

Research Bank

Book chapter

Dignity, being and becoming in research ethics

Kirchhoffer, David G.

Chapter 7: by Kirchhoffer, David G.

This material has been published in *Beyond Autonomy: Limits and alternatives to informed consent in research ethics and law* by Kirchhoffer, David G.; Richards, Bernadette

<https://doi.org/10.1017/9781108649247.008>

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BEYOND AUTONOMY

Limits and Alternatives to Informed Consent in
Research Ethics and Law

Edited by

DAVID G. KIRCHHOFFER

Australian Catholic University

BERNADETTE J. RICHARDS

University of Adelaide



CAMBRIDGE
UNIVERSITY PRESS

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University Printing House, Cambridge CB2 8BS, United Kingdom

One Liberty Plaza, 20th Floor, New York, NY 10006, USA

477 Williamstown Road, Port Melbourne, VIC 3207, Australia

314–321, 3rd Floor, Plot 3, Splendor Forum, Jasola District Centre,
New Delhi – 110025, India

79 Anson Road, #06–04/06, Singapore 079906

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www.cambridge.org

Information on this title: www.cambridge.org/9781108491907

DOI: [10.1017/9781108649247](https://doi.org/10.1017/9781108649247)

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First published 2019

Printed and bound in Great Britain by Clays Ltd, Elcograf S.p.A.

A catalogue record for this publication is available from the British Library.

Library of Congress Cataloging-in-Publication Data

Names: Kirchhoffer, David G., editor. | Richards, Bernadette, editor.

Title: Beyond autonomy : limits and alternatives to informed consent in research ethics and law /

Edited by David G. Kirchhoffer, Australian Catholic University, Bernadette J. Richards,
University of Adelaide.

Description: New York, NY : Cambridge University Press, 2019.

Identifiers: LCCN 2019014857 | ISBN 9781108491907 (hardback) | ISBN 9781108741309 (pbk.)

Subjects: LCSH: Informed consent (Medical law) | Medicine—Research—Moral and ethical aspects. |

Biology—Research—Moral and ethical aspects. | Bioethics.

Classification: LCC K3611.I5 B49 2019 | DDC 174.2/8—dc23

LC record available at <https://lcn.loc.gov/2019014857>

ISBN 978-1-108-49190-7 Hardback

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Dignity, Being and Becoming in Research Ethics

DAVID G. KIRCHHOFFER

Since the end of World War II, most guidelines governing human research seem to have relied on the principle of respect for autonomy as a key, though not sole, criterion in assessing the moral validity of research involving human participants.¹ One explanation for this apparent reliance on respect for autonomy may be that respect for autonomy, made effective through the practice of obtaining informed consent, functions as a useful proxy when dealing with competent adults for the more complex principle of respect for human dignity that underpins much of the moral discourse in this area. If this explanation holds, then assessment of the moral licitness of research involving human individuals whose autonomy is limited in some way requires a deeper analysis of the ‘thicker’ concepts of *human dignity*, since we cannot rely on respect for autonomy to do the work of respect for human dignity where autonomy (understood as a capacity to consent based on adequate information) is not present, is limited or is compromised.

In this chapter, I argue that, properly understood, human dignity is a multidimensional concept that has both an ontological and an existential dimension: dignity is something people objectively always already have by virtue of their being human and their essential possession of a range of human capacities (ontological); dignity is also something that people seek to subjectively realise in their lives through their moral engagements with the relationships around them (existential). Such a conception of dignity situates respect for autonomy as part of a hermeneutical ethical process of existential meaning-making. The consequence for human research ethics is that such a conception of human dignity provides a better explanation than respect for autonomy of the kinds of guidelines in place for vulnerable populations as well as of the expectations we have of research professionals. Such a conception of human dignity also gives

¹ See the Introduction.

more weight than respect for autonomy to the role of relationship, while still achieving the desired protection from 'bad' paternalism that respect for autonomy is supposed to secure in the case of competent adults.

First, I briefly examine how the principle of respect for autonomy presumes and operationalises some prior value. Second, proposing that this value is human dignity, I explain the idea of human dignity as a multidimensional concept, the aim of which is to assert the worth of the human individual as a meaning-making, historically situated, embodied subject in relation to all that is. Third, I argue that human research ethics should be understood at least in part as a hermeneutical process of existential meaning-making. Finally, I unpack some of the implications for human research ethics.

Respect for Human Dignity Grounds Respect for Autonomy

At its core, human research ethics grapples with a long-standing moral question: when is it okay to do something bad to achieve something good? What we mean by bad and good is of central importance to this question.

Clearly, when we do research ethics, regardless of the motives of the individual researcher, we morally approve or disapprove of the actual research based in part on its potential positive benefits for humanity. At the same time, we are aware that such research often involves doing, or at least risking, bad things, i.e., things that we might otherwise consider to be morally unjustifiable harms. For example, we would generally consider sticking a needle into someone without good reason to be a morally unjustifiable harm, and hence morally wrong. So, when we do research ethics, we want to find some way to say that research with potentially positive outcomes for humanity, complete with the risk or inevitability of any bad things, is nonetheless *morally* good. It would make no sense to talk about wanting to find a way to justify *morally bad* research.

By making the distinction here between *bad* and *good* on the one hand, and *morally bad* and *morally good* on the other, I am showing how human research ethics accepts that there are some harms (or at least risks of harm) that are inevitable in the process of conducting such research, but in and of themselves, with some important exceptions, these harms do not determine the morality of the research. Where there are proportionate reasons – i.e., goods in a suitable proportion to the harms caused or risked – and any harms are not morally bad in themselves, then research is justified as morally good.

Despite the idea of proportionate reasons being able to justify some harms, we do not typically consider research to be morally good or bad simply by subtracting the sum of harms from the sum of goods. This brings us to the question of what research would be considered morally bad in itself, regardless of the outcomes. What harms are so bad that no amount of good outcomes can justify them? This question suggests that there are some deontological principles, duties or rules at play in human research ethics, such that to contravene these would make the research itself morally bad regardless of any positive outcomes.

An example of research that we could say is morally bad solely by virtue of the harm caused would be the Tuskegee syphilis studies. Men were allowed to die from a preventable disease. Not only were they not informed that their disease could be treated with penicillin, but it was deemed acceptable not to inform them, knowing that this would lead to their death.² At first sight, this might look like the violation of respect for autonomy is the grave harm that makes this research morally bad, regardless of the outcomes. It would not be incorrect to make this assertion. Nonetheless, such an assertion does not fully answer why the research is morally bad in itself. If, for example, the men had been informed that an effective treatment was available and had nonetheless consented to the study and chosen not to take the treatment, we would still say that the research should not have gone ahead. This points to another value that must explain why we would still object even if it looked like autonomy was being respected.

Another way of making this connection between autonomy and some prior value is to ask: why do we consider respect for autonomy such an important principle in research ethics? One answer could be that we consider autonomy itself as an intrinsic moral good. On this view, autonomy, where it is present, should never be violated. One problem with this view is that this does not explain why we nonetheless care about the morality of research where autonomy is *not* present. A second possible answer to the question is that respect for autonomy is a principle that operationalises some other more primary principle. If this is so, then that primary principle would explain not only why we respect autonomy where it is present, but also why we are concerned about the morality of

² National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, *US Public Health Service Syphilis Study at Tuskegee*, website (Centers for Disease Control and Prevention, 14 December 2015); available at www.cdc.gov/tuskegee/index.html

research even, and perhaps even more so, when autonomy is absent, limited or compromised.

I propose that the reason that the Tuskegee study was morally bad is not merely because it did not respect the participants' autonomy – their right to be informed and to choose – but also because it violated the meaningfulness of their lives. Human lives were used wastefully. They should not have been allowed to die. Even if they had consented, there is nothing heroic about dying needlessly. Similarly, we are concerned about research where autonomy is limited, compromised or absent because we are concerned not merely with harms but with the meaningfulness of the lives of those individuals who would be harmed. In this chapter, I propose that this apparently prior concern for the meaningfulness of our lives and of human life more generally can be understood in terms of the dignity (or worth) of human individuals.

From what has been discussed so far, it should be clear that to speak of respect for the dignity of human individuals, while including respect for autonomy where this is possible, must account for, and yet mean more than merely respect for autonomy. If this were not the case, no research where you could not get informed consent would ever be possible; and, so-called research, where you could get informed consent but that had dire consequences for the participants, could be morally justifiable.

To propose that human dignity is the value in which we should be interested, and not, for example, beneficence or justice is not to say these other values are not important, or that they do not also go some way to explaining the way we think about research ethics both where autonomy is present and where it is absent. Rather, my point is that even these values and their corresponding principles point to a prior value that has to do with the dignity of human individuals themselves. Beneficence matters because we want to do good for human individuals; justice matters because we are concerned about human individuals getting their due. It is neither the good done nor the due given that is of primary importance because without human individuals as the objects of beneficence and justice, beneficence and justice are meaningless.

Moreover, though space does not allow for an extended argument on this, without some prior value like human dignity, even beneficence and justice can be twisted in a way that would make research to the detriment of *some* human individuals seem justifiable in the cause of some supposedly greater good. A supposedly good end would seem to justify the otherwise morally bad means, and we would find ourselves back at square one, namely that any research can be justified simply by weighing

benefits against harms done. Such calculative reasoning could be applied not only where there is no autonomy, but also where there is, since there would now be little reason to have to respect the autonomy of individual research participants as long as one could justify to 'society' that the research delivered some greater good. Without some prior value that grounds autonomy, beneficence and justice, such research, while perhaps distasteful to some, would nonetheless be morally justifiable. Such supposed justifications were offered by Nazi doctors at the Nuremberg trials.³

A Multidimensional Conceptualisation of Human Dignity

Proposing human dignity as a prior value that would help us to overcome the challenges of the limitations of autonomy in human research ethics is not without its own problems. One cannot make such a suggestion and ignore the problem of 'dignity talk'. Dignity talk is where two sides of a moral argument both appeal to dignity as the ultimate ground of their argument, even though they are proposing opposing moral behaviours as the right thing to do. In human research ethics, one such case is the debate about the use of human embryonic stem cells. Those in favour say that such research furthers human dignity by yielding new treatments. Those opposed would say that such embryos do possess the full dignity of human individuals and so any research that involves their creation solely for that purpose or their destruction is always morally bad.

Some have seen in 'dignity talk' an opportunity to call for the dismissal of the language of human dignity from moral discourse.⁴ Such an approach is unhelpful for two reasons. First, it would be practically difficult because the concept of human dignity is deeply embedded in human rights discourse and consequently in many of the guidelines governing human research ethics, particularly those stemming from the United Nations and Europe.⁵ Second, dismissing the language of dignity or replacing it with another concept like respect for autonomy does not solve the problems we have already discussed. As should already be clear,

³ G. J. Annas, 'The legacy of the Nuremberg Doctors' Trial to American bioethics and human rights', *Minnesota Journal of Law, Science & Technology*, 10 (2009), 19–40, 21.

⁴ For example, R. Macklin, 'Dignity is a useless concept', *BMJ*, 327 (2003), 1419–20.

⁵ For example, the first principle of the UNESCO, *Universal Declaration on Bioethics and Human Rights* (2005), Article 3.1 (available at www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/) states, 'Human dignity, human rights and fundamental freedoms are to be fully respected.'

a proper conceptualisation of human dignity would account for principles like respect for autonomy or respect for life, as well as for something more than those individual principles. In other words, there seems to be added value for ethics in a multidimensional conceptualisation of human dignity that both affirms and accounts for our concern to respect autonomy. In what follows, I elaborate such a conceptualisation of human dignity.⁶

Human dignity refers to the moral worth of a particular human individual. I have intentionally avoided the use of person or being, because the former is too easily associated simply with respect for autonomy, and the latter is too easily associated merely with respect for the sanctity of human life. Neither is appropriate, since then one would simply have two competing values – autonomy and life – both claiming to be the only reason human individuals possess moral worth. The conceptualisation of human dignity proposed here seeks to hold these and other values in dialectical tension by emphasising that it is the human individual understood as a multidimensional whole that we deem to have moral worth rather than any single feature characteristic of human beings. For the concept of human dignity to have meaning, then, we must first consider the human individual to whom it refers. When claiming that human research must respect human dignity, we are claiming that it should promote, or at least not hinder, the morally justifiable existential flourishing of each meaning-seeking and meaning-making embodied human subject who is in relationship to all that is.⁷

The human individual is both a specific, unchanging, timeless being, *and* a being who exists in personal, historical time, subject to physical and psychological change. In the first sense, it is true to say that I am the same individual who I always was and will be. I am identifiable by a unique genetic code, physical features like fingerprints, and a specific set of ancestral and familial relationships. I am someone's son, brother, cousin, and always will be. In the second sense, it is true to say that I am not the same individual that I was when I was a child or will be when I am an old man. Moreover, as I move through life, some of my

⁶ What follows summarises what is worked out in detail in D. G. Kirchhoffer, *Human Dignity in Contemporary Ethics* (Amherst, NY: Teneo Press, 2013).

⁷ This conception is based largely on the personalism of Louis Janssens and his notion of the human person adequately and integrally considered. See, for example, L. Janssens, 'Artificial insemination: ethical considerations', *Louvain Studies*, 8 (1980), 3–29.

relationships may change as I become a grandfather, an asylum seeker, or an elected member of parliament.

Asserting the idea that every individual always already exists as a human being, and that this being nonetheless changes over time, enables us also to make two related assertions. First, all human individuals possess in an essential way – i.e., characteristic of human nature – a broad range of capacities that are considered characteristic of the human species.⁸ These capacities are typical not only in kind or degree, but also as a set. They include not only the traditional notions of rationality and free choice (the basis of respect for autonomy), but also the capacities of emotion, play, imagination, creativity, the capacity to love, the capacity to take responsibility, and the capacity to behave and reflect on behaviour in a morally meaningful way. The capacities together constitute an essential potential, uniquely human and inherent in all human individuals, regardless of the actual level of development of these capacities. This is the potential to have a morally meaningful life in the unique set of historical relationships in which each human individual finds him- or herself.

Second, and at the same time, human individuals aim to realise this potential by pursuing a conscious sense of self-worth or pride through their moral behaviour. The need for the conscious sense of self-worth arises from the experience of the ambiguity of being in relationship. Some things, people and institutions are clearly good for us and affirm our sense of self-worth and the meaningfulness of our lives. Being loved, eating tasty food and being supported by a community when in need are examples of experiences that affirm our worth and the meaningfulness of our continued existence. Being threatened with violence, feeling the pain of hunger, and being cast out and excluded are experiences that make us painfully aware of our own vulnerability and mortality, raising in turn questions of worth, meaning and purpose. Our responses to these experiences are typically moral, i.e., they involve feelings, thoughts and behaviours that we assess to be good or bad, right or wrong. At the subjective level, these responses are motivated by the desire to affirm one's own sense of self-worth. Precisely what one considers to be self-worth affirming behaviour, however, will depend on one's own historical experience, perception and learning about such behaviours. For example, if I learn to equate respect with being feared, then I might think that self-worth can be obtained by engaging in violent behaviour towards others, causing

⁸ See, for example, M. Nussbaum, *Women and Human Development: The Capabilities Approach* (Cambridge: Cambridge University Press, 2000), 77–80.

them to fear me. By contrast, if I learn that saints are people who are honoured for their self-sacrificing behaviour for the good of others, then I might think self-worth can be obtained through charitable acts. In all cases, there is a complex interrelationship between one's own ideas of what would give one a strong sense of self-worth, and the expectations and behaviours of one's social context.

Stating that human individuals pursue, at a subjective level, a sense of self-worth through behaviour that we might describe as moral is not to say that there are no objective moral norms. In other words, what I subjectively believe to confer self-worth, and consequently what I subjectively consider to be morally justifiable behaviour, may not necessarily coincide with what is objectively a morally good sense of self-worth and morally right behaviour. There needs to be some way to assess in an objective way why the behaviour of a violent man who believes respect is the same as fear is morally wrong, and the behaviour of the saint is morally right.

Before addressing the question of the objective moral norm, we need to consider what this conception of the human individual means for our conception of human dignity.

Human dignity is a worth that all human individuals always already have by virtue of their being members of the human species with an inherent potential to realise a morally good sense of self-worth through morally right behaviour. Yet dignity can also be acquired, violated or diminished through one's own moral behaviour or the moral behaviour of others. This may be both in a subjective way – I feel like my own dignity, my own sense of my worth has been violated – and in an objective way – his dignity was violated. Both of these ways can refer either to the dignity that inheres in one's potential to live a morally meaningful life (inherent dignity), or to one's acquired sense of self-worth (acquired dignity). In the case of the latter, however, while it is meaningful and correct to say that any person can subjectively feel that her acquired sense of self-worth has been violated (the violent man, for example, might feel that those who do not fear him are disrespecting him), only objectively morally good conceptions of self-worth can be said to be violated in an objectively moral way (so it would not violate his dignity to restrain such a violent man with force in an effort to reform his conception of self-worth). By contrast, inherent worth is always objectively so because it inheres in our being human in an essential way, in human nature, and so can only be objectively violated (so, executing the violent man would violate his inherent worth and be morally wrong).

What is important to note is that this conception of human dignity is 'both, and' rather than 'either, or'. It is both something we have in an ontological sense *and* something we acquire in an existential sense, since the human individual is similarly both an ontological and existential reality.

This brings us back to the question of the objective moral norm. I propose that this moral norm be, 'Respect human dignity!' This means three things:

First, the inherent dignity of being human with a set of essential capacities that constitute the potential to live a morally meaningful life through morally good behaviour should be promoted, or at least not violated.

Second, an individual's acquired sense of self-worth, where this is itself an objectively morally good conception of self-worth (acquired dignity), should not be violated. An objectively morally good conception of self-worth is one that does not deny or contribute to the violation of the inherent dignity of other human beings or of their morally legitimate acquired dignity. If my sense of dignity depends on the diminishment of others' fundamental worth as human individuals, or their legitimate senses of acquired dignity as self-worth, then there is clearly something mistaken with my own acquired sense of dignity. By calling into question the claim of some human individuals to be treated as having a moral worth fundamentally equal to that of my own, I call into question the very claim that I have any fundamental human moral worth at all. In effect, such a conception of self-worth is bad because it amounts to a kind of existential bullying whereby I dehumanise or demonise others to feel better about myself.

Third, since inherent worth is realised as self-worth through morally good behaviour that furthers the dignity of others, such objectively morally good behaviour for the good of others should be encouraged, or at least not inhibited.

In those cases where a human individual does not, or cannot, express all of the characteristic features of being human, apart from membership of the species, then it falls to other human individuals to act morally on his or her behalf, as if the potential were realisable by the individual him or herself. This is because all human individuals are always already in relationship with all of humanity. In other words, we respect the dignity of all human individuals, even where they cannot respect it or strive to realise a meaningful sense of self-worth themselves. The reason for this is

that we realise our own dignity through our morally good behaviour. Not recognising the inherent moral worth of any other human individual undermines the very premise that I have dignity that should be respected and realised. So, where it falls to me to make moral choices on behalf of someone who is unable to do so for themselves, I must make those choices that promote the dignity in all respects of the individual on whose behalf I am choosing. That is, whatever capacities are there or potentially realisable should not be violated, and the choices should result in the individual's participation in objectively morally good behaviours for the good of the dignity of others such that the individual (though perhaps unable to realise self-worth) nonetheless is afforded acquired dignity by others as a morally good participant in society.

Hermeneutical Ethics

The multidimensional conception of the human individual that underpins the above conception of human dignity also has implications for how we think about what it is that we do when we engage in human research ethics.

In light of the multidimensional conception of the human individual and of human dignity outlined above, it could be said that all ethics is at least in part a hermeneutical enterprise. That is, the moral choices I make are the result of my interpretation of my experiences of being in relationship, and of how my engagement in these relationships makes my life meaningful and purposeful. Interpreting for meaning in an existential sense is a vital part of how we acquire dignity as self-worth by utilising the potential that inheres in our capacities as human individuals to engage in moral behaviour that affirms our dignity, worth and hence meaningfulness and purposefulness in the eyes of others.

In the context of human research ethics, by contrast, ethics is often reduced to legalistic proceduralism.⁹ In order to gain clearance from an HREC/IRB, one must submit a research protocol that abides by some or other accepted research guidelines, ensuring that by obtaining informed consent one does not violate autonomy, or that one can justify, usually by appealing to some other rule (e.g., it is low risk), why informed consent is not required in this case. Once all the boxes are ticked, the research can get underway.

⁹ See, among others, O. O'Neill, 'Accountability, trust and informed consent in medical practice and research', *Clinical Medicine*, 4 (2004), 269–76.

I do not want to say that such a procedural view does not have its place or its advantages. Yet, an excessive focus on procedures and rules does have a downside: it does not take seriously the conception of the human individual as making meaning about existence and his or her place in it through his or her moral behaviour. By focusing on rules and procedures alone, there is a danger of losing sight not only of the moral meaning of those rules and procedures in terms of why they are there, but also of the moral meaning of the entire research enterprise.

We do research because ultimately we think it will be good for human beings. Keeping this in view is important if we are to take seriously the multidimensional conception of human individuals and their dignity. We want to take this multidimensional conception of human dignity seriously because it helps us to think carefully about the moral implications of our research, to own those implications, and to take personal responsibility for those implications as moral meaning-makers ourselves. Taking dignity seriously also ensures that we tread lightly and with humility when we approach our research, aware that how we do it has implications for how we and others see the world, the meaning of our lives in it, and indeed the grounds for our own sense of self-worth. This is especially important where our research necessitates exposing people to harms or risks.

Respecting Dignity in Human Research Ethics

Morally acceptable research involving human individuals does not undermine:

- A. their inherent dignity as potential to live a morally meaningful life, or
- B. their acquired dignity as a morally good sense of self-worth (i.e., one that does not rely on diminishing A or B in others), or
- C. the moral rightness of their own behaviours (you cannot ask a participant to do something that they believe is morally wrong because it violates A or B in others).

This applies not only to the research participants, but also to the researchers and members of the HREC and IRB. Their dignity, their moral meaning-making are also at stake.

Respecting Autonomy Where It Is Present

I have proposed above that we can derive the principle of respect for autonomy from the principle of respect for human dignity (other

reasons for respecting autonomy notwithstanding). Since autonomy, as a combination of the essential human traits of rationality and free choice, is one of the key capabilities co-constitutive of the dignity of human individuals, it makes sense as a general starting point that respecting human dignity necessitates respecting autonomy where this is present through procedures like obtaining informed consent.

It also means allowing consensual research where there is no proportionate direct *physical* benefit for the participant, provided (A) is not undermined and (B) and (C) are morally good and right respectively (i.e., do not undermine the dignity of others).

Consider, for example, an individual who is already dying (and there is no cure). Such an individual could legitimately enrol in research that had no direct benefit but that was likely to contribute substantially to new knowledge that might lead to a cure for others. Consent in such cases would not violate dignity, for two reasons. First, the death of the individual is imminent and unavoidable and so in choosing to participate in the research the basic good of human life, which is part of inherent dignity (A), is not violated (i.e., life is not unjustifiably shortened). This would not be the case if a healthy individual engaged in research that they knew would kill them (see section on Overriding Autonomy Where It Conflicts with Dignity). Second, the individual interprets her participation as realising her dignity through engaging in morally good behaviour for the good of humanity and so furthers (B) rather than violates it. This may even be justifiable for research that would contain substantial risk of other harms, for example, pain. The individual freely and reasonably accepts this harm as a sacrifice she is willing to make in the name of a good cause.

Note, however, that this situation of being near death in itself potentially creates an additional vulnerability. Such people could be targeted by researchers for exploitation. So, willingness to make a sacrifice is not itself adequate to protect the dignity of the participant,¹⁰ and other considerations such as the legitimacy of the research methods, likelihood of success, and possibly even how the sacrifice participants make will be acknowledged (as is done in some places for people who donate their bodies to science after death) ought to be taken into account.

¹⁰ My thanks to Philippa Byers for pointing out this additional vulnerability.

Overriding Autonomy Where It Conflicts with Dignity

By grounding our respect for autonomy in the thicker conception of respect for dignity, however, we are also able to ensure that choice alone is not a sufficient reason to make research morally legitimate.

First, we would not allow research that undermines the potential that inheres in an individual's human capacities (the dignity we all already have) where the individual chooses to participate based on a mistaken notion of how this behaviour is meaningful for his acquired dignity. This is why the Tuskegee syphilis studies would still have been morally wrong even if there was informed consent by the participants. Unlike the previous example, we would not want an individual with syphilis to consent to a study that would allow him to die from the disease where we know we have a simple and effective cure. No motive in this case, no matter how heroic the individual may subjectively but mistakenly think he is being, could justify the destruction of his life. It would be a violation of (A) above. Moreover, the researchers who performed such a study would be violating (C), because their behaviour could not be described as objectively morally good because it violates (A) for the research participant.

Second, we would not allow research that is done with the full consent of the participant, but where this consent is only obtained because the individual has a bad conception of what dignity as self-worth entails, i.e., one that undermines the dignity of others. Research on such a premise would perpetuate an objectively morally bad conception of self-worth and thereby violate (B) above. Consider the violent man of an earlier example. It would be morally wrong to conduct research on him that depended on and perpetuated his mistaken belief that he can acquire dignity through violence.

Worrying Less about 'Informed' Consent When Research Respects Dignity

The consideration of both why we respect autonomy and when we think it is legitimate to override it in light of the thicker norm of respecting dignity is important because it also helps us to think about the morality of those greyer areas of limited or compromised autonomy where it is possible to obtain something that looks like consent, but where the extent to which the individual was adequately or could be adequately informed is questionable or where the 'freeness' of his or her consent is

questionable. In such cases, if the research meets criteria (A), (B) and (C) then, though we still need to respect autonomy to the extent possible, we need to worry less about how it makes the research morally acceptable. We can instead focus more on how dignity (including the individual's capacity to use the limited autonomy she does have to live meaningfully) is being respected or at least not violated. In other words, that an individual does not completely understand the information she was given would not necessarily make the consent invalid or the research morally illegitimate. Typically, this would only involve very low risk research, though it need not exclude minor inconvenience, e.g., consenting to giving a blood sample. On the other hand, research where the intention of the researchers was morally dubious, for example research that has a motive to prove that, for example, asylum seekers should not be treated as moral equals, would be morally wrong, because its purpose undermines the dignity of those whom it is researching.

This is not to say that we should not make a substantial effort to ensure that an individual is informed, because if he is informed, then the meaningfulness of his consent for his own dignity as self-worth is enhanced. Rather, it is to say that where this level of informing participants would be difficult or unreasonable to expect – perhaps because of the complexity of study or the capacity of the participants, or because it would compromise the method of the study – then as long as it does not otherwise violate their dignity, it is morally permissible.

Dignifying Participants in Cases of Absent Autonomy

Respect for human dignity, then, helps to explain why we should respect autonomy, can help to limit cases of an inappropriate use of autonomy, and provides a framework for considering the morality of research in cases of limited or compromised autonomy. Now we need to consider cases of absent autonomy.

As discussed above, morally justifiable research ought not to involve harms or risks that limit (B) and (C), or that damage (A) for *all* involved, including the researcher and the HREC/IRB members, the relatives of the subject and humanity more broadly conceived. The dignity of those involved in the research, and indeed of humanity in general, becomes even more important when the autonomy of the research participant is absent.

Where autonomy is absent, in most cases, proportionate direct physical benefit can justify research. But it is not merely the physical benefit

that justifies the research. Just as a rich conception of respect for dignity grounds our concern for autonomy, so it grounds our concern for direct physical benefit. Such direct physical benefits can be said to indirectly further (A) and (B). For example, if a trial drug is likely to improve the likelihood of an infant surviving to a point at which she is able to develop a meaningful sense of her own autonomy, and with it a sense of dignity as self-worth, then it could be morally justified.

The trickier case is where there is no direct physical benefit. Typically, this research is only acceptable in cases of minimal risk, with a benefit for the same group as the subject. My proposal is that we should extend our understanding of benefit to include (B) by (C), i.e., acquiring a dignity through morally good behaviour. This should not significantly change the existing guidelines, but it would change the way we think of the individual participating in research and consequently the way we justify the guidelines. Instead of merely being the non-informed and non-consenting research subject, the individual is now a participant in morally good behaviour to further the dignity of others, and thereby, becoming more, not less dignified herself. While it is true that this is not a choice that she could have made as an individual (it is made for her, on her behalf, by others involved: the researchers, the HREC/IRB, and especially her family and friends), by making this choice, the individual is being dignified as a meaningful being in relation to all that is. The fact of her existence as a human being is meaningful. She is not being treated merely as an object that will help 'us' produce useful research. Rather, she is being treated as if she herself was capable of making meaning through her own morally good choices in relationship to others.

This is not simply a change in words. This is a change in how we do human research ethics. One of the reasons that the emphasis on respect for autonomy arose was to protect research participants from bad paternalism that claimed it was acceptable to sacrifice some for the good of the many. What I am proposing does not involve such a sacrifice. It does not involve doing something *morally* bad to achieve something good. This is because I cannot undermine (A) and so I must treat the human individual as if the potential that inheres in human capacities is present and realisable, even in this exceptional case. For this reason, only minimal risk research is acceptable. Bad paternalism denied the dignity of the research subjects. They were expendable. I am proposing that this dignity be taken seriously. No one is to be treated in a way that suggests that we consider them to be expendable, sub-human or less worthy of our concern and respect. This is different from simply asserting that an

individual who cannot consent can be enrolled in a study that does not benefit him or her if it helps his or her group and is low risk. It takes seriously the human individuals – that is, everyone involved in a given research protocol, from the researchers and the members of the HREC, to the participants, their relatives and the potential beneficiaries – as meaning-making, historical, embodied subjects in relation to all that is. Since we all possess (A) and consequently seek (B), and since (C) is determined precisely by the extent to which it furthers (A) and (B), our own realisation of dignity (B) is dependent on how we treat others (C) regardless of the extent to which they actually display autonomy.