Dignity: A Salient Concept in Philosophy of Medicine

by

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ABSTRACT

DIGNITY: A SALIENT CONCEPT IN PHILOSOPHY OF MEDICINE

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We all claim to know intuitively what dignity is – we recognise it when we see it and we notice its absence. If we appeal to the traditional Kantian account of human dignity, we will find there are human persons who, although they are recognised and acknowledged as members of the human community, ostensibly do not and cannot possess dignity because they lack the requisite rationality, agency and freedom. For example, infants, and people with severe dementia or developmental disabilities cannot, strictly speaking, possess dignity on Kant’s account since they are not rational, have limited agency, and are not free (in any sense of the word). The concept of dignity is addressed in the health care literature (see for example Nordenfelt, 2003; Pullman, 1999; Pullman, 2003; Gallagher, 2004), yet, despite its salience for both patients and health care professionals, it is woefully undertheorised. The claim I make and defend in this project is that a carefully theorised concept of dignity will be particularly useful for patients with diminished or severely compromised capacities for autonomy. Not all patients are, or have the capacity to be, autonomous. I defend a relational account of dignity, whereby dignity is conferred through relations of care. In defending my claim that dignity is a useful concept in health care I am also challenging autonomy’s central role in bioethics.
Dedication

For Mrs. C., whose story helped bring this project to life.
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Chapter One

Why health care needs a theory of dignity

Introduction.

Let me start with the obvious: dignity is a vague concept. It is regularly invoked in human rights, law and bioethics. Yet, in each of these cases dignity is rarely given a robust or even clear definition. In chapter two’s survey of the health literature on dignity I address in more detail this lack of a robust definition. For now, let me point to the Universal Declaration of Human Rights’ references to dignity. The word dignity appears five times, but not once is it clearly defined. At best, we see hints of what it might mean. For example, in the Preamble we learn that dignity is inherent. In Article 1 we are told “All human beings are born free and equal in dignity and rights”. In Article 22 we are informed that “Everyone, as a member of society, has the right to social security and is entitled to realization … of the social and cultural rights indispensable for his dignity and the free development of his personality”. Finally, in Article 23 (regarding the right to work) section 3, we are told that “Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection”. To sum up, dignity is inherent, we all have an equal amount of it, social and cultural rights are required for human dignity, and, for those who work, decent pay for work done is needed to ensure an existence worthy of human dignity. I have no issue with any of these assertions (although surely there is more to an existence worthy of dignity than decent pay). My issue is with the notion that we all know what dignity is. The assumption is that we all know intuitively what dignity is – we recognise it when we see it, and that seems to be good enough. The claim I make and defend in
this project is that a carefully theorised concept of dignity will be particularly useful for patients with diminished or severely compromised capacities for autonomy. Not all patients are, or have the capacity to be, autonomous. Infants, persons with profound cognitive impairment and patients in a persistent vegetative state are not autonomous in any relevant or meaningful sense (that is, able to engage in health care decision making and provide informed consent); and even the unconscious patient is at least temporarily incapable of autonomy. In defending my claim that dignity is a useful concept in health care I am also challenging autonomy’s central role in bioethics. By no means am I suggesting autonomy and respect for patient autonomy are insignificant guiding principles, just that the apparent preoccupation with autonomy brings with it the very real risk we overlook the needs of our most vulnerable patient populations, particularly patients with significant cognitive impairments.

The approach I take to conceptualising dignity falls in line with feminist understandings and conceptualisations of autonomy\(^1\), where autonomy is not a capacity that transcends our embodiment or remains unaffected by our social and relational situatedness. The only way we can develop our capacities for autonomous action is with the help of others. The choices we make, and the freedom we have, are shaped by the relationships we have (both the relationships we have chosen and those we have not) and the society we are born into. In other words, we do not become autonomous in a social or cultural vacuum. Increasingly, a relational understanding of patient autonomy is reflected in the health care literature generally, and health care ethics more broadly\(^2\). Of course, dignity is conceptually different from autonomy in that dignity is not

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\(^2\) In recent editions of *Principles of Biomedical Ethics* Beauchamp and Childress give an overview of relational autonomy in their chapter on the principle of autonomy. A 2016 essay by Bruce Jennings,
a capacity or a set of capacities that can be honed over the course of a lifetime. Our intuitive understanding of dignity is that it is an absolute value or worthiness we each possess in equal measure. I agree with this intuitive understanding, as far as it goes – yes, dignity is an absolute value or worthiness we each possess in equal value, and it is the kind of value or worthiness that demands recognition and respect. There is nothing particularly controversial in stating that respect for dignity is relational in that respectful action and behaviour towards another occurs in the context of relationships. But the question I am interested in is, where does our individual dignity come from? Why do we have this moral worthiness we label dignity at all? The short answer is we have dignity because of others; it is in the relationships we bear to one another that we find the source of our individual moral worth. Through relations of care, our dignity – our moral worthiness – is at once conferred and acknowledged. Eva Kittay puts it this way: “we are all some mother’s child”\(^3\). On Kittay’s account the value we each have – our equal dignity – is a result of the care given to us. “Our dignity … is bound both to our capacity to care for one another and in our being cared for by another who is herself worthy of care.”\(^4\) There are some obvious objections to this view of dignity. What about the child who receives no care? Does the more cared for individual have more dignity? If care is withdrawn or a person has no significant relationships (think of the social recluse who has chosen to reject relationships with others) is dignity also withdrawn?


\(^4\) Kittay, “Equality, Dignity and Disability,” 111.
I will develop my argument supporting my view of dignity as highly dependent upon relationships, especially relationships of care, and the recognition of others in more depth in chapter three. For now, I offer the following responses to the objections outlined above. The first objection is nothing more than a thought experiment of the type we trot out in introductory philosophy classes. If we are realistic in thinking through the thought experiment, there is only one conclusion we can reach about the child who receives no care: she does not survive, and any talk of the child’s dignity is practically meaningless. The second objection, which suggests the more cared for individual will have more dignity, holds some merit. It is highly likely that the more cared for individual will have a greater sense or feeling or awareness of his own dignity, but that need not mean the individual has a greater moral worth (more dignity) than another individual who is utterly unaware of or has no sense of his own dignity. I think the objection is useful because it helps open up discussion on the significance of recognising and responding to another’s dignity. As for the third objection, a person who chooses to eschew the relationships she has in favour of a life of self-sufficient solitude has obviously benefitted from relationships of care to be able to make this kind of life choice, and as such is already a bearer of dignity. In many cases, like the case of the person with significant cognitive impairment, caring relationships are needed to sustain dignity but for those of us aware of our own dignity there will be times when we are the only witness to our own dignity.

A relational approach to dignity, as I conceptualise it, resists tying dignity to autonomy. Consider the traditional Kantian approach to dignity, where the capacity for (moral) autonomy is regarded as essential to the possession of a “value beyond price”. We are bearers of dignity

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5 Perhaps in the case of the child not cared for, there is a case to be made for potential dignity but not actualised dignity. I will take up this particular objection in more detail in chapter three.
precisely because we have the capacity for autonomy. And if the capacity for autonomy is required to be a bearer of human dignity, we risk seeing those humans who have either lost the capacity for autonomy, have compromised capacities for autonomy or never had it in the first place as having no or lesser value. Also, a relational account of dignity could be easily extended to include non-human animals. I am not trying to make the claim that humans in particular possess a special moral worth simply in virtue of being human, rather I am making the claim our individual special worth is conferred upon us by others. Essentially, others ensure we are morally valuable respect-worthy individuals.

In this introductory chapter I begin by telling the story of Mrs. C; a story that captures the type of patient I think a clearly theorised concept of dignity would be particularly useful for. The story also helps me highlight the inadequacy of the four principles approach. I then query the usefulness of the principles of respect for patient autonomy, respect for persons, beneficence and non-maleficence for patients with cognitive impairments, like Mrs. C. I demonstrate that none of these principles quite capture the worth of Mrs. C in a clear and unambiguous way, nor do they adequately grasp what it means to respect Mrs. C. I then move on to outline subsequent chapters.

**Holding onto Mrs. C: Dignity, Autonomy, Relationships.**

I met Mrs. C, my mother-in-law, some twenty years ago. Mrs. C was, and still is, a petite woman with a ready smile and an easy laugh. I was briefed on Mrs. C’s political leanings. Mr.

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6 I use the story of Mrs. C with the permission of her family. Since Mrs. C refuses to acknowledge her probable dementia diagnosis I have not spoken with her directly about using her story. I have been careful to blur details without losing the essence of the story. I also want to make it clear that these are my perceptions and interpretations, not necessarily shared by everyone or anyone in the family.
and Mrs. C are devout Catholics, so, for the most part, Mrs. C is socially conservative and adamantly anti-abortion. I was forewarned partly because Mrs. C is not one to politely shy away from discussing hot button social and political issues, and partly because I too am not coy about my own, comparatively left leaning, social and political convictions. The first question Mrs. C asked me was, “what do Canadians think about Bill Clinton?” So much for small talk! The stage was set for many heated, albeit friendly, political discussions in the years ahead. Most of our political debates would take place at the tail end of a family gathering. My partner is second of six children, so family gatherings at Mr. and Mrs. C’s were big, boisterous affairs with the adults talking over each other as they filled each other in on their day-to-day trials and triumphs. The children seemed to infiltrate every nook and cranny of the house. And the children no less talkative, enthusiastic and animated than their parents. Coming from a small family I was both overwhelmed and impressed by these huge family affairs. Overwhelmed by what looked to me like utter chaos: far too many cooks in the kitchen, children racing about the house, too many loud conversations going on to keep track of. Considerably more action and noise than the small gatherings I was accustomed to. Yet, in spite of the chaos a massive meal would come together and there would be seats enough for everyone to enjoy a relatively calm and orderly dinner. While I was impressed by the ability of the family to pull together a successful sit-down dinner, I was especially by the feeling of loyalty that seemed to ripple through the house at these gatherings. It was evident in many of the snippets of conversations I overheard: an insult to the honour of one was an insult to all in the family. Even in my earliest experiences with the entire extended family I knew the allegiance to the family as a unit was not to be taken lightly.

Some things have not changed over the years. Family gatherings are still boisterous chaotic affairs, and a surprising number of those gatherings still take place at Mr. and Mrs. C’s.
The majority of the children are now teenagers or young adults, so they are either very much present in the many overlapping conversations that nobody seems to be paying close attention to or they retreat into the secret sullen world of being a teenager. At the end of the evening I still find myself chatting with Mrs. C. I have spent hours defending socialism, universal health care, reproductive rights, or my views on which U.S. presidents served the country best. I never thought I would miss those conversations. But I do. Now the conversation consists of roughly the same questions over and over: “how are your parents doing?”, “How is work? What do you do again?” “Are you hungry? Can I get you a bite to eat?” Mrs. C has dementia, probably Alzheimer’s. She was very angry at the suggestion she had any kind of cognitive impairment and still refuses to acknowledge there is anything amiss. Because she refuses to accept the diagnosis she has not been prescribed any medication that might have slowed her, now very obvious, cognitive decline. I suspect it is too late now for any medication to be helpful.

For the most part, Mrs. C is still pleasant to be around. She still laughs easily, and clearly enjoys the company of family and friends. When lots of people are around I notice how she tries to be involved in every conversation at once. An impossible task for anyone, let alone for someone who forgets in an instant what has just been said. It is as if by trying to keep abreast of every conversation she feels oriented to the moment. She enjoys Sudoku, crossword puzzles and solitaire. She had her driver’s license revoked a few years ago. At the time she was furious but now she cheerfully explains that she gave up driving when she retired. On many Sundays a recurring pain prevents her from attending morning mass. She insists Mr. C go by himself and that she will go to a later mass. If Mr. and Mrs. C were infrequent church goers this wouldn’t be much of a concern, but they are devout Catholics and that means church every Sunday.
Admittedly, only Mr. C is concerned since Mrs. C forgets that she wasn’t there, and the rest of the day carries on as usual.

Mr. C is her primary caregiver. He takes care of all of the day-to-day household activities: shopping, cleaning, doctor’s appointments, meals, bills, family commitments. Although Mrs. C doesn’t need help with basic self-care needs - washing, toileting and dressing – she is rarely left alone for more than a few hours at a time. He gets some respite from family who live close enough to take over for a few hours. And after much family discussion, a paid caregiver with experience with dementia sufferers comes once a week to provide Mr. C with some time to himself.

Mr. and Mrs. C have a few lifelong friends, but Mr. C is cautious about with whom they socialise. He is wary about the way their friends treat Mrs. C now that the symptoms of dementia have become obvious and difficult to ignore. He complains that some of their friends no longer treat her with respect; instead they speak to her as if she is a child. He recognises that such treatment probably would not bother her or at least would not have a lasting effect – she will soon forget the visit – but he feels it is an affront to her dignity; and dignity is the word he uses. Whatever Mr. C means when he uses the word dignity it is important to him and maybe, if pressed, he would admit that part of what bothers him is having to witness his wife being talked to and treated like a child; that it diminishes her as a person. He may not articulate it in this way but witnessing anyone treating his wife with anything less than the respect he feels she deserves is an insult to his sense of dignity, not just hers. I suspect, but don’t know, the fear that others might treat Mrs. C like a child was one of the reasons he refused for so long to get any outside, professional help in caring for her. The other obstacle seems to be how to explain to Mrs. C that a stranger will come to the house and do what exactly? As much as the family discusses the
possibility of getting some professional help to give Mr. C a break from being present all day and
every day, nobody can figure out how it might be presented to Mrs. C without her becoming
furious and indignant at the mere idea. Perhaps part of his reluctance has to do with believing
that it is his duty to care for her; a duty that he accepted the moment they married some fifty odd
years ago. So, Mr. C takes on the vast majority of Mrs. C’s care needs and rarely gets much of a
break. It needs to be noted that the paid caregiver who comes once a week provides
companionship not professional nursing care. Fortunately, she has just the right Irish brogue to
appeal to Mrs. C, so Mrs. C just introduces her as a friend. And is clearly very pleased to see her
when she arrives each week.

What Mrs. C’s family means when they refer to her dignity is oriented more to her as a
unique individual, her social roles (as mother, wife, grandmother, great grandmother, friend etc.)
and her sense of well-being than an objective quality we all purportedly share. Considering Mr.
and Mrs. C’s faith-based values I was expecting some *Imago Dei* reference in their descriptions
or explanations of what dignity is, but what they mean by dignity is explicitly grounded in a
person’s individuality and the response of others to that individuality. For Mr. C dignity appears
to have much to do with how one is regarded and treated by others, as evidenced by his
reluctance to socialise with friends who treat Mrs. C like a child because of her dementia. Mrs.
C’s own thoughts on the meaning of dignity are exquisitely simple and explicitly subjective: “It’s
that feeling you’re ok.”7 Reflecting on these two views of dignity it is clear that for Mr. and Mrs.
C dignity is both relational (how others treat you either respects and promotes or diminishes
dignity) and highly personal (the ‘feeling’ ok). Judging by the way the rest of the family regards

7 “It’s that feeling you’re ok” are Mrs. C’s own words. The loose definitions of dignity I have attributed
to the rest of the family members are gleaned from conversations we have had at various times; and not
necessarily conversations instigated by me.
and responds to Mrs. C they too are very much in line with a relational and personal or subjective understanding of her respect-worthiness. Even in those moments when Mrs. C is confused or disoriented they are careful, respectful and kind when redirecting her to the task or situation at hand.

I am sure this type of story is familiar to anyone who has a family member with some form of dementia. I doubt Mrs. C is the only dementia sufferer who refuses to acknowledge there are significant cognitive changes occurring. Thus far, Mrs. C has been spared most of the more disturbing personality and behavioural changes that can come with dementia. Her short-term memory loss is the most glaring change. It takes patience to have a conversation that feels like an endless loop of the same questions over and over. It takes patience not to respond, “but I just answered that question.” It takes patience to hear the same anecdote five times in the span of a few minutes. It is an inconvenience to remind her of names or places or events. She can become disoriented and confused. If she is away from home for a few days she will become disoriented and ask where she is and when she will be going home. Sometimes she becomes agitated and confused toward the end of the day, a common symptom of Alzheimer’s called sundown or sundowning syndrome. Other changes are subtle and might not be noticeable to anyone unfamiliar with Mrs. C before the diagnosis. In general, though, Mrs. C is in decent physical health and most of the time she is in good spirits.

Mrs. C presents as a difficult case for health care. Let’s look at how the principle of respect for autonomy plays out or might play out for Mrs. C. Her competence to consent to some health interventions is still intact. For example, she is able to consent to tests to find the probable cause of the recurring pain in her side, even if she does need to be cajoled into seeking medical
advice in the first place. To assume dementia sufferers are incompetent to make any decisions related to their own health is far from accurate and outright disrespectful. Excluding dementia sufferers from decision-making processes regarding the course of their own lives, including their health care, could result in depression, frustration and anger, which will only add to the debilitating effects of dementia. To what extent a patient is competent to make a decision regarding her own health needs is often context dependent. Instances where the health intervention on offer is low risk the level of decision-making competence required is correspondingly low. The riskier the health intervention the more we ought to require in terms of decision-making competence. In the context of diagnosing the source of Mrs. C’s recurring pain the principle of respect for autonomy has been followed: the problem has been identified by Mrs. C, the recommended tests have been described and prescribed by the physician, Mrs. C has understood the risks and benefits of the tests, she then consents to the diagnostic procedure. She presents as something of a hard case for health care once we take into account her refusal to acknowledge she has any kind of cognitive impairment. It makes it difficult, if not impossible, to address or mitigate the issues surrounding her cognitive decline; at least in terms of medical intervention. If she will not accept the diagnosis then, as frustrating as it may be, all anyone (family, friends, health care practitioners) can do is do what will promote her overall well-being. Ensuring her overall well-being includes respecting her choices, when they do her and those around her no harm, and helping her be who she is by respecting her values, commitments and interests (many of which might belong more to the person she was than the person she is

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9 There are behavioural or social interventions that family (along with any other care provider) can perform to help alleviate Mrs. C’s confusion or disorientation, but strictly speaking even social or behavioural interventions could be seen as undermining or disrespectful of Mrs. C’s sense that she can make her own decisions and that she is in charge of the way she lives.
becoming). The take away point here is simply that respect for patient autonomy and the attending issue of the patient’s competence to make health related choices on her own behalf are not black and white issues. Mrs. C’s story shines light on the fuzzy gray area she occupies in terms of decision-making competence and autonomy.

**Reflecting on Mrs. C and the family context**

Why begin with a story? Particularly one that is not set in a health care context. My aim is to make a case for a principle of respect for dignity that is as crucial to good health care as the principle of respect for patient autonomy; so, it does seem odd that I would start with a story that takes place entirely in a family setting. I have two responses. First, by beginning with a story I hope to make the issue real. The story highlights the significance of relationships: how relationships enhance, promote and hold onto individual identity. Ethics, of any ilk, has to do with our relations with others; those others could be humans, non-human animals, the environment, or maybe even a great work of art. Regardless of who or what the other is, the ethically significant aspect is the relationship we have with the other. The point is ethics is by its very nature is a relational enterprise. Tracing the contours of what major philosophical thinkers have had to say about dignity is not going to bring the concept to life in the same way a story detailing the role dignity has in interpersonal relations will. Looking only to the philosophical literature for dignity’s meaning risks prioritising the abstract and logical at the expense of the individuals the concept is supposed to encompass. A more promising approach is to begin by looking at what non-philosophers think dignity is; even better is to look to what happens in respectful interactions between people\(^\text{10}\). At this point, it does not matter that dignity has not

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\(^{10}\) Charles Foster in his *Human Dignity in Bioethics and Law* (2011) takes a similar approach in his attempt to give dignity substantive meaning.
been given a precise definition. I admit that in the story I have told here dignity could be a place holder or an umbrella term for a whole variety of different, and perhaps more precise, concepts. For example, terms such as control, integrity, identity, and respect-worthiness could have been used with similar effect in some parts of the story. Consider this a temporary situation. In subsequent chapters (particularly chapters two and three) a more robust and precise definition of dignity will emerge; a definition that incorporates the various ways dignity and respect for dignity is understood and enacted.

The second reason I begin with a story not set in a health care setting is because I think we can learn something about what respect for (and respect-worthiness of) the person with dementia looks like by noting family interactions. Mrs. C’s family is not simply affording her the respect owed to just any human in virtue of simply being human. Rather, the family sees and respects her as a unique individual, which means recognising and respecting her particular interests, commitments and identity. One of the recurring themes in the dementia care literature is the need for a person-centred approach to the care needs of the dementia patient. Part of being person-centred is being inclusive of the family by considering their needs, as well as paying careful attention to their knowledge of the patient. A prerequisite for person-centred care, then, is to understand the person in terms of his or her relationships with significant others.

By beginning with a story, I am setting a tone for the rest of the project. Rather than pondering which pure abstract theory will map best onto a particular situation, I start with the messiness of a concrete and particular situation to find clues about dignity and what it means to those who believe it is significant. Instead of applying an existing theory of dignity my approach is to conceptualise dignity in a manner that clearly refers to people’s experiences and conceptions of dignity. I begin with the assumption that to be useful in health care ethics a
theory of dignity cannot afford to shy away from the vulnerable, needy, embodied, social and relational realities of being human. In other words, for a theory of dignity to be effective it cannot stay in some pure conceptual realm beyond the reach of the real humans for whom it needs to apply. I am proposing a non-ideal theory of dignity to address the non-ideal context in which it is most usefully invoked.

An obvious response to all this dignity talk is that health care already has ethical principles in place to help deal with situations involving patients like Mrs. C. Ruth Macklin, in her 2003 article “Dignity is a Useless Concept”, suggests the principles of respect for patient autonomy, respect for persons, and beneficence are conceptually more precise, hence more than adequate to address whatever dignity might mean. She concludes, “Dignity is a useless concept in medical ethics and can be eliminated without any loss of content”\(^\text{11}\) (To be fair, Macklin in a later article does concede that although dignity remains fuzzy and vague it “is not a useless concept because people use it in all sorts of ways”\(^\text{12}\).) The existing principles Macklin refers to are those outlined in the \textit{Belmont Report} (1978) and Beauchamp and Childress’s \textit{Principles of Biomedical Ethics} (2001); namely, the principles of respect for autonomy, respect for persons, beneficence, non-maleficence, and justice. But can these principles adequately capture dignity or respect for dignity?

\underline{\text{References:}}


Autonomy (Respect for Persons), Beneficence, Non-maleficence, Justice

The principles referred to above – autonomy (respect for persons), beneficence, non-maleficence, and justice – are intended to provide a framework for helping deal with ethical dilemmas in the medical context. The principle of autonomy, or more accurately respect for autonomy, is the obligation to respect the patient’s decision-making capacities as an autonomous agent. Beneficence is the obligation to act in the patient’s best medical interests by providing benefits and balancing those benefits with potential risk for harm. Non-maleficence is the obligation to cause no intentional harm to the patient. Justice is the obligation for fairness in the distribution of benefits and risks. The principle of justice can apply to individual patients when we consider the ‘fair treatment’ of patients or to entire populations when we consider the fair distribution of limited resources. What is intended by the principle of justice will depend upon the context in which it is invoked. Taken together, these principles are variously referred to as ‘the four principles approach’, the principlist approach, or principlism.

This ‘four principles approach’, favoured in contemporary bioethics, is not a theory in the standard way we might think of an ethical theory that we can take to a particular situation. We are not told how to apply the principles: we are not supplied with a ranking system for the principles; we are given no direction on what to do when the principles conflict in a given situation; and not all of the principles need apply in all situations. The principles act as points

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13 Respect for persons is often (perhaps not always) another way of articulating the principle of respect for autonomy. As often as respect for autonomy and respect for persons are used interchangeably there are times when they are used as if they have quite different meanings.

14 Principlist approach and/or principlism are the terms most often used by critics of Beauchamp and Childress; whereas the Four Principles Approach will be the terminology used by Beauchamp and Childress themselves as well as other proponents of this principle-based approach. See for example, Tom L. Beauchamp. "The Four Principles Approach to Health Care Ethics," in Principles of Health Care Ethics, edited by Richard Ashcroft, Angus Dawson, Heather Draper, and John Macmillan, 3-10. London: John Wylie, 2007.
for critical reflection highlighting values that deserve to be kept in mind when dealing with an ethical dilemma. These prima facie equal principles often conflict, which in itself presents as an ethical dilemma. This is not an indictment of the approach – no proponent of the four principles approach has claimed that the principles act together in an orchestrated manner or ought to, nor are the principles intended to be a comprehensive theory capable of providing answers to difficult moral dilemmas. Yet these are the principles clinicians are supposed to rely on when tackling ethically challenging situations.

What direction will these principles provide in a case like Mrs. C’s? I have already discussed that there are some health care situations where Mrs. C can consent to treatment. For example, regarding her recurring pain: since the tests, diagnosis and treatment recommendations were all fairly low risk the level of decision-making competence required from Mrs. C was correspondingly low; which means that in those types of health care situations the principle of autonomy has been followed. Mrs. C, in some clinical situations, like seeking treatment for her recurring pain, has been respected as an autonomous agent and her decision-making capacities have been honoured. However, what if, in the clinical encounter, the physician explained all of the tests and treatment options to her as if she were a small child? Since the physician has provided the requisite information for her to make an informed decision her autonomy has been respected. Yet, speaking to her as a small child is hardly respectful on anyone’s account. The principle of respect for autonomy does not necessarily encompass the respect part very well. A relational account of dignity would be similar to the way Mr. C thinks of dignity: informed by how you are perceived and treated by others; and it would speak clearly to how Mrs. C, and patients like her, ought to be treated. We could, I think, still use the principle of respect for autonomy to be critical of the physician’s behaviour. Part of respect for patient autonomy ought
to include behaviours and attitudes that actively show respect for the patient as a competent
decision-maker who is able to reflect upon her own values, interests and commitments; or at least
to show respect to the patient as person (whatever that might mean). Beach et al (2007) argue
that while respect for the patient as person does involve respect for patient autonomy that is not
the end of the story. They suggest “that the type of respect that physicians owe patients is
independent of a patient’s personal characteristics, and therefore, ought to be accorded equally to
all”\textsuperscript{15}. Further, they (claim to) “develop an account of respect as recognition of the
unconditional value of patients as persons”\textsuperscript{16}. While I think they are right to point out that
respect for autonomy does not necessarily amount to respect for the patient as person, I want to
know what they mean by \textit{person} and, more importantly, what it is about a \textit{person} that deserves
respect? If, as Beach et al. suggest, respect means recognising the unconditional value of the
patient as person, then give that unconditional value a name.

For a patient like Mrs. C, whose capacities for autonomous decision-making are highly
context dependent, the principle of autonomy is relevant and needs to be acknowledged in some
contexts. But, to recall Beach et al, respect for autonomy is not the end of the story, particularly
in a case like Mrs. C’s where autonomy is diminished or fleeting. There will be other contexts
where acknowledging and respecting Mrs. C’s autonomy will not be straight forward. When
Mrs. C refuses to accept the dementia diagnosis, hence puts a road block in the way of any
medical help to slow down the progression of her cognitive decline, the most anyone can do is
claim her response is irrational. Unless she poses a danger to herself or others, the principle of
autonomy directs her health care providers to respect her refusal to acknowledge the diagnosis.

\textsuperscript{15} Mary Catherine Beach, Patrick S. Duggan, Christine K. Cassel and Gail Geller, “What Does ‘Respect’
Mean? Exploring the Moral Obligation of Health Professionals to Respect Patients.” \textit{Journal of General

In a case like Mrs. C’s, the principle of autonomy does give the requisite direction for care. But sadly, in terms of caring for her dementia symptoms, one direction leads down a dead-end road where there are no further options that can be offered without taking an unacceptably hard paternalistic approach. Hard paternalism in this case would involve deception and coercion on the part of both health care providers and family. And this sort of approach can hardly be conceived of as respectful of Mrs. C’s autonomy, assuming we view her decision to refuse the diagnosis as that of an autonomous agent. That is one interpretation, an alternate interpretation is that the principle of autonomy drops out of the picture and we are left with balancing the principles of beneficence and non-maleficence. Autonomy drops out of the picture only if she is deemed incompetent to make an informed choice regarding treatment. It is certainly plausible that dementia will leave her lacking the rational capacities necessary to make an informed autonomous decision regarding her treatment. Let’s assume she does in fact lack the capacity to make an informed and autonomous choice. Both beneficence and non-maleficence will come into play in this situation. The principle of beneficence suggests that it is in Mrs. C’s best medical interests to prescribe treatment (medication perhaps?) to slow the progression of her cognitive decline. However, doing so against her clearly stated wishes will involve deception and coercion, which is harmful. But where exactly is the harm and what exactly are the object(s) of the harm if treatment is foisted upon Mrs. C against her wishes? If the principle of autonomy is no longer applicable, then there is no harm inflicted there. The harm will be to her sense of self and her identity, her sense of control over her own life, her sense of self-worth, her sense of dignity. Promoting Mrs. C’s best medical interests could well be seen as the beneficent course of action, but the harmful effects would far outweigh any potential medical benefit. Doing nothing to treat her dementia at least preserves her sense of self-respect and control over her life, as well
as mitigate the very real possibility of depression, frustration and anger (all of which would impact her closest caregivers – her family).

Neither interpretation is entirely satisfying. How convincing is it to suggest a patient with noticeable symptoms of dementia has the requisite mental competence to decide what ought to be done (or not) for a diagnosis she refuses to acknowledge? There are plenty of reasons to want to refuse a dementia diagnosis, such as fear, shame or pride, but none of those reasons will lessen the effects dementia has on the mental capacity needed to make significant – and autonomous – decisions. Suggesting that Mrs. C’s autonomy has been respected is an inaccurate assessment of her physician’s choice to respect her decision refuse the diagnosis. Respect for her autonomy is not playing much of a role at all. Rather, the physician’s choice to accept her refusal and do nothing in terms of treating her cognitive decline seems to be more of a weighing of the risks and benefits of not pursuing a treatment plan for her dementia. In other words, the ethical principles at play here are beneficence and non-maleficence, and to some extent justice. Yet, respect still seems to be playing a role. Just not respect for her autonomy. Why not coerce Mrs. C into some sort of treatment? Why be concerned about the risks and benefits of doing nothing (medically) to lessen the effects of her cognitive decline? My answer is that to do otherwise would be grossly disrespectful of Mrs. C; it would be disrespectful to her as a person and, specifically, to her as a bearer of dignity.

Although I see the principle of respect for persons, in practice, as little more than a dressed-up version of respect for autonomy it is trotted out as an ethical principle in its own right, which makes it worthy of closer examination. Would the principle of respect for persons fare any better in Mrs. C’s case? Does respect for persons capture more than respect for autonomy? Ruth Macklin, in her 2003 article argues, “Dignity seems to have no meaning
beyond what is implied by the principles of medical ethics, respect for persons: the need to obtain voluntary, informed consent; the requirement to protect confidentiality; and the need to avoid discrimination and abusive practices”\textsuperscript{17}. The need for voluntary and informed consent, and protecting confidentiality fall under the purview of respect for autonomy; avoiding discrimination and abusive practices is a reiteration of professional codes of conduct, as well as the principles of beneficence and non-maleficence. The upshot of Macklin’s article is that dignity is hopelessly vague, is used as a mere slogan, and, is conceptually useless for medical ethics. So, it seems Macklin is suggesting dignity be ditched from the bioethical lexicon in favour of the \textit{respect for persons}. The issue I have with respect for persons is that it tells us very little about what it is about persons that demands our respect, other than the capacity for autonomy. If respect for persons is not just a reiteration of respect for autonomy, then what exactly it is about \textit{persons} that demands our respect needs to be identified. Pointing to something other than autonomy would be particularly relevant for any patient with diminished capacities for autonomy.

Perhaps the definition given in \textit{The Belmont Report} (1978) provides some clarity:

“Respect for persons incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy.”\textsuperscript{18}

\textsuperscript{17} Macklin, “Dignity is a Useless Concept,” 1420.

The moral requirement to acknowledge autonomy is clear: acknowledge the decision-making capacities of the patient (or research subject) and respect the patient’s choice. The requirement to protect those with diminished autonomy is less clear. Two questions come to mind. If protecting the patient with diminished autonomy is an expression of respect, what is it about the patient that is respect-worthy? Put differently, what is it about the patient that is so valuable it needs protecting? Is the requirement to protect better articulated by either the principle of beneficence or of non-maleficence?

The principle of beneficence in the medical context is the duty to help patients by doing what is in their best medical interests. The principle of beneficence is the heart of medicine given that, depending on context, the aim of medical care is to either restore health or alleviate suffering. In more general terms, the principle of beneficence is the duty to help others (when we have the ability and means to do so). As a general moral directive to help others, beneficence only offers half of the equation – it does not explain why we ought to help others or what it is about others that is deserving of our help. One obvious reason is that we will eventually need the help of others, in which case if we do not follow the directive to help others when they are in need then what reason do we have to expect others to follow the directive when we would be the beneficiary. Another possible reason is that those others, whom we have a duty to help (when we have the ability and means to do so), have something in common with us: they are persons just like us or we judge them to have a worth equal to our own. The point is that the principle of beneficence implicitly smuggles in something else about persons that we are duty bound to respond to. That something is dignity. The principle of non-maleficence – to do no harm – does
much the same. The idea behind non-maleficence is to protect from harm something about the patient that is good and worthy. While the four principles approach does not explicitly refer to dignity, I see dignity tacitly at work behind the scenes but never named.

**The Value of a Story**

With the help of a story, I have pointed out what I regard as a significant gap in the four principles approach to health care ethics, particularly as the principles apply to patients whose autonomy is diminished or compromised. The principles of respect for patient autonomy and respect for persons are the only principles that directly address respect and what is respect-worthy. There is surely more to be respected about a patient than his or her autonomy, but even respect for persons (which at first glance promises to capture more than just autonomy) tends to collapse into respect for autonomy or either beneficence or non-maleficence. The implication being that what is respect-worthy about persons is their capacity for autonomy. Neither beneficence nor non-maleficence address respect or respect-worthiness as such; but I suspect dignity or something similar is working in the background.

The choice to relay the story of a person with dementia is purposeful. Dementia presents a variety of morally challenging dilemmas in the clinical context. I pointed to one in particular: the ability to consent (or perhaps just *assent*) to treatment in some contexts. The globally developmentally delayed patient would have perhaps been an easier case on which to base an argument for a carefully defined and conceptualized theory of dignity. After all, we know the globally developmentally delayed patient does not have, and never has had, the capacity for autonomy. But, if dignity can be conceptualized carefully enough to deal with the especially blurry, difficult case of dementia then it will be all the more useful in other cases.
Next Steps

The health literature supports my contention that respect for patient autonomy, respect for persons or the principle of beneficence does not quite grasp what patients, their families and health care professionals mean by respect for dignity. In the next chapter I review the health literature with an eye to what patients, families and health professionals mean by dignity. While I include literature that deals specifically with dementia and dignity (and/or the related concepts of personhood and respect), my aim is to review a broad range of literature that is not exclusively focused on dementia. I begin on the ground, so to speak, rather than in the philosophical literature because a conception of dignity useful for the health care context needs to mesh with the views of patients, their families, and health professionals.

In the third chapter I develop and defend a relational and care-based account of dignity. By relational I mean that our individual dignity relies on and finds its source in the relationships we have with others. Our individual worth depends on more than simply being a member of the human species, although to be a dignified human one does need to be human. For us to be unique, individual and valuable beings we need others. What gives us our value then is the care and recognition we get from others. Only with the help of others are we able to flourish and be in a characteristically human way. All of this means that our individual dignity is practically meaningless if it is not recognised by others.

In the fourth chapter I explore the capability approach, as developed by Martha Nussbaum, as a means to promoting the dignity of dementia patients. Nussbaum claims that the ten central capabilities on her list are to be understood “as ways of realizing a life with human
dignity”\textsuperscript{19}. I suggest that by focusing on the dementia patient’s capabilities caregivers promote and enhance the patient’s dignity. From the caregiver perspective, promoting the patient’s capabilities would be a means to actively respect the patient as a person worthy of dignity. By keeping the focus on the patient’s capabilities, the caregiver is able to acknowledge the patient’s increased vulnerability and corresponding decreased capacity for autonomy without losing sight of the respect-worthiness of the patient. Although my focus in chapter four is on dementia patients and those who care for them, there is no reason to assume a capability approach could not be used to enhance, promote and respect the dignity of any other class of cognitively impaired patient (including the globally developmentally delayed).

In the final, concluding chapter I address objections to my approach to dignity. I also explore to what extent a relational understanding of dignity can translate to other contexts. For example, what implications could my conceptualisation of dignity have for issues in global justice? Can my approach to dignity be extended to non-human animals? If it can, which animals and why?

Chapter Two

Dignity in the health care context: a literature review.

Introduction

There is a significant body of health literature that focuses on dignity, addressing patient and practitioner perceptions, significance of promoting or enhancing patient dignity, and the significance of dignity in the health care context more generally. While the literature reviewed here supports the importance of patient dignity, respect for patient dignity, and providing dignified (or ‘dignifying’) care, surprisingly few authors dedicate much space to examining the concept of dignity itself. There are exceptions to this generalisation, of course. Why look to the health literature for an account of dignity at all? Surely the place to start would be in the philosophy (or possibly theology) literature where there are clearly defined accounts of dignity. I begin with the health literature because it is my contention that for an adequately theorised concept of dignity to be useful and relevant in the health care context it needs to reflect patient and practitioner views, even if those views offer only vague and intuitive accounts of what dignity is. By looking to the health literature, I am effectively starting on the ground. In whatever way dignity is conceptualized it needs to be a concept that is accessible and understandable to a wider audience than just other theorists interested in the topic. With a solid grasp of what respect for, or insult to, dignity means to patients and health care practitioners the clearer the path to a carefully articulated concept of dignity becomes.

Considering western biomedical ethics does not offer a clear definition of dignity, at least not in the action guiding sense we find with the principle of autonomy, I am not surprised to find the health literature, in general, offers mostly vague assertions regarding the value of patient
dignity. When dignity is mentioned it is often presented as synonymous with autonomy or reducible on autonomy, which implies dignity has nothing to add that is not already covered by other existing principles. Because dignity has not been carefully conceptualized in the health care context its potential as a relevant action guiding concept stands on shaky legs. Steven Pinker appears to be right when he writes dignity is a “squishy, subjective notion, hardly up to the heavyweight moral demands assigned to it.” At best dignity appears to be relevant and interesting but under-theorised or, at worst, conceptually empty and useless.

My aim in this chapter is to offer a representative sample of the literature in the area. It is by no means a comprehensive review in terms of incorporating all relevant published literature on the subject of dignity. The comprehensive review would be too unwieldy for the type of deep analysis undertaken in humanities research and is therefore inappropriate for the project. However, attention has been given to the selections made, and they are justified as follows: dignity is the major topic (judged by whether dignity appears as a subject heading or descriptor, or as a keyword used by the author), dignity in the health care context (I do not explore perceptions of dignity in other contexts), recent publications (2000 and later), and excludes purely anecdotal accounts of or references to dignity.

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20 See Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics, 5th ed.* (Oxford: Oxford University Press, 2001). The principle of respect for patient autonomy constrains what can be done in the pursuit of the patient’s best medical interests. What is in the patient’s best medical interest might clash significantly with other important life interests, which are best defined by the (competent) patient.

21 The notion that dignity is reducible to or adequately captured by other ethical principles is the claim both Steven Pinker (“The Stupidity of Dignity”) and Ruth Macklin (“Dignity is a Useless Concept”) support.


Considering my overall claim is that dignity is of particular significance to patients whose capacities for autonomy are compromised, it is worth asking why pay so much attention to the perceptions of rational, competent patients’ and health practitioners’? First, it is clear from the literature that even for the competent autonomous patient, dignity and autonomy are different, but overlapping, concepts. Second, the competent patient’s views on how dignity is either promoted and respected or diminished and injured provides a basis for what dignity enhancing and respecting behaviour entails for the incompetent patient. While this literature review highlights dignity’s salience in the health care context it also highlights the need for a carefully theorised concept of dignity.

In the previous chapter I used a story to explain why and how dignity is significant in the context of dementia, I then argued that the principles of beneficence, respect for autonomy and respect for persons miss the mark for the patient with diminished capacities for autonomy. I conceded that beneficence goes some distance in terms of protection for the patient judged incompetent to provide consent, but the principle of beneficence does not adequately address respect for the patient. Beneficence does not explain what it is about the patient that demands respect and recognition. The principle of beneficence relies on the practitioner’s good character rather than the patient’s right to respectful equal treatment. The principle of respect for patient autonomy is just not applicable to the patient with compromised autonomy. The principle of respect for persons appears to effectively collapse into the principle of beneficence or the principle of autonomy. Neither the principle of autonomy nor the principle of beneficence is adequate to capture respect for the patient with diminished autonomy. The health literature on

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24 I do examine two articles that look at dignity and children - so those studies do provide a break from studies that focus on competent adult patients.
dignity is not always forthright regarding exactly what is not captured by the existing principles but I will demonstrate that overall it is evident that, for patients, families and practitioners, dignity and autonomy are distinct. Contrary to Macklin’s 2003 claim that dignity is easily captured by existing ethical principles it is clear from the literature that there is something missing from those principles; something not well captured by autonomy, beneficence or respect for persons.

**Five Themes**

In my review, I divide the literature into five general themes. I begin by looking at how dignity is understood in the health care context. The five papers I review in this section discuss dignity in broad terms. While all the papers differentiate between objective dignity (absolute, inviolable worth, which is impervious to injury) and subjective dignity (the feeling of personal worth, which is vulnerable to injury) they focus predominantly on subjective dignity. Since all the papers provide a rather thin account of objective dignity my analysis is on what exactly comprises subjective dignity and its significance to both patients and practitioners. The next section focuses more specifically on what patients and caregivers perceive as dignity promoting or diminishing behaviour. The focus is very much on the subjective experience of respect for dignity. In the third section I review Harvey Chochinov’s research on ‘dignity therapy’.

Whatever dignity is - Chochinov does not provide a definition - Chochinov’s research provides the clinical evidence that dignity is significant to patients who have a sense of their own individual worth. The fourth section looks specifically at dignity and dementia. While there are plenty of articles extolling the virtues of providing ‘dignifying care’ for dementia patients my focus is predominantly on patient, practitioner and family perceptions of dignity in the context of dementia care. The final section looks at children and dignity, specifically children’s experience
of dignity. I finish with dignity and children because for the most part children are not fully autonomous, hence are rarely in control over what happens in their lives, including the course of their health care. In this respect children, particularly young children, and hard cases such as dementia sufferers in the moderate to advanced stages of the disease pose similar challenges. If we are not respecting the child’s autonomy, because she is not autonomous insofar as minors are unable to provide informed consent to treatment, what are we respecting? The same can be said with regards to persons with dementia.

**Dignity in the health care context.**

The papers that discuss the concept of dignity in broad terms differentiate between objective and subjective dignity. Gallagher, Badcott, Nordenfelt, Edgar, and Pullman all refer to at least two conceptions of dignity – 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. I begin with David Badcott’s paper because, of the five papers, he offers an account of objective dignity that is not obviously contingent upon the possession of autonomy and, in comparison to the other four papers it is a fairly detailed account. Lennart Nordenfelt’s paper

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25 I am putting aside cases of ‘mature minors’ who, because of their relatively advanced knowledge and understanding of their illness, are often able to contribute significantly to their own care plan – including providing consent to treatment.


and Andrew Edgar’s response I group together since they both address different varieties of dignity. Admittedly, Edgar argues distinguishing between types of dignity is not always productive or useful, and certainly does not encourage a universalist approach to respect for dignity. Daryl Pullman spends roughly a paragraph on objective dignity (what he refers to as ‘basic’ dignity) and moves on to focus on subjective dignity (he uses the term ‘personal’ dignity). Ann Gallagher’s paper dedicates a small section to a discussion of objective dignity and then quickly moves on to discussing subjective dignity. Like Badcott, Gallagher does not view dignity as contingent on or reducible to autonomy.

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. The various rites and rituals surrounding the death of a human being suggests that at least some remnant of dignity lingers even when the human organism is obviously no longer living. 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.”

Subjective or emotional dignity, the focus of Badcott’s paper, 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 claim that subjective dignity is tied to feelings and relationships, our

32 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.
self-respect will be highly influenced by the actions and behaviours of 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 … might be a vital aspect of their lives – the impact of some event or other on how they feel (their emotional dignity).” Traditional philosophical treatments of dignity, such as Kant’s account, will simply be far too esoteric to be meaningful in a concrete way for many, probably most, 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 - an objective inviolable 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, subjective 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; 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.

33 Badcott, “The Basis and Relevance of Emotional Dignity,” 128.
34 Ibid., 129.
Lennart Nordenfelt\textsuperscript{35} and Andrew Edgar’s\textsuperscript{36} response to Nordenfelt’s paper also attempt to capture in broad terms the differences between objective and subjective dignity. Nordenfelt outlines four types 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 others or through a lack of self-respect. Dignity of merit encompasses the dignity a person may have in virtue of excellence in particular deeds or perhaps a profession. Examples of dignity of merit could include the achievements of a great artist, athlete 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.”\textsuperscript{37} It is the dignity of identity that is most relevant in illness and ageing since it is this type of dignity that can be easily enhanced or injured in the context of care giving.

Edgar’s response to Nordenfelt 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.\textsuperscript{38} 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 \textit{experience} of Menschenwürde. The subtle distinction between dignity and the \textit{experience} of dignity still seems to speak to two different types of dignity – one which cannot, strictly speaking, be lost and

\textsuperscript{35} Nordenfelt, “The Varieties of Dignity,” 69-81.
\textsuperscript{37} Nordenfelt, “The Varieties of Dignity,” 75.
\textsuperscript{38} Edgar, “A Response to Nordenfelt’s “The Varieties of Dignity”,” 84.
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 both attempt to
highlight the significance of social or subjective dignity (on Edgar’s account subjective dignity is
the *experience* of dignity). But 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.

Daryl 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.\(^{39}\) I take it that at least
some of the socially constructed notions and attitudes Pullman refers to 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 worthy
of dignity. On Pullman’s account the ability to experience personal dignity can be significantly
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. It needs to be noted that Pullman is careful not to
conflate integrity and personal dignity. Instead, he sees integrity as tied to or maybe a precursor
to personal dignity. If our sense of bodily and, depending on the type of illness, mental integrity
is shaken so our sense of personal dignity will also be shaken. Although much of what Pullman
says about the nature of personal dignity is closely tied with (perhaps even dependent upon)

\(^{39}\) Pullman, “Human Dignity,” 83.
autonomy, integrity and independence, he explicitly appeals to the salient role relationships play in expressing dignity: “[T]he beautiful life – the life of dignity – is expressed in the caring relationships we share with one another.” 40 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 is arguing that by sharing in the pain of others, acknowledging the suffering it causes us as witnesses, we affirm the dignity we all share.

Ann Gallagher’s 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.” 41 Exactly what makes us human is not addressed by Gallagher, but it is worth highlighting that she is careful not to tie dignity to autonomy.

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

40 Ibid., 89.
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.”42 Experiencing a sense of dignity is a reciprocal process – we need it affirmed in ourselves if we are 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. The vignettes also manage to highlight some ambiguities that will make us question 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?”43 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.44 A second vignette references 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 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.45 A patient, named 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.”46

42 Ibid., 591-2
44 Ibid., 594
46 Ibid., 595.
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.”\textsuperscript{47} Gallagher emphasises how protocols and processes can have the potential to be either dignity enhancing or dignity violating. For example, she points to the importance of having a privacy protocol in place; asking patients how they wish to be addressed;\textsuperscript{48} 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.\textsuperscript{49}

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). All of these themes are obviously relevant to the patient who has a sense of her own self-worth, but they also provide direction for the respectful treatment of the patient with diminished autonomy. More importantly, none of these themes regarding respectful behaviour need to be tied to autonomy.

\textsuperscript{47} Ibid., 595.
\textsuperscript{48} Ibid., 596.
\textsuperscript{49} Gallagher, “Dignity and Respect for Dignity,” 597.
Patient and caregiver perceptions of dignity.

In this section, I look at literature that examines how patients experience 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. 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”, 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. These sub-themes 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 these patients’ desire 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 all of the patients had 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 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

51 Ibid. 3.
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 requisite 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. In coming up with explanations for why their nurse was late or a different nurse came to the house, the patients were attempting (and succeeding) 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. The study took place in Sweden so perhaps there is something specific to Swedish culture that I am overlooking or unaware of that could mean the results are not transferrable to other parts of the world, but the overall conclusions are positive: homecare nursing recipients are able to balance receiving care (including the vulnerability that generally entails) and maintaining a sense of dignity, and nursing practice (good communication skills, continuity of care when possible, and keeping a timely schedule) does have a significant impact on patients’ sense or feeling of dignity.

Similar themes regarding what it means to maintain a sense of dignity are found in Wadensten and Ahlström’s two papers based on the same study: “The Struggle for Dignity by People with Severe Functional Disabilities” and "Ethical Values in Personal Assistance:

Narratives of People with Disabilities. The study involved open-ended interviews guided by the broad question ‘what is an ordinary day like?’ In both papers, the authors 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. In other words, the authors gesture to a thin definition of objective dignity although they focus on the experience of dignity. 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. As with Holmberg et al.’s study, for the 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 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. This study also took place in Sweden and, again, it is possible there are aspects of Swedish culture I am unaware of that would make the results of the study difficult to transfer to other parts of the world (doubtful!). It is noteworthy that the two main themes – control and privacy – are consistent with Gallagher’s findings and suggestions.

Caregiver perceptions of patient dignity and what is necessary for promoting or preserving patient dignity appear to mirror patient perspectives. Heijkenskjöld et al.’s study,

56 Barbro Wadensten and Gerd Ahlström. "Ethical Values in Personal Assistance", 760.
57 Wadensten and Ahlström. "Ethical Values in Personal Assistance,” 766.
59 Ann Gallagher is based in the UK.
"The Patient's Dignity from the Nurse's Perspective", focuses on nurses’ understanding of what constitutes dignity preserving or dignity violating behaviour.60 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.61 For the nurses, listening to the patient and dedicating time to the patient and ensuring patients can take part in their own care by listening to the patients’ desires for the way they want their care administered were regarded as dignity preserving. 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 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 patient62. 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 and desires of the patient. One example given in the paper is abiding by the patient’s desire to have the same nurse help with showering63. We see this echoed in the patient’s desire for continuity of care referred to in Holmberg et al.’s study. Interacting with patients as if they are children is identified as dignity violating. This overlaps with Gallagher’s suggestion there be a protocol on how patients are to be addressed64 – 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,

61 Ibid., 316.
62 Ibid., 317.
63 Heijkenskjöld et al., "The Patient's Dignity from the Nurse's Perspective;" 318.
64 Gallagher, “Dignity and Respect for Dignity,” 596.
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 exercising 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) or informing the patient what will occur next in the course of administering care. Heijkenskjöld et al. comment that the “habit of showing respect for one another creates an atmosphere of mutual respect”65; Gallagher also alludes to the importance of mutual respect as well as self-respect. Gallagher speculates that if nurses are not shown respect themselves, they may have difficulty behaving respectfully toward patients. The suggestion is that dignity promotion, and recognition, is reciprocal66. Now, for patients who appear not have any discernible sense of their own dignity displays of reciprocation – by affirming another’s dignity – might not seem particularly obvious. But from a caregiver perspective I would suggest promoting the patient’s dignity is a means of affirming the caregiver’s own sense of dignity. It does not matter that the patient cannot feel or will not notice the caregiver’s respectful behavior. Besides, other than the unconscious (hence unaware) patient, even the most profoundly cognitively impaired patient will respond positively to cheerful and respectful interaction, and surely such a positive response alone is enough to boost a feeling of worthiness in both parties.

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

66 Nora Jacobson takes up the reciprocity aspect of dignity promotion in her book Dignity and Health.
relationships. Both nurses and patients emphasise the importance of the relationship and these few studies strongly indicate that the practitioner-patient relationship is the necessary foundation for promoting, enhancing and preserving patient dignity.

**Dignity Therapy.**

Where the preceding 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), Harvey Chochinov’s work on dignity therapy as an intervention for patients nearing death provides strong evidence that tending to dignity has a significant and positive impact on patients. Admittedly, Chochinov does not offer an account of what dignity is. He shrugs off the question of what dignity itself is by saying that dignity means different things to different people.

The aim of dignity therapy is to address psychosocial and existential distress in dying patients. Dignity therapy is a brief psychotherapeutic intervention designed to “decrease suffering, enhance quality of life, and bolster a sense of meaning, purpose, and dignity.” 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.” In his 2011 book, *Dignity Therapy*, Chochinov insists that the role of the interviewer is to guide the patient through the session, leaving the patient free to decide exactly what should be included in the final

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69 Ibid., 5521.
70 Ibid., 5521.
transcript, rather than using the session as an opportunity to resolve any underlying 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?” 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 written document (aside from the patient, who will give final approval). 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 and 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” – for dignity therapy to be successful. 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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71 Chochinov et al., “Dignity Therapy: a Novel Psychotherapeutic Intervention for Patients Near the End of Life,” 5522.

Chochinov et al.’s findings provide significant evidence that dignity is important to palliative patients and that 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. “Hopelessness, desire for death, anxiety, will to live, and suicide all showed nonsignificant changes favoring improvement.” 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.

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 with older patients. Second, it requires the patient be able to communicate unaided. Third, it does not seem to be appropriate for children who are nearing the end of life. Finally, I expect it would be of extremely limited use for those with severe cognitive disabilities or persons in the advanced stages of dementia. However, Chochinov et al. suggest that 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.” I interpret the reaffirmation of personhood as dignity affirming.

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74 Ibid., 5523.
75 Ibid., 5524.
76 Ibid., 5525.
77 Chochinov acknowledges this limitation in Dignity Therapy.
Although he does not delve into a theoretical or practical account of what dignity is, or where it comes from or who has it or why, Chochinov’s Dignity Therapy research provides compelling evidence of the importance of dignity promotion in the health care context. Whatever dignity is, and it is worth reiterating that Chochinov does not define dignity, it is important to patients. While Chochinov’s subject pool was limited to palliative patients, there is reason to believe that dignity is important to any patient who can identify their own feelings of self-worth, not just the patient for whom death is imminent.

While Dignity Therapy clearly has its limitations, being focused on and designed for use with palliative patients, it has been adapted by Bridget Johnston and colleagues for use with people with early stage dementia. Rather than using the final document as a legacy document for family or friends, the way it is used for palliative patients, the aim is to use it to inform future care as the condition progresses. The idea is that the Dignity Therapy document would highlight the individual’s values, meaningful life events, self-identity, and the people who play or have played a significant role in his or her life. At some later point, when the disease has progressed, and communication becomes difficult, the Dignity Therapy document can be used as a reference by caregivers. The authors suggest that this kind of document, informed by the individual with dementia him or herself, will provide a better reflection of how the individual sees his or her own identity, significant events and people than anything the individual’s family could put together at some later date once the disease has progressed. The authors analysed the Dignity Therapy documents and identified several themes, not all of which directly pertain to a sense of dignity,

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79 Bridget Johnston, Sally Lawton and Jan Pringle. “This is My Story, How I Remember it: In-depth Analysis of Dignity Therapy Documents From a Study of Dignity Therapy for People with Early Stage Dementia.” *Dementia* 16, no. 5 (2017): 543-555.
but many are suggestive of what constitutes or contributes to feelings of self-worth. The themes identified are as follows: *origin of values*, which speaks to values learned in early life and events early in life that have had an enduring influence on the individual’s identity. *Essence and affirmation of the self*, which covers significant achievements and events linked to affirming or enhancing a sense of self. *Forgiveness and resolution*, which often dealt with family dynamics and family responses to illness in general. *Existentialism/meaning of life*, which touched on spiritual or faith beliefs in relation to loss, as well as highlighting the passage of time and the continuity of life through family as part of wishes for the future.\(^8^0\) One common fear surrounding a dementia diagnosis is the fear of ‘losing one’s self’, losing one’s identity and becoming ‘someone else’. Dignity Therapy, and specifically the document produced, stands to reaffirm self-identity in both the dementia patient’s eyes and the eyes of caregivers. The document produced could act as a reminder that the individual with moderate to severe dementia had, and arguably still has, an identity that is much more than a dementia diagnosis. Dignity Therapy for the person with early stage dementia could have a positive impact on later care for the person; the document produced serving as a constant reminder that there is a ‘fellow human being’ behind the diagnosis and its symptoms. What stands out to me is that for the individual with early stage dementia the significant events and concerns are related to self-identity not self-worth as such. For the palliative patient, the concern seemed to be more about finding meaning and purpose in the face of dying (not unreasonably).

\(^{80}\) Johnston et al., “This is My Story”
Dementia and Dignity.

Judging by the sheer number of recent (since 2000) health related articles with the terms dignity and dementia appearing as keywords in the title or abstract, caring for dementia patients in a manner that is dignity preserving, promoting or enhancing is undeniably significant to both patients and practitioners. It is worth pointing out that dignity is not listed as a MeSH (Medical Subject Heading), which means any search for articles that specifically address dignity needs to be a keyword search. CINAHL (cumulative index of nursing and allied health literature), on the other hand, lists ‘human dignity’ as one of its subject headings. There is overlap between CINAHL, Medline and other databases (in particular, Philosopher’s Index) but since I am specifically looking for research addressing dignity in the health context these two health literature databases have become my point of departure for finding relevant literature. As many articles as there are with dignity and dementia as keywords (or, in the case of CINAHL, as a subject heading) not all the articles are relevant for my purposes. First, some are specifically looking at end of life care and dementia, which I interpret as a variation or extension of the dying with dignity theme. Second, some are clearly short editorials or anecdotal reports intended to support or reinforce providing good care to dementia patients. Finally, for many articles the term dignity appears in the title or abstract but, upon closer inspection, is not the focus (this is generally the case when searching for dignity as a keyword as opposed to ‘human dignity’ as a subject heading). In this section I review a selection of papers that are focused on dignity as it is understood in the dementia care context. While the papers offer guidance around what respecting the dementia patient’s dignity entails and why it is an important element of caregiving, few papers give an account of what dignity itself is. An exception to this is

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81 Searching PubMed (medline) using the keywords ‘dementia’ and ‘dignity’, limited to articles published in 2000 and later, yields a whopping 182 publications.
Nordenfelt’s work, whose paper on the varieties of dignity has been reviewed above. I have also included two papers which address the experience of dignity from the perspective of the individual with a dementia diagnosis; obviously, these are the perspectives of individual’s in the earlier stages of the disease before any serious difficulties with communication are evident.

I begin with a short editorial by an individual diagnosed with Alzheimer’s disease, Kath Morgan. In this short piece, Morgan explains how her sense of dignity was, in her words, eroded in small subtle ways once she was diagnosed with Alzheimer’s. She notes the lack of attention her family physician paid to her questions; she felt ‘written off’ by him. When she accompanied her husband to the hospital emergency, and her husband revealed her illness the health care team effectively ignored her. She ceased to exist in a meaningful way for the health care team despite the fact she was coping quite well and providing the information they needed regarding her husband. Acquaintances would cross the road to avoid “that woman with Alzheimer’s”, as if she has no name, and would avoid looking her in the face when talking. In the home, Morgan feels her dignity remains mostly intact, but she clearly depends on her family to help: “but I did lose out in the dignity stakes when he [her husband] let me go out without my teeth and my hair uncombed: he just didn’t see. Of my daughters, my youngest understands me most, and does her best to maintain my dignity. She does my ‘beauty’ treatments (I tell her it’s a lost cause but she cares).” Dignity, for Kath Morgan, means being recognised as her not her disease, being treated as a woman who is still concerned with her appearance, being treated as a knowledgeable person (even if processing information and her own thoughts takes a little longer than it used to), and continuing to do the things she likes (gardening, reading, fashion). She says

83 Ibid., 281.
84 Ibid., 281.
something quite striking in her editorial: “In reality there is no dignity in dementia. If we are not careful, we can become so sensitive to loss of dignity that we see loss where there is none. We all view dignity and what affronts it differently. This must make it tricky to put dignity into training; can you train dignity?”85 She is speaking about the personal or subjective sense of dignity, that which can be stripped away by the attitudes and behaviours of others. What does she mean when she says, there is no dignity in dementia? Judging by her views on what erodes her sense of dignity the reason there is no dignity in dementia is because others cannot see it or refuse to see it. Clearly, she feels a heightened sense of vulnerability because of her diagnosis. I can only surmise that this heightened sense of vulnerability leaves her more aware of potential insults to her sense of self-worth, or more sensitive to any affront to her sense of herself as a unique and worthy individual. Indeed, being aware that her diagnosis seems to frighten others (the acquaintances who cross the street to avoid her) could well inspire a sensitivity to real or imagined threats to her sense of dignity.

The Kath Morgan who wrote the editorial was in the early stages of Alzheimer’s disease, and busy coping with the diagnosis. One of her fears seems to be that she will inevitably lose her sense of identity and when that happens other people simply will cease to see her at all. She acknowledges that she may well have to be cared for in a nursing home at some future date, and this worries her:

“Day after day must take its toll of the carer’s patience and stamina, which is when dignity comes under threat for both the dementia victim and the carer. Impatience, thoughtlessness and unkindness start a slow destruction of the compassion that nurtures dignity, a slipping into careless care that slowly, insidiously strips all dignity away.”86

What stands out to me in this short passage is that Morgan sees dignity as reciprocal – by treating the dementia patient with compassion, carers affirm their own dignity. We all have an equal share in dignity; when we ignore another’s dignity, we ignore our own too. Kath Morgan’s editorial was in her own words, she was in the early stages of the disease, still living in her own home and, while aware of the possibility that she might need to be cared for in a nursing home at some future date, her views reflect an at-home living situation not that of a nursing home resident.

In their 2013 article, “‘Like a Prison without Bars’: Dementia and Experiences of Dignity”\textsuperscript{87}, Heggestad and Nortvedt explore the ways in which dignity is experienced by dementia patients in the nursing home setting (specifically Norwegian nursing homes). It is a qualitative study utilising what the authors describe to as a phenomenological and hermeneutic approach, combining observation and interviews with nursing home residents. The aim of the study was to see what nursing home residents with dementia experienced as a threat to their dignity and what they view as important for maintaining dignity. In my view, there were no particularly surprising revelations in the results of the study. In fact, the studies by Holmberg, Valmari and Lundgren, reviewed earlier, highlighted the same themes: to be recognised as a unique individual and to have one’s autonomy respected. Although many care decisions would need to be made by surrogates, everyday decisions certainly could be respected and accommodated. When caregivers did not give residents, even those in the more advanced stages of dementia, the opportunity to make everyday decisions it was experienced as a threat to dignity. Even the resident with severe dementia, who has difficulty expressing her needs, wants to be affirmed and taken seriously as an individual. The freedom to make choices may well be a

\textsuperscript{87} Anne Kari Heggestad and Per Nortvedt, “‘Like a Prison without Bars’: Dementia and Experiences of Dignity,” \textit{Nursing Ethics} 20, no. 8 (2013):881-92.
rather thin account of autonomy, but for the dementia patient in the more advanced stages of the disease it is one way to affirm a sense of worthiness. After all, the dementia patient still has the agency to act in the world. Being recognised as an individual person, having the freedom to make everyday decisions and having a feeling of belonging were the dominant themes of this study. A few of the residents interviewed felt a combination of a lack of freedom and homesickness. Part of the feeling of homesickness also had to do with lacking a sense of belonging. The desire to be home is not just for the physical space of home but for the feeling of belonging that comes with being in one’s home. None of this should come as a surprise in a nursing home setting. The nursing home is an institutional setting, it is a work place, the day-to-day scheduling of activities is not controlled by the residents, and any curtailing of residents’ freedom is to maintain a safe and secure environment. While it might not be feasible to make every nursing home more like ‘home’ for residents (or at least there are limited ways of obscuring the fact a nursing home is still an institution), it would certainly help, the authors suggest, if health professionals could “to a larger extent, see persons behind the diagnosis and also focus more on the person’s abilities than limitations and who he or she has been, if we want to confirm them and hence maintain their dignity.”88 The authors also suggest that family members, because they usually know the resident well, should be collaborators with health professionals; that playing a more collaborative role with professional caregivers could go some distance in enhancing residents’ sense of belonging and maintaining resident dignity.

What can we take away from these two papers which look at dignity from the perspective of the person with dementia? They are quite different papers: Morgan’s editorial is an entirely first-person account, and Heggestad and Nortvedt’s study focuses on the experience of nursing

88 Heggestad and Nortvedt, “‘Like a Prison without Bars’,” 890
home residents with dementia. There are two themes which stand out to me. First, autonomy and dignity are linked such that an affront to the individual’s autonomy (or more accurately in some cases, the freedom to choose or simply being an agent in one’s own life) is experienced as an affront to dignity. Second, issues around identity are hugely significant in both pieces. Both papers are explicit that it is important for the individual with dementia to be recognised and seen as an individual, not as a walking diagnosis. To be avoided and labeled because of the diagnosis (as was the case for Kath Morgan) is profoundly undermining of a person’s sense of identity. Being in one’s own home is not just about a physical space that one has control over and the freedom to move about in as one pleases, it also implies familiarity in terms of the space and the people who inhabit the space. The familiarity with both the space and people is identity confirming. Identity, specifically being recognised, is a theme which should be familiar from many of the papers reviewed earlier. But it stands out more starkly in the literature on dementia, as the next few articles make especially vibrant.

I group together three articles that focus on ‘dignity work’ – each paper explores dignity maintaining care for the dementia patient. Each article insists that supporting patient dignity is a significant element of care. The two elements to supporting dignity are: supporting the freedom to make choices in everyday decisions (autonomy) and knowing the patient (identity).

Dorothy Seman’s 2007 paper, “Defining Dignity: a Means to Creative Interventions”89, uses a variety of vignettes to showcase the ways in which caregivers (particularly paid caregivers) work to preserve dignity. The vignettes are detailed and show how creative, quick thinking can work to maintain a dementia patient’s sense of dignity, as well as the patient’s dignity in the eyes of others. To be successful in supporting the person’s dignity, the caregiver

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needs to know the person and to incorporate this knowledge into his or her behaviour. For example, the author discusses two similar scenarios that were dealt with in quite different, but equally successful, ways. The first scenario involves a resident, a man with dementia, coming out of his room “wearing a T-shirt and a smile, but nothing more.” He knew the staff member and wanted to greet her, so walked up to her in the hallway. The staff member, without showing any indication that he was mostly naked and that this might be inappropriate, simply engaged him in conversation for a few moments before walking with him to his room where she helped him dress. Now, this man was not aware that his semi-nude appearance in the hallway might be a fine way to call unwanted attention to himself and was clearly not experiencing anything we might call ‘undignified’. However, the staff member could have easily drawn attention to his semi-nude state in a demeaning manner that would, most likely, have caused him embarrassment. The staff member’s calm, unperturbed response supported his dignity – perhaps not in his eyes (he was blissfully unaware) but certainly in the eyes of anyone else in the hallway. The second scenario took place in an adult day care program. A staff member encountered a participant just as she was leaving the bathroom and entering the hallway. The participant was clearly distressed and embarrassed: she was wearing a skirt, her bra was around her waist and she was not wearing a blouse. At the same moment, a group of other participants were walking along the hallway on their way to lunch. The staff member rather deftly positioned himself in front of her to shield her from those walking along the hallway and wrapped his sweater around her while steering her towards a quiet room. Seeing how distressed she was he quietly caught the eye of a female staff member to take over. He had rightly ascertained that in her evident distress and embarrassment she would be more comfortable with a female staff

90 Ibid., 216
member helping her with toileting. A little later she let him know, with the squeeze of his hand and a smile, that his efforts were appreciated\textsuperscript{91}. Two quite different approaches to supporting the person’s dignity, but both worked because they were suited to the individual and the situation. It took knowledge of the individual to respond in a dignity preserving way. Neither of these stories speak loudly to the theme of autonomy (freedom to make choices) but note that in neither case was the choice the individual was making (or in the midst of making) undermined in any way. The resident, in his T-shirt and smile, wanted to socialise. The adult day centre participant received the toileting help she needed in a manner that was entirely respectful.

The vignettes in Seman’s article all show how to support dignity, but very little is said about dignity’s meaning. Seman deftly skirts around providing a definition of dignity. In part, she deflects the question by suggesting we ought to try to understand what dignity means from the perspective of the person with dementia. Maybe resisting the urge to pin dignity down with a substantive definition has some value (I will explore this possibility next chapter).

In their 2007 paper, “Dignity Work in Dementia Care: Sketching a Microethical Analysis”\textsuperscript{92}, Linda Orulv and Nina Nikku examine the complexities of respecting dignity in the context of dementia care. Their focus is on the everyday instances of maintaining – or not – the dementia patient’s dignity as it plays out in the delivery of care. This is what they mean by ‘dignity work’, and they see it as an essential element of dementia care. Whatever dignity itself is, what it means or where it comes from is carefully glossed over in the introductory paragraphs. This is no indictment of their study; their aim is not to explore the meaning of dignity but to

\textsuperscript{91} Ibid.
explore how dignity is respected in the dementia care context. That dignity is important and needs to be supported is assumed.

Their use of the term ‘microethical’ refers to the subtle ethically driven choices any of us make on a day to day basis, all of which reflect and incorporate our own values. So, they are not looking at monumental life and death choices or any other choices that might require abiding to legal norms or guiding ethical principles. Rather, they focus on how health care professionals attempt to resolve conflicts between residents in a manner that is respectful of, and maintains, each resident’s dignity.

A good deal of what the health professionals do to maintain each resident’s dignity in the context of conflict between residents involves deciding when and how to intervene. The strategies used by the health professionals can be categorized in the following ways: non-interference, deciding not to interfere at all; *wait and see*, which leaves open the option to intervene at a later time; forestalling, intervening when they see a conflict arising; and immediate interference, where the health professional intervenes in response to an obvious conflict as it occurs\(^9\). Deciding which approach to take requires a delicate balancing act on the part of the health care worker. The goal is to maintain and respect both residents’ dignity. The overriding theme I see in this study is that a large part of maintaining the dignity of each resident, despite the interpersonal conflicts that arise, is to respect the capacities of each resident. For example, respecting a resident’s capacity to determine how he or she wants to deal with the (potential) conflict – respecting the resident’s capacity to decide for him or herself, in other words. Another, but not as pervasive, theme is to ensure the resident with dementia is able to maintain an assumed identity (gracious host, is the example the authors use) even though that identity may

\(^9\) Oruly and Nikku, “Dignity Work in Dementia Care,” 513
no longer be accurate or pertinent to the present reality. One aspect of dignity work, then, is to help the resident with dementia hold onto a his or her sense of identity. And this can be accomplished by validating the resident’s version of reality even if it is, to an outside observer, far from the reality the resident actually inhabits.

Oscar Tranvag and colleagues’ 2013 paper, “Dignity Preserving Dementia Care: a Metasynthesis”, echoes and affirms the themes found in Orulv and Nikku’s study (which, incidentally, is one of the articles Tranvag and colleagues review). Autonomy and identity come to the fore as predominant themes in promoting dignity in the context of dementia care. The term integrity comes up in relation to both autonomy and identity. As with some of the papers reviewed earlier, the term integrity sometimes appears to be used as a synonym for autonomy and/or dignity. Integrity as it relates to identity implies wholeness, sometimes in relation to the person with dementia holding onto a sense of personal identity and sometimes in relation to being recognised as a ‘whole person’ who has a distinct and unique life history. Respecting the person with dementia’s freedom to make everyday choices is highlighted as a crucial element in maintaining and respecting the person’s sense of self-worth. Being able to make choices based on subjective need and having those choices honoured appears to be closely aligned with being recognised as a unique individual; and both are key aspects to successful ‘dignity work’ with persons with dementia. That there is a connection between autonomy and dignity is clear in virtually all the papers reviewed so far, but it is equally clear that autonomy and dignity are not synonymous. Rather, respecting autonomy (understood as the capacity to make choices. Whether those choices are a result of reasoned judgment seems unimportant) is a means to

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94 Ibid., 519.
95 Naomi Feil is a proponent of ‘validation therapy’ for persons with Alzheimer’s. See, Naomi Feil and Vicki de Klerk-Rubin. The Validation Breakthrough: Simple Techniques for Communicating with People with Alzheimer’s and Other Dementias. 3rd ed., (Health Professions Press, 2012)
respecting the individual’s worthiness. The real challenge health care workers face is when the individual’s choices conflict with vital needs. For example, refusing medication or help with bathing can be experienced as particularly challenging by health care workers. There is no clear path to respecting an individual’s choice to refuse necessary medication or hygiene needs and ensuring his or her basic care needs are met. Depending on the level of cognitive decline the person with dementia is experiencing, persuasion is an option in much the same way it is for competent patients. But in the event persuasion is not an option, or does not work, there are times when overriding the individual’s choices does support dignity. In this paper, like many of the others reviewed, dignity is a slippery concept with no settled meaning, yet it is considered a crucial element of good care. The one thing to take away from these papers on dignity in dementia care is that, even without a settled and agreed upon meaning, dignity is a more salient value than autonomy. Yes, respect for autonomy always makes an appearance but often as a means to respecting the person as whole, unique, and worthy of recognition and respect.

In their 2010 paper, Jill Manthorpe and colleagues examine examples of how dignity is promoted in dementia care. The paper reports on a workshop that took place at a national networking conference for dementia care practitioners in the UK in 2008. The aim of the workshop was to discuss “experiences and expectations about dementia and dignity.” The overriding objective of the workshop was to identify the challenges in maintaining dignity in dementia care services. Vignettes were used as starting points for discussion. The vignettes ranged from what might be dignity enhancing in disclosing a dementia diagnosis to issues around

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96 Oscar Tranvåg, Karen A. Petersen, and Dagfinn Nåden, “Dignity Preserving Dementia Care: a Metasynthesis,” *Nursing Ethics* 20, no.8 (2013):876.
98 Ibid., 237.
99 Ibid., 237.
sex and intimacy to end of life care. In all the discussions around each vignette it was clear that how to go about enhancing or protecting the individual’s dignity was extremely complex. The themes of autonomy, integrity, and identity were present in most of the discussions. For example, the vignette about disclosing a dementia diagnosis to family members highlighted the need for the individual with the dementia diagnosis to be in control of when and how to disclose his diagnosis. The means to protecting this individual’s dignity was to allow him the freedom (the autonomy) to decide when and how and to whom he revealed his diagnosis. While the authors do not explicitly refer to identity in the sex and intimacy vignette, the implication is there that dignity and identity are related in the following way of thinking about sex and intimacy between individuals with different severity of dementia: “is the dignity in question self-referent (i.e. ‘I want to have sex and consider this to be part of my being and hence dignity’) or referent to a wider group (i.e. ‘that couple are having sex, it’s not very dignified’)”\textsuperscript{100}. Either way we understand dignity in this instance it does have to do with identity – how we view ourselves or how others view us.

While there are different ways we can go about enhancing or respecting dignity, what is missing is any deep analysis of what dignity as a concept means in the health care context. Without a well-articulated meaning, dignity risks being all kinds of different things to different people. Which, in itself might be a reasonable way to think about dignity – a multifaceted term that is easily adapted to different people’s needs – but if dignity is supposed to add something to the health care experience for patients then we need to settle on its meaning. As Manthorpe and colleagues point out in the conclusion of their paper, if dignity is now being touted as a means of defining good quality care (at least in the UK) then health care professionals will need to have a

\textsuperscript{100} Manthorpe et al., “Dementia, Dignity and Quality of Life,” 240.
good understanding of what it is; particularly if their performance is going to be judged on how well (or badly) they promote patient dignity.\footnote{Ibid., 243.}

I finish this section on dementia and dignity by returning to Nordenfelt, whose work I reviewed much earlier in the chapter. In a more recent, 2014, paper Nordenfelt looks specifically at dignity and dementia\footnote{Lennart Nordenfelt, “Dignity and Dementia: a Conceptual Exploration,” in Beyond Loss: Dementia, Identity, Personhood, edited by Lars C. Hyden, Hilde Lindemann, and Jens Brockmeier, (Oxford University Press, 2014), 39-52.}. He still makes use of his four varieties of dignity, which are: dignity as merit, dignity as moral stature, dignity of identity, and dignity of menschenwürde. But in this paper, he asks which varieties of dignity are most relevant to the person with dementia? Menschenwürde is still the predominant variety of dignity that is relevant to us all. Menschenwürde is our most basic inherent worthiness; a worthiness that we each have in equal degree and which is always deserving of respect. So, without question, this variety of dignity is relevant to persons with dementia in just the same way it is to the everyone else. Nordenfelt suggests that dignity of identity is particularly salient for the individual with dementia. He notes, rightly, that one of the signature characteristics of dementia is losing a sense of one’s former identity. The person with dementia is “not as autonomous as before, they have lost some of their communicative capacity, but as we also know, practically never all communicative capacity.”\footnote{Nordenfelt, “Dignity and Dementia: a Conceptual Exploration,” 48.}

These diminished capacities – autonomy and communication – take a toll on the individual’s self-image and identity. Now, Nordenfelt is not suggesting persons with dementia are left with no dignity of identity but that because their sense of their own identity has changed and is in the process of changing, their dignity of identity requires attention and promotion. Effectively, their dignity of identity is the variety of dignity potentially most under threat; particularly in the
nursing home context. Dignity of identity is highly relational in that it encompasses not just us as autonomous beings but our life histories and our relations with others. Our dignity of identity is by no means self-made; others do play a crucial role in who we are. The theme of identity has weaved its way through the whole section on dignity and dementia. For persons with dementia and those who care for and about them, identity plays a significant role in what respect for dignity demands.

**Children and Dignity.**

Most of the studies I have reviewed so far 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. Even the papers on dignity and dementia acknowledge that persons with dementia ought to have at least some degree of control and independence in their lives. In the health care context preserving or facilitating patients’ sense of control and sense of independence, along with protecting the private sphere seems to be what it means to respect dignity, particularly subjective dignity. Most of the study participants (excluding some of those in the dementia and dignity studies) – practitioners and patients – were recognisable as rational, competent persons capable of making choices and directing their own lives. Most were considered autonomous. All the study participants would 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. Even in the dementia context autonomy was often emphasized as a means to respecting dignity.

What about children? They are not usually able to provide consent for treatment. Children rarely have control over the way their lives are lived; 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? Anita Lundqvist and Tore Nilstun’s 104 observational study reveals that children who can 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, and not being abandoned are as paramount as they are for adults. Even in situations where the parents appeared to subjugate themselves (stifle their own sense of 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 105. 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 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.” 106 Again, just as with preserving adults’ dignity, children

106 Ibid., 226.
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.\textsuperscript{107}

Reed et al.\textsuperscript{108} 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. 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.”\textsuperscript{109} 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 very young children and the elderly person with severe dementia. For the elderly person with dementia a possible response is that we preserve subjective dignity (ensure privacy and refrain from obvious acts of humiliation) as a means of honouring and respecting who the person once was. A similar response can be proposed for respecting a child’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 whom the child will become.\textsuperscript{110}

\textsuperscript{107} 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’.

\textsuperscript{108} Pamela Reed et al., “Promoting the Dignity of the Child in Hospital,” \textit{Nursing Ethics} 10, no.1 (2003): 67-76.

\textsuperscript{109} Ibid., 74.

\textsuperscript{110} Ibid., 75.
Reed et al identify the challenge – we need a “working definition of dignity that is pertinent to all adults and children”\textsuperscript{111} – 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, there will always be individual humans whom we recognise as members of the human community but who do not, will not, and have never had whatever that crucial capacity is.

These two studies on dignity and children share themes found in the literature that deals with competent, autonomous adults. The child’s desire to have control over his or her bodily space overlaps with the adult patient’s desire to have his or her private sphere respected. Presumably for the adult patient the private sphere extends beyond the body and into physical areas that the patient regards as his or her own private, perhaps intimate, space. The child’s desire to be included in whatever treatment they are receiving echoes the adult patient’s need for control over and involvement in the treatment plan. The child’s desire to engage the health care provider is one shared by adult patients. It is the need to be acknowledged as an equal, and, as many of the reviewed studies point out, this need is fulfilled when the health care provider engages with the patient as a unique individual. Recognising and responding to the individual’s unique identity is a theme that runs through virtually all the papers reviewed.

\textbf{Conclusion.}

Most papers I have reviewed here look at dignity as it is understood and experienced by competent adults. In other words, it is the subjective experience of self-worth that is the focus of many of the papers. By contrast, few of the authors attempt to provide a robust account of what

\textsuperscript{111} Ibid., 75.
dignity is, where it comes from or why we have it. At best the authors gesture toward human rights or Immanuel Kant as the source of a definition or theory of dignity. As significant and informative as the subjective experience of respect for dignity is for individual patients, it is the lack of a robust account of objective dignity that stands out to me. It seems that as reader I am being directed back to the philosophical literature if I want an account of objective dignity.

A little charity is in order. The focus of my literature search is dignity as it is understood in the health care context. What I found was that most of the time the authors went to great lengths to explain why respect for dignity is a significant element of care, and how to go about respecting patient dignity. The studies that focused on patient experiences of respect for dignity tended to echo health care workers’ perceptions. Autonomy, integrity, control, privacy, and identity all play a role in what it means to respect a patient’s dignity. These values (autonomy, integrity, control, privacy, identity) are connected in some degree to whatever dignity is. Yet, dignity does not seem to be reducible to any of these other values.

So why did I not concentrate my efforts on the philosophical literature where I could be assured of finding a variety of theoretical accounts of dignity? For example, perhaps the most well-known and well formulated philosophical account of dignity is Kant’s. But the problem with the Kantian account is it makes dignity practically reducible to moral autonomy. On Kant’s account, what gives us value beyond price is our capacity for moral autonomy. If dignity is so closely tied to moral autonomy there really is no need for an account of dignity in health care (or any other area of life for that matter). In which case, Ruth Macklin’s claim that dignity is a useless concept in the health care context might just be correct. But patients and practitioners alike agree that respect for autonomy is only one means to respecting dignity. Which at least implies that dignity and autonomy are distinct concepts. All the papers reviewed here tell me
that dignity (however it might be defined) is important to patients (and their families). And, for most patients, respect for dignity is experienced as subtly different from respect for autonomy.

There is another reason I did not begin with the philosophical literature. If a concept of dignity is to be workable in the health care context it needs to have its foundations in the perceptions and experiences of both patients and health care providers. My aim is not to take an existing theory of dignity and force it into the health care context with the hope it will manage to accomplish some moral heavy lifting that will benefit patients. Dignity is heard so often in relation to good patient care, it risks becoming a cliché if it cannot be given some substantive meaning. If health care workers are to be answerable to patients and families who demand to be treated with dignity, then a clearly articulated concept of dignity is needed. And it needs to be a concept we can all understand.

In the next chapter I delve into the task of articulating what dignity is, why we have it, and where it comes from. My goal is to formulate a conceptual understanding of dignity that reflects the views of patients and health care practitioners. Since patients and practitioners often have vague understandings of what dignity is, I explore the possible value of leaving the concept of dignity undefined or at least vaguely defined. I suspect there is value to be found in not assigning dignity a clear and precise definition. It would allow each of us to define dignity in a way that is meaningful to us. I will ultimately reject that approach as untenable in the health care context; without clear meaning, dignity will not be able to do any of the moral work we demand from it.
Chapter 3
Dignity’s Source and Sustenance

Introduction.

In this chapter I propose and outline a care-based account of dignity. My proposal argues that care is the ultimate source of our dignity. It is only because we have been cared for by others that we have dignity at all. Our fundamental worth as humans is tied to our interdependence with others; both care and relationality are necessary for us to be dignity bearers. My claim that care is the source of our dignity is in sharp contrast to traditional Kantian inspired accounts of dignity, which claim we have dignity in virtue of our capacity for (moral) autonomy or rationality. The Kantian account assumes the capacity for autonomy or rationality is universal to all humans, but this is too bold an assumption. The profoundly developmentally delayed human individual provides all the evidence we need to reject the ‘capacity for autonomy or rationality is universal’ assumption. Dignity’s critics in bioethics appear to follow Kantian thinking as evidenced by their arguments that the existing bioethical principles of respect for persons, respect for autonomy, and beneficence adequately capture what we mean by dignity\(^\text{112}\). After all, if we have dignity in virtue of our capacity for autonomy then the source of dignity just is autonomy, and if this is the case any talk of dignity is superfluous. However, as the previous chapter’s literature review reveals, patients and health care practitioners both refer to dignity as if it is in some way distinct from autonomy. The principles of respect for persons and beneficence both seem to acknowledge there is something valuable about human persons (other than a

\(^{112}\) Steven Pinker and Ruth Macklin, for example, both argue that dignity is addressed by these principles.
capacity for autonomy) deserving of our respect and good-will, yet neither principle offers a particularly robust answer as to what that something is.

In the first chapter I used a story to show that a theory of dignity would be particularly helpful to persons with dementia (and others with cognitive impairment); I also argued that established bioethical principles do not adequately capture what dignity means to people. Chapter two’s literature review provides evidence from the health care context that dignity – in whatever way it is understood – is important to both patients and clinicians. Despite dignity’s purported significance it is woefully under-theorised in the health care literature.

In this chapter, my goal is to give an account of why we have dignity at all and what sustains it. An account of dignity that includes why and how we come to have this worth we label dignity in the first place will, I believe, be particularly useful for practitioners charged with providing ‘dignifying care’113. My intention is not to undermine work currently underway which focuses on and addresses patient concern for respect for dignity, rather the account I offer is intended to provide a firm starting point for thinking about dignity and how we ought to respond to it. There is plenty of research outlining the various ways dignity can be felt, diminished, promoted, enhanced, and ignored; as chapter two’s literature review highlights. The concerns patients (especially elderly patients) have expressed around respect for dignity has been heard, and there are attempts to improve care practices to address these concerns. A fine example of practice recommendations can be found in a report for Help the Aged by Ros Levenson (2007), *The Challenge of Dignity in Care: Upholding the rights of the individual*, which offers helpful

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113 The idea of providing dignifying or dignified care (particularly for the aged) is especially prominent in the nursing literature coming from the UK. The impetus to address the issue of dignity in the health care context appears to have arisen in response to a variety of reports in the UK popular media decrying the ‘deplorable’ state of patient care. See for example this article from The Telegraph: [https://www.telegraph.co.uk/news/health/news/9372138/Patients-dying-in-hospital-in-pain-and-lacking-dignity-survey.html](https://www.telegraph.co.uk/news/health/news/9372138/Patients-dying-in-hospital-in-pain-and-lacking-dignity-survey.html) (accessed March 13, 2018).
and practical guidelines regarding the way dignity in care could, and ought, to look like. The report focuses on care of the aged and many of the suggestions regarding what promotes patient dignity are informed by patients (and their families). It provides straightforward, no nonsense practical suggestions for how to best promote patient dignity. The report identifies the following six principles underlying dignity in care, which are:

1. Dignity in care is inseparable from the wider context of dignity as a whole.
2. Dignity is about treating people as individuals
3. Dignity is not just about physical care
4. Dignity thrives in the context of equal power relationships
5. Dignity must be actively promoted
6. Dignity is more than the sum of its parts

These principles inform the more detailed suggestions outlined in the report, and they provide practical points for health care practitioners to keep in mind when interacting with patients. For the practitioner who provides care to the elderly it is a really useful guide.

What the report lacks, in my view, is a detailed account or definition of dignity. The lack of a detailed account of what dignity is need not be viewed as a criticism of the report; after all the recommendations focus on the various ways caregivers can promote and respect patient dignity. While the report does not, in my view, offer much of an account of dignity (why we have it at all) it does have something to say about the vagueness of the term. The beginning of the second section - “Definitions of Dignity” – is worth quoting at length:

One of the problems of defining dignity is that it has become a ‘hurrah word’ – a term of general approval, to which no one can object. So for service commissioners and providers, dignity is often cited rather loosely as an essential ingredient of the services they provide, or something they aspire to assure more robustly in the future. They can be quite sure that no one will say that it is not necessary to consider dignity as a matter of importance. Similarly, service users in general, including older people, frequently use ‘dignity’ as a broad signifier of a service that they find appropriate in a variety of ways. Conversely, services that fall short of expectations in all kinds of ways are often castigated for not promoting dignity.

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To some extent, this general, but undefined, sense of dignity is of use. … However, if dignity is seen only as a subjective concept it becomes difficult, or even impossible, to agree on how care services can be organised to maximise and promote dignity. It is impossible to assess how far services are succeeding in maintaining and promoting dignity if there is a lack of consensus on what the word means.115

Despite immediately identifying the problems with defining dignity the report does go on to offer some definitions of dignity in recent use and cites the four types of dignity outlined by Nordenfelt (see chapter two, Dignity in the Health Care Context and Dementia and Dignity) namely dignity of merit, dignity of moral status, dignity of identity, and Menschenwürde. I am not surprised to see Nordenfelt’s work referenced, after all he does specifically address dignity and the elderly. While all four types of dignity Nordenfelt outlines are relevant in terms motivating respect for dignity and describing dignity’s significance, he makes no claims about why we have dignity in the first place. As close as Nordenfelt gets to making any kind of claim about why we have dignity, or where it comes from, is his reference to Menschenwürde; succinctly, and rather unhelpfully, described as “pertaining to all human beings to the same extent and cannot be lost as long as the persons exist.”116 It is the vagueness of this type of account that dignity’s sceptics object to. Understandably so! It says nothing substantial about what the source of our dignity might be, just that it pertains to all persons. Once we dig deeper by looking at the term Menschenwürde we find ourselves back to Kant’s account of dignity, which leaves us with the problem of how to accommodate those who do not have the capacity for morality, rationality or autonomy. As Paul Wainwright and Ann Gallagher point out, there are instrumental reasons why we ought to preserve and respect the lives of those who lack capacity, which can be summarised “by saying simply that it is not in the interests of society that

115 Ibid., 8
116 Nodenfelt, “The varieties of dignity.”
any human life be held to be disposable”\textsuperscript{117}; and those reasons are more likely to be based on psychological, sociological or anthropological grounds than on an appeal to philosophical arguments. Indeed, we can find plausible non-philosophical reasons to uphold the view that human life is not disposable but that should not stop us looking for a plausible philosophical argument to support this view.

Massaging Kant’s account of dignity to accommodate all humans gets us no further ahead. As long as we try to base our moral worth on characteristics we regard as distinctively human we will always be faced with the risk of excluding those we instinctively and intuitively view as human. Rather than clinging to traditional accounts of dignity, which ground our moral worth on characteristics or capacities we blithely assume are universal to all humans, we need to look elsewhere for that \textit{ultimate} source of our moral worth.

I propose we look to care as the ultimate source of our individual dignity. If care is the ground of our moral worth, we cast a net wide enough to include those who are not adequately captured in traditional accounts of our moral worthiness that ground our moral worth on our capacity for rational thought. Although I argue care is the ultimate source of individual dignity, how we promote and respect dignity requires us to pay special attention to relationships, identity and the capacity to flourish. Care happens in the context of relations with others, our identity as unique un-repeatable individuals develops in the context of relationships, and our ability to thrive or flourish is dependent on a whole variety of relationships. It needs to be emphasised that although we can conceptually keep care and relationship separate, we cannot separate care from relationship in practice. While it is the case that relationships need not be of the caring variety –

consider contractual relationships between persons or corporations – caring for another person cannot happen outside of a relationship.

This chapter is divided into two parts. In the first part I outline my account of dignity, concentrating on care, relationships and identity. Although, on my account, the capacity to thrive or flourish is integral to how we think about and respond to dignity I take up flourishing, and what we need to flourish as humans, in more detail in chapter four. In the latter part of the chapter I take a step back and explore whether (to paraphrase Levenson) a general, but undefined, sense of dignity might be useful. In other words, I address the question of whether we ought to simply leave dignity undefined in much the same way we leave the concept of ‘good’ vague and undefined. But since I am arguing that dignity has a role to play in the healthcare context leaving it vague and undefined would render it practically useless as an action guiding moral concept. As long as patients, and their families, highlight respect for dignity as something they value and want from their caregivers we cannot simply neglect an account of dignity just because it is a difficult and slippery notion.

**A Care Based Account of Dignity.**

I argue that our worth as individuals is conferred or bequeathed to us through relationships of care; which means the only capacity required to be a bearer of dignity is the capacity to give and receive care. The advantage to the view of dignity I am proposing is that it captures and affirms the intuition that, regardless of individual characteristics, all humans are equal bearers of dignity and as such are owed respect and moral consideration. Once bequeathed, dignity is sustained and promoted (or diminished) in the context of relationships – ranging from the intimate, familial and personal to the political. It is in the nexus of these various relationships (personal, familial, political) we flourish as humans. Concisely then, care
is the source of our dignity, relationships sustain dignity, and in the context of various types of relationships we flourish.

In proposing an account of dignity, I draw from and am inspired by the work of Charles Foster118, Alice Crary119, Eva Kittay120, Sarah Clark Miller121 and Hilde Lindemann122. While they do not all speak to dignity explicitly, they are all concerned with bringing humans (and non-human animals in Crary’s case) into ethical focus in a manner that does not rely on relatively high-level cognitive capacities. As Crary puts it, “the sheer fact of being human … and the sheer fact of being an animal of some kind is morally significant”123. To argue that bare humanity or bare animality is morally significant is to reject what Crary calls ‘moral individualism’.

According to Crary, the moral individualist approach to deciding who is worthy of moral concern, and to what degree, looks to cognitive characteristics as the measure of moral value. The higher the cognitive capacity an individual possesses the higher the degree of moral concern that individual is entitled to. Effectively this means the profoundly intellectually disabled warrant less moral consideration than their cognitively better endowed fellow humans. Disability theorists are vehemently against the suggestion that intellectually disabled individuals matter less because of their intellectual impairments. Many disability theorists are also making the case that bare humanity – being recognised and included in the community of humans – is

118 Charles Foster, Human Dignity in Bioethics and Law. (Oxford: Hart, 2001)
123 Crary, “Inside Ethics” 121
morally significant. My approach to dignity would help support the aims of disability theorists and activists.

The suggestion that respect for dignity means no more than respect for persons and/or their autonomy is, in my view, a result of thinking in terms of moral individualism. Autonomy, or more precisely the capacity for autonomy, is a characteristic possessed by the individual. What matters and what warrants moral consideration, on the moral individualist view, is not the mere fact of being human but of being a human with certain morally salient cognitive characteristics.

While I take no real issue with the argument that the capacity for autonomy or rationality is a distinctive characteristic of the human species as a whole, my concern with the argument is that it invariably excludes a significant number of individuals. For the vast majority of humans, the distinctive capacity to become rational autonomous beings is there, it just needs nurturing and developing. But there are still those who sit outside the majority, for whom the distinctively human capacity for rationality will always be out of reach. The individual with profound developmental disabilities fits into the category of persons for whom the capacity for rationality remains out of reach. For others, like the individual with dementia, the capacity for rationality becomes tenuous or fleeting as the disease progresses. Even the newborn child, with all of his or her potential, sits temporarily outside the majority for whom the distinctively human capacity for rationality has been realised. If all humans are to be recognised as morally significant then we simply cannot make the criteria so high that it is unreachable for so many.

In part, to be dignified is to be acknowledged and recognised as a member of the community to which you belong. For humans that community is all of humanity, the human species. Every human who has survived beyond infancy has been taken into the fold of the
human community. To borrow from Kittay, each of us has been the subject of care – even for the most destitute human individual, some level of care has assured survival beyond infancy – and the act of care itself is morally valuable. Kittay argues that the source or basis of dignity is not found in the characteristics we have as individual humans but in the relationships we bear to one another; specifically, relationships of care. It is through relationships we become the unique individuals we are. It is in the context of relationships that we develop a personal identity. We cannot flourish in a meaningful sense or become who we are without the help of others. Charles Foster makes a similar type of claim when he says that human dignity is found in both being a member of the human community and a member of the community who is entirely distinct from all the other members.\textsuperscript{124} To be a member of the human community suggests we are all embedded in a range of overlapping relationships with others, and it is in the context of these various relationships we become distinct individuals with our own unique personal identities. Kittay is right when she locates the source or basis of our dignity in the relationships we bear to one another. The moral worthiness we have as individuals is conferred by others; and without others dignity is practically meaningless. Not only do we acquire our individual dignity through the care we receive from others, our dignity continues to be promoted or diminished in the context of relationships with others. Miller articulates this claim in the following way:

“Relationality is the condition of the possibility of our fundamental worth as human beings. We are, in essence, dependent upon the presence of and interactions with others for our dignity.”\textsuperscript{125}

These aspects of dignity – care, flourishing and relationships – are identified, in one way or another, in the health literature. As I indicated in the first and second chapters, dignity’s meaning needs to reflect the views of the real people it stands to affect. In articulating what sort


\textsuperscript{125} Miller, “Reconsidering Dignity Relationally,” 119
of value dignity is and why we have it, we need to listen carefully to every-day understandings and views. Charles Foster, in his *Human Dignity in Bioethics and Law*, dedicates an entire chapter to discussing what patients themselves think dignity is. Foster claims, rightly or wrongly, that philosophers seem to believe patients (and laypersons more generally) will have nothing of interest to add to discussions about dignity.

While I find Foster’s arguments for and interest in patient dignity compelling, I disagree with his claim that dignity just is objective human flourishing. I am sympathetic to Foster’s approach, but I see flourishing as only one aspect to dignity and not the source of our individual worthiness. Roughly, his claim is that to be a bearer of (human) dignity is to be human well, and that involves flourishing as the kind of creature a human is. By ‘objective’ flourishing I take Foster to mean that whatever is required for humans to flourish is empirically discoverable. His claim suggests that flourishing – being human well – is an individual matter, which means there is no one-size-fits-all account of human flourishing. Foster’s approach at least opens the possibility that dignity is not the exclusive domain of humanity. Surely it is something to be a particular non-human animal, like a dog or a cat or a horse. We can certainly talk about the flourishing of non-human animals, although it will definitely be more difficult for us to ascertain what flourishing entails for them. Alice Crary accomplishes something similar when she argues we need to look at animals and humans in “the light of conceptions of what matters in the lives of creatures of their kinds.”

\[126\] Foster, *Human Dignity in Bioethics and Law*, 68.
when they endorse the view that non-human animals also have dignity appropriate to their form of life.\textsuperscript{129} \textsuperscript{130}

While care is dignity’s ultimate source, flourishing and relationships are dignity’s sustenance. To respect an individual’s dignity, we need to pay attention to what thriving or flourishing entails for that individual. And the only way we can do that is through observation. There is no one way to be human well. There are, however, broad observations we can safely make about what it is to be human: we are embodied creatures, and we exist in a nexus of relationships. We are always beholden to the vicissitudes of our bodies; a change or impairment in bodily functioning can radically alter who we are, and how others view us. What thriving means for any one individual is very much tied to the limitations and capacities of the body and mind. Individual flourishing occurs against the backdrop of a variety of relationships – interpersonal, social, political, institutional, environmental (with nature and non-human animals). But talk about flourishing takes us more into the realm of what it is to live a life worthy of dignity (to borrow Nussbaum’s phrase) than identifying dignity’s source. In chapter four I explore how we might maximise flourishing, and thereby promote and enhance dignity, by adapting Martha Nussbaum’s version of the Capabilities Approach; specifically, I suggest how it could be adapted to the long-term care context as a means to promote the dignity of dementia patients.

\textsuperscript{129} Kittay, “Equality, Dignity and Disability”
\textsuperscript{130} Martha C. Nussbaum, \textit{Frontiers of Justice: Disability, Nationality, Species Membership} (Cambridge, MA: Belknap Press, 2006)
Care as the Source of Dignity.

I come back to Kittay’s claim: “… that we not look for the basis of dignity in attributions we have as individuals, but in the relationships we bear to one another.”\(^{131}\) Kittay’s claim here is perhaps not precise enough though considering she goes on to say, “we find the ultimate source of our dignity … in a distinctly moral capacity to care.”\(^ {132}\) The “distinctly moral capacity to care” is surely an attribute at least some of us possess, and without that capacity to care no human would survive infancy. Although the capacity to care is crucial to our individual dignity we need not all be care-givers in order to be bearers of dignity. Being a care recipient is enough. It is in the context of a relationship of care that our individual dignity is at once conferred and actualised, and once conferred demands recognition, respect and support. In effect, being cared for sows the seed of dignity. If there is any capacity we need in order to be bearers of dignity, it is the capacity to receive care and flourish in response.

I view care as both practice and value\(^ {133}\) rather than as aspirational moral ideal or virtue. While we can certainly work to improve our care-giving capacities by, for example, working to develop our capacity for empathy, care-giving and care-receiving are practices we are all actively, and perhaps even unconsciously, engaged in as we go about our lives. For any of us who have achieved maturity we can thank some other for having cared for us, which makes being cared-for a genuinely universal experience. Care is a foundational human value in that

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\(^ {131}\) Kittay, “Equality, Dignity and Disability,” 111.
\(^ {132}\) Ibid., 111.
\(^ {133}\) I am using the terms \textit{practice} and \textit{value} more loosely than Virginia Held uses them in \textit{The Ethics of Care}. 
without it we would not be able to develop any other significant value. By claiming that being cared-for is a universal experience and that care itself is a foundational human value I am following, and affirming, the arguments made by feminist philosophers such as Virginia Held, Nel Noddings, and Eva Kittay\textsuperscript{134}.

In locating the source of human dignity in the care bestowed by one who has the “distinctly moral capacity to care” we are faced with at least one obvious objection (I raised this in the first chapter, but it bears repeating). What about the human who receives no care? Does she miss out on dignity altogether? In a sense, yes, she does miss out. This is because without care, even what we might judge to be bad or inadequate care, she will not survive into maturity. However, we can still say she suffers a moral wrong by having her potential to be part of the human community, including the bestowal and actualisation of dignity that care brings, denied. A slightly different objection asks whether the withdrawal of care means dignity too is revoked? Short answer is no. All dignity bearers are owed recognition and respect; so, the moral wrong when care is withdrawn is in the lack of recognition and respect afforded. It is not that withdrawing care means dignity is revoked, but rather that withdrawing care diminishes the individual in the eyes of others and erodes a sense of self-worth. We see this moral wrong occur on an alarmingly regular basis in everyday life, and it dehumanises the one who is disrespected and not recognised as well as the one who disrespects and refuses to recognise. The way the homeless or mentally ill are (often) treated is an all too familiar example of what dehumanising behaviour looks like: the homeless or mentally ill person is quite simply not seen, never mind not

recognised or mis-recognised; the lack of recognition and respect extended (wrongly) assumes the person is not worthy of care.

Nora Jacobson enumerates many of the ways respect is denied to the homeless, mentally ill, and marginalised in her 2012 book *Dignity and Health*. Reading the excerpts from interviews Jacobson conducted with a range of marginalised individuals should be difficult reading for anyone who claims to have some empathy for others. Jacobson’s interviewees share experiences of being dismissed, excluded, bullied, and diminished by the very people whose job it is to care and extend a helping hand. For example, health care professionals and social services staff all too often act as gatekeepers to the resources so urgently needed by those marginalised because of mental health issues, addiction issues or simply being poor. Jacobson identifies an astounding variety of ways dignity can be violated, but almost all of those ways seem to have one thing in common: an extreme difference in perceived power between the one undermining dignity and the one desperately trying to hold onto a semblance of dignity. As Jacobson points out, dignity is not only undermined in the context of interpersonal encounters between individuals but also in the very structures of society that encourage and reward hierarchies based on race, gender, class, wealth, occupation. It is not all doom and gloom though, Jacobson and many of her interviewees point out the simple gestures, behaviours and actions that promote dignity. What promotes and enhances dignity is being seen, being recognised. It takes very little effort to look someone in the eye and see who they are.

In the health care setting, where an individual relies on the care of another (or many others, as is often the case) the withdrawal of care is not only an affront to dignity but also a

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136 See especially Jacobson, *Dignity and Health*, chapters one, two and three.
clear violation of the principle of beneficence. By arguing that dignity has a place in bioethics I am not trying to downplay the significance of any other principles at work. I am not making the grandiose claim that dignity is the “Bioethical Theory of Everything”\textsuperscript{138}. The claim I am defending is comparatively modest: that a substantive account of dignity will help ensure we do not overlook the needs of our most vulnerable patients.

**Relationships and Identity.**

We do not become a self in a social vacuum; our identities develop in the particular social, environmental and political contexts we find ourselves. We rely on others to help us become who we are and ‘hold’ us in our identity. This is especially so for children, who are still in the formative stages of ‘becoming’. It is also the case for the dementia sufferer who is slowly losing a grip on her own identity. This ‘holding’ another in her identity can be done well, badly, carefully, carelessly or clumsily, but the real affront is when it is not done at all. To be clear, I am not suggesting that a failure to do one’s part in holding another in her identity strips away dignity. Rather, it amounts to an affront or insult, which may or may not be felt by the individual herself. Regardless of whether or not the individual feels the affront it diminishes her in the eyes of those who bear witness.

What does it mean to ‘hold’ another in her identity? I am borrowing the terminology, ‘holding’, from Hilde Lindemann’s work on the narrative construction of personal identity. Lindemann refers to holding another in personhood and it is worth noting that she is careful not to tie personhood entirely to particular individual capacities, instead “we have to see it

\textsuperscript{138} Charles Foster is effectively making this claim.
personhood] as largely an interpersonal achievement"\(^{139}\). By seeing personhood as a mostly interpersonal achievement Lindemann avoids the need for a complicated set of criteria that every ‘person’ must meet in order to be recognised as a person. Of course, this is not without its limits. We recognise and respond to other humans as personalities, rather than things or plants or other animals, based on what we have learned are distinctively human bodily expressions of inner psychological states. We learn how to read another’s emotional or psychological state through her bodily expressions and comportment so well and so early it becomes second nature to most of us\(^{140}\). It is this ability to ‘read’ another’s emotional or psychological state, hence recognise her as enough like us, which gives us the traction we need to begin the work of constructing a narrative identity for her. We can begin this identity work before the individual is able to contribute his or her own first-person narrative, which is what we do for infants and very young children. We may also be called upon to continue this identity work when the individual is no longer able, which, ideally, is what we do for the dementia sufferer. In some instances, such as with the profoundly developmentally delayed, the third-person narrative is all that holds the individual in his or her identity and personhood.

I will go a step further by adding that the social, cultural and political environment in which we live, as well as the natural world, have a part in shaping and even, to some extent, holding us in our identities. The social, cultural and political environment we live in affects how we see ourselves and how others see us. And these effects, while they may shape our identities, are not always empowering. Social and cultural attitudes toward age, race, (dis)ability, sex and


\(^{140}\) Persons with autism spectrum disorder would be a notable exception given their difficulties with non-verbal social cues. Also, we can learn to misrecognise others entirely, which can and has led to a whole host of moral wrongs ranging from pervasive sexism, racism, homophobia all the way to genocide.
sexuality can limit the development of our identity leading to the very real risk that our identities become stereotypical caricatures. Somewhat overlooked is the part the natural environment contributes to the development of our identity. Of course, I am not making the outrageous suggestion our natural environment takes part in a sort of third-person narrative construction of who we are. The landscapes I enjoy are not telling stories about me! Nor are the companion animals whose lives have framed periods of my life. But both do have a hand in shaping the first-person narrative of who I am. And it is likely they play a role in the narratives constructed about me by others. The point I am making is that the narrative construction of a self, a self with a particular identity, does not happen in isolation. It happens in the context of relationships.

Why are relationships and identity so significant for an account of dignity? While dignity is presumed to be universal and equal – “All human beings are born free and equal in dignity and rights” (Article one of the Universal Declaration of Human Rights) – it inheres in individuals who have unique personal identities, who are embedded in multiple relationships, and who flourish in different ways. We need others to have dignity at all: “We are, in essence, dependent on the presence of and interactions with others for our dignity”141.

If dignity is to have a hand in guiding ethical behaviour in the health care context (particularly patient care) we need to pay attention to relationships and how those relationships promote (or diminish) individual dignity. The significance of both identity and relationships to dignity is highlighted in the literature. In particular, the body of literature on dignity and dementia reviewed in chapter two emphasizes how important it is to patients to have their identity recognised and acknowledged. The value of relationships and being seen as an individual is a recurring theme in the patient care literature. Being regarded, respected and

141 Miller, “Reconsidering Dignity Relationally,” 119
recognised as a fellow human being enhances the patient’s sense of dignity (at least for those patients who have a sense of their own dignity)\textsuperscript{142}.

What does all this mean for the patient with severe cognitive impairments or the person with dementia? Individuals with congenital cognitive impairments, who may never have had a discernible sense of being a self with a distinct personal identity\textsuperscript{143}, are still held in their identities by others. They are part of the narrative fabric of the identities of other people – presumably, those who have cared for and about them – and, as part of the narrative fabric of others, their own identity is both constructed and held. For the person in the moderate to advanced stages of dementia this identity work is both easier in some ways and challenging in others. Easier because there is more material to draw from – a lifetime of stories and relationships. Challenging because of the disease’s effects on behaviour and the individual’s sense of his or her identity. The individual’s behaviour might well contradict what others know and understand as her personal identity. To hold well in the case of the individual with dementia involves not just looking back to a lifetime of stories, experiences and relationships but acknowledging and accommodating behavioural changes by weaving these changes into an updated narrative of the individual’s identity. For both individuals with dementia and those with congenital cognitive impairments it falls to others to do the lion’s share of holding and preserving identity. To do otherwise is to treat them as non-persons, effectively rejecting them as members of the human community. Part of dignity enhancing and respectful care for individuals with cognitive impairment is recognising, responding to and holding them in their identity.

\textsuperscript{142} See chapter two.
\textsuperscript{143} Which is not to suggest that persons with severe forms of cognitive impairment do not have a sense of their own identity, just that we cannot say with any certainty that they do.
Pulling the Threads Together.

The fountainhead or ultimate source of our individual dignity is found in the capacity to give and receive care. It is through being a recipient of care that we become bearers of dignity. If we are fortunate, as a result of being a recipient of care we will develop the capacity to care for and about others along with the characteristic human capacities for practical reason, rational thought, self-awareness and an understanding of ourselves in relation to others. If we are not so fortunate, we will depend on others to hold us in our identities and make choices for us that are in our best interests. For some of us, this dependence on others is life-long. For almost all of us, if we do manage to enjoy a normal human lifespan, our need for caring others will arise at various points in our lives. Assuming I am correct in claiming care is a truly universal experience for all humans then care itself is a foundational moral value and all other morally salient values, such as practical reason and rationality, are developed and nurtured in the context of relations of care.

Dignity: A Vague and Intuitive Concept.

Now that I have outlined a care-based account of dignity, I want to take a step back and query whether a general, but undefined, sense of dignity is of use in the health care context. Like Levenson (2008), I believe it is at least somewhat useful for some patients. But insisting that dignity is a vague and intuitive concept, which requires no particular definition or theory, will be of no help to the caregivers who are charged with promoting and preserving patient dignity.

The term dignity is cavalierly bandied about in many different contexts, including in medical care, without much concern for what exactly it means. Beyond the most basic assertion
that dignity is inherent worth and that we all possess this inherent worth in equal measure, the health literature on patient dignity manages to avoid giving a substantive and consistent account of dignity. The focus is oriented towards how patient dignity is enhanced, promoted, respected and experienced rather than articulating a clear definition of what dignity is or why we have it. Dignity is often described as related to or derivable from other concepts such as autonomy, control, independence, integrity, respect, self-respect, and identity. So, for some patients having their choices ignored or overridden is described as an affront to their dignity. For other patients, it could be something quite different, such as being addressed by their first name when they would rather be addressed as Mrs. or Mr. that is experienced as an affront to their sense of dignity.

As Kath Morgan’s editorial piece notes, “We all view dignity and what affronts it differently”\textsuperscript{144}, which affirms that dignity is a difficult, vague and slippery notion. If dignity means different things to different people, we really are in no position to grant dignity any kind of normative role in health care ethics. Indeed, as Morgan goes on to say, “This must make it tricky to put dignity into training; can you train dignity?” Without an agreed upon account there seems to be no way to “train dignity”. At best, the word dignity is used as a place-holder for other, presumably more precise, concepts such as autonomy, respect for persons, privacy, or control. Or so dignity’s detractors are quick to argue\textsuperscript{145}.

If we leave it up to individuals to decide what dignity means for them, we risk slipping and sliding back into autonomy’s turf. It becomes easy to see why dignity sceptics are saying dignity talk is incoherent and not particularly helpful. Why bother with a concept like dignity

\textsuperscript{144} See chapter two. Kath Morgan wrote the editorial after having been diagnosed with Alzheimer’s Disease.
\textsuperscript{145} Both Steven Pinker and Ruth Macklin argue that dignity’s lack of substantive definition leaves it too vague a concept to be useful.
when it seems to point to other, more precise, concepts like autonomy, respect and respect for persons? These are concepts with considerable pedigree in the world of moral philosophy. Dignity by comparison appears hopelessly nebulous and subjective. Despite the sheer amount of literature on dignity in health care, it is not a clearly or consistently understood concept. In contrast, autonomy, beneficence, respect for persons have currency in the health care realm; we understand what these concepts mean, and they are utilised in ways that can guide action. Dignity’s detractors argue that these concepts (autonomy, beneficence, respect for persons) adequately capture the meaning most of us ascribe to dignity. But is it equally plausible to suggest that dignity underlies these more credentialed concepts? For example, we might ask what the basis is for why respect for autonomy or respect for persons is warranted? Keep in mind that the literature reviewed in the previous chapter discusses dignity, and respect for dignity, as subtly distinct from autonomy or respect for autonomy. And further, as much of the literature reviewed shows, it is the case for many patients that respecting their autonomy or integrity or privacy (or whichever related term they choose) is a *means* to promoting and respecting their dignity, whatever it is that patients mean by dignity. But even respecting patient autonomy can be done well or badly. Look at it this way: I can honour a person’s well-reasoned choice but still treat her as less than my equal; I can still behave in ways that disrespect and dehumanise her.

In the health care context, one way that we tend to keep the meaning of dignity vague and open to various interpretations is by approaching any discussion of dignity in terms of describing what we deem *undignified*. Effectively we denounce what we believe to be contrary to dignity with the assumption we share the same intuitions. Sometimes we do share the same intuitions, but all too often dignity is trotted out as a last-ditch trump card in support of individual
autonomy. It is in this way dignity is leveraged in end-of-life care discussions. Dignity is often used as a rhetorical device – adding a little linguistic flair to the real concerns, which are best captured by the principle of respect for patient autonomy. For example, in end-of-life care the undignified aspect to dying is, usually, the lack of control experienced by patients. What patients find especially undignified are the loss of control over bodily functions, along with the need for assistance in basic daily activities (dressing and toileting, for example), and a perceived loss of personal identity. The issues around losing control are autonomy concerns: the loss of ability to take control over one’s own life and the loss of independence. Concerns around personal identity are related to feelings of self-esteem and fear of being seen as a non-person; neither of which is necessarily related to autonomy. However, while concerns around loss of identity need not be autonomy concerns as such, there is still something of a relationship between autonomy and personal identity in that it is the loss of independence which leads to patients’ perceived loss of a sense of self (and the fear of being seen as a non-person). If independence is linked to a sense of self, then there is a case to be made that personal identity is an autonomy issue after all. The implication is that if independence is restored so too is a sense personal identity. Rodriguez-Prat and colleagues’ review article, “Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography”, highlights that patients themselves see connections between dignity, control and autonomy, and it is difficult to discuss any one of these concerns without reference to the others. In a sense, dignity is embedded in concerns around autonomy and control, which seems to leave it unclear whether dignity does any work of

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147 Ibid.

148 Ibid.
its own or even if it is able to do any work that is not already accomplished by the principles of autonomy or respect for persons.

In end-of-life care discussions keeping dignity vaguely defined might offer some small rhetorical benefit to patients who are already adequately covered, so to speak, by the principle of respect for autonomy. It adds to the patient’s arsenal by giving them grounds to demand more support or respect from their health care providers. This approach works if the meaning of dignity rests on a shared intuition about what is valuable in a human life. If we all share the same intuition that dignity is best promoted by respecting and promoting individual autonomy then dignity, as a concept in its own right, does not need any further elaboration. We could simply acknowledge dignity has rhetorical force but nothing morally substantive to add to the already complex world of bioethics. The problem with this approach to thinking about dignity is that it completely overlooks the needs of our most vulnerable patients – namely, those who do not have the capacity for autonomy. For dignity to be a meaningful concept it needs to be considerably more inclusive than autonomy. Patients with profound cognitive impairments or in the more advanced stages of dementia are not autonomous by anyone’s account, but, intuitively at least, most would agree they are bearers of dignity, they are uniquely valuable. On my care-based account these types of patients are definitely bearers of dignity, and as such deserving of our concern and care.

Another way we keep the meaning of dignity vague and intuitive is by accepting it as a kind of foundational moral truth about persons, that they do in fact have an inner and inalienable worth. If dignity has a foundational status in this sense – it is just a brute fact about humanity that we have intrinsic worth – then we are in no position to prove, explain or justify its existence. In her paper, “Bedrock Truths and the Dignity of the Individual”, Teresa Iglesias makes just this
kind of argument. On Iglesias’s account the inability to explain or justify dignity is no failure, rather it reflects dignity’s foundational status in moral philosophy. G. E. Moore made a similar type of claim in his *Principia Ethica* about goodness: goodness is a simple and unanalyzable property. In legal and human rights documents dignity seems to be used in much the same way – it is understood as a foundational concept that requires no further explanation or justification.

Coming back to the health care context though, is dignity as a foundational, inexplicable, and probably unjustifiable bedrock moral truth much use? It might be if we all share the same intuitions about what dignity is and how we ought to respond to one another’s dignity. But as Kath Morgan’s short editorial points out, we all view dignity and what affronts it differently. Clearly, we do not all share the same intuitions and that makes dignity of limited value in an action guiding sense. I am not suggesting having a highly personal account of one’s own sense of dignity, and what promotes or diminishes it, is without value. But as long as we have widely divergent opinions on what dignity is, and what enhances or threatens it, we are in no position to put dignity to use. My claim is that dignity can and should take on an action guiding role, but it cannot if it is regarded as a foundational concept that defies explanation.

Dignity has the potential to be of great benefit to our most vulnerable patient populations but to actually be of benefit it needs to be a thick concept, with descriptive and normative meaning. The care-based account of dignity I have outlined offers an account that is capacious enough to include all patients, regardless of their capacities for autonomy, rational thought, practical reason or any other characteristic used to judge an individual worthy of moral concern.

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Conclusion.

Even though the literature on dignity in the health care context reviewed in the previous chapter lends some support to leaving dignity vaguely defined I have argued here that if dignity is going to take on a meaningful role in health care ethics it needs some substance. Since I am focusing on individuals who are not autonomous in the relevant sense (i.e. not able to provide informed consent) tying dignity to the capacity for autonomy gets us no further ahead. I have proposed a way of conceptualising dignity without reference to autonomy, rationality or any other distinctly moral capacity individual humans are presumed to possess. When the concept of dignity stands on its own – without reference to or derivable from other more credentialed moral concepts and values – it is better able to do its own moral work. In the next chapter I borrow from the human development literature and suggest adapting the capabilities approach as a framework for ensuring patients have the capability to flourish and, in Nussbaum’s words, live a life worthy of dignity.
Chapter Four
The Capabilities Approach as a Framework for
Promoting Patient Dignity in the Dementia Care Context

Introduction.

In chapter one, I explained why we need a theory of dignity suitable for the health care context. Chapter two’s literature review provided plentiful evidence that I am not alone in arguing that health care ethics needs an account of dignity. While chapter two highlighted how important dignity is to patients it also highlighted how murky our understanding of dignity really is. Although plenty of researchers make compelling arguments for dignity’s salience, and how important respect for dignity is in the clinical context, there is no consistency in the way the concept of dignity is understood. In other words, the literature has plenty to say about how important dignity is but not so much to say about what it is or why we have it. In chapter three, I addressed those questions - what is dignity and where does it come from? - with a care-based account. An account of dignity that is grounded in care rather than autonomy is unusual in the philosophical literature. Eva Feder Kittay150 and Sarah Clark Miller151 are the two theorists, that I know of, who make an effort to address dignity from a care perspective. Both Kittay and Miller emphasise the importance of relationships for dignity. Kittay argues that it is in the context of caring relations that dignity is both recognised and actualised. While Miller does not support my claim that care confers dignity, she makes a compelling argument that it is our

150 Kittay, “Equality, Dignity and Disability”
151 Miller, “Reconsidering Dignity Relationally”; Miller, The Ethics of Need
relationality which makes dignity possible at all\textsuperscript{152}. It is important to note that while Kittay specifically engages with dignity in her 2005 “Equality, Dignity and Disability”, her main research focus is care. While both Kittay and Miller recognise the significance of dignity by engaging dignity, care and relationality neither of them offers a substantial account of the source of dignity in quite the way I do. My goal in chapter three was to give an account of dignity that disentangled our moral worthiness from our capacity for rationality or autonomy; an account of dignity that is decidedly un-Kantian. In this chapter my goal is practical and applied in that the question I address is, ‘given the account of dignity I have outlined, how can we best respect and promote dignity in the clinical setting?’ To answer, I borrow from social justice and human development theory by proposing Martha Nussbaum’s version of the Capabilities Approach as a basis for a practical framework for providing care that enhances, respects and promotes patient dignity. I propose Nussbaum’s version of the Capabilities Approach rather than Amartya Sen’s because Nussbaum claims her version of the approach (which entails ensuring everyone achieves a threshold level of all 10 Central Capabilities she outlines) supports a life worthy of dignity (or a truly human life)\textsuperscript{153}.

This chapter is divided into four sections. In the first section I address Nussbaum’s conception of dignity and how her conception differs from mine. While I will show that there are clear differences in our accounts of dignity, these differences would not make an appreciable difference to the way Nussbaum’s Capabilities Approach could be operationalised in the dementia care context. In the second section I give a brief overview of the capabilities approach highlighting the differences between Amartya Sen’s and Martha Nussbaum’s articulations of the

\textsuperscript{152} Miller, “Reconsidering Dignity Relationally” “My aim is … not to say that other’s care of us bestows value upon us.” 119

\textsuperscript{153} Nussbaum has used both phrases – \textit{a life worthy of dignity} and \textit{a truly human life} – in her work.
approach. In the third section I look at some of the ways the capabilities approach has been applied to and adapted in the health care context. Some of those ways include: as a means of evaluating health related quality of life\textsuperscript{154} and evaluating supportive environments for the elderly\textsuperscript{155}; as an approach to understanding disability\textsuperscript{156}; as an approach to conceptualising health\textsuperscript{157}; and as an approach to delivering person-centred care\textsuperscript{158}. I finish section three with an in-depth look at two articles that focus specifically on how Nussbaum’s ten central capabilities can apply to dignity in the long-term care context\textsuperscript{159} \textsuperscript{160}. While Pirhonen focuses on elderly persons living in a long-term care home Melander et al focus specifically on persons with advanced dementia living in a long-term care home. In the final section I show how Nussbaum’s version provides the basis of a promising practical framework for promoting and enhancing patient dignity in the dementia care context.

**Nussbaum and Dignity.**

At first blush, Nussbaum’s richly detailed version of the Capabilities Approach is an obvious choice for my project since she explicitly argues that on her account capabilities and dignity are entwined. What she means is that there are certain capabilities one needs in order to

https://doi.org/10.1111/opn.12178
live a life worthy of dignity. And she very conveniently outlines the specific capabilities one ought to have in her 10 Central Capabilities, which I outline in greater detail later. But first, I need to take a step back from the capabilities approach itself in order to explore what Nussbaum means by dignity. While the term dignity and the phrase living a life worthy of dignity appear many times in Nussbaum’s *Frontiers of Justice* and *Creating Capabilities* (2011), I want to begin with her 2008 essay for the President’s Council on Bioethics: “Human dignity and political entitlements.” The title alone should give the reader an indication that Nussbaum’s conception of dignity will have something to do with other people and what is owed in virtue of dignity.

She begins with the Stoic account of human dignity, which views the human capacity for practical reason as a share in the divine. And this share in the divine gives us our priceless worthiness. The appeal of the Stoic account is that it sees humans as fundamentally equal because what is valuable about humans is not dependent on attributes we have by sheer luck: the pauper possesses an inalienable dignity just as the king does. However, as Nussbaum points out, the Stoic account of dignity is so radically removed from the vicissitudes of life it cannot do much moral work of its own. Why be concerned about affronts to dignity if dignity is inalienable? If the soul remains free and untouchable why refrain from “beating slaves or using them as sexual tools”? After all, it is only the body that is harmed not the unassailable dignity of the person (soul) within. While the Stoic account is important because it is egalitarian – we all have absolutely equal dignity – it does not explain why (or even if) respect is owed to

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161 Nussbaum, *Frontiers of Justice*.
164 Ibid., 3
individual humans. Nussbaum wants to keep this significant element of the Stoic approach to
dignity, but she also wants to broaden the picture of dignity to include and acknowledge the
world’s (people, institutions, environment, fellow animals) role in individual development. On
her account of dignity “human beings have a worth that is indeed inalienable, because of their
capacities for various forms of activity and striving. These capacities are, however, dependent
on the world for their full development”165. Much of the essay for the President’s Council on
Bioethics focuses on what respect for dignity entails, which, for Nussbaum, involves having the
right institutional supports in place to ensure individuals are able to flourish in a truly human
way. And according to Nussbaum, our capacity to flourish requires support from the world. A
life worthy of dignity just is a flourishing human life.

I have very little to quibble about with in Nussbaum’s account of dignity, except that her
conception remains under-theorised. Nussbaum, like so many others writing about dignity in an
applied way (see chapter two), spends a good deal of space emphasising what respect for dignity
requires while neglecting the basis or source of dignity. If, as Nussbaum says, the basis of
dignity just is a person’s strivings or basic capabilities166 I am left wanting. Paul Formosa and
Catriona Mackenzie, in their 2014 paper “Nussbaum, Kant, and the Capabilities Approach to
Dignity”, also appear to be left wanting. They go further than simply pointing out Nussbaum’s
conception of dignity is under-theorised and inconsistent by highlighting tensions in her version
of the capabilities approach between her Aristotelian conception of dignity and her political
liberalism167.

166 Ibid., 11.
167 Paul Formosa and Catriona Mackenzie, “Nussbaum, Kant, and the Capabilities Approach to Dignity,”
*Ethical Theory and Moral Practice* 17, no. 5 (2014): 876
For my purposes, I need only stress that Nussbaum’s account of dignity is under-theorised and often inconsistent. For example, she “notes that ‘the idea of dignity … is not fully clear, and there are quite a few different conceptions of it’”\(^\text{168}\) while elsewhere she offers more detailed accounts that underscore the importance of striving, flourishing, vulnerability and need\(^\text{169}\). I am left wondering which claim about dignity Nussbaum ought to defend to support her Capabilities Approach: the weak claim that the concept of dignity has broad appeal or the stronger claim that her comprehensive conception of dignity has broad appeal\(^\text{170}\)? Either way, it makes no difference to my proposal that we adapt Nussbaum’s version of the Capabilities Approach as the basis of a practical means for supporting patient dignity. On the one hand, a whole variety of conceptions of dignity can be accommodated by the Capabilities Approach according to the weak claim that the concept of dignity has broad appeal. On the weak claim, my care-based account of dignity is one conception among many possible conceptions. On the other hand, Nussbaum does offer (and sometimes defends) a more comprehensive conception of dignity – one that invokes the Aristotelian species-specific notion of flourishing as the type of creature you are and being a member of the human community – which meshes rather well with my own account of dignity.

The key difference between my account and Nussbaum’s is around the bestowal or conferral of dignity. On Nussbaum’s account, membership in the human species gives us some dignity (at least a formative or initial dignity) and membership in a human community in which one flourishes in a truly human way fleshes out the rest of dignity. On my account, dignity is conferred upon us through caring relations with others. Dignity is sustained and promoted when

\(^{168}\) Ibid., 876.
\(^{169}\) See Nussbaum, *Frontiers of Justice; Creating Capabilities* and “Human Dignity and Political Entitlements.”
\(^{170}\) Formosa and Mackenzie, “Nussbaum, Kant, and the Capabilities Approach to Dignity,” 877.
we have the opportunities to develop and flourish as best we can, given our individual idiosyncrasies, limitations and desires. Because of Nussbaum’s emphasis on the importance of being able to enjoy a flourishing life, her version of the Capabilities Approach is a good fit with my care-based account of dignity. With this brief explanation of Nussbaum’s conception of dignity in mind let’s move on to looking at the Capabilities Approach more broadly.

**The Capabilities Approach.**

Both Sen and Nussbaum’s work on the capabilities approach addresses issues around human development, human well-being and the ability to live the kind of life that holds value (or, in Nussbaum’s words, a life worthy of dignity). The approach is generally understood as a means of evaluating individual well-being (often on a global or national scale), particularly as an alternative to welfarism or utilitarianism to measure individual well-being. Where looking at Gross National Product gives us a picture of how big a nation’s economic pie is, it does not tell us how much of that pie each person actually has or has access to. The capabilities approach offers a more nuanced view of what individual citizens of a nation have the capability (or freedom) to achieve in contrast to what the nation, as a whole, has in terms of economic and human resources. In other words, the capabilities approach to measuring individual citizens’ freedom to be and live a life they value helps provide an answer to how big a piece of the national pie each individual citizen has access to.

The capabilities approach’s guiding question is ‘what is each person able to do and to be?’\(^{171}\) The focus is on freedom and choice. If individuals have the freedom to access a range of

\(^{171}\) Nussbaum, *Creating Capabilities*, 18
opportunities the choice to act upon those opportunities is theirs. The two main concepts at work in the capabilities approach are “functionings” and “capabilities”. Functionings are the various doings and beings a person has reason to value. Valued functionings range from basic, such as being adequately nourished and free from avoidable disease to complex, such as being able to take part in family, community or work life. Capabilities are the real opportunities that individuals have to realise particular valued functionings. What makes for a good life is having the capabilities to achieve valued functionings. Capabilities, then, are substantive freedoms to achieve the various functionings that reflect the type of life one values. Exactly which functionings one values and wishes to achieve remains an individual choice. For example, focusing on capabilities rather than functionings allows us to differentiate between the affluent person who chooses to fast for religious or personal reasons and the destitute person who is forced to starve. Both have the same “functioning achievement in terms of eating or nourishment…but the first person does have a different ‘capability set’ than the second (the first person can choose to eat well and be well nourished in a way the second cannot).”^172

Sen and Nussbaum have quite different aims for the capabilities approach. For Sen, the approach is an evaluative or comparative tool, so he does not endorse or propose a core list of capabilities. He does not make any substantive or universal claims about what is required to achieve the ‘good life’. As such Sen’s version does not explicitly propose an account of basic social justice - although a concern for justice is a significant part of his approach - nor does he make use of a concept of human dignity^173. Nussbaum’s version of the approach, by contrast, regards the capabilities approach as a basis for social justice and insists that a threshold level of certain capabilities needs to be met for any individual to achieve a life that holds value. To be

^172 Amartya Sen, Development as Freedom. (Oxford University Press, 1999), 75
^173 Nussbaum, Creating Capabilities, 19-20.
clear, Nussbaum is only saying something substantive and comprehensive about the requirements for achieving a ‘good life’ (a life that holds value) but nothing comprehensive about what the ‘good life’ itself entails. Individuals who are assured a threshold level of the ten central capabilities Nussbaum outlines (see below) are free to decide for themselves what the ‘good life’ is. In this way, her version of the approach can accommodate a variety of conceptions of what makes for a meaningful life. Her version of the capabilities approach promotes and endorses Rawls’ approach to political justice: the idea of political liberalism. All societies contain a plurality of religious and secular views on what makes for a meaningful life; the role of political justice is to ensure no one of these competing views is taken as definitive. Of course, political liberalism does take a moral stand by being committed to the values of impartiality and equal respect for human dignity.

In some respects, not having a set of specific capabilities is useful and allows for more flexibility in assessing individuals’ real freedoms in a way that can be adapted to particular contexts. For example, when the capability approach is adopted by health economists as a tool for evaluating and measuring health related well-being it is Sen’s version that is predominantly referenced. The idea being that the researcher can pick and choose capabilities that are relevant to the information sought. But my goal in using the capability approach is not to use it as an evaluative or measurement tool though. Rather, my aim is to use the capabilities approach as a practical framework that can be utilised by care providers to acknowledge, promote and respect patient dignity. To meet this goal, I need to begin with a clearly articulated set of capabilities,

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174 Ibid., 89.
175 It is perhaps worth noting that on Nussbaum’s version of the approach it is possible to encompass nonhuman animals. Exactly what capabilities ought to be ensured for animals is not clear, but it is clear that Nussbaum supports the notion that nonhuman animals possess dignity appropriate to the kind of beings they are. See Frontiers of Justice: Disability, Nationality, Species Membership 2006, chapter 6 “Beyond ‘Compassion and Humanity’: Justice for Nonhuman Animals”
which when promoted ensure an individual is living a truly human life; a life worthy of dignity. Nussbaum’s list of ten central capabilities provides a starting point.

It is important to remember that ensuring all of the capabilities on this list are open to all individuals ought to be the responsibility of a “decent political order”\textsuperscript{176}. In other words, ensuring all individuals meet a threshold level of each capability on the list falls primarily to government institutions. It would be unrealistically demanding to charge health care institutions or individual health care providers with the responsibility of ensuring patients meet a threshold level of all capabilities on the list.

\textbf{Ten Central Capabilities:}

1. \textit{Life}. Being able to live to the end of a human life of normal length; not dying prematurely, or before one’s life is so reduced as to be not worth living.

2. \textit{Bodily health}. Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.

3. \textit{Bodily integrity}. Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.

4. \textit{Senses, imagination, and thought}. Being able to use the senses, to imagine, think, and reason – and to do these things in a “truly human” way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in

\textsuperscript{176} Nussbaum, \textit{Creating Capabilities}, 33.
connection with experiencing and producing works and events of one’s own choice, religious, literary, musical, and so forth. Being able to use one’s mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid nonbeneficial pain.

5. *Emotions.* Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one’s emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)

6. *Practical reason.* Being able to form a conception of the good and to engage in critical reflection about the planning of one’s life. (This entails protection for the liberty of conscience and religious observance.)

7. *Affiliation.* (A) Being able to live with and towards others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.) (B) Having the social bases of self-respect and nonhumiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin.

8. *Other species.* Being able to live with concern for and in relation to animals, plants, and the world of nature.
9. *Play.* Being able to laugh, to play, to enjoy recreational activities.

10. *Control over one’s environment.* *(A) Political.* Being able to participate effectively in political choices that govern one’s life; having the right of political participation, protections of free speech and association. *(B) Material.* Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers\(^{177}\).

In section three I give an account and defense of how these central capabilities can be adequately promoted in the health care context with a particular focus on dementia patients. For now, it is worth pointing out that many of the capabilities on the list point to the variety and significance of relationships in which we are all, to some degree, engaged in and shaped by. Those relationships can be with other individuals (family, friends, colleagues, for example) or institutions (government, international institutions, non-governmental institutions, health care organisations, for example). While the ethical focus is on individuals, the capabilities approach is consistent with a relational understanding of selfhood, autonomy, and dignity. It clearly acknowledges how dependent each of us are on others to help us realise a life that holds value for us. Whatever a life of value means to us individually we cannot achieve such a life without the support of others – both other individuals and the various institutions that ensure we have the freedoms and opportunities to realise a life of value.

\(^{177}\) Nussbaum, *Creating Capabilities,* 33-34.
Capabilities Approach and Health Care.

Sen’s version of the capabilities approach has been applied to health care, with adapted use in numerous contexts that include: as a tool for measuring health related quality of life\textsuperscript{178} as an approach to understanding disability\textsuperscript{179}; as a tool for evaluating supportive environments for the elderly\textsuperscript{180}; as a means to conceptualising health\textsuperscript{181}; and as a way to support ‘patient-centred’ care\textsuperscript{182}. The capabilities approach’s use as an evaluative tool in health research seems to be a natural fit with Sen’s more open ended and, arguably, flexible articulation of the approach. As a means to understand what it is to be disabled or as a way to conceptualise health the capabilities approach offers a path to better grasp what we mean by the terms disability and health, and, in turn, will have implications for possible policy change. Entwistle and Watt come close to the way I suggest the approach could be used in the care of individual patients. Two articles examine the plausibility of using Nussbaum’s version of the capabilities approach as a framework for providing dignity promoting care for the elderly living in long-term care homes\textsuperscript{183} and people with advanced dementia\textsuperscript{184} (Melander et al. 2018). Since these last two articles adopt Nussbaum’s ten central capabilities as their research lens I dedicate significant space to reviewing, and to some extent, critiquing their understanding of how the capabilities apply to dignity.

As an evaluative tool the capabilities approach has been suggested as a viable approach to measuring quality of life issues in a manner that avoids relying on a subjective notion of

\textsuperscript{178} Verkerk et al. “Health Related Quality of Life Research”
\textsuperscript{179} Mitra, “The Capability Approach and Disability”
\textsuperscript{180} Gilroy, “Taking the Capabilities Approach to Evaluating Supportive Environments for Older People”
\textsuperscript{181} Law and Widdows, “Conceptualising Health”
\textsuperscript{182} Entwistle and Watt, “Treating Patients as Persons”
\textsuperscript{183} Pirhonen, “Dignity and the Capabilities Approach in Long Term Care for Older People”
\textsuperscript{184} Melander et al., “Human Capabilities in Advanced Dementia”
happiness. Verkerk, Busschbach and Karssing’s 2001 paper, “Health-related quality of life research and the capability approach of Amartya Sen”, makes a compelling case that Sen’s version of the capabilities approach gives researchers the flexibility to adapt to a specific context when designing quality of life questionnaires. They claim many of the standard quality of life questionnaires researchers rely on are too generic, hence lack the sensitivity to grasp what is important in terms of quality of life and will often overlook or be unable to capture the coping mechanisms research participants might use to deal with ill health. The capabilities approach’s differentiation between functionings and capabilities is the key to capturing some of the nuances many quality of life measures miss. By focusing on capabilities rather than functionings the difference between being capable of engaging in an activity, but choosing not to, and simply coping with a real inability to engage in an activity can be captured. For example, being able to move about freely in one’s community is the capability to choose to go out into one’s community, whereas opening one’s door and physically moving about in one’s community is the actual functioning. A quality of life instrument that adopts the capabilities approach can capture this very important difference. Once the lack of a specific capability is identified it can then be addressed. What is important, then, is not so much the functioning part (in my example above, the actual moving about in one’s community) but the capability (being able to move about in one’s community, if one chooses to do so). Perhaps the most significant nuance adopting a capabilities approach for quality of life measurements brings to the table is highlighting where institutional or policy change could improve quality of life and where the personal characteristics of individuals makes a difference.

Gilroy’s 2006 paper, “Taking a Capabilities Approach to Evaluating Supportive environments for Older People”, adapts the capability approach to a very particular case. The
aim of the paper is to examine how places can either support or diminish older people’s quality of life as they define it. Drawing on existing research, Gilroy’s paper suggests ways the environments, both physical and social, in which older people live could be improved. By focusing on what older people themselves have identified as significant, the findings are especially useful for policy makers. For example, all too often policy makers focus on the needs of the frail elderly at the expense of those who do not see themselves as especially frail or vulnerable. Gilroy concludes that what is needed is a broader look at possible environmental changes that could enhance feelings of independence and well-being for all older people, not just those identified as especially frail; many of these changes could be best addressed at a policy level.

Mitra’s 2006 paper, “The Capability Approach and Disability”, utilises the Capability Approach to help conceptualise disability in a manner that avoids the pitfalls of either the social model of disability or the medical model. The social model of disability tends to ignore the very real problems that come with a physical impairment by insisting disability is socially constructed; that in fact disability is not an attribute of the individual but is created by the social environment, hence the solution to disability is social change. The medical model denies any possible social bases of disability, instead viewing disability as an individual medical problem that requires fixing. Sitting somewhere between the social and medical models of disability is the World Health Organisation’s International Classification of Functioning, Disability and Health (ICF), which manages to capture how both social structures and the impairment itself contribute to disability. Mitra argues that the advantage the capabilities approach has over other models of disability is that it is better able to capture socio-economic dimensions of disability.

Although the ICF does consider economic achievements of individuals in terms of employment earnings and economic self-sufficiency, on the capabilities approach “poverty is seen as a factor that interacts with the individual’s characteristics and environment, leading to disability”\textsuperscript{186}. The capabilities approach may not necessarily be a better approach to understanding disability than the ICF, but it does manage to encompass a broader range of potentially disabling factors in an individual’s life that the ICF tends to overlook in practice\textsuperscript{187}.

Law and Widdows’ 2008 paper, “Conceptualising Health: Insights from the Capability Approach”, uses the approach to find some middle ground between a biostatistical account of health and disease, where health and disease are defined in objective scientific terms, and an especially broad and subjective account of health like the World Health Organisation’s definition, which is roughly ‘complete wellbeing’. The WHO definition effectively dodges any of the conceptual heavy lifting regarding what constitutes health and disease. As Law and Widdows point out, without providing a clear account of wellbeing the WHO definition of health is incomplete and ambiguous\textsuperscript{188}. They outline five ways a capability approach could improve our conception of health: one, it can find a middle ground between one dimensional accounts of health that are either overly narrow (biostatistical accounts tend to be overly narrow) or overly broad (like the WHO definition of health). Second, it can adapt to context – allowing for a set of health goods (or functionings) to change depending on contexts, “allowing certain constituents to be global, others local and others individual”\textsuperscript{189}. Third, there is room to adopt a conception of basic health functionings, akin to identifying basic functionings (basic nutrition or shelter would be examples that we can find in Sen’s version of the capabilities approach). Fourth, it can be

\textsuperscript{186} Ibid., 242.
\textsuperscript{187} Ibid., 243.
\textsuperscript{188} Law and Widdows, “Conceptualising Health,” 304.
\textsuperscript{189} Ibid., 311.
used globally; just as we can analyse the capabilities of rich and poor individuals or countries and analyse basic and complex capabilities. Finally, it has practical relevance, which can be seen in the influence the capabilities approach has had on the Human Development Reports\textsuperscript{190}.

Entwistle and Watt’s 2013 article, “Treating Patients as Persons: A Capabilities Approach to Support Delivery of Person-Centered Care”, overlaps with my own thoughts on the way the capability approach could enhance patient care. Entwistle and Watt argue that incorporating the capabilities approach into person-centred care could offer much needed direction regarding what person-centred care requires in clinical practice. A particularly salient issue the authors point out is that person-centred care is either thought of as a set of processes, focusing only on its instrumental value, or thought of in terms of respecting patient preferences or choice, even when those preferences or choices might not be well informed, strong or related to issues of any real significance\textsuperscript{191}. In the first case, thinking of person-centred care as a set of processes misses the point of person-centred care entirely by trying to create a recipe-like procedure for patient care that is then expected to work all the time and for all patients. In my view, this recipe-like procedure ignores the individuality and particularity of patients. In the second case, focusing too much on patient preference or choice places too much emphasis on patient autonomy; and respect for patient autonomy is only one aspect of good patient care. Furthermore, for the dementia patient (and others with severely diminished capacities for autonomy) respect for autonomy is probably a moot point. Even for the patient deemed autonomous being left to make choices about her health care options can be experienced as distressing and the patient may feel unsupported by her health care team. The authors argue that to be person-centred involves seeing the patient as relational rather than as the unfettered

\textsuperscript{190} Ibid., 311-12.
\textsuperscript{191} Entwistle and Watt, “Treating Patients as Persons,” 31.
independent individual; the capabilities open to any individual are at least somewhat constituted by her environment, relationships and social circumstances. What a capability approach can bring to the patient care context is a clear acknowledgement that a person’s capabilities are enhanced or diminished by social context, environment and relationships with others (including the health care team). The overlap with care ethics and chapter three’s care-based account of dignity is evident. For both care ethics and a care-based account of dignity the importance of relationships cannot be overstated. It is in the context of relationships we develop our capacities for agency and autonomy, develop a sense of self and personal identity, and it is the care of others that gives us our worthiness.

My aim has been to showcase a few ways the capability approach has been taken to the health care context. It needs to be noted that it is Sen’s version of the approach not Nussbaum’s which is referred to and adapted in the papers reviewed above. For most of these papers Sen’s version of the capabilities approach, which does not endorse focusing on a particular set of central capabilities (or functionings for that matter), seems appropriate given that the authors’ aims. For example, by suggesting the capability approach as an evaluative tool for measuring health-related quality of life Verkerk, Busschbach and Karssing’s paper highlights its usefulness as an alternative to more traditional frameworks. The point they make is that Sen’s version of the capability approach gives the researcher the flexibility to focus on a set of capabilities that help answer specific questions, which other more traditional frameworks tend to overlook. Nussbaum’s list of central capabilities would be of limited use given the authors’ aims. By contrast, Entwistle and Watt’s paper might have benefited from Nussbaum’s version of the approach with its central list of capabilities. They suggest focusing on a “subset of capabilities (and/or their corresponding functionings) that is particularly associated with the concepts of
persons and being treated as persons.” For example, they suggest capabilities to reason, to feel and respond to emotion, intend and initiate action, to be self-aware and to participate socially with others as capabilities which are “[a]lmost by definition, valued human capabilities”\textsuperscript{192}. They even acknowledge the capabilities they suggest are “imprecisely defined and underspecified”\textsuperscript{193}. Given this acknowledgement, why not reference a set of capabilities that are well-defined and specified, such as Nussbaum’s list of central capabilities? Generally, though, I agree with Entwistle and Watt’s argument that the capability approach could help support the delivery of person-centred care.

Where Entwistle and Watt’s 2013 paper refers to Sen’s broad conception of the capabilities approach my focus is on Nussbaum’s version. Nussbaum is particularly clear that the approach, as she articulates it, needs to encompass the concept of dignity and what a life worthy of dignity requires, and that there are core capabilities that must be met for an individual to be living a life worthy of human dignity.

Two recent studies have used Nussbaum’s version of the capabilities approach as a lens to evaluate how dignity is promoted in the clinical context. Catharina Melander and colleagues’ 2018 paper, “Human Capabilities in Advanced Dementia”, explores how Nussbaum’s version of the capabilities approach applies to dignity in the lives of nursing home residents with advanced dementia. Jari Pirhonen’s 2015 paper, “Dignity and the Capabilities Approach in Long-term Care for Older People”, aims to answer the question, “what implications does Nussbaum’s list of central human capabilities have for practical social care?”\textsuperscript{194} Both papers argue that Nussbaum’s approach could potentially provide an excellent framework for helping ensure caregivers move

\textsuperscript{192} Entwistle and Watt, “Treating Patients as Persons,” 34.
\textsuperscript{193} Ibid., 34.
\textsuperscript{194} Pirhonen, “Dignity and the Capabilities Approach in Long Term Care for Older People,” 29.
beyond attending to patients’ basic needs by considering the capabilities required to live a dignified life. Both papers support the way I think the approach could work in practice, and both provide important research data to support their claim. Melander and colleagues used an ethnographic approach where the researchers observed and interacted with the study participants, which included four women living in a dementia unit in Northern Sweden along with staff members. Pirhonen also relies on ethnographic data, which he collected for his master’s thesis. He spent time in a Finnish long-term care home observing resident life and making field notes.

Melander and colleagues’ paper focuses on the capabilities approach and dementia patients and supports my view of the way Nussbaum’s approach could provide a viable and valuable framework for ensuring patient dignity is maintained and promoted. Pirhonen’s paper draws similar conclusions to Melander and colleagues but is somewhat broader in scope in that he looks at elderly persons living in a long-term care home rather just dementia patients, although he does make a brief reference to cognitively impaired elderly patients.

**Applying the 10 Central Capabilities to Dementia Care.**

Following the style of Melander et al.’s and Pirhonen’s papers, I present each of the ten central capabilities followed by a brief description of the way these capabilities can be taken to the dementia care context.

**Life.** Being able to live to the end of a human life of normal length; not dying prematurely, or before one’s life is so reduced as to be not worth living.

Dementia can certainly shorten a life, particularly early onset dementia. However, in both studies the participants had lived a normal life span. For example, the four women in Melander et al.’s study were over 80 years old and can hardly be judged to have enjoyed an
abnormally short life. Providing opportunities for this capability entails providing the necessary
treatment and relief of symptoms like pain and anxiety and supporting a life that the receiver of
care regards as worth living. Of course, as Pirhonen points out, what constitutes a life worth
living is complex and highly individual. Ideally, we would each make our own definition of a
life worth living and ensure those who care for us, and might have to make decisions on our
behalf, know what a life worth living means for us. The ideal of creating and communicating
our own definition of a life worth living is fraught with problems; the most obvious problem
being that few of us want to discuss what a life not worth living looks like in the first place. An
advance directive gives caregivers some direction but only when such a document exists. In the
absence of an advance directive, securing the opportunities for the rest of the capabilities on
Nussbaum’s list should ensure patients are living a life worth living.

**Bodily health.** Being able to have good health, including reproductive health; to be
adequately nourished; to have adequate shelter.

Reproductive health might not be a concern for the elderly, or most dementia patients, but
good health, adequate nourishment and adequate shelter are. The older a person is the more
likely she will be prescribed multiple drugs in order to be in good health, hence careful
monitoring of drug therapy is important to realising the capability for bodily health. Pirhonen
argues it is important to ensure drug therapy is planned by a geriatrician or a physician with
geriatric expertise since older people metabolise drugs differently compared to younger people,
and that drug therapy ought to be evaluated on a regular basis to avoid unnecessarily prescribing
drug treatments. Ideally, and as a matter of justice, necessary drugs ought to be affordable so
that good health is not dependent on wealth. For those living in long-term care homes, adequate nourishment and shelter are significant issues. The long-term care home is intended to provide healthy and safe shelter for residents that considers their unique needs. For example, a good security system is important for specialised dementia units to prevent patients wandering and getting lost. The design and layout of the long-term care home ought to be accessible for those with physical impairments. For example, wide entryways to accommodate a wheelchair, bathrooms with grab-bars, non-slip flooring, adequate and large-print signage.

Dementia patients in the advanced stages of the disease will need help in almost all aspects of daily living. It will fall to caregivers to assess what the person with dementia needs to support her bodily health and ensure her needs are met. For example, the person with dementia might forget to eat or when she last ate and, in the long-term care setting at least, it would fall to staff to make sure the person is adequately nourished.

**Bodily integrity.** Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.

The capacity to move freely from place to place can be significantly curtailed by the physical decline that often accompanies ageing, let alone ageing with dementia. Physical ailments that affect the ability to move around comfortably and safely can be overcome with the use of assistive devices like a walker, a cane, or a wheelchair. For persons with dementia providing an environment where they can wander safely is a way to promote the capability for bodily integrity. As Melander et al point out, an obvious way to support the bodily integrity of

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195 Pirhonen, “Dignity and the Capabilities Approach in Long Term Care for Older People,” 32.
persons with dementia is by respecting their boundaries by supporting their choices (where doing so does not put them in harm’s way). For example, if the patient does not want to take part in a suggested activity it is not up to staff to force the issue.

Pirhonen argues sexuality ought to be taken into consideration in elder care as a matter of course and suggests “romances between residents are therefore favourable if there are no signs of abuse whatsoever”196. In Melander et al.’s study “there were no relevant observations that could be understood as related to sexuality”197, and the authors say nothing more on the topic.

Sexuality and sexual expression are complicated by issues of consent and competence for the person with dementia. This is not the place to fully address the possible ethical conundrums related to sexuality that could arise in the dementia care context, suffice it to say there is no reason to assume that sexuality is automatically off-limits for the person with dementia.

**Senses, imagination, and thought.** Being able to use the senses, to imagine, think, and reason – and to do these things in a “truly human” way [...] Being able to use one’s mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid nonbeneficial pain.

Long-term care homes need to provide the activities and opportunities for residents with dementia to engage their senses and imagination. It is also likely that some residents with dementia will need to be encouraged and helped to actually engage in such activities rather than simply watch from the sidelines. The point being, for persons with dementia simply providing access to activities might not be enough.

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196 Pirhonen, “Dignity and the Capabilities Approach in Long Term Care for Older People,” 32.
197 Melander et al., “Human Capabilities in Advanced Dementia,” 5.
Emotions. Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one’s emotional development blighted by fear and anxiety.

The emotional attachments we form are not only to other human beings – our family, friends, coworkers – but to physical spaces, like our homes and our neighbourhoods. For people with dementia who need to move into a long-term care home the loss of familiar surroundings can be very disorienting: unfamiliar routines, few reminders of home, unfamiliar people. It will always be a challenge to make a long-term care home home-like. But, as Pirhonen puts it, “home is more than walls and furniture. It is an emotional space”\(^{198}\). The daily routines of a long-term care home ought to be based around the schedules and needs of the residents not the needs of the facility itself or those who work there.

Practical reason. Being able to form a conception of the good and to engage in critical reflection about the planning of one’s life.

The capability for practical reason stands out to me in at least two ways. First, the distinction between practical reason as capability and as functioning is not clear\(^{199}\). Unlike food, practical reason is not a resource that one can choose to access or not. To have a threshold level of the capability for practical reason means an individual must have at least a degree of the relevant functioning too. It might be conceptually possible to separate the capability for practical reason and practical reason as a functioning, but it is not humanly possible\(^{200}\). Second, a fairly high level of practical reasoning ability (as an actual functioning) is required for any individual

\(^{198}\) Pirhonen, “Dignity and the Capabilities Approach in Long Term Care for Older People,” 33.

\(^{199}\) It is not the only capability on Nussbaum’s list with this problem. For example, how do we separate using one’s senses as a capability and as a functioning?

\(^{200}\) Formosa and Mackenzie, “Nussbaum, Kant, and the Capabilities Approach to Dignity,” 888.
to be viewed as autonomous in the manner relevant to the medical context (i.e. able to provide informed consent and/or choose amongst treatment options). The patient with dementia may well have met this high level of reasoning ability at one time, but as the disease progresses the less likely it is the patient is able to perform high level reasoning and complex decision-making. The point is that meeting a threshold level of the capability for practical reason will not necessarily mean that the individual also meets the requirements for autonomy (either in the health care context or more generally). Other than the patient in the very advanced stages of dementia, the ability to reason, to form a conception of the good, to make choices and to have a sense of personal agency are capacities that are very much present and ought to be respected.

In terms of day-to-day life in a long-term care home, most residents with dementia will be able to communicate their desires to staff. With patience and sensitivity, caregivers will be able to discern an individual’s needs and desires even when the individual is having difficulty communicating those needs and desires. Problems might arise when what the individual wants runs counter to what is beneficial. The example Melander et al. use is when a resident chooses not to eat, which becomes a balance between respecting the individual’s choices and providing for the individual’s basic needs. Respecting the whole person requires being able to judge when the risks of respecting the individual’s choice outweigh the benefits. Skipping a meal once in a while is usually not harmful, but consistently refusing to eat is.

Deciding whether or not to eat certainly requires exercising one’s practical reason but it does not require particularly complex thought and decision-making. Meeting a threshold for a capability for practical reason is not the same as being competent to make health-related decisions. Many decisions and choices a resident with dementia might make in a day are low risk and high benefit. With whom to socialise, what types of activities to take part in, and when
to eat, are low risk decisions that are part of planning day-to-day life and it would be undermining to take away the opportunity to make these types of choices. In their study, Melander et al are very clear that people with dementia want to take part in the planning of their own lives; the authors regard the capability for practical reason as challenging for caregivers to support but crucial to promoting dignity.

For health-related decisions health professionals will need to seek the help of a proxy decision maker, ideally someone who knows the patient well enough to know what her preferences are. Whoever has the decision-making responsibility, we need to be wary of the substituted judgement standard to choosing or reasoning on behalf of the patient. The substituted judgement standard claims that, when faced with a serious care dilemma, health professionals should seek to find out from the patient’s family what the patient would want if able to make the choice. The aim of substituted judgement is to respect patient autonomy even when the patient is clearly in no position to make health care decisions herself. The philosophical appeal is obvious – the intention behind the substituted judgement standard is to capture respect for patient autonomy; to do anything less risks being overly paternalistic. But as Torke and colleagues (2008) point out there is evidence that relying on substituted judgement often does not line up with what the patient herself would have wanted. Substituted judgement is most often invoked for patients who have no advance directive in place, and it tends to be these patients who are the most likely to change their minds regarding treatment. In the case of dementia patients, it will most likely be a family member (or perhaps a few family members) who will be asked to determine what the patient would want in terms of treatment if she could choose. Of course, dementia can present the added problem of subtle (or not so subtle) personality changes making

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it especially challenging to even imagine what the patient would choose if she were able. One option is to remain faithful to the patient’s expressed values before a dementia diagnosis, which is the aim of the substituted judgement standard. But this could prove to be inappropriate or even harmful to who the patient is now. Rather than relying on the substituted judgement standard health professionals and family members need to “make decisions that consider the individual’s interests and values in the context of their current situation”\(^\text{202}\). In other words, when the need arises for health-related decision-making the proxy needs to appreciate the patient’s life in all its richness and this means neither stubbornly holding onto the patient’s past interests, preferences, commitments and values nor focusing solely on the moment at hand. The mistake the substituted judgment standard makes is that it assumes the patient’s identity, values and commitments remain settled and stable over time. While it needs to be acknowledged that a proxy decision-maker will be required for health care related decisions, relying on what the patient would likely have chosen as a course of action prior to a dementia diagnosis is not respectful of who the patient is with the diagnosis.

**Affiliation.** (A) Being able to live with and towards others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.) (B) Having the social bases of self-respect and nonhumiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin.

\(^{202}\) Ibid., 1516.
The capability for affiliation has two aspects. First is having the opportunity for social interaction with others, including with whom, as well as the choice not to exercise the opportunity at all. In a long-term care home this might mean ensuring there is physical space for residents to gather, as well as private spaces to withdraw from social activities. Whether the individual acts on the opportunity to have social interactions with others or not is up to the individual. In the long-term care home setting the individual may have very little control over with whom she interacts, and it is important that this aspect of institutional living is not overlooked, and the individual’s social preferences are respected and accommodated to the degree possible. For individuals with dementia who live in their own home the opportunities for social interaction will depend to some degree on whether the individual lives alone or not; whether the individual has any kind of support in place (family and/or professional); and the extent to which the individual desires the company of others. Each living situation presents unique challenges. In the case of institutional living, opportunities may well be provided for interacting with others but not much choice offered in terms of the timing of social interactions or with whom those social interactions occur. After all, a long-term care home is not just someone’s home but is also someone’s work place – balancing the needs of residents with those who work in the facility is no easy task. Living at home might provide more freedom in some ways but, without the means to get out and back safely, the opportunity for social interaction is limited to those who come to the home or the opportunity might not be realised at all. The issue is not whether persons with dementia ought to engage with others but that they have the freedom to do so, and that barriers to exercising this freedom are recognised and addressed.

Melander et al. point out that, as a consequence of communication difficulties and problematic behaviours, some people in their study had difficulty being part of a social group
and lost out on the opportunity to interact with others or take part in social activities. One of the symptoms of late stage dementia is difficulty with verbal communication and given that verbal communication is one of the key ways we interact with others, it is no surprise some people with dementia are going to find social interactions challenging. The problematic behaviours associated with dementia, such as repetitive vocalizations, agitation and aggression, present a significant challenge for some with advanced dementia to have an opportunity to connect with others. In their discussion, Melander et al. highlight that creating opportunities to achieve the capability for affiliation requires “staff to be present and engaged in each individual’s situation”\(^{203}\). Just providing the opportunity and space to socialise might not be enough for some people with dementia. Instead, caregivers need to watch for non-verbal cues that social interaction is desired and help support the individual’s efforts to connect with others. I have in mind non-verbal cues like sitting close to others, reaching out to touch another’s hand or shoulder, leaning against another or leaning in to pay attention to a conversation. These types of non-verbal actions are indicative of an interest in caring for and paying attention to others, at least to the extent the individual is able.

The second aspect of the capability for affiliation speaks to the social bases of self-respect and nonhumiliation. In dementia care it might not be possible to measure or assess a patient’s sense of self-respect or self-worth with any real accuracy. And perhaps it is not as important that the patient \textit{actually} experiences a sense of self-respect or self-worth as much as it is that the patient is treated \textit{as if} she does. Caregivers need to be mindful of the way they interact with patients and make efforts to interact with patients in a manner that shows respect and recognition. Effectively this means interacting with the patient \textit{as if} the patient does have a

\(^{203}\) Melander et al., “Human Capabilities in Advanced Dementia,” 8.
robust sense of self-respect and self-worth. This might mean validating the veracity of an oft repeated anecdote even though the anecdote is far from accurate. What matters is not whether the patient is telling a true story but that someone is listening and avoids humiliating the story-teller by correcting details. Even if the patient is likely to quickly forget a humiliating encounter with a caregiver or obviously does not experience the encounter as humiliating, it is still disrespectful and demeaning.

**Other species.** Being able to live with concern for and in relation to animals, plants, and the world of nature.

In the long-term care home context providing opportunities for people with dementia to experience the world of nature and other species can be challenging. For example, a change in environment can be stressful and anxiety provoking for some individuals. Moving from the familiarity of the inside of the long-term care facility to the unfamiliar outdoor space can prove overwhelming and stressful. There are concerns around safety and security, particularly for individuals who are prone to wandering. Wandering is a fairly common behaviour in the middle and advanced stages of dementia and the consensus seems to be that caregivers need to accommodate the behaviour rather than attempt to stop it altogether. Inside a long-term care home wandering can be fairly easily accommodated since exits can be locked or even camouflaged to hide the fact they are exits. But outside can present more of a challenge. Although safety and security are important, the outdoor areas of a long-term care home should not resemble a prison yard. Even small outdoor spaces can be aesthetically pleasing and provide a welcome respite from being indoors. In all of Canada, most of Europe and a large portion of the United States getting outdoors and into the sunshine will provide the added benefit of a natural dose of vitamin D; something which can be sorely lacking in the winter months.
Some long-term care homes have a resident pet along with regular visits from therapy dogs, which provide a welcome opportunity to interact with companion animals (at least for those who enjoy being around animals). Accommodating and providing opportunities for interaction with nature, plants, and animals in the long-term care home setting can be challenging given the variety of health needs of residents along with the needs and preferences of staff. However, these are relatively small challenges that only take creativity and care to overcome. For so many people, companion animals, like cats and dogs, are an integral part of a home.

**Play.** Being able to laugh, to play, to enjoy recreational activities.

Providing the opportunity for play starts with ensuring a positive and relaxed atmosphere in the long-term care home. Cultivating a positive atmosphere in the long-term care home context begins with management. A good working atmosphere for staff leads to a good living atmosphere for residents and creating a good work atmosphere starts with good leadership.

Pirhonen shares some words of wisdom from a long-term care home manager: “…it is good to hear residents complaining about their circumstances. …complaining indicates that residents feel safe. In an atmosphere of fear, the residents would be silent” (2015, 35). The opportunities to laugh and play go hand-in-hand with the opportunity to socialise (Melander et al. 2018); and feeling free to laugh and play and complain are elements of a good life.

Speaking from my own experience, being able to laugh and be playful is profoundly important for both the person with dementia and for the caregiver. Laughter and play can provide a welcome reprieve from an otherwise devastating disease.

**Control Over One’s Environment.** *(A) Political.* Being able to participate effectively in political choices that govern one’s life; having the right of political participation, protections of free speech and association. *(B) Material.* Being able to hold property
(both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.

The capability for having control over one’s environment has both political and material dimensions. The capability for political involvement includes being able to vote, to have a say in one’s community, the right to associate with whom one chooses, and the right to free speech. Material capabilities are those relevant to property ownership, property rights and equal opportunities for employment. While these are significant capabilities the ability to promote them in the long-term care home context is limited. At least the responsibility for promoting these capabilities need not be shouldered solely by those responsible primarily for the dementia patient’s health related well-being. How to promote these capabilities for the cognitively impaired is complicated and controversial. Still, Nussbaum makes an interesting case for ensuring the profoundly cognitively impaired have a say about whom to vote for and that they are able to serve on juries204. She argues that without these capabilities persons with profound cognitive impairment are not equal citizens, and that to be truly equal citizens they need to be assured civil and political rights. But how exactly? Nussbaum argues that it is the role of a guardian or surrogate to step up to vote or serve on a jury on behalf of the cognitively impaired person. Nussbaum even acknowledges that this opens the door to corruption – the guardian/surrogate could just cast a vote that does nothing to improve the lot of the person she is

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voting on behalf of, effectively giving the guardian/surrogate two votes. Nussbaum shrugs off
the concern for corruption by pointing out corruption can occur in other instances where a legal
guardian or surrogate is needed: health care decisions, property rights. Why view these
capabilities for political participation any differently? One objection is if the profoundly
cognitively impaired person cannot make an informed choice regarding whom to vote for and
then express that choice to his/her guardian then what is the basis of the guardian’s choice of
candidate? The obvious response is that the guardian’s choice of candidate should be based on
the interests of the cognitively impaired person she is voting on behalf of. The assumption is that
the guardian or surrogate has a close enough relationship with the cognitively impaired person to
have a good grasp of what will be in the person’s interests. It is a fair assumption considering a
decent guardian ought to be aware of the individual’s current preferences and aware of the
individual’s day-to-day needs. And it is these preferences and day-to-day needs that helps
determine what is in the individual’s interests. Presumably then, a good guardian/surrogate
(casting a vote on behalf of her ward) would vote for the candidate most likely to improve
conditions for her ward.

Is dementia a different type of case though? Yes, in that prior to a diagnosis of dementia
the right to vote would not have been questioned. Nussbaum’s argument for upholding the
profoundly cognitively impaired person’s capability to be represented in the voting process is
controversial only because those with profound cognitive impairment have been dismissed as
incompetent to partake in the political process. This is not the case with most dementia sufferers.
Some will have been passionately interested in the political process and their role in it, carefully
monitoring candidates’ views on issues that are dear to them. Whereas others will have spent
most of their adult lives uninterested in politics or their voting rights – perhaps never bothering
to vote or be involved in the political process in any way. For the person with dementia, the severity of the disease will dictate to what extent the person is able to be politically involved. What might this mean for caregivers (family or professional)? The role caregivers have is to make sure it is relatively easy for the dementia patient to remain politically involved – making sure the patient is able to get to a voting station, for example, or taking the time to discuss some of the policy issues important to the patient. It is not unreasonable to ask caregivers to do their part in facilitating the dementia patient’s ability to take part in the political process.

In the more advanced stages of dementia, political involvement becomes a moot issue. There will come a point where the individual simply cannot be politically involved in a meaningful way. Despite Nussbaum’s argument in favour of a proxy vote for the cognitively impaired, I am not convinced of its significance for the person with advanced dementia. It amounts to an added and unnecessary burden for caregivers if they are to try to ensure individuals with advanced dementia get some sort of say in the political process.

Melander et al. took this particular capability very literally by briefly discussing the limits individuals with dementia had in terms of controlling their immediate environment and making no mention of the political dimension of the capability. In a long-term care home setting it should come as no surprise that there would be limits to the ability of residents to exert control over their environment. A long-term care residence is both a home and a workplace, and that alone limits the amount of control and freedom individuals can have. Melander et al. point out that some of the care interventions employed by staff to curtail problematic behaviours would quite literally limit the physical space that an individual could move around in. Placing such limits on an individual’s physical movement would presumably be for the safety of both the individual and other residents. Melander et al. regarded the residents having their own furniture
and personal items in their living areas as a way of promoting the capability for having control over one’s environment.

The way Pirhonen discusses the capability for control over one’s environment implies he sees this capability as the government’s concern, not a capability that can be promoted effectively in the long-term care home context. Now, it is worth remembering that Pirhonen’s focus was on the elderly living in care homes, not just people with dementia. I am not sure how Pirhonen would have approached this particular capability had his study involved more people with dementia. Perhaps he would have espoused Nussbaum’s own thoughts on how to ensure people with cognitive impairments are meaningfully included in the political process. Recall that Nussbaum suggests a guardian or surrogate needs to step in on behalf of the person with cognitive impairments. And she acknowledges this might be an imperfect solution; after all, it is a situation that could be easily abused by a guardian or surrogate. My own thoughts are at least sympathetic to Nussbaum’s proposed surrogate/guardian solution but, as I indicated earlier, ensuring people with dementia are able to exercise their right to vote and to be politically engaged just might not be worth the effort. Why exactly? In the nursing home context, promoting this particular capability is burdensome to the staff – it is too much to ask. Many, but definitely not all, persons with dementia have family members whose political interests will include how best to ensure good care for those with dementia. Considering dementia, in all its varieties, tends to be a disease of the elderly we all ought to be concerned with what sort of support our government will provide for dementia care. At least those of us who expect to reach old age ought to be concerned, since our risk of dementia increases the older we get. My point is that dementia tends to receive more political attention than does congenital cognitive
impairment, and as long as this is the case I am not convinced we need to make sure all persons with dementia have a surrogate who will cast a vote on their behalf.

Suffice it to say, the ten capabilities Nussbaum outlines as central to a dignified life are relevant and applicable in a practical way. Both Pirhonen and Melander et al. conclude that Nussbaum’s version of the capability approach has the potential to improve the lives of elderly persons living in long-term care homes. Pirhonen sees the potential for change (predominantly) at the social policy level whereas Melander et al. see the potential for positive change at the bedside. They are both right: effective change needs to happen both at the social policy level and at the bedside. I want to emphasise that neither article provides research data on the efficacy of a capabilities approach framework in action. Rather, both articles look at life in a long-term care facility through the lens of Nussbaum’s version of the capabilities approach – effectively using the approach more as an evaluation tool than as a framework or guideline for providing good care. These two articles are valuable inasmuch as they provide the preliminary evidence that a capabilities approach framework has the potential to significantly improve the lives of long-term care home residents, particularly those with dementia.

While these two articles are valuable and useful they are not without their shortcomings. In an attempt to give all of Nussbaum’s ten central capabilities equal time neither article makes the effort to examine which capabilities are particularly relevant in the long-term care context. Instead, both articles offer a fairly superficial examination of how each capability applies or could apply. And this means that some of the capabilities are glossed over rather quickly.

Promoting all ten of Nussbaum’s central capabilities equally is outside the scope of responsibility of caregivers working with people with dementia. For example, as I argued above, while the capability for political participation (an aspect of having control over one’s
environment) is hugely important in terms of social justice, caregivers in a long-term care facility are not ideally suited to promote this aspect of having control over one’s environment. However, the capability to have control over one’s environment can be interpreted in a manner more fitting to the dementia care context (or the long-term care context more generally), where the focus would be on respect for the individual’s personal space and belongings rather than voting rights. Melander et al. seem to take this route by simply ignoring the political aspect of the capability, but they do not give any justification for why. Pirhonen points out that Finland secures basic political participation for its citizens through voting rights, and that if needed an individual can make use of an assistant in order to vote.  

I take it both articles, in attempting to address each of the ten capabilities, are implicitly acknowledging that Nussbaum insists the capabilities on her list are not open to trade-offs (i.e. more of one capability does not make up for the absence of another). Even so, there are capabilities on Nussbaum’s list that caregivers are able to promote more effectively than others, and this needs to be acknowledged. To be charitable, both articles are clear about their limitations and both conclude there is more work to be done. Pirhonen acknowledges he is not giving a thorough philosophical analysis of each of the capabilities as they play out in the long-term care context. Melander and colleagues state that they used the approach as a data analysis tool and that the capabilities approach “served as a theoretical framework for the conditions necessary for a dignified human life.” Both articles could have been improved had the authors opted to determine which capabilities were particularly relevant to the long-term care context and expanded upon those capabilities.

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205 Pirhonen, “Dignity and the Capabilities Approach in Long Term Care for Older People,” 36.
206 Ibid., 31.
By suggesting Nussbaum’s version of the capabilities approach would make a practical framework for providing dignity promoting care, I am building on the work of Pirhonen and Melander et al. They too recognise the importance of dignity promoting care and the role caregivers have in ensuring patients (particularly elderly patients and those with dementia) are treated in a manner that acknowledges and upholds their dignity. The appeal of Nussbaum’s list of ten central capabilities is that it reflects the social and relational aspects of a human life, and what humans need in order to flourish. Humans need other humans to live a recognisably human life. Without others the notion of dignity is practically meaningless. Nussbaum’s version of the capabilities approach maps well onto the account of dignity I describe and defend in the previous chapter in that it encompasses the social, relational and identity aspects I view as constitutive of a dignified human life.

What Pirhonen and Melander et al. seem to overlook is that some of the capabilities on the list are already addressed in long-term care homes (or at least should be!) as part of the basic care of residents. The first three capabilities – life, bodily health, and bodily integrity – are already promoted in the healthcare context; after all, healthcare is predominantly focused on the body. Of course, it would be wrongheaded to assume decent health and protection from unnecessary bodily harm is all there is to caregiving in the long-term care home context (or any other healthcare context for that matter). Person-centred care is the approach long-term care homes profess to adopt and practice in North America and much of Europe. Dementia care in particular reminds healthcare providers and caregivers to ‘see the person within’.

The recurring theme in chapter two’s literature review is the desire to be seen as a person, a fellow human being, and not just a body to be tended. The capabilities for using one’s senses,
imagination, thought, emotions, and practical reason (four through six on the list of central capabilities) all speak to personhood and identity. It is through our imagination, our thought, our emotions and our ability to reason (as best we can) that we express ourselves and, in so doing, assert our identity. When caregivers pay attention to and help support these specific capabilities they affirm the individual’s personhood and unique identity. In effect, paying attention to these capabilities and, if necessary, helping facilitate their expression acts as a reminder for caregivers that the individual is much more than a diagnosis or an ailing body or a compromised mind (in the case of dementia). The capabilities for affiliation, other species, play (to some extent), and control over one’s environment are capabilities that speak to the relational characteristics of being human. If our identities are in large part formed and influenced by our relationships with others (see chapter three) then these four capabilities are highly significant in the long-term care context. Relationships, care, identity and flourishing all contribute to our dignity. To respect and promote a person’s dignity requires that we see them in the context of their relationships with others and remember that they have been (and ideally continue to be) cared for.

Although not all of the capabilities on Nussbaum’s list may appear to be equally relevant to long-term care they can each be more clearly specified and adapted for the long-term care context without losing their significance. By carefully specifying each of the capabilities for the dementia care context, Nussbaum’s ten central capabilities could serve as an excellent and practical guide for caregivers. The real beauty of such an approach is that there is room to accommodate a variety of conceptions of the good life. As long as each of the ten capabilities are accessible to persons with dementia, caregivers can feel confident they are helping their patients to live a dignified life. Many dementia patients will need help turning a capability into a functioning. For example, the person with dementia will need help getting out into nature and
interacting with other species. Offering choices to the person with dementia supports the capabilities to have control over one’s environment and practical reason. I am not suggesting that adopting Nussbaum’s capability approach will be the grand panacea for the various and unpredictable issues a person with dementia might face. Rather, I am arguing it has the potential to provide a practical framework to help caregivers see and care for the patient as a whole person who is worthy of care and respect; and not just a body, a faulty mind or a diagnosis.

For the patient with dementia respect for dignity is part of ‘holding onto’ the person. By holding on I mean doing our bit to hold onto the person’s identity. Our identities are not created in isolation nor do they evolve in isolation. The constant creation and recreation of ourselves is always done with the help of others. We speak of dementia as a loss of self or a loss of identity. But the more accurate rendering is to say that dementia brings about the loss of some bits, the devolving of bits (only remembering distant memories), the unpredictable re-creation of bits, and, often, the unabashed revealing of bits of identity. Not so much that the person really loses themselves but that the person’s identity becomes unbounded in particular, and often surprising (sometimes good, but more often alarming) ways. As if the person’s identity container has sprung multiple small leaks. The duty of caregivers, family and friends is to respond to this leakiness with empathy and compassion; to do our best to refrain from shock, ridicule, pity and humiliation. Respecting dignity is part of holding onto the dementia patient’s identity.

By focusing on promoting the patient’s capabilities – especially the capabilities to relate to others, to engage the senses and imagination, and to play – caregivers have the opportunity to help patients be all they can be given the limitations imposed by dementia. Dementia patients in the more advanced stages of the disease will be unable to direct the course of their lives in any meaningful way, but the capacities for engaging with their world through their senses, through
imagination, through social interactions with others, and through play are still significant and ought to be promoted. There is more to being human and living a life worthy of dignity than our supposed ability to reason and our capacity for autonomy. This is especially so for the dementia patient (and any other patient whose cognitive impairment renders her unable to take significant control over her life), yet the dementia patient is still worthy of our respect and needs to be treated as a being of equal dignity. One of the advantages of adopting a capability approach in the care of dementia patients is that it offers caregivers clear direction regarding how to treat patients with respect. While it may be the case that the dementia patient is no longer autonomous in the relevant way it is not the case that she is no longer able to live a life worthy of human dignity or that lacking the capacity for autonomy makes her less morally worthy. By promoting the dementia patient’s capabilities, caregivers can be assured they have treated the patient with respect, and in doing so have also explicitly, through their behaviours toward the patient, demonstrated the virtue of respect.

**Conclusion.**

Given how important dignity is in the health care context (see chapter two) caregivers need to have some kind of guide to respecting patient dignity. My goal in this chapter has been to suggest a framework for promoting and respecting dignity. I chose to adopt Nussbaum’s version of the capabilities approach as a framework for a few reasons. First, it professes to be the basis of a theory of justice, and justice demands we respect one another as bearers of dignity. Second, Nussbaum is very clear that her version of the capabilities approach needs to encompass the notion of dignity and what it is to live a life worthy of dignity. We could say then, that

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209 In the medical context to be autonomous in the ‘relevant way’ is to be able to provide informed consent for treatment, which most cognitively impaired patients cannot do.
Nussbaum’s ten central capabilities provide the necessary scaffolding for a dignified life. Third, the capabilities approach has tenure and credibility in a variety of disciplines. In this chapter I pointed out how it has been adopted and adapted in health care, but it is also utilised in law, economics, development studies, education, sociology, human rights and other disciplines. The fact that the capabilities approach crosses disciplinary boundaries was also part of its appeal; while Nussbaum’s version of the capabilities approach applies to moral problems, it is recognised outside the confines of moral philosophy. Fourth, the capabilities approach promises to be applicable to real world contexts. It meshes the best of ideal and non-ideal theory. On the one hand, Nussbaum’s central capabilities list gives us a goal to aspire to – the real opportunities to achieve all ten capabilities for all persons. On the other hand, it can also give us a guide on how to measure and support the dignified life. In the health care context, the capabilities approach to caregiving goes well beyond taking care of the patient’s basic needs and looks at the whole person. The final reason I have for adopting Nussbaum’s version of the capabilities approach is that it overlaps with and supports the care-based account of dignity I proposed in chapter three.

One of the articles reviewed in chapter two was a short editorial by Kath Morgan, who had recently been diagnosed with Alzheimer’s Disease. Morgan’s editorial highlighted the difficulties surrounding how we view dignity and the attendant difficulty around putting dignity into caregiving practices in the health care context: “We all view dignity and what affronts it differently. This must make it tricky to put dignity into training; can you train dignity?” Adopting a capabilities approach framework is a way of ‘training dignity’. It might not be the only and definitive means to ‘train dignity’, but it is a viable option as Melander et al. and Pirhonen’s research confirms.
I have focused on the dementia care context throughout because any account of dignity used in the health care context needs to be able to address the hard cases. Dementia is complex and hard in a way that congenital cognitive impairment just isn’t. The vast majority of the time, persons with dementia were once competent to direct the course of their own lives, whereas we cannot say the same for persons with congenital cognitive impairments. If an account of dignity is going to be capacious enough to include hard cases, then it cannot be tied to mental competencies like rationality and autonomy. On my account, dignity manifests itself in the context of relationships and care, and as such does not rely on any characteristics or competencies of the individual. Dignity is conferred and actualised through the act of caring, which means dignity always comes from others. Dignity is maintained and promoted and respected in the context of relations with others. The capabilities approach, particularly Nussbaum’s version with its ten central capabilities, can provide a framework for respecting and promoting the dignity of hard cases like the person with dementia. And if it can provide a framework for promoting dignity in hard cases, then it is definitely a viable framework for the easier cases.

In the next, and final chapter I underscore the contribution my care-based account of dignity makes to the existing research on dignity in the health context, and in philosophy more generally. I also address a possible objection to my account, namely, what makes us worthy of care in the first place. I finish the project on a positive note by pointing out that the account of dignity has the ability to fit comfortably with a variety of moral commitments. Considering the assortment of diverse people we find in the health care context (patients, family, clinicians) with equally diverse values and beliefs, this ability to hang with different normative commitments is especially valuable.
Chapter 5

Conclusion

“dignity is not a useless concept because people use it in all sorts of ways.”\textsuperscript{210}

“What does dignity mean to you?”
‘It’s that feeling you’re ok.’\textsuperscript{211}

“We are all some mother’s child.”\textsuperscript{212}

What I have accomplished with this project is: first, highlight dignity’s salience in the health care context; second, provide an account of dignity that not only honours this salience but is capacious enough to include everyone, including the hard cases; and third, offer a practical approach to promoting and enhancing patient dignity. I appealed to dementia as my go-to example of a hard case in health care, and I did so for pragmatic as well as personal reasons. I came to this project with a surprisingly (to me) good knowledge base on dementia – the pragmatic reason. I also have been able to draw upon experience with someone close to me who has a dementia. Although I have carefully blurred many details, Mrs. C is a real person whose dementia continues to alter not just her world but the worlds of those who care for and about her. I began the project with the strong conviction that the ethical principles guiding patient care and respect – namely, autonomy, respect for persons and beneficence – are simply not enough for many patients. In particular, the patients I had in mind were those whose capacities for

\textsuperscript{211} Mrs. C’s definition of dignity.
\textsuperscript{212} Eva Kittay
autonomy were tenuous or fleeting (like the person with dementia or any brain disease or trauma that affects cognitive function) and, perhaps more importantly, those who have never had and never will have the capacities for autonomy. As the end of the project came into view, I started to realise dignity, and respect for dignity, is important for all of us.

In this final chapter I will highlight the contribution my project brings to the research on dignity taking place in the health care context, and in philosophy more generally. Along the way I will address a potential issue a critical interlocuter might have with the care-based account of dignity I proposed in chapter three. The potential issue or problem I have in mind is: what makes an individual worthy of care in the first place? Considering my care-based account of dignity argues we have dignity in virtue of being cared for, the question of what makes us worthy of care at all needs to be addressed. I will take up this potential problem a little later in the chapter. But first, let me briefly recap the main arguments I have proposed in defense of a care-based account of dignity.

I could have launched my project in a more philosophically argumentative manner by, for example, challenging Ruth Macklin or Steven Pinker and their cavalier and disparaging responses to the possibility of dignity being a robust and meaningful moral concept. However, since dignity and respect for dignity involves real people, I chose to bring the significance of individual dignity to life by using a real story that I am intimately involved with (some details have been altered for the sake of preserving the privacy – and dignity – of Mrs. C and her family). It felt disingenuous to me to begin this project in the purely abstract theoretical realm rather than the everyday lived experience. My hope is that by doing so I managed to provide the reader with a realistic glimpse into the complicated and sometimes messy world of dementia.
The real thrust of my project has been to show that regardless of what dignity means to particular individuals – and as my literature review shows, dignity seems to point in different directions for different people – it is significant, and we would be committing a serious error if we tried to eliminate it from our moral lexicon. I came to this project feeling ambivalent about dignity’s ontological roots, if indeed dignity is something we carry with us as a kind of metaphysical kernel of worthiness. I now end the project unable to shake that initial ambivalence. If the world rests on the back of a turtle and you ask, ‘what does the turtle rest upon?’ my blithe answer will be ‘maybe it’s turtles all the way down’\textsuperscript{213}. This is just another way of saying, why does it matter what the turtle rests on? We live in the world and what happens in the world and how we cope with those happenings is, in my view, considerably more important than what the world rests on – both morally and practically. In other words, I take a relational approach to our normative commitments to one another. It is our relationality that makes moral life possible at all. After all, what is ethics about other than how we ought to conduct our lives in relation to others. My attitude toward dignity is much the same: we may not be able to unequivocally identify any inherent trait or quality that makes us worthy of care, yet one thing is for certain, all of us who have survived beyond infancy have been subjects of care. As chapter three argues, care is the ultimate source of our dignity. If there is any foundational moral value that we have as humans, it is the ability to care for another being\textsuperscript{214}. We have been cared for because we have been deemed worthy of care – it is through being cared for we are granted the respect worthy value we call dignity.

\textsuperscript{213} See https://cosmology.carnegiescience.edu/timeline/1610/turtles-all-the-way-down

\textsuperscript{214} I am careful to use the term ‘beings’ as opposed to ‘humans’ because we often care for non-human beings, and I think there is an argument to be made that in caring for non-human beings we bestow upon them a type of dignity.
Relations of care make dignity possible and it is in the context of caring relations that individual dignity shines its brightest. The notion that dignity is a highly relational concept is not particularly unique or radical. After all, individual dignity means very little without a witness, even if that witness is one’s self. Dignity demands recognition from others, and the moral wrong occurs when individual dignity is not seen at all. The health care literature bears this out time and time again, as chapter two shows. If there is a ground of dignity – something dignity rests upon – it is not found in individual traits or distinctively human characteristics but in the care other people give us. While dignity as a relational concept is uncontroversial and widely accepted, locating dignity’s source in caring relationships is unusual and stands in sharp contrast to mainstream accounts that regard dignity as either derived from or resting on the distinctively human capacity for rational thought.

What makes us worthy of care in the first place? This is the most obvious question an interlocutor could pose in response to my care-based account of dignity. It seems to me to be a brute fact that, most of the time, we do care for our young. What makes the new born human infant worthy of care seems an odd and jarring question. Our very survival as a species depends on caring relations; at least in the earliest part of our life. Even the hermit has benefited from caring relationships with others. Without those formative - and on my account dignity conferring - caring relationships the hermit would not have the privilege of choosing to shun the relational life most of us inhabit. We are worthy of care in virtue of the fact someone has cared, to some degree, and cared long enough for us to reach maturity.

There will be tough cases that my care-based account of dignity might struggle to provide satisfactory answers to. For example, how might a care-based account of dignity deal with a violent psychopath? Do we owe the violent psychopath care and respect? Does the psychopath
undermine her own dignity by her lack of care for others? Keeping the psychopath away from others is an act of caring that, in my view, both respects her personhood as well as the dignity of those she could harm. It respects the fact that even the violent psychopath is, to use Kittay’s words, some mother’s child and as such was once deemed worthy of care.

Arguing for an account of dignity that finds its source in care and relationships is interesting and useful in itself, but because my focus is on dignity in the health care context, I needed to answer the next obvious question: how to put this care-based account of dignity into health care practice? So, where chapter three provided answers to the meta-ethical (what is dignity?) and the normative (what obligations does this account generate?) questions, chapter four’s aim is to showcase one way my account of dignity could be applied to a particular health context: the capabilities approach. By no means is the capabilities approach the only way to support and promote patient dignity. My choice to utilise the capabilities approach was driven by a few factors, including its proven application in the health care context (as the selection of literature included in chapter four shows); its explicit appeal to dignity and/or a life worthy of dignity; its acknowledgement of our social and relational nature as humans, which overlaps extremely well with my account of dignity; and its focus on justice (access to decent health care is a matter of justice). Since this is a philosophy project, the best I can do is speculate that modifying the capabilities approach to the dementia setting would provide useful and concrete guidance for caregivers. Ideally, what I propose in chapter four could be trialed in a long-term care setting, the results measured and, if it proved successful, policy changes made. But that is well beyond the scope of this project.

My care-based account of dignity is appealing regardless of one’s moral commitments; it will mesh with a plurality of values and normative approaches to moral life. The deontologist
can make as much use of my account as the consequentialist. For deontologists, my account of
dignity lends itself to both agent-centred (agent-relative) and patient-centred deontological
theories. The agent-centred deontologist acts out of duty or obligation and the reason for a given
action is relative to the agent herself. Agent-centred or agent-relative deontology is concerned
with moral agency; put differently, the agent is, or ought to be, concerned with her own moral
goodness. A poignant example might be the duties (of care) a parent has to her child. A parent
has duties of care to her own child that are particularly hers and as such there is no expectation
that a stranger has the same moral obligation to care for the child. Notice how we intuitively
assume it is a parent’s duty to care for her child; we make this assumption based on the
expectations we have of the parental role. The role of a parent is to care for her child. We have
similarly intuitive assumptions about the role of a health care provider or caregiver: it is inherent
in the role of a health care provider or caregiver to provide good care for her patient. For a
health care practitioner at least one agent-relative reason to provide good care, hence dignity
promoting care, is because it is morally required from the professional role itself. I am not
suggesting health care practitioners are only motivated by what is required of their professional
role, just that it is one more justification for the duty to treat others with the respect dignity
demands.

In general, health care ethics has a distinctly deontological flavour. Especially in the
context of the patient-practitioner relationship. Consider, for example, the principles of respect
for patient autonomy and beneficence. We can interpret both of these principles through a
deontological lens. The principle of autonomy is about respecting patient choice regardless of
whether or not the choice is in the patient’s best medical interests. The predicted consequences
of a patient’s refusal to act on his own best medical interests gives the health care team the
opportunity to persuade the patient to reconsider his choice, but not the right to override the patient’s decision with the excuse that a good end will justify the means. Respect for patient autonomy can be interpreted as either agent-centred or patient-centred: it is the duty of the health care provider to make sure the patient has the requisite information to make an informed choice, and it is the patient’s right to have his choice honoured and not to be used a means to an end not his own. Similarly, the principle of beneficence can be interpreted as both duty and right: it is the duty of health care providers to promote and act on the best medical interests of their patients, just as it is the patient’s right to be treated in a manner that is beneficial to his medical interests. Of course, these two particular principles can be in conflict but not because they are derived from different moral theories. They do not conflict (if they conflict) because one relies on a consequentialist theory and the other on a deontological theory. They conflict for the simple reason we sometimes do not want what is, all things considered, in our best interests. If we were to add a principle of dignity to the existing pillars of health care ethics (autonomy, beneficence, non-maleficence and justice), we would have similar agent-centred and patient-centred reasons to acknowledge, recognise and promote patient dignity as outlined above with regard to autonomy and beneficence.

Consequentialists should also have easy time accepting my care-based account since there is no need to begin with an argument for why we have duties to recognise and promote dignity or why we have rights to have our individual dignity recognised and promoted. Rather, for a consequentialist of almost any variety, the reason we ought to promote the dignity of others is simply because it is mutually beneficial to do so. Taking for granted that my argument for care as the ultimate source of dignity is convincing, it is not much of a stretch to point out that
caring for one another benefits us all. Through mutual care and recognition – in any context – we manage to promote and enhance the dignity of both ourselves and those around us.

The trickiest of the consequentialists to convince of the value of my account of dignity would be the Peter Singer variety of utilitarian. Peter Singer is best known for his work on bioethics, animal liberation, and our duty to alleviate global poverty. He is arguably one of the most recognisable philosophers in North America, and with good reason considering how controversial his work in bioethics is. To the outrage of disability activists (especially) he has defended the view that infanticide and euthanasia are morally permissible in some circumstances. On the face of it, the utilitarian argument Singer uses to defend euthanasia for the severely disabled infant seems anathema to my account of dignity. But I am not so convinced that Singer and I need to always be viewed at opposite ends of the value spectrum, where I see value as conferred through relations of care and Singer sees value in the aggregate of preferences satisfied by a particular action or set of actions. While Singer and I clearly have quite different normative commitments, hence different starting points, this need not mean we are not both aiming in the same direction. Yes, my arguments do support the claim that value – dignity – inheres in the individual, whereas Singer’s arguments support no such thing. However, the goal we both share still seems to be for any sentient life to be a life worth living. Recall that there is nothing in the way I theorise dignity that makes it incompatible with non-human animals. Singer and his acolytes have no grounds to accuse me of being speciesist based on my substantive account of dignity. There is nothing in my account that explicitly denies non-human animals’ dignity; I just do not know what confers dignity or how it happens in the non-human animal world. There is also nothing in my account that explicitly forbids euthanasia. It is

\[\text{215 Singer would argue value is to be found not inhering in individuals but in actions that increase preference satisfaction of the greatest number.}\]
plausible – even likely – that not every life, human or otherwise, is one worthy of dignity. I cannot imagine anyone convincingly defending the notion that a life of unremitting devastating pain is a life worth living. So, while Singer might not be the least swayed by my account of dignity, the positive outcomes of promoting individual dignity will usually have the positive effect of promoting and supporting preferences. Even if the motivation for treating individuals with respect and enhancing their ability to flourish comes from very different moral commitments, the positive outcomes associated with respecting individual dignity should satisfy even the strictest of utilitarian, including Peter Singer. Still, I must concede that I have no way to plausibly convince a utilitarian of the Peter Singer variety that dignity (my account or anyone else’s) can or does motivate particular actions or behaviours.

Are any of us moral purists though? Even Peter Singer contributed financially to his mother’s care when she was in the advanced stages of Alzheimer’s disease. And if we are to take Singer at his word, the money he spent on his mother’s care could have been put to much better use in some other way (donating to Oxfam perhaps)\(^\text{216}\). What I am hinting at is that, at least with regard to his mother, even Peter Singer is something of a moral pluralist. I suspect most of us are moral pluralists once we step into the real world. It is relatively easy to make moral decisions based on monolithic ethical principles from the safety of our cozy armchairs. But when it comes to making moral decisions that will have an impact on our lives and the lives

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of others around us, we are very often driven by context and the details of a particular situation. Moral pluralism is not an easy stance to defend but it is easy to see in action.

In a pluralistic society, where many values and beliefs are at play, my account of dignity is particularly useful because it can fit comfortably with a variety of value systems and normative commitments. If we could pin down an account of moral pluralism, I suspect my account of dignity would find a home there too. Where dignity’s critics have bemoaned dignity’s vagueness, I have given it substantive meaning. Although I have offered a philosophical and clearly secular account of dignity, there is no obvious reason my substantive account could not be accepted by a devout theist. After all, our human capacity for care is not so far from god’s enduring love of humanity.

By giving dignity substantive meaning my goal has been to show that it can be an action guiding concept in the health care context. Its ability to fit into different moral frameworks is a strength given the range of diverse values both patients and health care providers bring to the clinical context. While it might be difficult to determine what the principle of beneficence demands in a given context, the account of dignity I have defended makes it quite clear what dignity demands: care and identity affirming recognition. *Don’t call me honey, call me by my name* 217.

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217 I was once a member of an ad hoc ethics committee for a long-term care facility, and the issue of how residents wanted to be addressed was a perennial topic. Apparently, no resident wants to be called ‘honey, dear, sweetie, darling, love’ by their personal support worker.
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