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This is a pre-copyedited, author-produced PDF of an article accepted for publication in *Journal of Bioethical Inquiry* following peer review. The definitive publisher-authenticated version [Parsons, A. Hooker, C., (2010), Dignity and Narrative Medicine. *Journal of Bioethical Inquiry* 7, 3, 345-351 DOI 10.1007/s11673-010-9254-2] is available online at <http://link.springer.com/article/10.1007/s11673-010-9254-2>

Dignity and Narrative Medicine

Annie Parsons and Claire Hooker, 2010

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Abstract

Critiques of the dehumanising aspects of contemporary medical practice have generated increasing interest in the ways in which health care can foster a holistic sense of well being. We examine the relationship between two areas of this humanistic endeavour, narrative and dignity. This paper makes two simple arguments that are intuitive but have not yet been explored in detail: that narrative competence of carers is required for maintaining or recreating dignity, and that dignity promotion in health care practice is primarily narrative in form. The multiple meanings that dignity has in a person's life are what give the concept power and can only be captured by narrative. This has implications for health care practice where narrative work will be increasingly required to support patient dignity in under-resourced and over-subscribed health care systems.

From the late twentieth century there have been increasing critiques of the dehumanising aspects of contemporary medical practice. Criticisms have focused on the displacement of the person of the patient by technologies, the redefinition of the patient in biomedical terms, and the distress suffered by patients navigating a highly impersonal, overpressured health care system (Conrad 2007, Little 2002, Stepien and Baernstein 2006, Haslam 2007, Gordon 2005, Evans 2008). In response to this there has been increasing interest in the ways in which medical practice can foster, not just physical healing, but wellbeing. In this article we examine the relationship between two areas of this humanistic endeavour: narrative and dignity. That the two are closely connected is perhaps intuitive, even obvious; several commentators have noted them in passing (Coulehan 2007). However, these connections have not yet been explored in any detail.

While there has been an enormous amount of research on patient dignity, very little has looked explicitly at how and where narrative competence might be utilised as a key skill in sustaining and promoting that of dignity. Conversely while the move towards a humanistic approach to medicine has been pioneered by scholars interested in literature and narrative (Charon 2006, Frank 1995), how this impacts on and relates to the concept of dignity has never been fully explored. This paper makes two simple arguments whose implications are of importance for practitioners: that narrative is the core competency required for maintaining or recreating dignity, and that dignity promotion in health care practice is reliant on competent narrative communication. In this paper we first offer a brief exploration of the concept of dignity, then map some connections between dignity and narrative in illness contexts, and finally explicate the implications for health care practice.

The argument that dignity promotion in health care practice is usually narrative in form offers a modest response to the question of the real utility of the idea of dignity. This question has occupied much of the 1200-odd publications on dignity in recent times (Jacobson 2007), and continues to occupy contributors to this symposium. The word is used widely in many areas including human rights and bioethics: policy statements declaring the right to “a life in dignity”(General Comment No.14 2000) and the importance of giving care “with respect for the equal value of all human beings and for the dignity of the individual”(Swedish Health and Medical Services Act 2001) abound. But what, really, is meant by dignity? Uses of the word are so varied as to make a precise definition at best difficult and at worst undesirable. Dignity may be broadly defined as “the state of being worthy of honour or respect”(Concise Oxford Dictionary 1999), and when ‘the preservation of human dignity’ is enshrined in a Bill of Rights or a code of ethics, it is to safeguard attention to these qualities for all human beings. But why should all people be regarded as equally worthy of honour or respect? In these documents the word dignity tends to amount simply to an a priori assertion that humans have worth and/or require respectful treatment.

Historically the rationale for the concept of dignity derived from medieval Christian philosophy and from the particular reformulation of these ideas by the philosopher Immanuel Kant. Medieval Christians ascribed dignity to ‘man’ (and not to animals) because he alone was made in God’s image: God’s perfection gave man his dignity. In the eighteenth century Kant offered a new theory of dignity that has largely defined the terms of debate ever since (Jacobson 2009). Kant theorised the concept of human dignity as *Menschenwürde*, an inalienable value (literally, ‘worth’) that has no equivalent, and belonging to every person by virtue of their (human) capacity for moral judgement. He derives this dignity as a consequence of his famed formulation of the ‘categorical imperative’: that in order to be able to regard one’s own existence as something that has objective value, all people must apply that recognition equally to others (Shell 2008). Hence the principle that all humans should be treated as ends in themselves and never as a means to an end.

While Kant generated the frame for an assertion of inalienable human worth, his concept has since then been used in many arenas, such as the legal enshrining of rights, codes of ethics, and bioethical scholarship – often rather uncritically, and without attention to either the limitations of his theory (which appears to potentially exclude all sorts of morally incompetent people such as the mentally compromised or children, as discussed by others in this volume) or to its potential implications for various areas of use, such as healthcare. Instead, in these documents dignity is in practice collapsed back into being either a mere assertion of value or becomes a proxy for other ethical principles. At least one commentator has stated that dignity is a worthless concept, and could be better expressed in terms of the familiar bioethical concepts of respect and autonomy. In this view dignity constitutes nothing more profound than respect for an individual’s autonomy, and its consequences do not extend beyond those of medical ethics, namely: the need to obtain voluntary, informed consent; the requirement to protect confidentiality; and the need to avoid discrimination and abusive practices (Macklin 2003).

Yet the word dignity remains compelling, and we, along with several other recent writers on dignity, argue that this is because of its capacity to address the multidimensional aspects of human value and self worth. Nordenfeldt, for example, very usefully identifies four ‘types’ or concepts of dignity as operating within Western discourse: dignity as merit, dignity as moral stature, dignity of identity and *Menschenwürde*. While the first two are dignities that derive from social circumstances, the third, dignity of identity, arises from our sense of ourselves as integrated and autonomous persons, and hence is something more complex and more profound than mere feelings of self-worth (Nordenfeldt 2004). Whilst Nordenfeldt accepts a simple autonomy-based interpretation of Kant’s *Menschenwürde*, his formulation of ‘dignity of identity’ is indicative of the deep sense in which dignity is expressive of the self, something far beyond mere social ascriptions or interpretations. Similarly, in her excellent review of the scholarship on dignity, Jacobson proposed a classification termed ‘social dignity’, which in turn encompasses ‘dignity of self’ and ‘dignity in relation’, both

vested in the social, that is, interactive context of the individual's life and hence expressive of a complex selfhood (Jacobson 2007).

For other scholars this complexity and multidimensionality is directly entailed by Kant's own formulation of the concept of *Menschenwürde*. Shell, for example, argues that scholars like Macklin, Nordenfeldt, Beyleveld and Brownsword (Beyleveld and Brownsword 2001) who see *Menschenwürde* as primarily predicated on autonomy, offer only a 'thin' interpretation of his ethics of dignity, which she posits instead is vested in people's *embodied rationality*, their 'humanity' (Shell 2008). Other scholars have been at pains to show that *Menschenwürde* is indeed related to our individual sense of self-worth and the fundamental value self-worth has in people's lives (Maslow 1970; Kohlberg 1973). Edgar's reply to Nordenfeldt, for example, suggests that *Menschenwürde* might be secured and predicated upon three profoundly human potentials (no matter to what degree these are realized): the potential to control one's body, the potential to develop complex social competencies, and the potential for complex linguistic competencies. These are deeply *moral* in Edgar's view, because they provide the basis through which humans are capable of conferring experiential, even existential, dignity on themselves and others.

Regardless of where one hangs one's philosophical hat, all three scholars point to the extensive and profound degree to which dignity is part of our embodied and relational repertoire, and hence, multivalent without being meaningless. It is fairly obvious that some of the most important aspects of dignity are those that emerge through the subtleties of interactions between individuals – for example, when a loss of dignity is experienced. Dignity in this sense is a comparative value, but unique to the individual. It can be promoted or violated by others and affected by the challenges of illness and ageing. It is "equated with self-worth... To lose one's dignity is to feel that one's value as a person is irreparably diminished" (Toombs 2004, 193). Such a formulation of dignity gives *Menschenwürde* power and meaning because it highlights relational autonomy. This stresses that people are socially embedded and that social relations play an inextricable role in defining identity and conceptions of individual autonomy (Mackenzie and Stoljar 2000). These forms of dignity, and the impact of their loss on not just an individual's feelings but on their sense of self, are what make the concept of dignity more than a simple notion of autonomy or even respect (however dominant these features remain), and why it matters particularly in health care.

In fact, we suggest that dignity's multivalent and often imprecise use, which is so problematic for principlist bioethical analysis, is partly what makes it a useful word in health care. It has rich literary and aesthetic qualities, which have slowly accumulated and shaped it from as far back as Aristotle (Gallagher et al. 2008). Centuries of discourse have imbued the word with layers of meaning. Dignity emerges "at the interface of the moral and the aesthetic" (Pullman 2002, 77); our culturally derived notion of what constitutes a beautiful life, for example, informs our views of the characteristics of dignity. The connection between what is uniquely personal, highly nuanced and complex, and what is more generalisable (such as ideas about worth, autonomy or respect) in many uses of the term, and in the useful definitions offered by Nordenfeldt and others, is precisely the sort of connection that is given value in analyses of the ethical qualities of literature (Nussbaum 1990). Nussbaum and others have argued that literature holds a unique and valuable place in ethics because its very subtleties are what provide us with the capacity for cultivating our moral imaginations and for developing a fine-grained appreciation for moral action and moral capacities in ourselves and others (Nussbaum 1990).

We further suggest that if our view of dignity as primarily embodied, relational and vested in identity is correct, then it follows that dignity will often be enacted through narrative, and will mostly become meaningful in a narrative context. This may be especially the case in health care. The narratives relayed by patients to their carers, and the narratives reflected back to them by doctors and nurses, constitute the opportunity for the demonstration of the sometimes fleeting and subtle forms of attending, validating, caring and responding that constitute relating. This 'microethics' may be dignity-enhancing depending on the skills of and constraints on each party (as is well understood

within feminist ethics (Jaggar 1998; Nussbaum and Sen 1989)). We will explore these issues by further examining the inherently narrative qualities of social dignity and dignity of identity.

Narrative is basic to our sense of self. We live and create meaning through temporal, contingent stories: “[s]tories link past, present, and future in a way that tells us where we have been, where we are, and where we could be going. . . [They] turn mere chronology, one thing after another, into the purposeful action of plot, and thereby into meaning”(Taylor 2001, 2). All stories have a *point*, a message that they convey, and usually not a simple message either. By selecting events, characters and actions and showing the relations between them, stories build coherence and generate meaning. When communicated (and their purpose is to communicate, including to their author(s)), narratives bring author and audience, speaker and listener, into relation with one another, generating *intersubjectivity*, a shared understanding. This process is imbued with ethical responsibility: “[t]he telling of narratives itself becomes a moral action that has the potential to shape the lives of both the teller and the listener, leading to a form of culture-wide knowledge that ultimately determines how human beings rediscover and recreate their individual selves”(Charon 2001, 63).

It is unsurprising then that narrative features figure prominently in the discourse surrounding dignity, for example in Jacobson’s analysis of the features of dignity interactions (Jacobson 2009). Jacobson argues that four broad elements of an interaction define the degree to which dignity will be preserved, enhanced or violated during its course. The four elements are: the position of each actor; the characteristics of the relationship between the actors; the setting; and the features of the wider social order in which the encounter is situated (Jacobson 2009). These create a story which can bolster or disrupt a sense of dignity. It is striking that these echo the plot, form, time and frame of narratives that are found in literature and in life. Dignity is thereby recognised as being dependent on and even as representing the integrity of the personal narrative itself, as Pullman comments: “[m]aintaining a unified and meaningful life narrative is both a moral and an aesthetic project Suffering occurs when any aspect of the person is threatened or is perceived as undergoing disintegration. Such aesthetic upheaval is often referred to as a loss of dignity”(Pullman 2002, 84).

The absence of narrative work on the part of carers is glaringly apparent in circumstances of dignity violation. Features of dignity-violating encounters include actors paired in positions of vulnerability and antipathy, asymmetry in perceived power or status of the actors, and harsh circumstances (Jacobson 2009). Social processes identified in these encounters include indifference, condescension, contempt, objectification and exploitation. In health care settings the disruption of a coherent self narrative by illness weakens the position of the patient such that he or she is particularly vulnerable to the effect of hostile circumstances, which over time may register as sequential losses, leading to victimisation, social isolation, reduced help-seeking behaviours and chronic poor health (Jacobson 2009). Whilst many aspects of dignity violation may be hard to avoid (simply because of the degree to which dignity of identity arises from the integrity of the body, now threatened by illness) and have doubtless occurred in virtually all times and varieties of health care system, it is also not difficult to argue that the strain provided on western health care systems at present are such as to provide particular threats to patient dignity. The severity of under-resourcing has, for example, resulted in long wait times and underattendance on patient needs (for example, one the production of incontinence in the elderly as a result of inability to access facilities in a timely fashion (Lekan-Rutledge and Colling 2003, Zhang and Grabowski 2004). Health care workers frequently express frustration at their inability to spend the time patients need to discuss information and options while navigating increasingly complex complaints and highly technological interventions into them.

Perhaps most profound though least obvious or measurable are the losses to the sense of self attendant upon highly bureaucratic management systems, in which the criteria applied for ‘quality audits’ etc may conceptually erase the existential aspects of illness and healing, putting

them beyond articulation for patients and their carers alike (Evans 2008). In fact, the very nature of medical narratives may at times threaten dignity and patients may need to reclaim dignity by directly countering or resisting these narratives. Medicine is effective because scientific methodologies have made it possible to extract the common features of illness and to address these features through therapies with relatively uniform efficacy. However this approach may be in tension with other aspects of well being for the patient, because it can “suppress subjectivity and the uniqueness of experience, dominating and objectifying the person who is the patient. The danger is that these metanarratives can be internalised as valid descriptions of self and experience”(Sakalys 2003, 230). As is well known in the history of medicine, this is particularly problematic when a diagnosis either erases some aspect of patient experience or translates parts of identity and experience into wholly pathological terms – think of body weight/obesity, depressive illness, or ‘lengthy’ labour. The inability to reflect on and perhaps deviate from an established medicalised ‘route’ of diagnoses and interventions may, in the end, be experienced as profoundly undignified by both patients and doctors alike, as is frequently the case with the use of high-intervention intensive-care technologies and practices in terminal situations (Basta and Tauth 1996)

When we view dignity from a narrative perspective we can understand the threat that illness poses to dignity as a result of narrative disruption. The diagnosis of disease and the physical experience of ill health upset a conventional conception of time and the trajectory and contingency of a person’s life. As narrative analyst Arthur Frank comments,

“the central resource that any storyteller depends on [is] a sense of temporality. The conventional expectation of any narrative...is for a past that leads into a present that sets in place a foreseeable future. The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable”(Frank 1995, 55).

A loss of congruency between mind and body through the experience of an unpredictable and independent body is an enormous betrayal (Pullman 2002). This threatening existential aspect of illness, so undercutting to a sense of self and dignity of identity, was articulated by sociologist Barbara Rosenblum:

“You don’t know from moment to moment whether to call a particular sensation a ‘symptom’ or a ‘side effect’ or a ‘sign’... Words and their referents are uncoupled, uncongealed, no longer connected. You live in a mental world where all the information you have is locked into the present moment...I’m hostage to the capriciousness of my body, a body that sabotages my sense of a continuous and taken-for-granted reality”(cited in Rimmon-Kenan 2006, 242).

Rosenblum felt she had lost the central narrative features of a sense of temporal continuity and causality. Her orderly description of disintegration offered a means of overcoming helplessness and lack of control, and, in restoring herself to herself constituted a reclamation of dignity.

The implications of such tales of reclamation are simple: narrative competence on the part of both patient and carers – which is to say, the ability to develop complex narratives, to analyse texts, recognise patterns within them, and through them to develop capacities for self reflection and empathy – provides the means to promote and sustain dignity for both parties through recognition, integration and reformulation of an authentic self narrative. Central to narrative therapy is the idea that “the narrating of the patient’s story is a therapeutically central act, because to find the words to contain the disorder and its attendant worries gives shape to and control over the chaos of illness”(Charon 2001, 1898). The importance of patients’ illness narratives for their healing is, of course, well established (Frank 1995; Charon 2004). By ‘healing’ we intend to convey a shift towards ‘well being’, something more than mere reductions in the pathologies of the body. Illness narratives enable this shift both by giving expression to suffering and by developing a new coherence in the self that suffers. These narratives have two sides: “One side ... expresses the threat of disintegration

presented by illness ... while the other side seeks a new integration of body-self" (Frank 1995, 171). We suggest that the most dignity-promoting of the three types of illness narratives distinguished by Arthur Frank (Frank 1995) is the more complicated 'quest' narrative, in which coherence, meaning and purpose are major features, along with a need to communicate one's narrative to others and hence to cast it in a more relational form. Dignity is sustained throughout the quest narrative because of the developing moral capacities of its author as he or she encounters and moves through difficulties. The narrative functions so as to draw attention to this moral development in ways that parallel its function in literary settings (Nussbaum 1990).

Because of its unique capacity to return the ability to attribute meaning to the patient's experiences and sense of self, narrative medicine (something deliberately practiced by carers) is intrinsically dignity promoting. Narrative ethics requires that stories are fully told and heard, that all sides and voices are honoured and that all suffering is acknowledged (Charon 2008). Narrative medicine simply translates these principles into health care settings and insists on their priority as a part of health care. A leading exponent of narrative medicine, Rita Charon, writes that narrative practice is powerful because:

"not only is diagnosis encoded in the narratives patients tell of symptoms, but deep and therapeutically consequential understandings of the persons who bear symptoms are made possible in the course of hearing the narratives told of illness. Along with scientific ability, physicians need the ability to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient's behalf" (Charon 2004, 1897).

Current dignity-oriented care programs primarily use narrative techniques, though they are not always labeled as such. Most famously, Harvey Chochinov's dignity therapy in palliative care focuses on generativity, continuity of self, role preservation, and maintenance of pride – all narrative themes (Chochinov et al. 2005). The central element in dignity therapy in palliative care is legacy work, that is, therapy sessions that explore and unify past events to reflect a legacy that is meaningful to the patient. This active work on the life narrative is rightly seen as the critical component of supporting the person's dignity. It is unfortunate that it is only at the end of life that this investment in the patient's dignity is positioned as a priority.

It would be impractical and unnecessary to do extensive dignity work with every patient. Furthermore, we do not believe that 'narrative medicine' always, often or necessarily involves much investment of time – something we have already identified as lacking in under-resourced health care environments. It is often fairly brief validating interactions – physical expressions of support, humorous interchanges, the pose of 'active listening' – that can be restorative or sustaining of dignity of identity that is threatened by illness and the experience of institutional health care. In our view, following Charon, these are part of the cultivation of narrative competence. They take advantage of the forms of knowledge and opportunities for relating that are open to patients and their carers within the constraints of their circumstances. For example, brief interventions are naturally built into the history that is taken with narrative competence. Some aspects of life narrative interviewing could be a core part of routine patient care where distress is identified, regardless of cause. "During times of stress, individuals need to reminisce and recall positive aspects of their lives, especially their strengths and resources...What is essential is recognition of opportunities and conscious intent to listen" (Sakalys 2003, 235). Carel reiterates the value of integrating narrative awareness into daily practice and highlights how dignity work need not be separate from medical care:

"A phenomenological approach would clarify to the health professional what the impact of illness is on the ill person's life and it would address the asymmetry of the encounter. Addressing this aspect of the patient-clinical relationship may be beneficial to other issues, such as compliance...This

approach could also enhance interviewing techniques and ways of listening that could, in turn, lessen the danger of misdiagnosis. And finally, the patient experience...may be radically changed if they feel that their loss and the ways in which their world has become limited have been acknowledged” (Carel 2008, 45).

This approach has the additional and not unimportant merit of promoting the dignity of the practitioner at the same time, since this is affected by how they treat and respond to patients in what can be redesigned as a self reinforcing positive cycle: “[o]ur sense of personal dignity is wrapped up in the lives of others, how we respond to the pain and suffering of one another will either enhance or undermine that dignity”(Pullman 2002, 85).

Narrative medicine is an ethical practice, and we feel it is appropriate to continue to place the maintenance of and respect for patient dignity at its heart. The concept of dignity provides a strong foundation for the very challenging work of maintaining a sense of self in the face of the disintegrating forces of illness and the alienating aspects of late-industrial health care systems. As Christina Middlebrook wrote of her illness, what was important was the way hospital staff “came regularly to the bedside and, unwittingly, held my identity for me when I dared not”(cited in Charon 2006, 97). The idea of dignity has been much called upon in moves to bring the notion of the patient as a distinct self back into the centre of medical practice. This self is necessarily narrative in its expression, so that to speak of bringing the patient's self-hood, and dignity, back into the discourse is to speak of bringing their personal story to the fore. Thus the link between dignity and narrative is fundamental to the creation and sustenance of humanistic practice in medicine.

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