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PATIENT DIGNITY: THE SIGNIFICANCE OF RELATIONSHIP

PATIENT DIGNITY: THE SIGNIFICANCE OF RELATIONSHIP

By

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the Requirements for the Degree Master of Arts

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Abstract

How do we preserve patient dignity in the health care context? I begin with a brief overview of dignity according to Kant, and follow this with an examination of what dignity means to patients and practitioners. I then propose a relational and care approach to dignity that does not indelibly tie individual dignity to any particular capacity or set of capacities. A relational and care account of the equal dignity all individuals possess ensures all human beings have value as particular individuals – value that demands respect – regardless of individual capacity. With a relational and care approach to dignity in mind I suggest and defend that patient dignity is best preserved and promoted in the context of the patient-practitioner relationship. I reject the notion patient-practitioner relationships are contractual in nature and suggest adopting a model of 'relationship as engagement' (Bergum and Dossetor, 2005) as a means to respecting patient dignity. I look at two major barriers to 'relationship as engagement' – the manner in which health care is delivered and the evidence-based medicine movement – and suggest ways to address and overcome these barriers. I conclude the paper by highlighting the various accounts of centredness (patient, person, client, family, relationship) espoused by many health care organisations, affirming relationship is the appropriate vehicle for respecting patient dignity.

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Introduction

The question guiding this paper is: how do we preserve patient dignity in the health care context? I propose and defend a relational and care approach to dignity where the basis of dignity is found in the relationships of care we bear to one another. More specifically, we each have individual equal worth because we have been cared for. Without care we would not reach maturity and thrive to the degree we are each able. It is in forging a relation of care with another, or the actual willingness of some to do so, that individual dignity is at once conferred and actualised. In a relational and care approach to dignity the basis of equal individual worth is not inextricably linked to a particular capacity or set of attributes we as individuals are assumed to possess. Rather than focusing on the 'what' of dignity – finding the essence of dignity – a relational approach allows us to focus on how and why respect for individual dignity is important. With this approach to individual dignity in mind, I suggest and defend that it is in the context of the practitioner-patient relationship that patient dignity is best promoted and preserved. If, as I claim, dignity is not tied to any capacity or set of attributes individual humans are presumed to possess then the principle of autonomy, so central to health care ethics, cannot adequately capture dignity. Autonomy and dignity are distinct concepts and how we go about respecting dignity can be quite different from the way we respect autonomy.

Chapter One: Dignity

In this chapter I explore the meaning of dignity, with special reference to the meaning of dignity in the health care context. While I examine everyday understandings of what it means to respect dignity in the health care context the final aim of this chapter is to make a case for individual dignity that is not tied to agency, rationality, or autonomy. The alternative to grounding dignity in our capacities for rationality or any other norm of human functioning, I will argue, is to locate the basis of human dignity in the relationships we as humans are all enmeshed in.

While my overarching goal is to argue dignity need not be intricately tied to agency, rationality or autonomy, it would be remiss of me to make no mention of any theory that does tie dignity to the capacity for autonomy. I begin, then, with a brief overview of Kant's argument for human dignity. Certainly, Kant is not the only philosopher to take up the issue of dignity but he does present a particularly persuasive argument for the inherent and equal worth of all human beings. We need only look to many of the human rights documents endorsed or drafted by the United Nations to see Kant's influence at work. Kant's argument for dignity relies on our capacity for autonomy – he who is in possession of an autonomous will also possesses dignity, hence he must be treated as an end in himself and not merely as a means – and this presents us with a serious problem. If Kant's argument is correct then there are some humans who have never had and never will have dignity, as well as many who will lose their dignity as they lose their capacity for autonomy. On Kant's account infants, the severely mentally retarded, the demented, and perhaps all patients (due to their vulnerability hence diminished capacity for autonomy) have no dignity. I propose a possible

solution to this rather serious problem, one that pushes Kant's original argument but preserves the Kantian spirit. I finish the section by asking why we need to tie dignity to the capacity for autonomy at all; a question I return to in the final section of this chapter.

In the second section, I turn to the empirical literature. How is dignity defined in the health care literature? What are patients saying? What are health care practitioners saying? Is dignity preserving care an important issue for patients and health care practitioners? While dignity is unquestionably important to both patients and practitioners it does appear to be vaguely defined and under-theorised at best. Regardless of dignity's uncertain and nebulous meaning in the health care context (dignity is often conflated with integrity or independence or autonomy) there is no doubting its importance to practitioners and patients alike. Most of the studies cited are from the nursing literature and pertain to the elderly, persons requiring home based nursing care, or persons with disabilities. This should come as no surprise; these segments of the patient population are so often overlooked (their voices are not heard), and equally often perceived as having severely limited capacities for autonomy. I offer a brief overview of Chochinov's 'dignity therapy' for the palliative patient. Chochinov's work is particularly significant because it is recognised and recognisable as clinical evidence supporting the importance of enhancing patient dignity.[1] Dignity therapy itself is an entirely evidence-based model[2] giving it credence in the health care context we would have difficulty finding in the purely theoretic literature. I finish the section with a brief look at preserving the dignity of children in the health care context. While the studies I refer to clearly highlight

[1] Consider some of the journals that have published Chochinov's studies: Lancet Oncology (2011); Journal of Clinical Oncology (2005); Lancet (2002); Journal of Palliative Medicine (2006); Journal of Palliative Care (2004)

[2] See Chochinov, H. M. *Dignity therapy, a handbook for clinicians*. Oxford: Oxford UP, 2011. Especially chapter one.

the importance of dignity enhancing care to both practitioners and patients there remains a significant limitation. Virtually all of the studies presume the patient has at least minimal rationality and a sense of personal autonomy or, in the case of children, the potential for rationality and autonomy. In a sense, then, we are left believing dignity (and, in particular, a *sense* of dignity) is solely the purview of those patients who have the capacity for rationality, agency and/or autonomy. While the severely mentally retarded or the anencephalic infant might arguably not feel a *sense* of dignity, it does not follow they are not possessors of dignity that deserves respect and preservation.

In the third and final section I return to the question of whether we need to tie dignity to the capacity for autonomy at all. I take a relational and care approach to dignity, an approach that is grounded in our relationships with one another rather than the presumed unique capacity of humans to be rational beings capable of abstract thought, agency and/or autonomy. After all, in the age of technology a computer is capable of rational abstract thought, and, intuitively at least, few of us would be willing to credit a computer with dignity. As Eva Feder Kittay articulates it, there is dignity in being 'some mother's child'[3] in that some other(s) enters into a relation of care with that child, taking on the responsibility for his or her well-being. Dignity then is not grounded in some common property we all possess as humans (or membership in a species capable of rationality, autonomy and moral action, as my possible solution to the problem posed by Kantian dignity suggests). Rather, the

[3] Kittay, Eva Feder. "Equality, Dignity and Disability." *Perspectives on Equality: the second Seamus Heaney Lectures*. Ed. Mary Ann Lyons and Ed. Fionnuala Waldron. Dublin: The Liffey Press, 2005. 95-122.

relationships of care we are all enmeshed in at once confer, acknowledge and actualise intrinsic worth.[4]

I. Always treat humanity as an end, and never merely as a means.

I begin with Kant for several reasons. First, and foremost, Kant presents us with a persuasive argument for the *equal* dignity of all human beings. For Kant dignity is not something earned nor is it bestowed by virtue of a person's station in life. We do not earn dignity through morally exemplary behaviour, military victories, or through any other arbitrary, yet admired, act. A reigning monarch has no more, or less, dignity than a homeless person who makes her home in a quiet sheltered space under a bridge. According to Kant, as human beings we all have inherent value and we all have it equally. Second, Kant's entire ethical project sets us up with particular rights and corresponding duties. We see this in action quite clearly in the health care context in terms of patient rights and health care practitioner duties or obligations. Where the patient has the right to autonomy, usually exemplified by his or her right to adequate information to make an informed choice regarding treatment, the health care practitioner has a corresponding obligation to provide the requisite information and by so doing respect the patient's autonomy. Third, on a much larger scale we see Kant's influence in the entire realm of human rights that most nations at least purport to value, respect and protect. In particular, we can see the *equal* dignity of all

[4] Ibid. 117.

human beings invoked in the Universal Declaration of Human Rights.[5] Last, by and large health care ethics, especially in the patient care context, is more a duty-based ethic than a utilitarian ethic. In the patient care context, ethical decision-making seeks to do what is good or right for a particular individual patient rather than what stands to improve overall well-being for the largest number of people. To be very clear, I am not implying all health care decisions relevant to individual patients and their families are unconcerned with consequences, and in many cases – organ donation is a good example – a decision might manage to address both utilitarian and deontological concerns.

In order to gain a clear understanding of Kant's account of human dignity we need to see what underlies dignity. According to Kant what makes us so distinctive is our rationality, and as rational beings we have the capacity for moral autonomy. For Kant, autonomy *is* the capacity for moral action. More precisely, autonomy is the ability to be moral 'self-legislators' in that we create the moral law that we obey. We create the moral law that we must follow by following Kant's universal law formulation of the Categorical Imperative: "*act only in accordance with that maxim through which you can at the same time will that it become a universal law"* or "*act as if the maxim of your action were to become by your will a universal law of nature.*"[6] When Kant discusses autonomy he is discussing moral autonomy – our ability to ensure our actions are morally right – not the ability to be aware of and in control of our personal desires and goals. The universal law formulation of the Categorical Imperative is quite straightforward

[5] "The Universal Declaration of Human Rights." United Nations, 2012. Web. 23 Jul 2012. <http://www.un.org/en/documents/udhr/>.
[6] Kant, Immanuel, and Mary J. Gregor. *Groundwork Of The Metaphysics Of Morals*. New York: Cambridge UP, 2000. 31

and certainly easy to follow even if it can lead to rather dire consequences.[7] But Kant is not concerned with good consequences; he is concerned with right (moral) action that stems from right motive. Despite the potential for dire consequences Kant's account of moral autonomy has definite appeal: it is universal and it does not require any appeal to authority.

Kant does not assume all rational beings are autonomous; rather all rational beings have the *capacity* for autonomy. The distinction is subtle but important in that it shows Kant acknowledges we are social as well as rational beings, often moved to action by desire, whim or social pressure, and as such we are often motivated to act in ways that are either morally unimportant or that ignore moral duty altogether. It is the rational being's *capacity* for autonomy that underpins dignity: "…humanity insofar as it is capable of morality, is that which alone has dignity."[8] Is there a way to observe the *capacity* for moral autonomy? Indeed there is: if all rational beings have the capacity for moral autonomy then we need the means to assess rationality. In the health care context the process of determining mental competency to make an informed choice or give informed consent generally addresses the assessment of rationality.

Would Kant consider patients rational at all? Patients may be vulnerable, mentally incapacitated, unconscious, demented, profoundly mentally retarded, children. Can such patients be regarded as rational if we look through Kant's lens? If they are not rational they will not have the capacity for moral autonomy and presumably, for this reason, will lack dignity. If we understand dignity as closely tied with rationality it would seem our inherent worth, our dignity, waxes and wanes. But nothing Kant says about the dignity of human

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[7] For example, do I tell the truth when a known killer asks where his next victim is?
[8] Kant, Immanuel, and Mary J. Gregor. *Groundwork Of The Metaphysics Of Morals*. New York: Cambridge University Press, 2000. 42

beings implies dignity is a fluid quality that stands to dissipate when in a drunken stupor, in love, or any other time a usually rational person becomes irrational. While it is perhaps arguable on Kant's account that many patients – particularly the very young, the demented or the comatose – are not rational hence do not have the capacity for autonomy, it is still plausible that the very young, demented or comatose either will have or have had the capacity for rationality (hence a capacity for autonomy) and for this reason should still be assumed to have inherent worth. So, while these classes of patients will not be able to demand respect for their autonomy they do still have dignity and as such there is an imperative to respect their dignity. To be clear, the imperative is not just the hypothetical variety where one must adopt the means necessary to achieve a desired goal; the imperative to respect dignity – to always treat humanity as an end and never merely as a means – is categorical. Of course, this works well for the class of patients who are rational and sometimes autonomous and plausibly for those potentially rational and autonomous. But what about the patient who does not and never will have the capacity for rationality (never mind autonomy)?

On what grounds ought we treat non-rational patients with dignity, or at the very least *as if* they have dignity? One possible answer is that we ought to treat every one *as if* he or she possesses dignity for the same reason we ought to treat an animal with kindness: it is an expression of our humanity; it is a means of respecting our own dignity. But, this type of answer skirts the issue at hand – treating another human (regardless of their capacity for rationality) *as if* they possess dignity in order to preserve and respect our own dignity is just treating him or her merely as a means for our own ends, which, on Kant's account, is expressly what we must not do. I expect there are a number of ways to use Kant's own

arguments on autonomy, rationality and dignity to support treating the class of humans who never have had and never will have the capacity for rationality with dignity, however I see one method which clearly acknowledges our relational and social nature. Rather than considering the rationality or the dignity of individual humans we ought to consider the rationality and dignity of humanity as a species or community. On the macro view of humanity as species it is positively awe inspiring to contemplate our capacity to reason, to innovate and to care. Equally awesome is our capacity for cruelty, violence and sheer immorality (however defined). Consider that on Kant's account even the most heinous criminal cannot forfeit his or her dignity. Granted, the successful criminal probably has the ability for rational thought that the severely mentally retarded will never have, and for this reason has at the very least the capacity for moral autonomy (even though he or she chooses not to exercise this capacity). Undesirable and immoral behaviour of particular human beings does not give us grounds to rescind their membership in the human community – this seems clear in Kant's writing. What bearing does the dignity of heinous criminals have on the dignity of the person who is incapable of rationality? On the surface, it seems a rather impertinent argument to put forward: since heinous criminals retain their dignity despite their despicable actions we ought to assume the severely brain damaged or mentally retarded also have inherent value. Still, the immoral criminal who chooses to ignore his capacity for moral autonomy and the mentally retarded individual who simply does not have the capacity are both members of the human community. At least insofar as other, presumably rational, members of the human community have recognised and accepted them as such. As members of the human community we can presuppose every individual human has the capacity for rationality without seeking empirical proof for such a capacity. While I do not

see in Kant's writing a clear path for arguing in support of the dignity of *individual* humans who do not have the capacity for moral autonomy, taking an extra step on Kant's behalf, by regarding humanity as species or community, the dignity of every *member* of the human species can be adequately captured.

Stretching and massaging Kant's argument for human dignity might work admirably, but it still leaves us with an understanding of human dignity that is indelibly linked to human rationality. Focusing on the human capacity for rational thought and behaviour completely ignores how incredibly irrational humans can be. Right or wrong, we follow our hearts as often as our heads. The sour taste of jealousy, the sweetness of love or the burn of rage can hardly be regarded as shining examples of our capacity for rationality. Yet, such bouts of irrationality are no less exemplary of what it means to be human. Unwavering rationality leaves little room for empathy, compassion and care. If we insist upon using the capacity for rationality as our measure of humanity then perhaps we ought to extend a deeper respect to computers, since they are capable of an unfaltering adherence to rational behaviour. I suspect a computer would be more adept at applying and adhering to Kant's universal law formulation of the Categorical Imperative than any human being. Tying dignity to the individual's capacity for rationality, agency or autonomy is as arbitrary as tying it to the individual's capacity for empathy, compassion or any other trait we assume is the sole domain of humanity.

For now, the question of whether it is needed or appropriate to tie dignity to rationality (and by extension autonomy) at all I leave open.

II. What does dignity mean to health care providers and recipients?

The first point to note when we ask about the meaning of dignity in health care is that the health care literature does not yield any one clear definition of dignity. The terms dignity, integrity, 'to be a person' and autonomy, in many instances, appear to be practically interchangeable. All too often it appears the reader is expected to know what dignity means, hence no real exploration of the meaning of dignity is deemed necessary. I am not especially surprised by this considering western biomedical ethics makes no clear mention of a principle of dignity, at least not in the action guiding sense we find in the principle of autonomy.[9] Dignity appears to be relevant, interesting but under-theorised at best or, if we accept Ruth Macklin's assessment, useless at worst.[10] The second point I wish to make clear is that the studies and papers referred to here represent a survey of the literature rather than a representative selection taken from a comprehensive literature review. I have purposely selected papers that do attempt to provide a clear definition of dignity.

i) Themes and definitions.

The papers that discuss the concept of dignity in broad terms differentiate between objective and subjective dignity. Gallagher[11], Badcott[12], Nordenfelt[13], Edgar[14], and Pullman[15]

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[9] See Beauchamp, Tom L. and James F. Childress. *Principles of Biomedical Ethics, 5th ed.* Oxford: Oxford UP, 2001. Dignity is not one of the four guiding principles of biomedical ethics according to the authors, and yet at least one edition of this book it can be found in virtually every mid-sized medical library in the Western world.

[10] Macklin, Ruth. "Dignity is a Useless Concept." *BMJ.* 327. (2003): 1419.

[11] Gallagher, Ann. "Dignity and Respect for Dignity – Two Key Health Professional Values: Implications for Nursing Practice." *Nursing Ethics.* 11, 6. (2004): 587-99.

all refer to at least two conceptions of dignity – an objective dignity, which we all possess by virtue of being human, and subjective dignity, which includes both how we value ourselves and how value is bestowed or stripped away by others. While all five authors agree on the inalienability of objective dignity their primary concern is with the relevance of subjective dignity to individual patients.

In terms of objective dignity Badcott appeals to the dignity of humans as a species. By appealing to the dignity of humans as a species Badcott avoids the search for some ubiquitous essential element all individual humans possess in life and is nevertheless retained by the dead human body. For Badcott, human dignity is an entirely normative concept: "we are all part of a continuum of *Menschenwürde* that spans and includes the fully autonomous living, the compromised and the deceased. If there is an *essence* that attracts dignity, it is through membership of the human species."[16] [17] Subjective or *emotional* dignity, the focus of the article, is tied to our feelings and relationships. Disrespectful or inconsiderate behaviour undermines our emotional dignity. Our sense of inherent worth can be bolstered by the respectful attitude and behaviour of others. A lack of self-respect will also undermine emotional dignity. Given Badcott's assertion that emotional dignity is tied to feelings and relationships, our self-respect will be highly influenced by the actions and behaviours of

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[12] Badcott, David. "The Basis and Relevance of Emotional Dignity." *Medicine, Health Care and Philosophy.* 6. (2003): 123-31.
[13] Nordenfelt, Lennart. "The Varieties of Dignity." *Health Care Analysis.* 12, 2. (2004): 69-81.
[14] Edgar, Andrew. "A Response to Nordenfelt's "The Varieties of Dignity"." *Health Care Analysis.* 12, 2. (2004): 83-9.
[15] Pullman, Daryl. "Human Dignity and the Ethics and Aesthetics of Pain and Suffering." *Theoretical Medicine.* 23. (2002): 75-94.
[16] Badcott, David. "The Basis and Relevance of Emotional Dignity." *Medicine, Health Care and Philosophy.* 6. (2003): 123-31. 127.
[17] Menschenwürde: the literal translation is the dignity of man. Many authors choose to use the German when referring to a universal notion of human dignity.

others. We can internalise the attitudes of others and adopt those attitudes as our own, resulting in a loss of self-respect. Regarding subjective dignity Badcott makes the following observation: "undue focus on traditional philosophical treatments of dignity can deflect attention from what for the individual older European *might* be a vital aspect of their lives – the impact of some event or other on how they *feel* (their *emotional* dignity)."[18] Traditional theoretical treatments of dignity, such as Kant's account, will simply be far too esoteric to be meaningful in a concrete way to many patients. The insults to our sense of dignity will be felt in a very real way, and attempts to rationalise away those insults by contemplating a purely philosophical account of dignity will do nothing to soothe the emotional sting of humiliation such insults bring. He goes on to suggest that there may be significant social and cultural differences between younger and older Europeans, which may lead the younger generation to inadvertently undermine or damage the older person's sense of emotional or social dignity. Those who are less physically active but still mentally sound may have a heightened sense of dignity and be particularly sensitive to perceived threats to their dignity;[19] the suggestion being that perhaps all that remains of a once active life is a strong sense of personal dignity. His overarching aim in the final sections of his paper is to insist that while we all have a share in equal human dignity it is important to pay attention to and respect the older person's sense of *emotional* or subjective dignity. By respecting *emotional* dignity we affirm objective, equal human dignity.

[18] Ibid. 128.
[19] Ibid. 129.

Nordenfelt[20] and Edgar's[21] response to Nordenfelt's paper also attempt to capture in broad terms the differences between objective and subjective dignity. Nordenfelt outlines four types of dignity: universal dignity (Menschenwürde), dignity of merit, dignity of moral status and dignity of identity – the last three of which can potentially be undermined by the self or others. Dignity of merit encompasses the dignity a person may have by virtue of excellence in particular deeds or perhaps a profession. Examples of dignity of merit might be the achievements of a great artist or physician. Dignity of moral status is directly related to the moral value of one's actions. We might look to Mother Teresa and Desmond Tutu as exemplifying the dignity of moral status. Dignity of identity is, in Nordenfelt's terms, "the dignity that we attach to ourselves as integrated and autonomous persons, persons with a history and persons with a future with all our relationships to other human beings."[22] It is the dignity of identity that is most relevant in illness and aging since it is this type of dignity that can be easily altered (undermined or enhanced) in the context of care giving. Edgar's response argues against the usefulness of dignity of merit, dignity of moral status and dignity of identity by claiming these interpretations of dignity are open to challenge since they depend so highly on moral values that may be culturally distinct.[23] Rather than distinguishing between types of dignity as such, Edgar urges that we consider only Menschenwürde and what can have a detrimental effect on the individual *experience* of Menschenwürde. The subtle distinction between dignity and the experience of dignity still seems to speak to two different

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[20] Nordenfelt, Lennart. "The Varieties of Dignity." *Health Care Analysis.* 12, 2. (2004): 69-81.
[21] Edgar, Andrew. "A Response to Nordenfelt's "The Varieties of Dignity"." *Health Care Analysis.* 12, 2. (2004): 83-9.
[22] Nordenfelt, Lennart. "The Varieties of Dignity." *Health Care Analysis.* 12, 2. (2004): 69-81. 75.
[23] Edgar, Andrew. "A Response to Nordenfelt's "The Varieties of Dignity"." *Health Care Analysis.* 12, 2. (2004): 83-9. 84.

types of dignity – one which cannot, strictly speaking, be lost and another which can. While neither paper goes much further than differentiating between types of dignity (or on Edgar's account, dignity and the experience of dignity) they at least both attempt to highlight the significance of social or subjective dignity (again, on Edgar's account subjective dignity is the experience of dignity). In other words, neither paper makes any strong claim regarding how the concept of subjective dignity or the individual experience of dignity ought to guide health care practice.

Pullman's paper argues that personal dignity and whether one possesses personal dignity is contingent on "socially constructed notions and attitudes", it is this type of dignity that can be either enhanced or diminished depending on life circumstances.[24] I take it that at least some of the socially constructed notions and attitudes include attitudes toward disability, infirmity, illness, dependence and perhaps any other circumstance that removes a person from the prevailing norms of what a person in a given society ought to be capable of doing or being. In which case, there will be people who have a very tenuous experience of personal dignity simply because they do not live up to what their society regards as a life of dignity. On Pullman's account the ability to experience personal dignity can be markedly undermined by suffering. According to Pullman, our capacity to suffer is conditional upon our capacity for conscious reflection, which in turn is necessary for developing a sense of self. Certain types of suffering – such as the type of suffering that accompanies chronic or terminal illness – can disrupt our sense of integrity. Pullman does not conflate integrity and personal dignity, rather he sees integrity as tied to or maybe even a precursor to personal

[24] Pullman, Daryl. "Human Dignity and the Ethics and Aesthetics of Pain and Suffering." *Theoretical Medicine.* 23. (2002): 75-94. 83.

dignity. If our sense of bodily and, depending on the type of illness, mental integrity is shaken so will our sense of personal dignity be shaken. While much of what Pullman claims about personal dignity is highly dependent on a sense of autonomy, integrity and independence, he also appeals to the relational nature of the self. As he puts it, "[T]he beautiful life – the life of dignity – is expressed in the caring relationships we share with one another."[25] By responding to the pain and suffering of others we affirm our mutual dignity. Pullman does not provide any concrete answers as to why we ought respect the dignity of those who may not be able to feel a sense of personal dignity, but by emphasising the interdependent and relational nature of human life he makes it quite clear that by sharing in the pain of others, acknowledging the suffering it causes us as witnesses, we affirm the dignity we all share.

Gallagher's[26] paper also carefully distinguishes between objective dignity and subjective dignity. As with the previous authors Gallagher points to objective dignity as the inherent worth we have as humans simply by virtue of being human. "This more objective view of dignity is not dependent on the utility of the person or on his or her autonomy. People have this dignity of worth regardless of their levels of competence, consciousness, autonomy, or their ability to reciprocate in human relationships. They have this dignity purely because they are human."[27] Exactly what makes us human is no less vague in Gallagher's paper than in any of the others.

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[25] Ibid. 89.
[26] Gallagher, Ann. "Dignity and Respect for Dignity – Two Key Health Professional Values: Implications for Nursing Practice." *Nursing Ethics.* 11. 6. (2004): 587-99.
[27] Ibid. 590.

Rather than speaking in broad and often speculative terms Gallagher uses vignettes to highlight the significance of subjective dignity. She addresses the importance of dignity as a self-regarding value in nursing practice, which I think is highly relevant in the health care context. If the caregiver lacks the ability to see him or herself as a person of inherent value it becomes difficult, if not impossible, to honour the inherent value in others. But this is at least partly contingent upon how others see us. As Gallagher states, "[I]t is plausible (but requires more investigation) that, when the worth, value or dignity of nurses is not respected in tangible ways then their own self-respect may be compromised and their ability to respect the dignity of patients, families and colleagues is reduced."[28] Experiencing a sense of dignity is a reciprocal process – we need it affirmed in ourselves in order to see it and affirm it in others.

It is Gallagher's use of vignettes that highlights the simple themes underlying an 'everyday' notion of dignity, as well as some ambiguities surrounding how best to respect dignity. In one vignette Gallagher relates the experience of a 64 year old wheelchair dependent woman who musters the courage to ask a nurse to take her to the toilet, to which the nurse responds: "Why don't you ask someone else?"[29] The nurse's response left the patient feeling humiliated, and while it is impossible to know exactly what the nurse was thinking she may have fallen into the bad habit of not seeing patients as individuals at all.[30] A second vignette refers to reader responses to a photograph in a newsletter. The photograph was of an older woman with an incorrectly buttoned up cardigan alongside a well-groomed uniformed nurse. One reader responded that she thought it undignified that the older

[28] Ibid. 591-2
[29] Ibid. 594.
[30] Ibid. 594

woman in the picture was improperly dressed, whereas another reader pointed out that if the older woman had buttoned her own cardigan, possibly requiring much effort, and did so in order to maintain a sense of independence then perhaps it was dignified.[31] A patient, Mary, explains "how important she thought it was that nurses smiled and acknowledged patients, and how important it was to her to have a nurse call her by name and ask if she was in pain."[32] The nature of subjective dignity can be highly variable, as Gallagher points out: "One older person said that dignity to her meant having a saucer with her cup."[33] Gallagher also highlights protocols and processes that have the potential to be either dignity enhancing or dignity violating. For example, she highlights the importance of having a privacy protocol in place, asking patients how they wish to be addressed,[34] examining processes such as clinical supervision (there is no need for any nurse to be humiliated by her superior), and how the talk that occurs during end-of-bed handovers (shift change) stands to enhance or violate patient dignity.[35]

While all five papers have dignity as their focus, Gallagher's paper, more obviously than the others, addresses the practicalities of respecting patient dignity and highlights the small acts that serve to enhance or diminish subjective dignity. Some of the more obvious themes to be drawn out are: control and independence (depending upon how we might regard the older woman with the incorrectly buttoned cardigan), being acknowledged as an individual, being addressed according to one's preference, privacy, being included (not talking about or over the patient during the end-of-bed handover).

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[31] Ibid. 595.
[32] Ibid. 595.
[33] Ibid. 595.
[34] Ibid. 596.
[35] Ibid. 597.

ii) Patient and caregiver perceptions of dignity

I begin by looking at how patients experience respect for dignity. Holmberg, Valmari and Lundgren identify three themes relevant to patients' experience of receiving homecare nursing while trying to maintain a sense of dignity and self-determination.[36] They had 21 participants in the study, who all depended on homecare nursing to varying degrees and for varying amounts of time. Each study participant took part in a 60-90 minute open-ended interview. The main themes drawn from the interviews were: *to be a person, to maintain self-esteem,* and *to have trust.* For the participant to be a person meant "to be respected as a unique individual",[37] and this included the ability to maintain privacy, the ability to make choices, participating in their nursing care, and the ability to be social with their nurse. All of these subthemes speak to the patient's need to be seen and recognised as a person rather than an object or another chore by their nurse. The ability to make choices and participate in their own care needs highlights the desire of these patients to have their sense of self-determination or autonomy acknowledged and respected by their caregivers. For the patients, receiving homecare nursing enhanced or affirmed a pre-existing healthy self-esteem. It seemed none of the patients lacked a healthy sense of self-worth prior to needing nursing care in the home. In terms of trust, the patients all had great confidence in the nurses' skills but expressed a desire for more continuity by having the same nurse come each time. The

[36] Holmberg, Marie, Gudrun Valmari, and Solveig M. Lundgren. "Patients' experiences of homecare nursing: balancing the duality between obtaining care and to maintain dignity and self-determination." *Scandinavian Journal of Caring Sciences*. Mar 16 (2012): [epub ahead of print]
[37] Ibid. 3.

biggest issues for patients were around continuity of care (having the same nurse perform specific tasks), having their nurse keep to a timely schedule (i.e. not leaving the patient tied to home waiting for the nurse to turn up), and good communication including everyday social chat. While none of these issues is particularly threatening to good care in the sense of caring for a particular ailment (no doubt, a variety of tardy uncommunicative nurses can change wound dressings or administer a daily injection with the necessary technical skill), they all contribute to the patient's feeling of being respected as a valuable individual. What I find particularly interesting is that many of the patients came up with rational explanations for why their nurse arrived late or why they had a variety of different nurses providing care. By doing so the patients managed to preserve their own sense of control and dignity. None of the participants had any pressing complaints regarding good communication between themselves and their nurses, but did find it pleasing when their nurse shared opinions or anything remotely personal.[38] To what extent the study observations and conclusions can be translated to locales other than suburban Sweden is uncertain, but given these limitations the overall conclusion is positive: homecare nursing recipients are able to balance receiving care (including the vulnerability that might entail) and maintaining a sense of dignity, and nursing practice does have a significant impact (good communication skills, continuity of care when possible, and keeping a timely schedule).

Similar themes regarding what it means to maintain a sense of dignity are found in a study by Wadensten and Ahlström.[39] [40] The study involved open-ended interviews guided by

[38] Ibid. 6.
[39] Wadensten, Barbro, and Gerd Ahlström. "The Struggle for Dignity by People with Severe Functional Disabilities." *Nursing Ethics*. 16.4 (2009): 453-65.

the broad question 'what is an ordinary day like?'[41] In both papers, Wadensten and Ahlström appear to use the terms integrity and dignity as either interchangeable or consider integrity as closely related to dignity. The only definition of dignity they provide is that all people are of equal worth, and all people have the same human rights.[42] The study participants focused heavily on integrity in their discussions and the ways in which their personal assistant could either undermine or enhance their sense of integrity. While I want to be as precise as possible around the meaning of dignity, reading what the study participants say about integrity and what it means to them it is quite clear maintaining a sense of integrity and maintaining a sense of dignity amount to much the same thing. As with Holmberg, Valmari and Lundgren's study, for the study participants maintaining a sense of integrity (or dignity) meant having a sense of control over the care situation, as well as maintaining a private sphere; and having a good relationship with the personal assistant was extremely important to maintaining a sense of control and privacy. All of the participants emphasised the importance of having a good relationship with their personal assistant, and that it was important their personal assistant be loyal and respect their need for privacy.[43] [44] This study also took place in Sweden and it is possible the results cannot be readily transferred to other

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[40] Wadensten, Barbro, and Gerd Ahlström. "Ethical Values in Personal Assistance: Narratives of People with Disabilities." *Nursing Ethics*. 16.6 (2009): 759-74.
[41] Wadensten, Barbro, and Gerd Ahlström. "The Struggle for Dignity by People with Severe Functional Disabilities." *Nursing Ethics*. 16.4 (2009): 453-65. 455.
[42] Wadensten, Barbro, and Gerd Ahlström. "Ethical Values in Personal Assistance: Narratives of People with Disabilities." *Nursing Ethics*. 16.6 (2009): 759-74.760.
[43] Wadensten, Barbro, and Gerd Ahlström. "Ethical Values in Personal Assistance: Narratives of People with Disabilities." *Nursing Ethics*. 16.6 (2009): 759-74. 766.
[44] Wadensten, Barbro, and Gerd Ahlström. "The Struggle for Dignity by People with Severe Functional Disabilities." *Nursing Ethics*. 16.4 (2009): 453-65. 456.

locales, however the two main themes – control and privacy – are consistent with Gallagher's findings and suggestions.[45]

Caregiver perceptions of patient dignity and what is necessary for promoting or preserving patient dignity are much the same as patient perspectives. Heijkenskjöld, Ekstedt and Lindwall's study focuses on nurses' understanding of what constitutes dignity preserving or dignity violating behaviour.[46] The participants were asked to identify and speak about incidences in which they either preserved or violated a patient's dignity. The two overriding themes are: nurses preserve patients' dignity by seeing patients as fellow human beings, and nurses violate patients' dignity by seeing patients as objects.[47] For the nurses, listening to the patient and dedicating time to the patient was regarded as dignity preserving. Ensuring patients are able to take part in their own care by listening to the patients' desires for the way they want their care administered preserved dignity. These two methods of seeing and respecting patients as fellow human beings reflect what patients themselves say about the importance of good communication and good relationships as a means to maintaining a sense of control. For nurses, part of preserving patient dignity is attempting to stop other nurses' inappropriate behaviour by speaking up for the patient.[48] Dignity violating behaviour included not respecting the patients' will, and this can occur when nurses insist upon strictly following procedures rather than adapting to the expressed needs or desires of the patient. One example given in the paper is abiding by the patient's desire to have the same nurse help

[45] Ann Gallagher is based in the UK.
[46] Heijkenskjöld, Katarina Bredenhof, Mirjam Ekstedt, and Lillemor Lindwall. "The Patient's Dignity from the Nurse's Perspective." *Nursing Ethics*. 17.3 (2010): 313-24.
[47] Ibid. 316.
[48] Ibid. 317.

with showering.[49] This echoes the patient's desire for continuity of care we see in the Holmberg, Valmari and Lundgren study. Approaching patients as children is identified as dignity violating. This overlaps with Gallagher's suggestion there be a protocol on how patients are to be addressed[50] – according to patient preference. By acting indifferently towards patients' bodies nurses add to the patients' sense of vulnerability, and this type of action, according to the nurses interviewed, violated patient dignity. Abandoning the patient by leaving the patient alone and unable to call for assistance was also identified as dignity violating. Again, these sorts of incidences can be easily avoided simply by utilising good communication skills: informing the patient that they will not be left alone for more than a few moments (or better still not leaving the patient in a situation where they cannot request assistance at all), or informing the patient what will occur next in the course of administering care. Heijkenskjöld, Estedt and Lindwall comment that the "habit of showing respect for one another creates an atmosphere of mutual respect"[51]; Gallagher also alludes to the importance of mutual respect as well as self-respect.

The overlap between what patients think is dignity preserving and what nurses think is dignity preserving is striking. The means to dignity preserving care, from both nurse and patient perspectives, is remarkably simple: the patient needs to be recognised as a fellow human being. Recognising others as fellow human beings involves good communication and developing good relationships. Both nurses and patients emphasise the importance of the

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[49] Ibid. 318.
[50] Gallagher, Ann. "Dignity and Respect for Dignity – Two Key Health Professional Values: Implications for Nursing Practice." *Nursing Ethics*. 11, 6. (2004): 587-99. 596.
[51] Heijkenskjöld, Katarina Bredenhof, Mirjam Ekstedt, and Lillemor Lindwall. "The Patient's Dignity from the Nurse's Perspective." *Nursing Ethics*. 17.3 (2010): 313-24. 318.

relationship and these few studies strongly indicate that the practitioner-patient relationship is the necessary foundation for preserving patient dignity.

iii) Dignity Therapy.

Where the above studies serve to highlight the importance of dignity to both practitioners and patients alike, along with some of the elements deemed crucial to maintaining a sense of dignity (control, privacy, communication, relationship), Chochinov's work on dignity therapy as an intervention for patients nearing death[52] provides strong evidence that tending to dignity has a significant and positive impact on patients. The aim of dignity therapy is to address psychosocial and existential distress in dying patients.[53] Dignity therapy is a brief psychotherapeutic intervention designed to "decrease suffering, enhance quality of life, and bolster a sense of meaning, purpose, and dignity."[54] The patient is offered an "opportunity to address issues that are important to them or speak to things they would most want remembered as death draws near. An edited transcript of these sessions is returned to the patient for them to share with individuals of their choosing."[55] In his 2011 book, *Dignity Therapy,* Chochinov makes it quite clear that the interviewer guides the patient through the session, leaving the patient free to decide exactly what should be included in the final transcript, rather than using the session as an opportunity to resolve any underlying

[52] See Chochinov, H. M. et al. "Dignity Therapy: a Novel Psychotherapeutic Intervention for Patients Near the End of Life." *Journal of Clinical Oncology.* 23.24 (2005): 5520-25. and Chochinov, H. M. *Dignity Therapy, a handbook for clinicians*. Oxford University Press, 2011.
[53] Chochinov, H. M. "Dignity Therapy: a Novel Psychotherapeutic Intervention for Patients Near the End of Life." *Journal of Clinical Oncology.* 23.24 (2005): 5520-25.
[54] Ibid. 5521.
[55] Ibid. 5521.

issues (in other words the session is not intended to be intensive last minute psychotherapy for the patient). The interviewer gently guides the patient with questions such as: "When did you feel most alive? Are there specific things that you would want your family to know about you, are there particular things you would want them to remember?"[56] The questions are designed to give the patient the opportunity to address what he or she considers important and memorable and, if needed, prompt the patient if the session stalls at any point. The choice of a written document as opposed to a videotaped session ensures it is the patient's words that are remembered, not their physical state. Also, there is opportunity to edit out the extraneous *ums* and *ahs* that pepper everyday speech, and make corrections if need be (for example, correcting geographic locations or names mentioned by the patient). Ideally, the interviewer is also the editor of the final (aside from the patient, who will always have the opportunity to give final approval) written document. To be effective as editor of the final document the interviewer needs to be able to communicate well with the patient, and this includes active attentive listening skills. The final document needs to capture the 'voice' of the patient if it is going to have the ring of authenticity and resonate with those who will be in possession of the document once the patient has died. Chochinov emphasises the need to engage with the patient – to be living in the moment rather than obsessed or overwhelmed with "forward thinking" – in order for dignity therapy to be successful.[57] Since dignity therapy is designed for end-of-life patients there is a sense of immediacy about the intervention that needs to be respected. The entire process, from initial offer of dignity therapy to the production of the final edited document, should only take a matter of days.

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[56] Ibid. 5522.
[57] Chochinov, H. M. *Dignity Therapy, a handbook for clinicians*. Oxford University Press, 2011. 23-24.

The study findings provide significant evidence that dignity is important to patients and that patient dignity can be enhanced. From the 100 patients who completed the study 67% stated that dignity therapy enhanced their sense of dignity, 68% stated that it increased their sense of purpose, and 67% stated that it heightened their sense of meaning.[58] "Hopelessness, desire for death, anxiety, will to live, and suicide all showed nonsignificant changes favoring improvement."[59] To say the changes were nonsignificant just means they were not statistically significant in that they did not meet a set threshold of statistical significance, which means the changes could be attributed to chance alone. However, even if the changes were nonsignificant statistically speaking this does not mean they are not practically significant. Taking note of statistically nonsignificant changes can often point to a trend that might be significant and noteworthy in practical terms. Also, as Chochinov goes on to note, "[I]t is not surprising that, given that patients were moving toward death, the level of well-being and current quality of life diminished slightly."[60] Eighty-one percent of patients felt that dignity therapy was or would be helpful for their families, and this perception was related to an improved sense of purpose along with a diminished sense of suffering.[61] To put this into perspective, 100 patients participated in the study. This is not a particularly large sample.

The evidence the study provides in support of dignity therapy is certainly convincing, but that does not mean there are no limitations. First, the study was conducted primarily

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[58] Chochinov, H. M. "Dignity Therapy: a Novel Psychotherapeutic Intervention for Patients Near the End of Life." *Journal of Clinical Oncology.* 23.24 (2005): 5520-25. 5523.
[59] Ibid. 5523.
[60] Ibid.
[61] Ibid. 5524.

with older patients.[62] Second, it requires the patient be able to communicate without intervention. Third, it does not seem to be appropriate for children who are nearing the end of life.[63] Finally, I expect it would be of extremely limited use for those with severe cognitive disabilities. However, Chochinov et al do point out the evidence from their study does have wide implications: "Health care practitioners should also note that evidence from this trial speaks to the importance of using every clinical encounter as an opportunity to acknowledge, reinforce, and, where possible, reaffirm the personhood of patients charged to their care."[64] I suggest reaffirming personhood means seeing the patient as a fellow human being, and this is dignity affirming.

iv) Children and dignity.

So far the studies I have referred to look at dignity from the perspective of those who have some degree of control over their lives, who strive to maintain a degree of independence, and are aware of intrusions into their private sphere. In the health care context preserving or facilitating the patients' sense of control and a sense of independence, along with protecting the private sphere amount to what it means to respect dignity, particularly subjective dignity. Effectively, the study participants – practitioners and patients – were recognisable as rational, competent persons capable of making choices and directing their own lives. They were all considered autonomous. All of the study participants would

[62] Ibid. 5525.
[63] Chochinov acknowledges this limitation in *Dignity Therapy*.
[64] Chochinov, H. M. et al. "Dignity Therapy: a Novel Psychotherapeutic Intervention for Patients Near the End of Life." *Journal of Clinical Oncology*. 23.24 (2005): 5520-25. 5525.

have given their informed consent to participate in the studies, and having the competence to give informed consent is the usual mark of autonomy in health care. In a sense then, dignity, particularly subjective dignity, is still very much tied to notions of autonomy.

What about children? They are not able to provide consent for treatment. Children rarely have control over the way their lives are lived; their age and their parents usually limit the degree of independence they enjoy; their need for and awareness of a private sphere comes with increasing age. Given these limitations, to what degree do children have a sense of their own dignity? Lundqvist and Nilstun's[65] observational study reveals that children who are able to communicate their desires certainly do have a sense of dignity and make it known when their personal dignity has been violated and make persistent efforts to preserve their dignity. The study looked at both children's and their parents' dignity. For children old enough to communicate their wishes (4 or 5 years old and up) issues around control, privacy, being included in the treatment procedures, not being abandoned are as paramount as they are for adults. Even in situations where the parents appeared to subjugate themselves (stifle their own dignity) to the practitioner the children remained persistent in their protests against invasions of bodily space. The children would protest with tears, words and gestures.[66] Based on the observational data quoted in the paper when the children's questions concerning treatment (what was going to happen next and why?) were answered and/or they could be involved in some way with the treatment procedure the children were considerably more confident and received the treatment with little or no complaint. As the authors say in their discussion of the findings: "It is interesting that children, from toddlers to teenagers, try

[65] Lundqvist, Anita, and Tore Nilstun. "Human Dignity in Paediatrics: the Effects of Health Care." *Nursing Ethics*. 14.2 (2007): 215-28.
[66] Ibid. 223-4.

to maintain their dignity intact in spite of practitioners' irresponsive treatment. The children put questions, cry, shout or make protests when they are forced to undergo treatment against their will … whereas the family members stifle their own dignity."[67] Again, just as with preserving adults' dignity, children respond well to good communication – answering the child's questions – and both parent and child appreciate the practitioner who pays attention and engages them as unique individuals.[68]

Reed et al[69] also take up the issue of the dignity of children in the health care context. The authors take an ethnographic approach to the subjective dignity of children. Their findings echo much of what the studies already outlined have concluded. Namely, we can look at dignity in two different ways – objective (or, in their words, macro) dignity and subjective (micro) dignity. In order to acknowledge and respect objective dignity we need to pay attention to, and preserve, subjective dignity. The challenge is to find a "working definition of dignity that is pertinent to all adults and children."[70] If we focus so heavily on the sense of dignity (subjective dignity) then we are left with the question why we ought to respect and preserve the dignity of the patient who has no awareness of subjective dignity. The dilemma is similar for both children and the demented elderly. For the elderly demented person a possible response is that we preserve subjective dignity (ensure privacy and refrain from obvious acts of humiliation) as a means to honour and respect who the person once

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[67] Ibid. 226.
[68] Ibid. 222. The authors relate one incident where the child makes many attempts to engage with the nurse by talking about his guinea pig, but the nurse ignores the child's attempts and focuses solely on the task at hand (weighing the child). Fortunately, the child's father is obviously supportive and the child's dignity remains intact. Child and parent 'hold their own'.
[69] Reed, Pamela et al. "Promoting the Dignity of the Child in Hospital." *Nursing Ethics*. 10.1. (2003): 67-76.
[70] Ibid. 74.

was. A similar response can be proposed for respecting children's' dignity: we ought to act in a manner that is appropriate to the child at the time and in such a way that is appropriate for who the child will become.[71]

Reed et al identify the challenge – we need a working definition of dignity that is pertinent to all adults and children – but they still imply the reason we ought to respect and preserve dignity has something to do with a crucial capacity that children potentially have and demented elderly once had. Whatever the crucial capacity is I expect there will always be individual humans we recognise as members of the human community who do not, will not, and have never had whatever that crucial capacity is.

III. The Dignity in being 'some mother's child'

It appears even children have a strong sense of their own dignity; at least children who have an obvious awareness of themselves, their bodies and are able to communicate their wishes.[72] Based on the selection of literature I have briefly outlined thus far, we can conclude that preserving patient dignity involves respecting the patient's privacy, respecting and facilitating the patient's sense of control over their situation, and enhancing or facilitating patient independence. All of this assumes the patient has at least some minimal sense of him or herself as an actor in the world; that he or she is able to make choices (even if those choices are ignored, as is often the case with children); that he or she recognises his or her

[71] Ibid. 75.
[72] Lundqvist, Anita, and Tore Nilstun. "Human Dignity in Paediatrics: the Effects of Health Care." *Nursing Ethics*. 14.2 (2007): 215-28. Lundqvist and Nilstun's study did include children under the age of two but since their study looked at the dignity of parents *and* children any observational data focused on the parents' dignity rather than the child's dignity.

own private sphere and when that private sphere has been intruded upon. There still seems to be a distinct link between dignity and autonomy in all of these descriptions, assuming we include control and independence as part of a loose definition of autonomy. For those patients who do have a sense or feeling of their own dignity then perhaps the link between autonomy and dignity is real and, in reference to those patients, Macklin makes a valid point by insisting dignity is a useless concept.[73] For Macklin, dignity is easily captured by respect for persons: the need for voluntary, informed consent; protection of confidentiality; and avoiding discriminatory and abusive practices.[74] I cannot dispute the evidence, which clearly indicates an affront to patient self-determination (control, independence, privacy) is experienced as an affront to dignity. But what about the patients who have no autonomy (however loosely defined), no obvious self-awareness, no discernible sense of privacy – do they have dignity? Is a sense of dignity required to have dignity? As long as dignity is tied to rationality or autonomy or the capacity for autonomy there will be many humans who are denied dignity all together. As I indicated earlier, a computer is rational – it can make rational choices given appropriate parameters, it can certainly abide by and adhere to Kant's categorical imperative better than any human, it can deal with abstract concepts – yet few of us would consider a computer worthy of dignity.

If we want to insist the new born infant, the anencephalic infant, the severely mentally retarded and the comatose possess dignity then the bases of human dignity must rest on something other than rationality, autonomy or any other presumed essential and unique property (or set of properties) of individual human beings. Rather than basing dignity

[73] Macklin, Ruth. "Dignity is a Useless Concept." *BMJ.* 327. (2003): 1419.
[74] Ibid.

on particular attributes or capabilities we have as individual humans, I take up Kittay's suggestion that we look to the "relationships we bear to one another"[75] as the foundation of individual dignity. By taking seriously the relationships of care in which we are all enmeshed to some degree we can avoid what Badcott calls the *problem of essentialism*.[76] We need not search for some property or set of properties that forms the essence of what it is to be human. The species membership argument I proposed earlier falls prey to a version of the *problem of essentialism* in that it still appeals to an attribute or set of attributes the species as a whole possesses. Badcott's version of the species membership argument refers to a *continuum*[77] (possibly avoiding the essentialism problem), but what underlies and ensures the *continuum* from birth to death (and often beyond)? It is the relationships of care that keeps the *continuum* alive. Without adequate care no infant would survive; we all need and received care in the context of a relationship with another in order to thrive at all. We continue our caring relationships even in death – at least some in our network of relationships care enough to honour our corpse by ensuring appropriate rituals surrounding death are adhered to; many of us will have our lives celebrated by those who cared for us, and most of us have taken part in such celebrations of life.

By proposing that we locate the basis of individual human dignity in the relationships we bear to one another I still acknowledge we are each members of the community or species of humans and there is value to be found in group membership. However, I am not

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[75] Kittay, Eva Feder. "Equality, Dignity and Disability." *Perspectives on Equality: the second Seamus Heaney Lectures*. Ed. Mary Ann Lyons and Ed. Fionnuala Waldron. Dublin: The Liffey Press, 2005. 95-122. 111.
[76] Badcott, David. "The Basis and Relevance of Emotional Dignity." *Medicine, Health Care and Philosophy*. 6. (2003): 123-31. 123.
[77] Ibid. 127.

simply proposing that because human beings as a species are capable of caring relationships we must therefore treat each member of the species with dignity regardless of his or her capability to care for another just because they share in the group's dignity. Individual equal human dignity requires more than species membership. Still, I do acknowledge a place for group dignity regardless of how we argue for it or which arbitrarily chosen attribute we decide is characteristic of humanity; but the notion of group dignity cannot adequately explain why an *individual* has dignity *aside* from being a member of the group. If we only appeal to species membership as the basis of dignity then it remains possible to argue that individuals who do have the capacity to exercise the characteristically human attribute have a greater dignity than those individuals who do not. It might even be possible to argue that the individuals who actually exercise the chosen human attribute have somewhat more dignity than those who merely have the capacity to exercise said attribute. Group dignity allows all members of the group to have dignity by association, which is certainly useful and valuable, but dignity by association does not explain the dignity of each particular individual. Consider the following example roughly adapted from Kittay[78]: the moral outrage we feel at the abandonment of an infant is in part due to the affront to the dignity the infant has by virtue of being a member of the human species. It is the infant's dignity by association (the infant's group dignity) that has been violated. But dignity by association does not speak to the worth the infant would have as a particular individual if she or he were cared for. It is through caring that the intrinsic worth of a particular individual is both conferred and actualised. Our moral outrage alone – the recognition an infant has been abandoned – speaks to at least the

[78] Kittay, Eva Feder. "Equality, Dignity and Disability." *Perspectives on Equality: the second Seamus Heaney Lectures*. Ed. Mary Ann Lyons and Ed. Fionnuala Waldron. Dublin: The Liffey Press, 2005. 95-122. 115.

beginnings of a relation of care. Our moral outrage implies a belief the infant already had intrinsic worth and should not have been abandoned, and that others recognised the infant as a member of the human community and worthy of care. Individual, equal human dignity requires some kind of relation in order to exist.[79]

In Kittay's words there is dignity in being 'some mother's child'.[80] Consider the times we hear 'she is some mother's child', 'he has a mother who loves him and cares for him', 'she is someone's child': when the remains of a young soldier is transported back to his or her family we will hear it. When a person is convicted of a heinous crime we hear it. When a child is stillborn. There is great value in being some mother's child, a value we all seem to recognise and respect. The intrinsic value I have as 'some mother's child' is a property I have only in virtue of a property someone else has (for they too are 'some mother's child').[81] The value I have is a direct result of being cared for; the network of caring relationships I am embraced into at once recognises, bestows and actualises the dignity I have as an individual.

Being some mother's child is a biological reality we all share, but I do not mean to imply a simple fact of biology is all that gives us individual worth. Once a child is born, it is the actual willingness of others to enter into a relation of care with the child that confers the dignity that inheres to the child as a particular individual. I have borrowed Kittay's highly gendered language – women are mothers, not men – but any person who takes on the responsibility for the well-being of the child is what I would consider a mothering person. Yet, we know that not everyone who takes on the responsibility of caring for a child will

[79] Ibid. 114-115.
[80] Ibid. 113-4.
[81] Ibid. 114.

provide good care. Some children are left to the care of those who neglect and abuse. Even the abused and neglected child has been the recipient of care (lousy though it may be), for any child denied all care would simply not survive. But if mere survival, because it requires some minimal threshold of care, is what bestows an individual with dignity then it is plausible different levels of care bestow different levels of dignity. However, measuring levels of care is no easy task. Consider that the level of care needed in one context to ensure mere survival might be extremely high, requiring the caregiver to subordinate his or her own needs in order to fulfil the needs of another, and in another so low neglectful and abusive behaviour will not appreciably hamper mere survival. It is not just the provision of the means for survival that confers dignity; it is the willingness of some to forge a relation of care. When a child has been neglected, abused or outright abandoned we can insist there was an affront to the child's dignity in the mother's refusal to take up the responsibility of care and that others who were actually willing were denied the opportunity to enter into a relation of care with the child. The bestowal of dignity requires an individual be recognised as part of the human community and worthy of care. It is the willingness of others to be mothering persons and to take on the role of caregiver that confers individual dignity.

While different levels of care certainly exist in the various relationships we are each embedded in there is no reason to assume that our individual dignity rises and falls according to the level of care we receive. If individual equal dignity is conferred as a result of being embraced into the human community because there is an actual willingness on the part of some to enter into a relation of care then what level of care is offered beyond this point should have no bearing on individual dignity. Once conferred, dignity demands a response and when we fail to respond we violate that dignity, but violating dignity does not amount to

stripping it away. What different degrees of care might plausibly contribute to is a *feeling* of personal dignity. The more involved and loving the relation of care is the more likely a child will be encouraged to believe in his or her own value. And, as we have seen in the previous sections, a feeling of personal dignity does require maintenance, a response, and can be undermined. For the person who does not have the capacity to feel a sense of personal dignity, locating the source of individual dignity in the relationships of care we are all, to varying degrees, enmeshed in ensures she too has an absolute dignity that demands our respect and affirmation.

Respecting an individual's dignity might be best accomplished by simply leaving the individual the space and freedom to live according to her values in a manner that suits her individual idiosyncrasies. As long as she is not harming others by her actions then quietly acknowledging and respecting her desire to live as she pleases is entirely appropriate. But there will be times when respect requires more than providing space. There are instances where respect requires us to actively respond to an individual's dignity. It could be by helping her maintain a private space, facilitating her continued independence, or ensuring she maintains some control over her life. For those who have a sense of their own dignity these three areas (privacy, control, independence) are particularly important. For the person who has no capacity to feel any sense of personal dignity the need to respond is equally important as it provides an affirmation of individual dignity. By responding to another's dignity with care we affirm the value of care itself, hence affirm our own dignity since it is through a relation of care or the actual willingness to forge a relation of care individual dignity is conferred. In finding the source of our individual dignity in the relations of care we bear to

one another, we have a duty to respond.[82] Respect for individual dignity often requires more than an abstract love of humanity but a more concrete, involved care of a particular human. In order to respect individual dignity we acknowledge the relation of care by coming to the relationship with an attitude of responsiveness to the other's needs.[83] We respect an individual by attending to her particular distinct 'me-ness'. I borrow the reference to a distinct 'me-ness' from Dillon, whose account of care respect outlines what it entails to respect another in all her individuality.[84] Briefly, care respect recognises equal human worth; acknowledges and attends to the particularity of individuals, suggesting that while we are all equal we are also distinct; acknowledges the connectedness and interdependence of individuals; and involves responding to need, promoting well-being and helping others realise their ends (at least for those who have ends that we are able to actively promote).[85] By acknowledging our distinct particularity – we are unique, unrepeatable individuals with unique desires, needs and wants – and pointing out that we each have a distinct 'me-ness' Dillon manages to capture the idea that while we all have dignity that is equal in worth, we are also distinct from one another and our distinctness deserves respect not just our commonality. By seeing the relations of care we bear to one another as the fountainhead of individual dignity, a relational and care based approach to dignity does more than just acknowledge our connectedness and interdependence. Responding to need and promoting well-being are certainly applicable for any individual in any situation where preserving dignity

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[82] Held, Virginia. *The Ethics of Care: Personal, political, and global*. Oxford: Oxford University Press, 2006.
[83] Ibid.
[84] Dillon, Robin S. "Respect and care: toward moral integration." *Canadian Journal of Philosophy*. 22.1 (1992): 105-32.
[85] Ibid.

is the goal. It might take careful attention to figure out what those needs are and what exactly might promote well-being for the severely demented or profoundly retarded, but careful attention is surely an aspect of an attitude of responsiveness. While stating that respect for dignity involves helping others achieve their ends (where possible) is clearly important for those who have a sense of personal dignity and indeed have ends, it is practically meaningless for those who do not have the capacity to have particular ends. In order to help others achieve their goals we need to be able to understand their self-concept, how they see their world and how they fit. It requires we truly enter into a relationship. While we may not generally approve of their self-concept – it may involve idiosyncratic values we find jarring, strange or alien – we are still bound to actively respond by helping them reach their goals. There is a caveat though, if their self-concept is an obvious result of a life of degradation or discrimination we owe it to them not to value and respond to a destructive self-conception but to do what we can to promote self-respect.

By taking a relational and care approach to individual dignity we can avoid a potentially fruitless search for an attribute or capacity all individuals possess. Dignity by association (group dignity) still seems to require we locate an attribute or capacity that is uniquely valuable. Deciding which attribute is the valuable essential property of humanity will always amount to making an arbitrary choice. Are we as a species essentially rational? Are we empathetic? Are we essentially a caring species? Even if we can make a choice we can all agree to there will still be individuals we certainly recognise and care for as human but who do not possess the chosen attribute. And this will leave us open to the argument some individuals possess more dignity than others because some individuals actually do have the attribute or attributes. To recognise the equal dignity of every individual, in all of his or her

particularity, is to recognise (and honour) he or she is in very large part the creation of a network of relations of care.

What does a relational and care approach to dignity bring to the health care context? A dignity grounded in the connections we have with one another highlights our need for care, our dependence on others, and our vulnerability. In our focus on and valorisation of individual autonomy and independence we tend to forget we were born into a vulnerability we only survived because of the care of others. Even the most destitute of us were the recipients of care. A relational approach to dignity serves as gentle reminder periods of great vulnerability and need are part of the ebb and flow of human life – nothing to cause us shame, and certainly nothing to inspire disdain. Patients themselves emphasise the importance of the relationship as a means to enhance or preserve their sense of personal dignity.[86] To be recognised as a fellow human being can only mean being recognised as another person of equal individual worth.

For the patient who cannot noticeably discern when his or her sense of dignity has been violated a relational approach reminds us it is the connections of care that at once confer, recognise and actualise an individual's dignity. It is the connections of care that have made the patient the unique, valuable person he or she is. The practitioners who care for such a patient become part of that web of connections. By treating the patient (any patient regardless of his or her capacities) with dignity the practitioner affirms his or her own dignity by affirming the value of the care given. I am not suggesting practitioners afford patients dignity-preserving care *only* as a means of respecting their own dignity; rather, that in recognising and respecting the dignity of another they reaffirm the equal dignity both patient

[86] See section II, subsection ii) above.

and practitioner have as individuals. A relational and care based approach to dignity assures every patient equal individual dignity precisely because dignity is not tied to a presumably unique human attribute that the patient may or may not have.

I began this chapter with an overview of Kant's argument for human dignity. While Kant's argument is admirable and solid it rests on the human capacity for moral autonomy. If an individual human does not have the capacity for moral autonomy does the individual have dignity? Strictly speaking, it seems on Kant's account such an individual would not. In some instances it appears dignity is liable to wax and wane with the individual's ability to be rational (hence have the capacity for moral autonomy). The most obvious examples of the possible waxing and waning of dignity can be found in the demented patient who once had a capacity for autonomy or the infant who potentially has the capacity for autonomy. There is nothing in the *Groundwork for the Metaphysics of Morals* that strongly implies Kant believes dignity waxes and wanes, however there is no clear path in Kant's own arguments to show dignity does not pop into or out of existence along with the individual's capacity for moral autonomy. At this point I massaged the thrust of Kant's argument to make a case for individual human dignity based on species membership. While I expect the argument preserves the Kantian spirit, dignity was still very much tied to the capacity for moral autonomy. Which left the glaring question of whether it is necessary to leave dignity indelibly bound to a capacity for autonomy. Rather than immediately taking up the question and presenting a case for dignity based on something other than our capacity for rationality I briefly reviewed what the health care literature views as integral to individual human dignity. The health care literature is highly revealing, what patients and practitioners alike have to say

about the concept of dignity is extraordinarily simple and can be summed up in Heijkenskjöld, Ekstedt and Lindwall's words: preserving patient dignity means "treating patients as fellow human beings."[87] Chochinov's studies explicitly show there is evidence to support the strongly held intuition dignity is important to patients. In today's health care culture we need evidence to show that a treatment is effective (understandably so) and this need for evidence spills over into the less quantitative (those areas of patient care that cannot be easily submitted to the gold standard controlled clinical trial) aspects of health care provision in order to be considered good practice. The resounding themes in the health care literature surrounding dignity were: control, independence and privacy. The vehicle by which health care practitioners preserve patient dignity was also very clear: the practitioner-patient relationship is vitally important in preserving patient dignity. Armed with the evidence from the health care literature I returned to the question of whether it is necessary to tie individual human dignity to a capacity for autonomy. By taking up Eva Fedder Kittay's suggestion we look to the "relationships we bear to one another" as the basis of dignity[88] I explored the feasibility of a relational and care approach to individual equal dignity. By looking to the relationships of care in which we are all embedded as the basis of our individual worth we can avoid the quest for the essential yet ubiquitous quality or capacity that all individual humans have that imbues us with dignity. In the following chapter I look at the key elements of a dignity preserving relationship in the health care context.

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[87] Heijkenskjöld, Katarina Bredenhof, Mirjam Ekstedt, and Lillemor Lindwall. "The Patient's Dignity from the Nurse's Perspective." *Nursing Ethics*. 17.3 (2010): 313-24. 316.

[88] Kittay, Eva Feder. "Equality, Dignity and Disability." *Perspectives on Equality: the second Seamus Heaney Lectures*. Ed. Mary Ann Lyons and Ed. Fionnuala Waldron. Dublin: The Liffey Press, 2005. 95-122. 111.

Chapter Two: Relationship

Based on the views of both practitioners and patients a caring, attentive relationship is key to providing dignity preserving care. A relational and care approach to individual equal dignity clearly articulates that the caring relationships in which we are each embedded provides us with, to use Kittay's words, the "fountainhead" of dignity.[89] Not only do caring relationships confer and actualise our individual equal worth, they are also the means by which we recognise and affirm that worth in another. In this chapter I examine and describe the type of practitioner-patient relationship that exemplifies what it means to respect the patient as fellow human being.

I begin by outlining Emanuel and Emanuel's four models of the physician-patient relationship[90] and the conceptions of patient autonomy those relationships support. Even though my focus is not on patient autonomy per se, I cannot neglect some reference to autonomy if, in practice, patients themselves see a link between autonomy and dignity. My aim is to provide plausible reasons to reject what I refer to as a contract model of the practitioner-patient relationship as inappropriate and unrealistic. From here I move on to outline 'relationship as engagement' as an alternative to the contract model. There are a number of potential challenges to the viability of relationship as engagement – time, resources, finding balance – which I address. These challenges are micro level and fairly obvious, and I believe relatively easy to overcome.

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[89] Kittay, Eva Feder. "Equality, Dignity and Disability." *Perspectives on Equality: the second Seamus Heaney Lectures*. Ed. Mary Ann Lyons and Ed. Fionnuala Waldron. Dublin: The Liffey Press, 2005. 95-122. 113.

[90] Emanuel, Ezekiel J., and Linda L. Emanuel. "The Four Models of the Physician-Patient Relationship." *Readings in Health Care Ethics*. Ed. Elisabeth Boetzkes and Wilfred J. Waluchow. Peterborough, ON: Broadview Press Ltd., 2000. 39-49.

In the second section I look at macro level threats to the possibility of relationship as engagement. The two threats I focus on are the organisation of health care delivery and the evidence-based medicine movement. I expect there are other significant threats, but these two are representative of the accepted norms in health care. The threats they pose to the possibility of engagement between practitioner and patient are not necessarily noticed, but they can be significant. The institutional nature of health care delivery – the monolithic hospital, the long-term care facility – can be dehumanising to both patient and practitioner. The evidence-based medicine movement can leave patients feeling like statistics rather than unique individuals with unique needs, and can leave practitioners feeling their clinical expertise is secondary to the medical research. The evidence-based approach to health care contributes to a mind-body separation, which is untenable for successful patient care since patients simply cannot figuratively or literally disengage from their bodies.

I finish the chapter by coming back to the relationship and the two necessary elements of any relationship: trust and respect. I also touch on the notion of centredness in health care, evidence-based medicine's current running mate. The various types of centredness (client, patient, person, relationship) promoted by many, if not most, health care institutions serves as reminder the patient has not been lost and does remain the focus of health care. What this means in terms of dignity preserving care is that there is more to respecting and responding to the patient and his or her needs than an obsessive focus on patient autonomy.

I. Relationship as engagement: rejecting the contractual model

For at least some patients dignity-preserving care is directly linked to respecting their sense of control and independence. Patients feel their dignity has been respected if their need for a sense of control and independence has been responded to and, if necessary, the practitioner has helped facilitate real action to fulfil this need. Judging by the studies reviewed in the previous chapter both practitioners and patients regard the relationship as a crucial element in maintaining and respecting patient control and independence, thus preserving dignity. To be in control of one's life and to exercise the independence necessary for making choices is loosely speaking what patient autonomy entails. As exciting, innovative, contentious and contradictory as the theories surrounding the concept of autonomy are, it remains that in the health care context patient autonomy is about decision making and the ability to make an informed choice regarding care. While it may be a highly inadequate measure of autonomy to health care practitioner and philosopher alike, patient autonomy is effectively conflated with informed choice or consent.[91] I am not entering the ongoing debate around patient autonomy in any meaningful way here, but if some patients see their sense of dignity tied in even the most tenuous manner to their sense of autonomy it would be negligent on my part not to devote some space to patient autonomy. I focus on

[91] See Beauchamp, Tom L. and Childress, James F. *Principles of Biomedical Ethics, 5th ed.* Oxford: Oxford University Press, 2001. In the chapter on patient autonomy the authors provide overviews of different conceptions of autonomy, but the emphasis is still on the patient's choice. See also, Stoljar, Natalie. "Informed Consent and Relational Conceptions of Autonomy." *Journal of Medicine and Philosophy*. 36 (2011): 375–384. 375. "The received view in medical contexts is that informed consent is both necessary and sufficient for patient autonomy."

how patient autonomy is understood in the context of the practitioner-patient relationship and how this might relate to patient dignity.

The informed consent process as measure of patient autonomy means that in many instances the practitioner-patient relationship takes on the nature of a contract where both parties are tacitly considered equals. Roughly, the informed consent process is as follows. The patient's competence to make decisions on their own behalf is assessed. Assuming the patient has been deemed competent to make their own decisions the patient is presented with treatment options (which may be very limited, there may be only one viable treatment option) along with information outlining the risks and benefits associated with each option. The patient then makes a choice (assuming there are options to choose from) and either consents to treatment or refuses treatment altogether. The process may not be quite this explicit but these are the basic steps.

Emanuel and Emanuel refer to what I label the contractual relationship between practitioner and patient relationship as the informative model of the practitioner-patient relationship – the patient's autonomy is assumed stable and unchanging rather than continually evolving and open to revision.[92] The approach to patient autonomy is distant, as if talking with the patient in an effort to understand his or her values would be perceived as an imposition of the practitioner's will. The practitioner gives the patient as much information as possible and leaves it entirely up to the patient to make the treatment decision. The emphasis on informed consent provides a powerful endorsement of the

[92] Emanuel, Ezekiel J., and Linda L. Emanuel. "The Four Models of the Physician-Patient Relationship." *Readings in Health Care Ethics*. Ed. Elisabeth Boetzkes and Ed. Wilfred J. Waluchow. Peterborough, ON: Broadview Press Ltd., 2000. 39-49. 41, 45.

informative model.[93] In my view, conflating informed consent with patient autonomy gives rise to the possibility of a strictly informative model of the practitioner-patient relationship. I should note that Emanuel and Emanuel outline conceptions of patient autonomy that do not conflate autonomy with informed consent. I am not suggesting the informative or contractual model is what patients want or expect, nor is it the model we are likely to see in action. Regardless of how we conceive of respecting the patient – whether that means respecting autonomy or dignity – it is clear, just based on the limited literature reviewed in the previous chapter, the practitioner-patient relationship is more involved and nuanced than the informative model Emanuel and Emanuel describe.

It is worth looking at the three other models Emanuel and Emanuel identify and the understanding of patient autonomy associated with each model. Not to reveal the different notions of autonomy, but to highlight the level of practitioner engagement with the patient. The level of engagement needed to help patients examine their values as they pertain to autonomy will be similar to the engagement required to preserve patient dignity (at least for those patients who do see a link between dignity and control). In the interpretive model the goal of the relationship is to help the patient understand his or her values and make choices that adequately reflect these values. It requires the practitioner help clarify which values are most important to the patient. The role of the practitioner is similar to an advisor or counsellor; the practitioner does not dictate to the patient, leaving the ultimate decision in the patient's hands.[94] The deliberative model gives the practitioner room to persuade the patient of the moral worthiness of a particular treatment or particular health related values.

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[93] Ibid. 43.
[94] Ibid. 40.

It involves a higher degree of engagement with the patient than either the informative or interpretive models. The practitioner needs to get to know the patient and have his or her best (health related) interests in mind in order to persuade the patient of the worthiness of a particular course of treatment or perhaps a healthy lifestyle choice. The deliberative model requires engaged dialogue with the patient to guide the patient in an examination of his or her values. The practitioner is doing more than just elucidating the unexamined values of the patient and suggesting treatment based on those values. Instead, the practitioner aids in the patient's self-development regarding health related values by making suggestions and gently persuading the patient to consider alternative values relevant to treatment or health maintenance.[95] The paternalistic model assumes the patient and practitioner share the common objective of restoring health even if the means to restore health may not be the patient's choice – the patient will be grateful once health is restored.[96] The practitioner does not need to interact or engage with the patient in any meaningful way to figure out what is best for the patient. The focus is on the patient's health rather than patient choice.[97]

All of the models Emanuel and Emanuel outline are open to some form of criticism. The informative model simply does not reflect reality, most of the time. Patients expect to be able to ask their practitioner for advice on what the best course of action might be. In practice, practitioners do interpret and monitor the amount of information given. Too much technical medical information stands to overwhelm even the most knowledgeable and seasoned patient. Most patients would perceive the practitioner who adhered strictly to an informative model of patient interaction as cold and uncaring. It would amount to the lousy

[95] Ibid. 40-41.
[96] Ibid. 39.
[97] Ibid. 39.

bedside manner most competent and conscious patients dread encountering. The interpretive model, at first glance, appears to be the model most respectful of patient autonomy, with the clear goal of assisting patients in identifying the personal values most relevant to the context. But it seems unrealistic to assume a practitioner could only interpret the patient's values and not unconsciously impose their own values. The overwhelmed patient unsure of his own values might just accept the practitioner's views as their own and consent to treatment they might otherwise not agree with, pushing the interpretive model dangerously close to a paternalistic model in practice.[98]

Are practitioners really such paragons of moral virtue (even if it is only in the realm of health care) to make the deliberative model viable? Do practitioners have the necessary moral training (if there is such a thing) to judge patient values and promote worthier values? As Emanuel and Emanuel point out, we live in a pluralistic society where different and conflicting values compete for the higher moral ground – conflicting values will be found between practitioner and patient, as well as practitioner and practitioner.[99] The paternalistic model may only be justified in an emergency situation, but beyond that the notion that practitioner and patient share views on what constitutes benefit is simply not tenable. In practice, most practitioners do not advocate a purely paternalistic approach in everyday clinical encounters.[100]

It is the level of engagement outlined in each of the four models of the practitioner-patient relationship that is relevant for my purposes, not the corresponding conceptions of patient autonomy. Based on what patients themselves say about what helps maintain a sense

[98] Ibid. 45.
[99] Ibid. 45.
[100] Ibid. 44.

of dignity it is the minimal definition of autonomy (choice and control) given for the informative model of practitioner-patient interaction that is important. However, the level of engagement required to respect dignity is much higher than the informative model of the relationship implies is necessary for respecting patient autonomy, in that the practitioner needs to understand what it means to the patient to have control and choice in order to facilitate patient control and choice. Only by understanding what choice and control mean to the patient will the practitioner be able to take the next step of extending choice and control. Curiously, it seems that to respect dignity by respecting and facilitating the patient's control over and choice of treatment or care – which the evidence suggests is what many patients regard as dignity preserving – the level of engagement with the patient needs to be much higher than is required to respect a control and choice conception of autonomy. Respecting dignity requires more than a hands-off approach to the patient-practitioner relationship. Where it is plausible (in theory at least) that to adequately respect patient autonomy the practitioner ought to step back and give the patient space to make his or her own health related decisions, it is not the route to respecting dignity especially when to preserve a patient's sense of dignity requires understanding and responding to the issues that the patient sees as relevant. It is also quite clear, according to both patients and practitioners, that finding balance is not always easy. On the one hand, many dependent patients may need active involvement on the part of the practitioner in order to exercise any choice and control over their care. And on the other, for competent patients the well-meaning imposition of practitioner values can be experienced as undermining the patient's sense of control, integrity and independence.[101] From the care provider perspective trying to achieve a balance

[101] Wadensten, Barbro, and Gerd Ahlström. "Ethical Values in Personal Assistance: Narratives of

between respecting patient autonomy and dignity, particularly for the cognitively impaired patient, can be experienced as highly distressing.[102] We are not always in a position to respect both. If the interpretive and deliberative models can easily slide into paternalism, as the criticisms Emanuel and Emanuel outline suggest, and the informative model leaves us entirely alone, we need to re-examine the practitioner-patient relationship if it is to be a relationship that responds to patient dignity *and* autonomy.

i) Getting engaged.

Does personal dignity mean having control over the way one dresses? Exercising the independence to button up one's cardigan even if the buttons and buttonholes are mismatched? Does it mean being free to choose to sit around the house with uncombed hair without your personal assistant tut-tutting your choice?[103] Or does it mean drinking your tea from a cup and saucer rather than a mug? These may be minor, trivial issues for many of us but if they are important to the patient's sense of dignity they ought to be honoured if and when it is realistically possible. Granted, such attention to detail is not going to be possible in every care-giving situation. I am also not suggesting caregivers slavishly respond to their

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People with Disabilities." *Nursing Ethics*. 16.6 (2009): 759-74.

[102] Jakobsen, Rita, and Venke Sorlie. "Dignity of older people in a nursing home: narratives of care providers." *Nursing Ethics.* 17.3 (2010): 289-300. 292-3. Care providers found it difficult to preserve the patients' right to autonomy and preserve dignity.

[103] Wadensten, Barbro, and Gerd Ahlström. "Ethical Values in Personal Assistance: Narratives of People with Disabilities." *Nursing Ethics*. 16.6 (2009): 759-74. . 765. The study participant made it very clear she experienced her assistant's concern over her uncombed hair as degrading and insulting. Not only does the assistant's interference undermine the participant's choice and control, it is also an unwelcome intrusion into the participant's private sphere.

patient's every whim at the expense of their own sense of dignity and self-respect[104] or at the expense of other patients under their care. The foundation of dignity affirming care is the relationship, no less so for the patient who lacks the *feeling* of dignity than for the patient who is acutely aware of his sense of dignity.

> "Relationship as *engagement* is not contractual, as in a simple contract between equals in which each party negotiates from a position of self-interest. Nor is relationship paternalistic, with the professional making decisions for the patient. Nor is it independent choice in which the client or consumer, alone, makes the treatment decisions. Engagement between practitioner and patient is an encounter in which one party, the practitioner, is committed to respond as a neighbor to the person in need of care – to be a Good Samaritan."[105]

For the relationship between practitioner and patient to be one of engagement requires attention to the patient as whole person, to resist the urge to label the patient according to his or her diagnosis. If we only view the relationship as a technical relationship dealing with bodies that are somehow disengaged from the person, or as patients as problems to be solved, not only does the patient become an object, identified only by diagnosis (stroke patient in room 5), but the practitioner, whose responsibility it is to care, also becomes an interchangeable object (the nurse, the doctor) mechanically going about his

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[104] Servility is a moral wrong in itself. See Hill, Thomas E. *Autonomy and Self-Respect*. New York: Cambridge UP, 1991 chapter one, "Servility and self-respect" 4-18.
[105] Bergum, Vangie and John Dossetor. *Relational Ethics: the full meaning of respect.* Hagerstown, MD: University Publishing Group, 2005. 110.

or her work. In a sense the clinical encounter is a relation that connects strangers in a meaningful and often intimate way.[106] But as the Good Samaritan story reminds us the stranger is also neighbour. While the Good Samaritan story is usually seen as an example of unselfish, compassionate regard for another, Bergum and Dossetor cast a different light on the story that does not see the Good Samaritan acting in a selfless way. Rather it is the Good Samaritan's ability to recognise the humanity in the injured man that enables him to respond with compassion and caring. Only by being aware of his own humanity is the Good Samaritan able to see the humanity in the other. So the Good Samaritan has to be self-full – aware of and attentive to his own humanity – rather than self-less – disengaged and inattentive to his own needs and his own humanity - in order to respond with compassion. Relationship as engagement does not require selfless regard for the other but attentive regard for the self and other at the same time.

ii) But I have no time!

The most obvious criticism of a move to relationship as *engagement* between practitioner and patient comes when we point out the limited time and resources health practitioners have access to. There are undeniably instances when the practitioner simply does not have the opportunity to develop any sort of relationship. It may not be limited time and resources that prohibits any kind of relationship between practitioner and patient, it may simply be the nature of the care-giving interaction itself. The patient may be unconscious, and the practitioner will only spend a few fleeting moments with the patient.

[106] Ibid. 109.

For the fully conscious patient, we might ask how we can find the time to learn about the patient as a whole person? When a nurse may spend only a few minutes a day with any one patient, and see many patients in the course of the day, where is there time to engage meaningfully with the patient? First of all, it does not take excessive time to engage with another. What is required, though, is to meet the patient with an attitude of responsiveness by being fully present in the moment rather than always looking forward to the next appointment or only keeping focused on the anticipated outcome of the health care encounter. It should come as no surprise that we are unable to focus our attention on a particular moment if we are only driven by end goals – we find ourselves missing out on the present by looking only to the future.[107] "If one is held in the grip of the past or the future, there can never be enough time, since one is already in two places at once."[108] Relationship as engagement is not some future goal to be achieved but an ongoing endeavour, and this requires us to be fully present to the other rather than trying to be in two places at once.

Even in the briefest of moments there is time to acknowledge another's individual dignity by seeing the other as a fellow human being, even if the most a practitioner can do is provide the patient some measure of privacy. Pointing to a lack of resources or different types of clinical encounters (the urgent care department of a large hospital as opposed to a long term care facility) as a serious objection to the possibility of engagement assumes engagement requires a particular quantity of time. But engagement is qualitative, not quantitative. There is no magic number of moments it takes to enter into a relationship as

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[107] Chochinov, H. M. *Dignity Therapy, a handbook for clinicians*. Oxford University Press, 2011. 23-4. Chochinov emphasizes the importance of living in the moment rather than being overwhelmed by forward thinking.

[108] Bergum, Vangie, Dossetor, John. *Relational Ethics: the full meaning of respect.* Hagerstown, MD: University Publishing Group, 2005. 122.

engagement with another, and equally there is no magic amount of time the relationship need last to qualify as a relationship. Engagement with another occurs when we enter a relationship – even a fleeting relationship – presupposing the other is a whole person, a person who is more than the sum of her parts. So while it may not always be possible in many health care contexts to engage for a significant amount of time (hours or days) it is always possible to meet the patient with an attitude of responsiveness.

As for actually learning about the whole person (when context and circumstance allow), the crucial step is to move away from labelling the patient. In any relationship, chosen or unchosen, we can never know all there is to know about the other – there will always be something more to know – so it is unrealistic to expect the practitioner to be aware of every detail that has gone into the formation of the patient as whole person. To recognise and respect the patient as whole person can be as simple as taking note of the patient's unique qualities or the patient's stated preferences. There is room to note technical information dealing with the daily care plan – how many people are needed to transfer the patient from bed to wheelchair, food allergies, oral care needs etc – why not include things as simple as how the patient prefers to be addressed, what recent significant life events have occurred, or what sort of work the patient does? Such seemingly insignificant pieces (particularly insignificant with regards to healing or caring for the patient's body) of personal knowledge – and of course, putting those pieces of knowledge to work – greatly enhance the patient's sense of dignity.[109]

[109] See Gallagher, Ann. "Dignity and Respect for Dignity – Two Key Health Professional Values: Implications for Nursing Practice." *Nursing Ethics.* 11. 6. (2004): 587-99.

iii) Finding balance.

A further criticism of relationship as engagement might be how do we know how to strike the right balance? How much engagement is too much? At what point does engagement become unhealthy, unproductive and unprofessional entanglement? What I have outlined above can be achieved within the professional boundaries outlined in the professional codes of conduct health care practitioners are expected (by law) to abide by. Some instances of unprofessional entanglement are glaringly obvious – financial, physical or sexual abuse for example – and are clearly referenced in professional codes of conduct. If health practitioners are mindful of the boundaries set out by codes of conduct and also attentive to their commonalities with patients the risk of sliding from healthy, reciprocal engagement to an obviously unhealthy entanglement seems slim at most. I see no foolproof way to mitigate the risk a healthy productive relationship will turn sour for either party. I could frantically gesture toward the importance of practitioners remaining self-aware, reflective, attentive and in the moment, of keeping the lines of communication open with patients as well as colleagues, but none of these measures will truly alleviate the risk that accompanies any relationship. If we absolutely must dispense with risk, then we must abandon the prospect of meaningful and therapeutic relationships in the health care context. If we abandon the relationship because of its inherent risk we also abandon everything that comes with good healthy relationships: trust, respect and empathy – all of which are central to the provision of effective health care. Nursing theorists are acutely aware of the

importance and benefits of the therapeutic relationship between care provider and patient.[110] The standards of practice developed by the College of Nurses of Ontario (to take just one example) clearly address the therapeutic relationship and the risks involved.[111] All relationships are risky but surely we would not choose to miss out on the possible benefits of healthy interpersonal relationships simply because they involve risk. Why should the practitioner-patient relationship be any different? Practice standards are quite clear on maintaining boundaries in the nurse-client relationship, and while the standards cannot provide a foolproof method for avoiding unhealthy relationship behaviours they at least recognise the risky nature of relationships. Being aware of a potential problem at least offers a chance of being able to recognise when problems arise and how they might be dealt with.

iv) Reciprocity.

There is the question of reciprocity in relationship as engagement – who gives and who receives? What does the practitioner give and what does the patient give? The assumption is that in a time of vulnerability and need the patient is not in a position to give anything to the caregiver beyond gratitude (and there is no guarantee a patient will feel or express gratitude). But maybe the question of who gives what to whom is not the right question. Perhaps a better way to look at the reciprocity question is to see that caregiver and patient, and often many others (such as family members, friends and other members of the

[110] Whether we look to the words of Florence Nightingale or Hildegard Peplau or Jean Watson (all acknowledged as nursing innovators) we will always come back to the notion caring and healing can only take place in the context of the interpersonal relationship.
[111] College of Nurses of Ontario. *Therapeutic Nurse Client Relationship*. Revised 2006. Toronto: College of Nurses of Ontario, 2009.

health care team), give something to the relationship itself rather than directly to each other. Patient and practitioner are not the only ones who are in a position to nurture the relationship; particularly when we consider patients who are genuinely in no condition to bring anything beyond physical presence to the relationship – the brain damaged, the severely demented or the unconscious patient. What others, especially the patient's friends or family, bring to the relationship is knowledge beyond the collection of symptoms or the diagnosis that often serves as a label for the patient. Any knowledge of the patient as person (whether it is the patient who provides this knowledge or various others) serves to humanise the patient and, while it might be easier to deal with collections of symptoms as opposed to the human who is exhibiting the symptoms, if we lose sight of the person we risk seeing the patient as only an object or a problem to be solved. If we are blind to a person's humanity (her individual worth) by instead seeing her only as a means to or an impediment to something else we undermine the value of the care we give and risk becoming objects ourselves.

It is not always better to give than receive. If we are unable accept or recognise what each party brings to the relationship we run the risk of burnout. Patients and their families often bring important knowledge regarding care needs. If practitioners are distanced from patients – concentrating on applying their expertise to a particular problem – rather than paying attention to the knowledge the patient (or family) brings to the relationship caring for the patient's needs becomes ever more difficult. Paying attention to and incorporating knowledge of the individual patient as person ensures the practitioner is able to respond to the patient's needs. It effectively replenishes and adds to the practitioner's resources.

Returning to Bergum and Dossetor's re-conception of the Good Samaritan story: we need to be self-full in order to respond to the other. The practitioner needs to be aware of his or her own sense of dignity in order to see, and respect, dignity in the patient. Does the patient also have the responsibility of seeing and respecting dignity in his or her caregiver? I am reluctant to refer to a patient *responsibility* to respect their caregiver's personhood - or dignity or, more simply still, to see their caregiver as a fellow human being. However, to the extent that respect is a normal expectation in any interpersonal relationship then there is an expectation patients will respect their caregivers, at least an expectation that is commensurate to the patient's ability. As the Holmberg, Valmari and Lundgren study points out patients do appreciate it when their caregivers take the time to be social, and engage in everyday chit-chat, as this helps the patient feel she is being respected as a unique individual.[112] It is not much of a stretch to infer from this that patients want to see their caregiver as a unique individual too. Being respected as a unique individual works both ways in the context of a relationship. To label the reciprocity (I respect you, you respect me) that is inherent in most interpersonal relationships a responsibility or obligation is heavy-handed. But it is a reasonable expectation to have of those patients who are capable.

v) But I don't like the patient.

Relationship as engagement implies the need for an emotional connection between practitioner and patient, and this seems hardly appropriate for what is a professional rather

[112] Holmberg, Marie, Gudrun Valmari, and Solveig M. Lundgren. "Patients' experiences of homecare nursing: balancing the duality between obtaining care and to maintain dignity and self-determination." *Scandinavian Journal of Caring Sciences*. Mar 16 (2012): [epub ahead of print]

than chosen relationship. It also seems to imply the practitioner and patient actually like each other, or at least should like each other. There is a place for emotion in the health care relationship; for a patient a life altering diagnosis is going to be a highly emotional experience. Being present at the death of a palliative patient might be a particularly emotional experience for the nurse who spent the most time and developed a relationship with the patient. In the engaged relationship, practitioner and patient may share emotional experiences that can strengthen the relationship, but more importantly acknowledging and sharing emotional experiences can help both practitioner and patient move away from seeing each other as nameless roles. The tendency to label is not just the domain of health care professionals; patients can just as easily identify practitioners by the role they fill instead of viewing them as individuals. If there is an emotional connection or investment it ideally needs to be directed to the relationship itself. What I mean by referring to the 'relationship itself' is the metaphorical space inhabited by patient (a substitute decision-maker might be included in the relationship) and practitioner, at least for as long as the relationship lasts. Think of the practitioner-patient relationship as akin to travellers on a journey together where each has essential information needed for reaching the desired destination, and where neither traveller could reach the destination alone. They will both be invested in reaching the destination but in order to get there they also need to be invested in the journey. Think of the destination as the treatment goal and the journey as the therapeutic relationship. The focus needs to be more on the relationship itself than on the individuals involved – this metaphorical space needs to be nurtured if it is going to be effective for the persons inhabiting the space. The aim is to be person centred by creating an effective relationship, or more precisely an effective relational space.

As for patient and practitioner actually liking each other, I am not convinced this is absolutely necessary for the relationship to be successful. It has to be the responsibility of the practitioner to examine and reflect upon his or her emotional responses (liking or disliking), and this ability to reflect needs to be the result of a *curiosity* rather than *judgement* of the self. Recognising and acknowledging an emotional reaction gives the practitioner the opportunity to understand the reaction and possibly let go of the emotional response and move on to reflect on how best to establish a relationship.[113] It needs to be the responsibility of the practitioner simply because only she has control over her own responses. This is a rather trite answer to the dilemma posed by a negative emotional reaction to a patient, but it does fall in line with the tenets of reflective practice in nursing.[114] To practice reflectively requires self-awareness, self-understanding and the ability to learn from experience. We do not need to like a person or feel any emotional connection to forge an engaged relationship between practitioner and patient.

II. Threats to Relationship

Many of the potential barriers to successful interpersonal relations I have addressed above are quite obvious threats to the possibility of an engaged practitioner-patient relationship. The issues raised so far are micro-level issues and I have argued that they can

[113] Bergum, Vangie, Dossetor, John. *Relational Ethics: the full meaning of respect.* Hagerstown, MD: University Publishing Group, 2005. 125-6.
[114] There is plenty of literature on reflective practice in nursing. See for example: Johns, Christopher, and Dawn Freshwater. *Transforming Nursing through Reflective Practice*. Osney Mead, Oxford; Malden, MA: Blackwell Science, 1998.; Freshwater, Dawn. *Therapeutic Nursing: improving patient care through self-awareness and reflection*. London; Thousand Oaks: Sage, 2002.

be adequately addressed if the practitioner remains self-aware and reflective. However, there are other threats to the possibility of establishing a successful patient-practitioner relationship, threats that are more difficult to overcome because they are so often unnoticed. The two threats I focus on are: the organisation of health care delivery and the burgeoning evidence-based medicine movement. These two threats exemplify norms of health care delivery that are rarely seriously questioned.[115] Any improvements to the patient experience will occur at the bedside, in the context of a successful relationship long before any organisational changes could have a direct impact on patient care. I am not suggesting many of the underlying tenets of evidence-based medicine are entirely and always antithetical to good care – there will always be a place for medical research; we need to test our assumptions on what constitutes good treatment and what use is the research if it never reaches the health care practitioner to be put into practice? There are two major concerns I have with the evidence-based medicine movement: first, it encourages a mind-body dualism that tears at the notion of the patient as 'whole person' and second, it reduces individuals to statistics, which can be damaging for both patient and health care provider and for the possibility of successful relationships.

[115] Two things to note: first, I am not implying these two issues are the only possible impediments to establishing successful relationships. Second, I acknowledge there is a growing backlash against EBM in that EBM is under critical scrutiny but its pervasive influence on the way health care is delivered is undeniable.

i) Organisation of Health Care Delivery

The mega hospitals that take up a whole city block, and sometimes several blocks, we find in most large cities across North America are landmarks hard to miss. They are large, imposing structures usually teeming with activity – the busy professional with clipboard or briefcase in hand rushing purposefully along a labyrinth of corridors; the health professional easily discernible by scrubs, white coat or stethoscope slung around the neck; the bewildered patients and their families. Step inside one of these monoliths and you could be in any hospital anywhere - alarmingly like airports or shopping malls. The mere architecture of most large hospitals oozes power, officialdom and authority leaving all but the most seasoned patient feeling anonymous and possibly intimidated. It certainly is not the type of place one would think of as conducive to establishing any kind of meaningful relationship. Yet, for many patients this is exactly where their health care journey begins. For the patient who actually has to stay in the hospital for any length of time issues arise beyond the overwhelming sense of anonymity and intimidation the air of officialdom and power the architecture of the hospital inspires. There is a lack of privacy, hospital gowns that never seem to fit properly, an unfamiliar bed, unfamiliar people, and an abundance of technology.

For a patient the workings of the hospital environment can look like organised confusion. It is in this environment the notion of engagement becomes so important. As I said earlier there is no reason to assume engagement needs to take a great deal of time. The first contact the patient has with anyone (it may not necessarily be a nurse or a physician) connected to the hospital and the care they will be receiving has the potential to restore the patient's shaken sense of dignity (the lack of privacy and the gaping gown do nothing to

enhance dignity). However, there is a problem of continuity – will the patient be engaging with the same practitioner or practitioners each time some form of care is required or requested? While the hospital may become the patient's home for a period of time, it remains a workplace for the health care practitioner. And like most other types of work there are vacation days, sick time, a limit to the number of hours worked, meetings, and a whole host of work related obligations, beyond patient need, to take care of that need to be addressed from the health care worker's perspective. The potential disruption in continuity regarding the faces the patient sees is certainly unavoidable to a degree. But there are ways to mitigate the disruption to patients, which I think require careful attention. Most patients are well aware that the people who provide their care are doing so as part of a specific job and know that their caregiver simply cannot work 24 hours a day, 7 days a week. Still, it takes only a moment for the practitioner to inform the patient when the next shift starts, who will be working that shift, and when he or she will be back. Such a small, practically insignificant act has the effect of lifting the patient out of the anonymity of the hospital ward by acknowledging their personhood. Fair warning when a room change is required or being apprised of the day-to-day rhythms of hospital routines (shift changes, meal times, visiting hours, or times when rooms are cleaned) add to the mitigation of disruptions. Further, communicating these small, unremarkable to the hospital staff, everyday rhythms gives the patient the sense of control that comes with knowledge. In short, paying attention to effective communication between staff and patient is a key element in managing the disruptive nature of a hospital stay.

Similar issues arise, and require the same attention to communication, in the less monolithic health care facilities like the nursing home or chronic care hospital. The glaring

issue in both of these types of facilities is that for the patient the facility really is their home. Continuity might not be as big an issue since most of the patients/residents will have fit themselves into the daily rhythm of the facility and be fairly aware of who works which shift. But resisting the homogenising effect of living in an institutional setting is a challenge for both patient and practitioner. I should imagine for the practitioner regarding the resident population as one homogenous body makes the work easier in some respects but also stands to lead to disengagement with the work itself and eventually the residents. New residents entering the facility face the challenge of adjusting to a new environment. For some, the move to a health care facility means leaving an independent way of life, where they had control over their immediate environment, to a living situation that seriously impinges on their ability to control the everyday routine and decide exactly where their private sphere begins and ends. The role of the care provider becomes crucial in easing the transition from independent living to relying on a full complement of caregivers to ensure the daily activities of living can be accomplished. However, studies show paid caregivers in nursing homes find the ability to provide good care, which includes preserving the dignity of residents, is often severely constrained by the actual structure of the work environment including working within the regulations imposed by government, limited time allotted for patient care, dealing with family members, dealing with the conflicting views of their colleagues and an often chaotic environment.[116] The obvious answer is to change the nursing home environment by increasing allotted time for the provision of care and encouraging meaningful respectful practitioner-patient relationships. Such changes are not going to happen in a hurry, which

[116] See Toles, Mark, and Ruth A. Anderson. "State of the Science: Relationship-oriented management practices in nursing homes." *Nursing Outlook*. 59. (2011): 221-7.

means we are left with dealing with the environment as it stands. What is evident in many of the studies on the quality of work life in the nursing home is that the caregivers are acutely aware of the barriers to providing good care and that good care begins with respectful, engaged relationships.[117] The issue of maintaining the nursing home resident's autonomy could prove to be a moot concern since many of the residents who need round-the-clock care no longer have a realistic ability to govern their own lives in the full and robust sense often referred to in discussions of autonomy, and a significant number of residents will not have the ability to exercise any degree of autonomy due to significant cognitive impairment. Even the basic desire to hold onto a sense control and privacy (what amounts to dignity for many patients) may be difficult for cognitively impaired patients to exercise in a meaningful way. However, when the realistic prospect of exercising any degree of autonomy is effectively lost for residents nursing home caregivers are still concerned with the maintenance of resident dignity, despite the nebulous understanding of what exactly dignity means.[118]

Since chronic care patients require more specialised treatment and care than is possible in a nursing home, the ratio of registered health care providers to residents will be somewhat higher in the chronic care facility than in the nursing home. In the nursing home personal support workers provide the majority of direct patient care. I have no issue with exactly who provides the hands-on care, be it the registered health care professional or the

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[117] See Anderson, Ruth A. et al. "The Power of relationship for high-quality long-term care." *Journal of Nursing Care Quality*. 20.2 (2005): 103-6.

[118] See Jakobsen, R. & Sorlie, V. (2010) "Dignity of older people in nursing homes: narratives of care providers." *Nursing ethics, 17,* 289-300. Dignity appears as one of the title words, as well as a keyword, but the actual meaning attributed to the term varies. There seems to be almost an intuitive understanding of what dignity is and this is very much based on the caregiver's socio-cultural background.

personal support worker, or the environment in which the care takes place – at home, in a nursing home, in an acute care hospital, chronic care facility, outpatient facility, walk-in clinic – as long as the focus remains on the patient as relationally embedded person. Everyone is part of a complex network of relationships and this should be clearly acknowledged in the manner in which the care providers interact with each other. Good relationship behaviours need to be modelled and facilitated at the management and administrative level if such behaviours are going to be effective at the bedside. If the health care team members are disengaged from each other, have little or no respect for each other, do not exhibit trust or trustworthiness, seem unable to communicate productively and treat each other like cogs in a machine these attitudes are going to spill over into the patient care realm. Two articles by Anderson, Issel and McDaniel [119] address this very issue. They point out that the more trust, respect, decision-making autonomy, communication, and relationships between colleagues are encouraged and facilitated the better patient outcomes are. I could be dismissive of the research by pointing out that while the results show a distinct correlation between a relationship oriented leadership style and good patient outcomes it could be just a matter of good fortune and the relation between the two is no more than lucky coincidence. If I was a proponent of the hierarchy of evidence where the gold standard is the double blind randomised controlled clinical trial, and preferably a quantitative analysis of the results, I could dismiss the research as qualitative hence practically impossible to replicate with any accuracy or consistency. Dismissing the results as pure coincidence could be said about

[119] Anderson, Ruth A., L. Michele Issel, and Rueben R. McDaniel. "Nursing homes as complex adaptive systems." *Nursing Research*. 52.1 (2003): 12-21.
Anderson, Ruth A. et al. "The Power of relationship for high-quality long-term care." *Journal of Nursing Care Quality*. 20.2 (2005): 103-6.

many studies that use the preferred double blind randomised controlled clinical trial. I have no idea how we might go about measuring the quality of interpersonal relations in quantitative terms. What the articles do not clearly explain is why better relationships amongst the nursing home staff lead to improved patient outcomes – and the improved outcomes are significant, for example, reduced use of restraints and reduced incidence of pressure ulcers.[120] It is only conjecture on my part to assume positive interpersonal relations among staff translates into improved interpersonal relations between staff and patient. But it certainly is a plausible conclusion to reach if we consider nursing theory rests so much on the assertion effective nursing care can only occur in the context of a relationship. If patient outcomes improve then it must be in large part due to improvements in patient care, and improvements in patient care imply improvements in the caregiver-patient relationship.

ii) The perils of evidence-based medicine

The evidence-based medicine movement poses a different threat to the possibility of developing relationship as engagement between practitioner and patient. Like labelling the patient or only viewing the patient as a collection of symptoms to be addressed, evidence-based medicine is another objectifying tendency as van Heijst puts it in her paper "Professional Loving Care and the Bearable Heaviness of Being."[121] The reliance on gold standard evidence (i.e. the double blind randomised clinical controlled trial) that the

[120] These two particular issues are a constant concern in nursing homes since they speak to two significant classes of patients: dementia sufferers (restraint use) and the very frail (pressure ulcers).

[121] van Heijst, Annelies. "Professional Loving Care and the Bearable Heaviness of Being." *Naturalized Bioethics: toward responsible knowing and practice.* Ed. Hilde Lindemann, Marian Verkerk, Margaret Urban Walker. Cambridge: Cambridge UP, 2009. 199-217

proponents of evidence-based medicine strongly urge health professionals use to base their treatment options effectively reduces patients to statistics, obscuring the fact that individual patients are unique persons with unique histories. This approach to medical care undermines the person-focused aspects of clinical practice – such as actually talking to patients or mindful watching (as opposed to immediate interference). I have a particular objection to the potential usefulness of the meta-analysis or review article[122] for treating particular patients. The pool of research subjects, particularly in the meta-analysis, is far too homogenised in terms of pre-existing health concerns and, often, in terms of age as well. This is a particular concern when attempting to put research findings to use with patients who have multiple co-morbidities, which is very often the case with elderly patients. There are entire segments of the population that are never recruited for clinical trials. Pregnant women and the elderly (with their pesky co-morbidities!) are two groups that come to mind, and there has been a long history of not bothering to conduct research that focuses on women.[123] But the real problem to my mind is that keeping an unwavering focus on evidence encourages health professionals to focus on parts of the patient rather than the whole patient. We fall back into thinking the ailing part of the patient's body can be somehow separated from the patient as a whole – it encourages a mind-body split, albeit a secular or scientific split.

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[122] The review article synthesises the data found in a variety of published research studies. The meta-analysis uses the actual data from a variety of clinical trials as opposed to just looking at published results (and presumably interpretations of those results) – an expensive and time-consuming endeavour.

[123] See Baylis, Francoise. "Women and health research: working for change." *Journal of Clinical Ethics*. 7.3 (1996): 229-42.

As Goldenberg points out, with its roots firmly in epidemiology evidence-based medicine undermines the authority of the individual practitioner and practically silences patients' own perceptions of their illness.[124] In the rush to base treatment decisions on the best available 'evidence' the risk of ignoring the patient's preferences, values and perspective increases. The patient effectively disappears from view. The rigid hierarchy of evidence works to limit the range of treatment options for patients once the impetus is to *base* treatment decisions on only the best, most reliable evidence. But this is simply unrealistic for many segments of the population. Consider the frail elderly patient who lives at home, takes medication for diabetes, arthritis, high cholesterol, and depression, and now requires drug intervention for heart problems. Where can we find the best evidence on which to base a treatment decision for this type of patient? Ideally, we are looking for results from a randomised clinical trial, but will the research subjects be anything like the patient we seek to treat? What works for a middle-aged man may not work so well for an elderly woman with multiple health concerns. Yet, evidence from the "lesser" research methodologies – such as the lowly case study involving one research subject – are regarded with suspicion by the sincere adherent to the evidence-based approach to medical care. Where does this leave the patient who has complex care needs? What of his or her preferences for treatment? It would seem, at its most extreme, evidence-based medicine loses sight of the subjectivity of individual patients in favour of the objectivity of the clinical trial. Evidence-based medicine urges its adherents to move from qualitative understandings of the individual patient to quantitative understandings of a homogeneous group of research subjects that do not seem

[124] Goldenberg, Maya J. "Clinical evidence and the absent body in medical phenomenology." *International Journal of Feminist Approaches to Bioethics*. 3.1 (2010): 43-71.

to reflect any particular individual. It is a little like trying to find the family that has 2.5 children.

The patient has not quite disappeared yet though. Evidence-based medicine's current running mate is "patient-centred care." Most health care facilities will advertise their patient-centred (or family-centred and occasionally relationship-centred) approach to care, offering comforting definitions of what patient-centred care is all about.[125] The upshot of the patient-centred care message is the promise that care will be person focused, the patient's perspective will be respected and the care tailored to meet patient need. As Goldenberg points out there is little by way of definition to be found in the academic literature, and what is offered seems to be more about what patient-centred is not – not centred on physicians, technology, or hospitals. These two, quite different, approaches to medical care seem to be at odds with one another. Patient-centred care takes evidence-based medicine to task for not putting the patient front and centre. "The calls for patient-centered care challenge at some level EBM's strong assumption that the evidence somehow dictates best practice."[126] Patient-centeredness does not imply a lack of support for medical research or for finding the *best* evidence, but does reject the insistence medical best practice is evidence-*based*. What could be considered best evidence in a patient-centred model of care may not be the quantifiable data of the clinical trial but the qualitative data that stands to provide a more accurate view of the patient-practitioner relationship that is so integral to patient-centred care. So, patient-centred care effectively upends the hierarchy of evidence. It would be

[125] Ibid. Goldenberg refers to Toronto's University Health Network website, but I fully expect many health care organisations will have something advertising their approach to medical care is patient-centred.
[126] Goldenberg, Maya J. "Clinical evidence and the absent body in medical phenomenology." *International Journal of Feminist Approaches to Bioethics*. 3.1 (2010): 48.

inaccurate and highly uncharitable to fail to acknowledge evidence-based medicine has evolved, and its more recent incarnations do make reference to both clinical expertise and patient values.[127] Perhaps it is now more accurate to refer to evidence-*informed* medicine, and this I have no real objection to, and I assume neither would proponents of patient-centred care. Certainly all of us, as potential recipients of health care, want to feel confident the treatments on offer are *informed* by the best available research; including the more subjective and qualitative ways of knowing as part of what we consider *best* evidence still needs to be accomplished. Medicine is not just science; medicine deals with the person and it takes a certain artfulness, sensitivity and creativity to care for a person. Medicine is as much art as it is science.

For patients too, evidence-based medicine can be misleading if not outright harmful – they too will believe the odds of successful health outcomes are dictated by the statistics produced by large, and by all appearances, successful clinical trials. Basing hopes for a healthier future on the statistics produced by large clinical trials can be a misleading and often demoralising prospect, and may lead some patients to focus so much on the possible outcomes of treatment they forget their own individuality. The constant focus on statistics, facts and figures works to distance practitioner and patient from one another as both focus on outcomes, which may or may not come to fruition. We miss out on the present moment and the care potentials we find in the present if we are always obsessed with what may or may not occur in the future.

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[127] Ibid; see also, Sackett, David L., Sharon E. Straus, and W. Scott Richardson. *Evidence-based medicine: How to teach and practice EBM.* 2nd ed. Edinburgh: Churchill Livingstone. 2000.; Sackett, David L. et al. "Evidence-based medicine: what it is and what it isn't." *BMJ* 312. (1996): 71-2.

The larger problem posed to patients by the evidence-based approach to health care is it can limit the range of treatment options, since not all evidence is equal. With research evidence ranked according to a stringent hierarchy it is highly likely only the research that sits at the very top of the hierarchy will be put into practice. Those patients who do not come close to fitting the profile of the ideal research subject will feel the detrimental effects of evidence-based medicine most acutely. More troubling still is the lack of research evidence for the efficacy of treatment for rare disorders. If there are not enough research subjects to conduct a clinical trial with a decent sample size the research produced will sit low on the hierarchy of evidence, and the lower the ranking of research the less trustworthy it becomes in the eyes of both practitioner and patient.

I am not surprised the allure of evidence-based medicine is so enticing. We are all to one degree or another educated to believe in the promise and reliability of the scientific method. Both patient and practitioner can hold onto (in a manner of speaking) the evidence offered by rigorous, quantifiable medical research. For the patient hard numbers and optimistic research results found in ostensibly good research studies can undermine the authority of the practitioners who provide direct patient care. For the practitioner the research evidence is so much more concrete, digestible and trustworthy than the lived experience of illness that the patient tries to share. In the process of keeping their eyes on the evidence both patient and practitioner lose some of the authority they need for a successful, engaged relationship. The patient's experience of illness stands to be pushed

aside in favour of the latest best evidence. For the patient the clinical experience and wisdom of the practitioner is not nearly as enticing or promising as the scientific research.[128]

III. Trust and Respect

The cornerstones of any relationship are trust and respect. Even the cool calculated contract requires minimal trust between the parties, and while respect for each party as person might not be an essential ingredient for a successful contract there must be respect for the terms of the contract itself. There is at least a surface similarity between this one sentence account of the contract relationship and what I have referred to as relationship as engagement earlier. In both cases a certain level of trust is required and in both cases the major investment needs to be in the relationship or contract itself more so than in the other party or parties. Yet, I have also been quite adamant in denying the nature of the practitioner-patient relationship can be or should be captured in purely contractual terms. Where lie the differences then?

There are significant reasons for not regarding the practitioner-patient relationship as a contractual relationship. First, practitioner and patient are not equals in the same sense parties to a contract are and because of the inequality[129] between practitioner and patient a greater level of trust is needed for the relationship to be successful. Second, we do not respect the relationship in the same way we respect the terms of a contract, rather the relationship is a conduit for respecting the person or persons who invest and nurture the

[128] "Backed by scientific research!" might just as well be synonymous with Evidence-based medicine for many patients and their families.
[129] Mostly inequalities of power – the practitioner generally has the 'power to' that the patient does not have – but the inequality could conceivably be more than simply the practitioner has the expertise the patient lacks. There could be significant differences in social and economic status, knowledge, etc.

relationship. In a relational and care approach to individual particular worth the relationship becomes a vehicle for affirming dignity.

Before I go any further I want to reiterate there is no *responsibility* as such on the part of patients to trust or respect their health care providers, and of course not every patient will have a concept of trust or respect to put into practice. However, since trust and respect do fit into the normal expectations we have of any relationship, at least to the extent each party is able to overtly extend trust and respect to the other, I think it is reasonable to expect patients will trust and respect their caregivers. Having said that, it cannot be denied health professionals as a group are customarily regarded as trustworthy by virtue of their profession regardless of whether we have any kind of interpersonal relationship with them that might give us evidence of trustworthiness. Unlike salespersons, lawyers or mechanics[130] our overall impression of doctors and nurses is that they are trustworthy. Organisations like *Médecins sans frontières* or *Physicians for Human Rights* would not thrive if health care professionals (physicians in particular) were considered inherently untrustworthy. It is uncontroversial to claim that, by and large, we consider health care providers trustworthy – it is part of their job to be trustworthy. Just as it is part of any work and the duties associated with that type of work: "We take it for granted that people will perform their role-related duties and trust any individual worker to look after whatever her job requires her to do. The very existence of that job, as a standard occupation, creates a climate of some trust in those with that job."[131]

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[130] I am not implying all salespeople, lawyers and mechanics are inherently untrustworthy – nothing of the sort. But it is certainly customary or socially acceptable to regard these three professions with some suspicion. In defiance of all socially acceptable stereotypes, I find my mechanic absolutely trustworthy (at least as far as my car goes).

[131] Baier, Annette. "Trust and antitrust." *Ethics*. 96.2 (1986): 231-60. 245

As O'Neill points out it is health care as a system that we so often feel wary about trusting.[132] From the patient's point of view it seems trust for the individuals who work in health care (regulated professional staff or not) is not as big an issue as the patient's need to feel respected as a person. Recall that in the Holmberg, Valmari and Lundgren study patients reported no issues around trusting the nurses who provided care; in fact they had great confidence in the nurses' technical skills and knowledge.[133] As Hallowell and at least one of the interviewees puts it: the patient needs to be "taken seriously."[134] The interviewees in Hallowell's paper clearly point out that as patients they certainly trusted their health care practitioner to be knowledgeable; what was at issue was not the practitioner's lack of trustworthiness but their failure to treat the patient with respect.[135] The study looked at "women who had managed or were in the process of managing, their risk of ovarian cancer using prophylactic surgery or ovarian screening"[136]; the women were interviewed regarding the experience of the health care interactions they encountered during their attempts to access either screening or surgery. "The decision to undergo prophylactic surgery is not experienced as an easy one."[137] The women opting for this route need support and information, however as Halloway discovered it is not the *type* of information that is given

[132] O'Neill, Onora. *Autonomy and Trust in Bioethics*. Cambridge: Cambridge UP, 2002. See especially chapter 1, section 1.3 "Trust in the Risk Society"
[133] Holmberg, Marie, Gudrun Valmari, and Solveig M. Lundgren. "Patients' experiences of homecare nursing: balancing the duality between obtaining care and to maintain dignity and self-determination." *Scandinavian Journal of Caring Sciences*. Mar 16 (2012): [epub ahead of print]
[134] Ibid, 427, 433.
[135] Hallowell, Nina. "Encounters with medical professionals: a crisis of trust or a matter of respect?" *Medicine, Health Care and Philosophy*. 11. (2008): 427-37.
[136] Ibid. 430.
[137] Ibid. 430.

that is regarded as important so much as the *way* the information is delivered.[138] The concern expressed by many of the participants was with the way in which they were perceived by their health care practitioner. They were not being taken seriously. The women trusted their practitioner to be knowledgeable and trustworthy, but they felt they were not being respected as persons (their dignity was ignored).

For health care practitioners there is a responsibility to respect the patient as person and to at least assume the patient is trustworthy insofar as the patient is able, to the best of his ability, to describe symptoms, offer an account of the experience of his illness, follow treatment recommendations, take medications as prescribed and relay any other information pertinent to his treatment.[139] (Trustworthiness and respectability are not assumed in a patient in the same way they are for health care professionals.) Certainly some patients will withhold the true nature of their health care needs or attempt to deceive the health care provider for personal gain. The obvious example is the patient who requests powerful painkillers that are either disproportionate to his need or not needed at all. But to assume all patients are wilfully deceptive will do nothing for the possibility of a caring, mutually trusting, mutually respectful relationship. There will always be cases of practitioners and/or patients who are found to be untrustworthy; just as it is in any other relationship where we discover the one we trusted is not in fact trustworthy. For the practitioner, being revealed as untrustworthy could mean the end of his or her professional career; and the public's moral outrage if the practitioner is unlucky enough to find his or her transgressions splashed across the front page of the local newspaper. For the patient, being revealed as untrustworthy stands to

[138] Ibid. 430.
[139] Medication non-compliance is a widely documented issue in health care but it is not necessarily a result of the patient's wilful dishonesty or lack of trustworthiness.

hamper the provision of good care. Trust is a necessary component of a successful practitioner-patient relationship. It falls on the practitioner to be the first to extend and cultivate both trust and respect. By virtue of their occupation they are expected to inhabit the moral high ground.

Trust does not necessarily occur or evolve *only* in the context of a relationship between equals, as contract theory would imply. The trust between citizen and government is hardly one of trust between equals. The single citizen rarely has power equal to that of his government. The trust between infant and mother is perhaps the best example of trust between the powerful and vulnerable. There is nothing contractual about the mother and infant relationship. Mothers do not attempt to win the trust of their infants, although they certainly can, over time, destroy that trust. Infants do not consider the trustworthiness of their mothers – they have no capacity to do so. To assume all we understand about trust and trustworthiness can be gained by understanding the contract (explicit or implicit, hypothetical or actual) ignores the relations between those of unequal power.[140] We are fooling ourselves if we think the relationship between practitioner and patient mirrors that of a contract where the stakes are equal for each party. The informed consent process virtually every competent patient goes through (either explicitly or implicitly) might provide the happy illusion the patient is on equal footing, in terms of power and knowledge, with the practitioner. But it is only an illusion. The patient still relies on the practitioner's responsibility to respond to the patient's need for care with compassion.

For the patient who cannot give informed consent the relationship is nothing like a contract. For this patient the relationship is the space in which his dignity is witnessed,

[140] Baier, Annette. "Trust and antitrust." *Ethics*. 96.2 (1986): 231-60. 241

affirmed and actualised. The self-aware, reflective practitioner (these are the tenets of good patient care in practice) cognisant of her own dignity is committed to respond to the call to recognise and affirm dignity in another. As are we all, if we take seriously the relationships we are all embedded in and are beholden to for conferring and actualising our own intrinsic value.

IV. Centredness in healthcare.

I do not want to give the impression there are so many potential barriers and threats inherent in the norms of the current health care system and the way health care delivery is organised to irreparably undermine the possibility of positive, dignity preserving and enhancing patient care. The relationship is integral to the provision of good patient care, but like every interpersonal relationship the practitioner-patient relationship can stumble. Thoughtlessness, not paying attention, competing demands, imposing our own values, making lousy assumptions can all cause any relationship to temporarily falter. But stumbling or falling down does not mean we cannot pick ourselves up, make amends and carry on. While I have outlined much of what I view as central to a good practitioner-patient relationship I do not expect health care practitioners to be paragons of moral virtue who never misstep. Most of us that view ourselves as reasonably self-aware and aware of those around us do take the time to reflect on our experiences, try to learn from our experiences and incorporate what we have learned into our lives. This is the route to wisdom. Reflecting upon past clinical experience and incorporating what can be learned from reflection is the route to clinical wisdom. Reflective practice is so integral to good practice it is discussed, taught and theorised at length. While the monolithic structures that house health care

facilities, the way in which health care workers are managed and expected to work, and the evidence-based medicine movement (and I expect these are not the only significant barriers to dignity preserving care) do have the potential to put a wedge between practitioner and patient, the patient has not been lost. Health care is still about patients.

The different types of centredness we find championed by most, if not all, health care institutions and practitioners provides some evidence that the practitioner-patient relationship is, not surprisingly, focused on respect for patients – specifically respect for patient as *person*. For health care to be patient, client, family, person, or relationship centred[141] just means the patient is to be the focus of care, and to respect something or someone is in part to focus on that thing or person. More than just focusing long and hard though, the person or thing needs to be perceived as worthy.[142] The overriding theme Hughes et al found in their review of the various types of centredness in health care was that regardless of the terminology (for example, relationship versus person centred) it is always the patient who is the focus of respect. To espouse relationship-centred care at least gestures toward the notion patients are relational beings and – perhaps more significant in terms of respect for patient autonomy than patient dignity - might consult others with whom they have strong relational ties when faced with health related decisions. Viewed through a relational and care approach to dignity and individuality, relationship-centred care may also suggest an acknowledgement of the importance of relationships to the formation of the individual. Person-centred care is strongly associated with providing care for dementia sufferers; again the not so subtle implication is that there is something about the non-

[141] See Hughes, Julian C., Claire Bamford, and Carl May. "Types of Centredness in Health Care: Themes and Concepts." *Medicine, Health Care and Philosophy*. 11. (2008): 455-63.
[142] For Kant this is treating persons as ends.

autonomous dementia patient that is of value, namely their personhood.[143] The point I want to make here is that while respect for dignity tends to sit in the shadow of respect for autonomy it is implicit in the approaches to patient care adopted by many health care professionals. Even if the patient-centred care model is vaguely defined, the fact so many health care institutions actively promote a patient-centred care model suggests there is a move to make what is already implicitly understood by many health care professionals as necessary for dignity promoting and person focused patient care explicit.

To respect patient dignity and autonomy (presumably patient-centredness attends to both) in the context of the practitioner-patient relationship involves more than simply offering the patient space to be who they want to be, work on their projects free from interference and tacitly acknowledging their inherent value as persons. Such a distanced and distancing type of respect seems hardly appropriate for the health care context where patients come precisely because they are vulnerable and need care. Considering we often need help achieving our ends such a distanced and distancing approach to respect seems inappropriate for any kind of interpersonal relationship let alone a relationship in which one party is noticeably vulnerable and in need of care. Patients depend on their health care practitioner to provide a level of care that will improve their sense of well-being, and that involves more than simply attending to the ailing part of the body as it if it is possible to separate the person from the body. The type of respect necessary for a successful patient-practitioner relationship is one that requires a particular type of attitude toward the patient.

[143] Tom Kitwood initially developed and championed the person-centred approach for dementia care. He was also founder of the Bradford Dementia Group, renowned in the world of dementia care.

It is the attitude of responsiveness, or care respect, I referred to earlier as a crucial element of the relationship as engagement.

This approach to respect works well in terms of respecting a person's sense of dignity by responding to patient's need for control and independence, and helping them exercise control and independence. Achieving control and independence are the ends patients who have a clear sense of personal dignity want help with, for them control and independence are integral to their sense of personal dignity. But what does care respect mean for the patient who is incapable of having ends? Does it mean anything to the patient who has no sense of being a distinct 'me'? Just because a person lacks the self-awareness to conceive of himself or herself as a distinct 'me' does not mean they lack individual worth. On a relational and care approach to dignity it is not the capacity to conceive of oneself as an individual that makes one an individual. Rather, it is the relationships of care that a person is embedded in that makes him or her recognisable as a distinct and valuable individual. We become who we are only through the caring of others; it is only through the caring of others that we are able to thrive. So, while it is simply unintelligible to promote the ends of a person who is incapable of having ends this does not preclude affirming the person's dignity. To affirm the individual value of a patient who may not be able to perceive a slight to his or her dignity requires that we shelter the patient from dehumanising treatment. This may be all care respect requires of us in reference to respecting the patient who is incapable of having ends. We can take our cues on what dehumanising - dignity undermining – treatment is from those who are aware of their own sense of dignity. In providing dignity preserving care, by sheltering the patient from the dehumanising gaze and the equally dehumanising urge to label the patient, the caregiver affirms both her own dignity and the value of the care she provides.

The aim of this chapter has been to examine the necessary elements of a relationship where the primary focus is on preserving patient dignity rather than just respecting patient autonomy. Not all patients are autonomous, even in a loose sense of the concept, yet all patients deserve the respect that comes with being recognised as a fellow human being, a person of value. We may not be able to engage in a particularly robust manner with a comatose patient but we can always be cognisant they are some mother's child, and in being some mother's child they have individual, equal worth as a result.

While the potential barriers and threats to relationship might go unnoticed by some patients they do stand to affect the practitioner's view of the patient and the way practitioners view themselves. Falling into the habit of labelling the patient according to her ailment has a dehumanising effect. Focusing on what the medical research deems the best evidence for a treatment undermines the practitioner's clinical expertise and wisdom. Evidence-based medicine can silence the voices of both practitioner and patient. It is easy to forget the dignity enhancing effects of interacting with the patient as a fellow human being if the focus is on the lovely statistics and probabilities outlined in a published clinical trial rather than the patient. Those lovely statistics and probabilities encourage a mind-body dualism that is not tenable in the patient care context – patients cannot simply hand over their bodies to be cared for.

Although the organisation of health care delivery and the evidence-based medicine movement can pose a serious and insidious threat to the possibility of relationship as engagement, it is not all doom and gloom for the practitioner-patient relationship. In the final section of the chapter I returned to the relationship by looking at trust, respect and the

trend toward centredness in health care. Health care professionals, by virtue of their occupation, are generally viewed as trustworthy and worthy of our respect. According to the literature, patients are confident their practitioners are trustworthy and have great confidence in their technical knowledge. What is at issue (and I refer to this in the first chapter also) is respect – patients want to feel respected in their interactions with health care professionals. The way in which information is provided needs to be respectful of the patient as person. Delivering bad news needs to be done in such a way that respects the patient's sense of worth (as Halloway's study points out); it need not be belittling. As discussed in the first chapter, patients are quite clear in stating that having a good relationship with their caregiver enhances their sense of dignity – it makes them feel they are valuable, unique individuals. Health care as a system is promoting patient-centred care as a means of reminding patients they are in fact the focus of care; that the focus of health care is not physicians or technology. What does this all mean for the patient who has no discernible autonomy? It means health care practitioners and the health care system itself do endeavour to recognise that patients are persons deserving of the equal respect owed to all humans. If the basis of our individual, equal worth is located in the relationships we bear to one another then the foundation of respect for patient dignity needs to be based in the practitioner-patient relationship.

Concluding remarks

I began with the question: how do we preserve patient dignity in the health care context? In order to suggest a viable answer, I looked to what patients and practitioners

themselves had to say about dignity. The issues identified by patients as being linked to their understanding of dignity – control, independence, privacy, integrity, being treated as a fellow human being – are markedly more concrete than Kant's conception of human dignity as practically synonymous with the autonomous will. If I were to suggest to a patient that her dignity is based on her capacity for moral autonomy and attempt to give an account of Kant's conception of the autonomous will, I expect I would receive a cold and blank stare. Dignity, for many patients, is something they feel. What I set out to do in this paper is give an account of human dignity that is informed in large part by what patients and practitioners conceive dignity to be and then suggest how we might best go about respecting dignity so understood. The approach I have taken to individual dignity avoids the capacity or capability problem found in many accounts of human dignity. Whatever capacity or capability we associate with dignity we will inevitably discover some human, whom we certainly recognise as a member of the human community, who lacks whatever capacity or capability we have chosen to associate with dignity. Tying dignity to any presumably unique human capacity will inevitably leave some humans out. By taking a relational and care approach to dignity I avoid a possibly fruitless search for some quality that we can all agree is essentially human *and* valuable.

The relational and care approach to dignity I have outlined would benefit from further investigation and elaboration. However, the question that guides this paper is a 'how' rather than a 'what' question. In terms of the 'how' question this paper investigates, getting tangled in the intricacies of the theoretical foundations of human dignity may have been counterproductive.

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