in relation to offering guidance for researcher conduct in emergency conditions, it is immaterial which view is taken. This argument is based partly on dignity as a social norm constraining researcher conduct, partly on the dignity of researchers acting in accordance with their standing as professionals and partly due to the vulnerability of incapacitated research participants.

Human dignity and bioethics

The word *dignitas*, from which dignity is derived, refers to 'social honour, position or rank', things that themselves are dependent on the recognition of achievement.^[9] Human dignity is the complement of dignity, meaning that it recognises that which is common to all humans, and not that which elevates one above another on the basis of acts or achievements.^[10,11] It is not an exceptional, transient high-water mark, but rather a fundamental minimum possession of all humans, equally, as a result of their 'humanness'. It is not, conceptually at least, gained or lost.^[10]

Human dignity has a long history, with origins in Western religion and philosophy. Religious roots of dignity are grounded in the notion of humans created in the image of God – the *imago Dei*. In the religious sense, the hierarchical, rank-related meaning of dignity is not in the differentiation of one from another, but rather in the prime position that humans occupy in relation to the rest of creation.^[9] The notion of human dignity – *hominis dignitas* – is attributed to Cicero, extending through a historical philosophical development from Aristotle and including the Stoic philosophers. The resultant idea that all humans are 'fellow-citizens' is developed by Cicero in his articulation of *hominis dignitas*, the most important aspect of which is not mere human exceptionalism because of the shared ability to reason, but also that this quality is shared equally by all humans.^[12]

The Enlightenment saw a subtle but progressive deterioration in the influence of religious authority, partly due to secularisation of society but also due to scientific progress and its increasingly mechanistic, atomistic and deterministic view of nature, leaving little place for God, either in a role as creator or as a means of accounting for observed phenomena. Towards the end of the Enlightenment, the development of sociopolitical theory produced a swing away from religious grounds as a justification for human rights, with new ideas centred on democratic forms of social structure.^[9] By late Modernity, a further recession of the influence of human dignity in society was evident from the mid-19th to 20th centuries, followed by a resurgence later in the 20th century primarily in response to the devaluing of human life experienced in the two World Wars.^[9]

To understand the many nuanced dimensions of human dignity, I have adopted a taxonomy that draws on three main themes: equality, status and virtue.^[13] This is by no means the only way of dissecting dignity, but it brings to the surface several perspectives that prove useful in placing dignity within the context of emergency care research and incapacitated patients.

Equality as human dignity

The first of these broad themes is about the concept of human dignity as it relates to humanness – a 'basic' human dignity said to be irreducible and enjoyed equally by all humans regardless of their circumstances or actions. This conception of human dignity is the easiest to grasp intuitively, perhaps because of its alignment with human rights. Byleveldt and Brownsword^[10] view human dignity as the bedrock of human rights, and argue that in this sense, dignity can be considered as a form of empowerment grounded in the human capacity for autonomous action. Such capacity, in turn, requires the capacity for rational thought and free will. A similar principle is embodied by the Kantian idea of dignity arising from the unique capacity of humans to follow their own laws of moral reason and the duty of respect for the dignity of others that this implies, as a form of equality. Indeed, not only did Kant see dignity in this way, but as Rosen^[14] points out, he went further than just capacity for moral reasoning, stating that dignity is a feature of those who 'follow the moral law's commands'.

Equality as human dignity can also be interpreted as something seemingly at odds with the idea of individual autonomy and empowerment described above. This rests upon Kant's 'formula of humanity', that humanity (both in the form of the individual themselves and in the form of others) should be treated 'always at the same time as an end, never merely as a means'.^[14] This can be interpreted as a duty of self-esteem to uphold one's own dignity, but equally as a duty to respect the self-esteem and dignity of others. More recently, this duty to respect the self-esteem of others has taken on a communitarian form emphasising the setting of limits to the choices of individuals as an expression of a societal interpretation of dignity – what Byleveldt and Brownsword^[10] call dignity as constraint. Thus, when human equality is the perspective taken on dignity, we can see dignity as a form of individual empowerment or societal constraint. The former may well be threatened by a state of incapacitation, while the latter may be an important check on researcher conduct in such contexts, as argued below.

Status as human dignity

In contrast to the basic or intrinsic dignity described above, status-based dignity arises from status conferred on an individual by society – historically, the conception of dignity with the oldest roots. Schroeder^[15] provides a useful overview of status-based dignity, dividing this form of dignity into two main types. *Comportment* dignity is that founded upon social rank or position and outwardly displayed, but in this case, what is displayed is the human quality expected of an individual with this type of societal standing. *Meritorious* dignity is that related to status, but conveying the essence that status (or honour) is deserved or earned rather than just displayed. While it seems obvious that these two forms of status-based dignity stand in opposition to the idea of a basic or intrinsic dignity, Killmister^[16] has proposed a different way of thinking about these that involves

a replacement of societal values as the reference point. By replacing societal values with personal values, Killmister creates what she refers to as aspirational dignity – dignity as a function of being in alignment with one's own values and principles. This is described in a way that effectively transforms what started out as status-based dignity into a Kantian type of dignity more closely approximating basic dignity – something inherent in the human condition.

Aspirational dignity has an important contingency that weakens the argument that it is a form of basic dignity, because dignity defined in this way could not be applied to those lacking the capacity to uphold their values. In order to overcome this problem, Killmister differentiates between capacity and ability – the former being a 'latent potential' while the latter is an 'immediate possibility of action'.^[16] From this differentiation flows the idea that capacity as latent potential must be present in all persons even if ability is either temporarily or permanently absent. Hence a solution to the problem of incapacity, although rarer instances where individuals have never and may never have capacity lingers as a challenge.

Virtue as human dignity

In contrast to other moral theories that emphasise the role of obligations, rules or consequences of actions, virtue ethics emphasises the social and moral value of an individual's character – their virtues.^[17] Virtue ethics is thus about the virtuous individual living up to the standards of excellence that they set for themselves.^[18]

Dignity can be conceptualised from a virtue ethics viewpoint in two ways. The first is derived from related concepts such as meritorious or comportment dignity described above. In this sense, dignity is associated with those displaying virtues such as excellence, superior achievement or high social status.^[19] Virtues that are associated with dignity of this nature are not moral virtues, and so, like the exclusive nature of this type of dignity, the associated virtues do not really contribute to the moral discourse. The second way of relating virtue to dignity is to consider the complementary relationship. In other words, to see that there is virtue in respecting the dignity of others.^[19] Unlike the first conception above, this one assumes our acceptance of a basic or intrinsic dignity.

The virtue of respecting the dignity of others was first articulated as *observantia* by Thomas Aquinas.^[19] Undoubtedly, in Aquinas' time this referred to status-based dignity, but Jones^[19] argues that it can be thought of as a more general virtue. He argues that the related virtue of *dulia* – respect for an individual premised upon their status – means that there is a general respect to be shown for all humans because the nature of human dignity stems solely from being human, and should not actually be thought of as status-based.^[19]

Much of what is contained in our understanding of dignity, whether it is the status-based type or the basic, intrinsic type, emphasises the normality of the human condition. That is, when we think about human dignity we tend to imagine the autonomous, rational and perhaps even flourishing individual acting in accordance with their values and principles. Yet the healthcare environment often involves individuals in very different circumstances. Taking this into account, Jones^[19] proposes a further virtue of *miseritordia* that he argues could apply more generally, but that has special relevance in the dignity-virtue ethics relationship in healthcare. *Miseritordia* is the virtue of fitting empathy for the adversity of others. This is not the same as pity, which is an affirmation of elevated status of one over another. As

a virtue it stresses the normality of dependence of humans on each other, rather than obscure this fact by foregrounding independence as a key feature of dignity. Drawing on Thomas Aquinas again, Jones suggests that *observantia* and *miseritordia* are complementary virtues.^[19] *Observantia* unbalanced by *miseritordia* might suggest an uncaring overemphasis on autonomy, while the opposite might verge on paternalism – together they produce the balance and unity required to respect the dignity of those in need.

Human dignity, autonomy and the incapacitated adult in emergency care research

The importance of human dignity in emergency care research, in particular research involving incapacitated adults, lies with understanding how consideration of dignity informs researcher conduct. The claim that all research participants have basic, intrinsic dignity and are therefore owed respect, which in turn translates into a number of different responsibilities on the part of researchers, is well accepted.^[3,20-22] However, as described above, this claim is premised upon two main ideas. Firstly, that this dignity is justified because of the human capability for rational thought. Secondly, as an expression of Kantian moral theory, that this dignity is justified not only by the ability for rational thought but by the human ability for moral reasoning and its associated law-giving role.

With human dignity seemingly tightly bound to rationality, whether in the simpler form of Kant's abiding by the moral law, it is important to consider what the position might be in the case of individuals who lose this ability for rational thought. This has obvious application to research in an emergency care context where patients may have reduced levels of consciousness varying from disorientation to complete unresponsiveness due to a range of conditions or injuries. Thus, for whatever reason, a patient in acute, severe pain or one with impaired consciousness lacks the fundamental cognitive substrate upon which dignity rests as part of the human condition. What does this mean for researchers?

Two interpretations of the above problem are possible. Firstly, that the loss of ability to think rationally on the part of such patients means that they do not meet the threshold condition for basic 'intrinsic' dignity and therefore there is no duty for others to respect that which is not present. Secondly, that dignity is not actually contingent upon the demonstrable ability for rational thought (or following the moral law), but rather that it is contingent upon capacity for this, which is more like latent ability of the kind that could be argued to exist in any human who had such ability before an acute compromise.^[16] Simply put, the first argument is that dignity wanes together with cognition, and is not a permanent feature of being human. The second argument is that dignity lives on with the individual regardless of cognition, even after death.

If the first interpretation above is true, that dignity can be 'lost' by individuals who lose the ability to think rationally, what are the implications for the conduct of researchers wishing to include such individuals in research? Does it literally follow that in this case no respect for dignity is owed by researchers who can and will more or less do as they please in research with incapacitated patients, treating them as a means to an end rather than an end in themselves, as prohibited by Kant on the basis of dignity? A counter-argument to this position can be based on the following:

(i) Byleveldt and Brownsword's^[10] notion of dignity as constraint is described above: that is, a societal interpretation of dignity that constrains the actions of individuals because these actions are considered to be in conflict with this interpretation. In essence, dignity as constraint is founded upon the idea of respect for the dignity of others, but in a general, normative sense rather than on a case-by-case basis. Consequently, even if a logical argument could be made in an individual case that a lack of capacity results in a loss of individual dignity, such a societal norm would likely prevent the undignified treatment of the individual concerned. This may be a more significant factor when the norm for dignified conduct applies to a researcher who may also be a member of a profession and bound by a code of conduct or an oath.

(ii) As Killmister^[16] points out in her article on dignity, respect for the dignity of another is not the only (or necessarily the most important) consideration in the ethical conduct of research. Dignity of the researcher also determines what conduct would be considered acceptable under such circumstances. This sounds similar to the point above; however, the locus is different. In this case, rather than being constrained by a societal norm for dignified conduct, in treating an incapacitated patient with respect, the researcher is acting in a way that also respects their own dignity and standing as a professional.

(iii) Incapacitated patients, particularly those *in extremis*, are particularly vulnerable. A discussion about vulnerability in emergency care research is beyond the scope of this article, but for now vulnerability can be considered to mean a lack of capacity for autonomous action and an inability (to at least some degree) to protect one's own interests.^[23] Identifying research participants as vulnerable means that there is a responsibility on the part of researchers, but also on the part of research ethics committees providing ethical approval for research, to ensure that additional measures are in place to protect and safeguard the interests of such participants.

The arguments above, especially the second one, sound very familiar – they are closely associated with the virtue ethics notion of *observantia* (the acknowledgement of another's dignity) described above. However, a component of *observantia* acknowledges the autonomy of others, which in the case of an incapacitated patient would not be applicable. What is more applicable and speaks to the idea of dignified conduct by a researcher when dealing with an incapacitated patient, is the virtue of *misericordia* – fitting empathy that reminds a researcher of the dignity of others, especially those who cannot protect their own interests.

The arguments above (*i - iii*), about what might prevent undignified treatment of incapacitated patients by researchers, are important if the position is adopted that it is possible for an incapacitated patient to 'lose' their dignity and therefore, theoretically at least, not be seen as owed a duty of respect. The alternative position, that dignity is contingent upon latent capacity for rational thought and self-legislation rather than immediate ability,^[16] bypasses the need for such considerations because according to this position an incapacitated patient would not 'lose' their dignity at all and would be seen – even if completely unresponsive – as still being owed full respect.

At this point, when considering what dignity means for researcher conduct in emergency care research and for the treatment of incapacitated patients, it is relevant to ask whether it matters which

position is taken. The important end-point is that considerations of dignity guide researchers in their conduct, whether this assumes either position above, and offers protection to those who cannot protect their own interests. There is doubtlessly a lingering unease, in fact as Killmister^[16] points out, a sense of irrationality, in accepting that the most vulnerable patients may also not 'have' dignity that needs to be respected. While this may be an important deeper, philosophical problem that requires future work (for example how 'intrinsic' or 'inalienable' dignity can be 'lost' in the first place), at a pragmatic level consideration of dignity in emergency care research, whichever way it is viewed, offers a useful framework to guide researcher conduct.

Conclusion

In this article, I have questioned whether considerations of human dignity ought to apply to incapacitated patients in the context of emergency care research, or only those capable of rational thought. This is an important question because of the role that consideration of human dignity plays in moderation of researcher conduct and protection of research participants in such contexts. After describing human dignity as equality, status and virtue, I focused on themes of dignity as constraint and dignity as empowerment of not only the research participant but also the researcher. In this way, I draw an association between dignity as researcher empowerment and the virtues of *observantia* and *misericordia*, and suggest that both of these may serve as a useful framework to guide researcher conduct in the context of emergency care research. I suggest further that this is not dependent on the mental status of research participants, nor whether the position is taken that human dignity is contingent upon this.

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