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Perceptions and understandings of dignity

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ABSTRACT 'Dignity' is a term used widely, often interchangeably, with the term 'respect'. It is challenging to illustrate these concepts as they relate to health and social care. Through a retrospective analysis of our research, we explore the meaning and relevance of dignity in care through the participants' narratives. Although human dignity is complex to define and operationalise in practice, it is quite clear when it is lacking. Participants referred to key attributes of holistic care and treating patients as people, through establishing and maintaining meaningful interpersonal relationships, and the implications when human dignity is not maintained.

KEYWORDS dignity | compassion | person-centred care | self-worth | realising human potential

Chapter objectives

1. Explore the meaning of dignity and its relevance to the delivery of health/social care.
2. Introduce some of the key theories of dignity in care, providing narratives from our research to highlight their relevance to health/social care practice.
3. Reinforce the importance of this concept for the delivery of compassionate and person-centred care and in preserving the dignity of those who provide care.

Chapter overview

This chapter provides you with an overview of the concept of human dignity by introducing and reviewing some of the key theories associated with the concept. At the end of the introduction, we concluded by stating the three conceptual 'lenses' (promoting self-worth, realising human potential, and safeguarding dignity) through which our retrospective analysis has been formulated. These lenses

were used to revisit the findings from several studies that were previously undertaken to reanalyse whether human dignity featured explicitly or implicitly in participants' responses.

Before providing information about how we conducted the retrospective analysis of the studies, we endeavour to guide readers beyond the theoretical foundations of human dignity to a more practical application of the concept. As part of this section ('beyond definition'), we conclude with further information about how we undertook the retrospective analysis before offering an overview of the studies. The overview states the primary focus of each study, the core methodology, and significant findings. Following this, we examine in detail the three 'lenses' through which participants' responses implicitly or explicitly were mapped to the concept of human dignity. Finally, we offer a conclusion of the main findings and implications for research and practice.

INTRODUCTION

Dignity, derived from the Latin 'dignitas', is associated with worth, honour and self-respect. Although these words and their associated phrases illustrate the fundamental and sacred nature of humanity, Nordenfelt (2009) in respect of philosophy of medicine and healthcare states that the word *dignity* is not a commonly used term in everyday language and refers to "an extremely abstract property" (p. 26). Despite the abstract notion of dignity within nursing, Matiti and Baillie (2011, pp. 15–16) present a review and summary of the main themes that comprise dignity. Specifically, through the concept of *Menschenwürde* [human dignity] (Nordenfelt, 2003), dignity is *inherent in human beings* and an *internal quality of the self*. Furthermore, dignity is a *dynamic* concept that relates to a person's *feelings of self-esteem, self-worth, pride, confidence, self-respect, importance, happiness, well-being and hope*. A person's behaviour also reflects their expression of dignity, for example, in *the way they behave to their own personal standards, convey respect, treat others as individuals and are able to maintain a public self by means of their physical appearance and modesty*. This illustrates the *relational quality of dignity*, where it is considered to indicate the *quality of relationships that foster reciprocal behaviour*. Other key themes suggest that dignity is present when a person has *control and autonomy, independence and can maintain their privacy* (Matiti & Baillie, 2011).

A major indicator and predictor of how human dignity is valued in contemporary societies is reflected in the way *care* is provided to those who may be considered as living on the margins, such as those who are homeless, unemployed,

experiencing mental and physical disability, living with addiction, substance misuse, the lonely and the elderly. From a medical sociological perspective, these groups are the ones who often encounter, and to a lesser degree report, dignity violation (Jacobson, 2009). These violations may be experienced either overtly or covertly through the disregard, disrespect and neglect, indifference met and the negative impact this has upon one's sense of self-worth, self-esteem and personal identity.

The word 'care' used above refers to "the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something" (Oxford Dictionaries, 2010). Based on this definition, we consider that the notion of *care* in respect of human dignity refers to the way people feel valued, acknowledged and recognised as individuals, each possessing their own uniqueness and identity. It is the duty and responsibility of society to ensure that the dignity of every citizen is preserved, and key organisations, institutions and care agencies are responsible for safeguarding and upholding such values with duty and sensitivity. The provision of care involves an array of people either individually or collectively in teams delivering care to some of the most vulnerable people in society. They provide this care in a range of situations and settings. Care for some people may be within the confines of their own home, some may be homeless living in temporary accommodation, and for others care may require more specialist treatments and interventions as provided in hospitals, hospices or residential and nursing homes. It is also important to acknowledge that health/social care professionals provide care for people across the lifespan, from pre-conception, birth to death. Every single person, irrespective of age, gender, belief or ethnicity, is worthy of dignity and respect and should not be subjected to any dignity violation. In many nations, this is enshrined in human rights legislation and law. For example, in the United Nations Universal Declaration of Human Rights (1948), dignity is mentioned five times; the key article (1) being:

> All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

This calls for health/social care professionals to be vigilant and aware of any challenges/threats to dignity, which may arise intrinsically from among the professionals themselves or extrinsically within the environment or organisation. To further explore the relevance and importance of dignity in the delivery of compassionate and person-centred health/social care, a retrospective analysis of some of our research (published/unpublished) has been conducted. This has explored students',

patients', carers' and health/social care professionals' perceptions of dignity, through the lenses of:

1. Promoting self-worth.
2. Realising human potential.
3. Safeguarding dignity.

These specific lenses were used to present the retrospective analysis as participants' implicit or explicit responses concerning dignity could be further contextualised and understood; for example, through the way in which participants' notion of dignity promotes one's self-worth, enables realisation of human potential, and the importance of why dignity must be safeguarded.

BEYOND DEFINITION

From a biomedical ethics and medical history perspective, interest in the concept of human dignity is not new and discussions around the nature, relevance and importance of this concept have occurred across early civilisations, cultures, and subject to intense philosophical enquiry (Andorno, 2014). Within health/social care, there appears to have been a refocusing upon the centrality of the concept and its fundamental value to the delivery of high-quality care (Tranvåg, Synnes, & McSherry, 2016). Interestingly, this refocusing usually occurs after there have been concerns raised about the preservation or violations of people's dignity, especially within care (e.g., Francis, 2013 [UK]).

Barclay (2016, p. 141) concludes her philosophical account and conceptual clarification by capturing the main attributes of human dignity and its relevance for healthcare:

> It [dignity] signals that each and every one of us is equally worthy, capable of the unique human ability to shape a life according to a set of standards and values which infuse that life with meaning. This conceptual clarification identifies the unique harm that is inflicted on people when we fail to respect their dignity, namely, humiliation and the loss of self-worth, and an implicit allocation to an inferior rank.

Over several years, the authors have conducted studies involving different groups of people, with the focus of these studies not specifically upon the concept of human dignity but exploring other aspects of health/social care. This chapter

draws upon the findings of these research studies, and by using a retrospective analysis, identifies whether the concept of dignity and its associated attributes is present in the participants' responses either implicitly or explicitly. Excerpts from participants' transcripts from the different studies were collated into a Word document and subjected to keyword searches based on Barclay's (2016) reflections on human dignity. For example, keywords searched included: 'dignity', 'respect', 'worth', 'self-worth', 'values', 'compassion', 'meaning', 'purpose', and 'harm'. The next step of this retrospective analysis involved a grouping together of the participants' transcripts according to these keywords. Subsequent analysis of these transcripts led to the development of the three 'lenses' through which this chapter is structured.

OVERVIEW OF THE STUDIES

The first study included an online survey of nurses' and midwives' perceptions of spirituality and spiritual care (Royal College of Nursing [RCN], 2011; McSherry & Jamieson, 2011, McSherry & Jamieson, 2013). At the end of the online survey, participants were asked to make any final comments about these concepts within a free-text box. Over 2000 qualitative comments were provided (McSherry & Jamieson, 2013) and analysed revealing that the word 'dignity' was used on 80 occasions in the responses.

The second study was titled 'An evaluation of the impact of a Dementia Leadership Programme (DLP)' (McSherry, Suckling, & Boughey, 2014; McSherry, Suckling, & Boughey, 2016a). The DLP was designed to provide knowledge and skills to enhance the leadership qualities of health/social care professionals to lead positive changes in dementia care. A total of 17 health/social care professionals were interviewed about their experiences of the DLP and approaches to planning care for a hypothetical 63-year-old lady ('Martha') in a dementia-based scenario.

The third study was a qualitative evaluation of a primary care chaplaincy initiative ('Chaplains for Wellbeing') (Kevern, McSherry, & Boughey, 2015;[1] McSherry, Boughey, & Kevern, 2016). The aim was to explore what impact Chaplains for Wellbeing had on the patient experience and their perception of health and well-being. A total of 16 patients having accessed the service since its introduction in 2011 were also interviewed on their experiences.

1. This was an unpublished report from 2015 detailing the evaluation of the Chaplains for Wellbeing service. If you would like a copy of this report, please contact the authors directly. The main findings from this evaluation were published in two phases: (1) Kevern and Hill (2014); (2) McSherry et al. (2016).

The fourth study featured a cross-sectional analysis of adult nursing students' values, attitudes and perceptions of compassionate care (McSherry, Bloomfield et al., 2016). A total of 22 students' understanding of personal and professional values were explored in six focus groups, along with identification of factors that shaped these values, and whether they influenced their ability to provide compassionate care.

The final two studies for NHS England (McSherry, Suckling, & Boughey, 2016b (study 5); Boughey & McSherry, 2017 (study 6)) focused on (1) exploring how co-production informed collaborative decision-making and joint planning for carers, and (2) a qualitative exploration of carers' stories from across four working groups (dementia, parent carers, young carers under 25 years, and forensic carers). The first study comprised four focus groups and a total of 22 participants (carer representatives and health/social care professionals). The second study comprised analysis of 21 stories submitted by key stakeholders within the Carers' Voice Network across the four working groups.

The findings of these selected studies were subjected to a retrospective analysis to establish whether the concept of dignity was directly expressed or evident in the responses provided by participants. The findings are presented through the lenses of *promoting self-worth*, *realising human potential,* and *safeguarding dignity*.

PROMOTING SELF-WORTH

A significant theme that was present across most of these studies was how health/social care professionals can promote and maintain the self-worth of individuals in receipt of care and those who provide care. Within the RCN survey, respondents emphasised that providing holistic and fundamental care was an implicit way of promoting a person's self-worth:

> *Looking after patients in a holistic manner respecting their dignity and treating each individual as a separate person with views of their own.* (Respondent 34[2])

The above response also introduces the concept of *holism*, which could be considered as equally abstract a concept as dignity. This illustrates the interchangeable nature of these concepts along with the notion that these are understood in accordance with other attributes such as individualised care and personal autonomy (Matiti & Baillie, 2011). Another subjective yet fundamental concept: spirituality

2. Registered Nurse. Study 1: RCN Survey (2011).

and provision of spiritual care, were also considered to be interchangeable with the notion of promoting self-worth. McSherry and Jamieson (2013) have highlighted the importance of delineating spiritual care as a way of re-establishing and understanding core values in care that have been eroded. Some respondents offered insights into the links between spiritual care and promoting self-worth:

> *Spiritual care is based on a recognition of the humanity and dignity of the other person. Any aspect of care which is delivered in such a way as to reflect the humanity and dignity of the other person can be counted as spiritual. For example, helping another person with personal hygiene needs, or listening carefully to them as part of a conversation, count as spiritual care to me.* (Respondent 1465[3])

Again, attribution to other aspects of health/social care helped respondents to make sense of how spiritual care can maintain a person's self-worth. For example, "listening carefully" is an attribution of good spiritual care, but also honours another person's *presence* and *being with* that person at their time of need. McSherry and Jamieson (2011) report that nurses typically use a range of approaches and skills to identify patients' spiritual needs, usually by listening actively and observing what is important to patients, relatives, and friends. This tangible and measurable way of providing spiritual care contributes to the promotion of self-worth and endorses an integrated approach to health/social care.

> *Spirituality is about beliefs, morals, dignity, respect. It is concerned with the person as a whole.* (Respondent 2172[4])

> *Spiritual care should not be added as an 'add on' to patient care but should be embedded in an integrated holistic healthcare approach.* (Respondent 1999[5])

These responses indicate that dignity is intimately related to how we understand the human experience. In some ways, the responses present us with a conundrum and juxtaposition. While they highlight the complexity of human nature with its many dimensions and layers including morals, relationships, communication and personal needs, they also imply a real sense of simplicity that dignity is inherent

3. Nursing Lecturer/Academic. Study 1: RCN Survey (2011).
4. Other category (Consultant Nurse, Nurse Practitioner, Nurse Prescriber, Practice Nurse, etc.). Study 1: RCN Survey (2011).
5. As per footnote 4.

and something absolute to all people. This approach in many ways cuts through all the complexity and alludes to the notion of *intrinsic dignity*, which Sulmasy (2007) considers to be the worth and value that people have *regardless* of their individual qualities or social standing. It affirms that dignity should always be at the heart of all relationships and preserved and conserved. This applies to those receiving care and those who provide it (Samuelsen, 2016).

The relational quality of dignity and promoting self-worth was also evident in the findings from the evaluation of the DLP. In this study, health/social care professionals emphasised person-centred care and support for people living with dementia and their family/carers as a fundamental aspect of effective dementia care. Participants made sense of person-centred care in terms of assessment and adapting care based on identified needs. Although 'dignity' was not frequently mentioned explicitly, the promotion of self-worth was implicit through the various methods of assessing needs and adapting care. Person-centred communication was considered crucial when determining the direction of care:

> *... talk to 'Martha' and get her opinions then talk to the family and get their opinions as well ... then formulate your plan more appropriately ... depends what they say as to where you go ... what the important things are to them.* (Interview 1[6]).

This person-centred and collaborative way of working ensures that self-worth is promoted, because there is attention to protecting autonomy around decision-making (Social Care Institute for Excellence [SCIE], 2015). Although it might raise questions around the sorts of decisions that people with dementia are able to make depending on the severity of their condition, decision-making autonomy emphasises the importance of health/social care professionals being sensitive to their individual patient and supporting them where necessary. This alludes to the relational qualities of effective care and support, but it also illustrates the importance of dignity work in dementia. Some specific elements of this include the maintenance of normality to help minimise cognitive decline and threats to self-worth (Öhlander, 2009), and knowing how to intervene and manage problematic situations whilst maintaining self-worth (Örulv & Nikku, 2007). Participants highlighted that an important method of managing behavioural challenges in dementia care was to *understand the person living with dementia*:

6. Care Home Liaison Nurse (Memory Service). Study 2: Dementia Leadership Programme (DLP) (McSherry et al., 2014, 2016a).

> *... the issue is how can you make [Martha] feel better? And valued and still loved? Because her family are perceiving her as not the person that she was ... [Martha's] always had a strong personality ... she still has got a strong personality, but it's just manifesting in a different way.* (Interview 7[7]).

Findings from the DLP evaluation found that promotion of self-worth requires understanding of "personhood" (Kitwood, 1997, p. 8). This refers to the notion that "being [with a person]" is a sacred activity where "each person has absolute value", and that there is an "integrity, continuity and stability" of the self (Kitwood, 1997, p. 8).

REALISING HUMAN POTENTIAL

Kirchhoffer (2013) considers that human dignity refers not only to one's sense of self-worth that validates the meaning of existence, but also their potential to *realise* this sense of self-worth for themselves and others. Findings from the Chaplains for Wellbeing study supported patients' ability to realise their potential for self-worth at a time of their lives when they experienced profound "loss and existential displacement" (McSherry et al., 2016, p. 151). This was only possible through the therapeutic intervention skills and partnership working that Chaplains undertook when consulting with patients. In the second phase of the study, exploring the induction and training of Chaplains (Kevern et al., 2015), they reported on the intensity of their therapeutic work with patients:

> *The variety ... vulnerability ... diversity of people that we see – all of that – is just so vast, because people can come [to the Chaplain] with anything, and [the Chaplain] has to be able to provide whatever that person needs.* (Chaplain 3[8]).

Chaplains considered that providing "whatever the person needs" is only possible through having developed extensive frontline experience along with continued training and professional development. This empowered them to work in ways which enable the patient to realise their own potential for self-worth, receive care which is adaptive and centred around their needs:

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7. Dementia Care Home Manager. Study 2: Dementia Leadership Programme (DLP) (McSherry et al., 2014).
8. Study 3: 'Chaplains for Wellbeing' (Kevern et al., 2015).

> *... to work with that openness of brief almost ... what's helpful for each person and not to feel the need to be too rigid in a way of working, to have that flexibility ... to be adaptable and patient-led and responsive to the patient's needs.* (Chaplain 2[9]).

This adaptive way of working and in a person-centred manner enabled Chaplains to overcome the challenges of intensive work and guide the patient to a place where they felt safe, comfortable and whole. This gave patients 'permission' to feel whole, valued and realise their potential to navigate the dark times of their life:

> *[Chaplains have] to be able to impart to any one given person that you are interested in who they are, what they are, what they've brought to you ... let them feel that they're in a safe place, confidential place ... where confidence is kept and to be able to enable them to feel as whole as is possible.* (Chaplain 3[10]).

> *[The Chaplain cared for my personal dignity] very highly, because I had no self-dignity then at all ... [I] was in the gutter, and [had] no self-worth at all, no self-esteem, nothing. [The Chaplain] actually respected my dignity.* ('Victor', Line 106[11]).

It is quite remarkable that patients presented to the Chaplain with "no self-worth or self-esteem" and is testament not only to their resilience but also to their need to realise their potential for self-worth, as one Chaplain explains:

> *When [patients] first come in [to see the Chaplain], they've built themselves up to coming, it's a huge event for them ... every patient that comes through the door, it's a big miracle that they've got there ... just to offload is a major thing ... they've got there and whoosh! Further on, as [the patient] begins to understand that [the Chaplain] understands them ... they are going to be loved and cherished within and accepted, (that's a big thing), ... it becomes a safe place ... they can be held into.* (Chaplain 4[12]).

This abstract notion of 'holding' a patient or "walking a journey with someone … watching and learning to see how [people] handle [their situations]" (Chaplain 4),

9. As per footnote 8.
10. As per footnote 8.
11. Service user pseudonym. Study 3: 'Chaplains for Wellbeing' (McSherry et al., 2016).
12. As per footnote 8.

provides valuable opportunities for patients to realise their potential for self-worth by being able to *offload* their life situations to the Chaplain. As such, patients reported often feeling "lost", and amid their loss, were afforded a time and space to have their sense of self-worth honoured, respected and validated through their consultations with the Chaplain:

> *[The Chaplain] gave me that time to kind of just breathe ... I felt free with [them] I could be myself with [them] [and they] were not judgemental ...* ('Sylvia', Line 144[13]).

The key elements in the excerpt above allude to patients feeling comfortable to disclose challenging information, realising that they could "be [them]selves" and not subject to judgement. Ultimately, the capacity to realising one's potential at a time of immense life challenges depends on the "little things" (Williams, Kinnear & Victor, 2016, p. 785) that matter to patients, for example how clinicians interact with them by demonstrating "extra care and consideration" (Williams et al., 2016, p. 785) and having a good manner and demeanour.

Evidence supporting these notions of care provision were also found in the cross-sectional analysis of adult nursing students' values, attitudes and perceptions of compassionate care. In this study, students reported a transparency between their personal and professional values and recognised the importance of respect and dignity as ways of upholding elements of fundamental nursing and compassionate care. Students considered that in order to enable patients to realise their potential for self-worth, it needed to be implicit in the way they provided care to ensure that they got to know patients and establish trusting relationships, as a first-year adult nursing student explains:

> *... to see an individual in a patient, not just a patient ... and not a number ... just showing people that you see them as individuals and care for them as individuals, for that very person, for their preferences and likes and dislikes.* (Focus Group 2, Participant 4, Lines 119, 121, 123[14]).

A third-year adult nursing student elaborated that the above notion of person-centred care depended on the provision of compassion in the interpersonal interaction. It could be implied that the realisation for human potential might be compromised

13. Service user pseudonym. Study 3: 'Chaplains for Wellbeing' (McSherry et al., 2016).
14. First-year adult nursing student (focus group age range: 28–44 years). Study 4: Cross-sectional analysis (McSherry, Bloomfield et al., 2016).

if compassion is not communicated well. An integral part of this communication is recognition that we are all unique with our own life narrative. Therefore, it is important to approach individuals in a sensitive manner and ensure that care honours them as human beings, which goes beyond simply performing a task:

> *... if you're just doing tasks ... you're not actually realising that the person's probably been through two world wars ... the person may never have been outside their home for the last six years, and you're the last person they've come across.* (Focus Group 3, Participant 2, Line 60[15]).

The above statement does not imply that task orientation alone poses a threat to the provision of compassionate care, especially if the clinician is actively "caring about", as well as "caring for" patients (Williams et al., 2016, p. 788). The distinction between these two concepts refers to the focus of the interaction. Specifically, 'caring for' patients implies the 'hands on' aspects of care delivery, compared with 'caring about' patients, which refers to the provision of social, emotional and spiritual support. Therefore, clinicians must be acutely aware of subtle differences between providing 'care' and 'caring', as illustrated:

> *... there are [tasks nurses] have to do. But [fundamental nursing is] the extra bit ... so you can come in [and] be your task allocation nurse ... but it's the bits in-between, so when you're doing the observations, talking to your patients ... that's the caring side of it ... the extra bits you do around the tasks, not just the tasks*. (Focus Group 3, Participant 2, Line 54[16]).

The suffix 'ing' transforming the noun: 'care', to the adjective: 'caring', carries more conceptual value than its morphemic property. Essentially, the business of "caring for" becomes incorporated with the notion of "caring about" patients (Williams et al., 2016, p. 783). Although there is this conceptual distinction made between these terms, 'care' is typically used to refer to the qualities of both and has been elaborated on in the context of the '6Cs'[17] (NHS England, 2012, p. 13):

> Care is our core business and that of our organisations, and the care we deliver helps the individual person and improves the health of the whole community.

15. Third-year adult nursing student (focus group age range: 22–48 years). Study 4: Cross-sectional analysis (McSherry, Bloomfield et al., 2016).
16. As per footnote 15.
17. 6C is a term used in the NHS England (2012, 2016) Compassion in Practice strategy. It includes care, compassion, competence, communication, courage and commitment.

> Caring defines us and our work. People receiving care expect it to be right for them consistently throughout every stage of their life.

SAFEGUARDING DIGNITY[18]

The above quote focusing exclusively on one of the 6Cs ('care') provides the backdrop for the other 5Cs (compassion, competence, communication, courage and commitment), for without 'care', the remaining values and behaviours may become redundant. These principles collectively reiterate the importance of safeguarding dignity through the seemingly unremarkable components of care, or the 'little things' that matter to patients. It should be noted, however, that reception to these explicit statements of such implicit principles in health/social care can be met with some scepticism, specifically that principles like the 6Cs can resolve problems experienced in failing health/social care services (Baillie, 2015). Furthermore, Cuthbert and Quallington (2017, p. 12) state that, "it is regrettable that we need government-driven policy and legislation to remind us of some of the most fundamental and enduring values for health and care work".

Despite these reservations, NHS England (2016) concluded from qualitative evaluations of the Compassion in Practice strategy and the 6Cs that these concepts helped to provide a focus for improvements in care, and safeguarding dignity as a 'fundamental' property of care. For example, NHS England (2016, p. 28) states:

> The 6Cs encapsulated everything … nurses are becoming very technically proficient in many ways, but that the fundamental essentials of being a nurse and coming across as a nurse who can be approached, relied upon, friendly, knowledgeable … is perhaps beginning to be missed a little bit … nationally.

In order to place patients and carers first when planning, delivering and evaluating care, it is important to know what is important to them so that care can always be person-centred and safeguard their dignity. The final two studies conducted for NHS England utilised a paradigm of story-telling and listening to the carers' voice, respectively. Although the focus of these studies did not explicitly examine the safeguarding of dignity, it was evident in the findings that this was of paramount importance to carers and their patients.

18. The studies that inform this theoretical lens, and also the rest of the chapter, were conducted in the United Kingdom (UK). However, while we acknowledge that there are many cultural and societal differences in the delivery of health and social care, the findings should still be relevant and applicable to a Norwegian and indeed a global context.

It has been mentioned earlier that dignity is present when a person has *control, autonomy and independence*. This was the case in the first study for NHS England, examining collaboration, decision-making, joint planning and integrated care; that there were problems when it came to the contracting of care and the negative impact this can have in safeguarding a person's dignity at a time of increased vulnerability:

> *Mother discharged into the care of the newly formed Integrated Community Services (ICS) team ... contracted care to care agency ... not the team who had worked with her for several years previously ... mother didn't take to this new team at all ... would have done a lot letter with her regular care team ... continuity [is] all-important with dementia [care].* (Narrative 6[19]).

It is clear in this excerpt that a patient's dignity is at risk of violation when they (or their carers) are not involved in care planning. Clearly, there are lessons to be learned with respect to safeguarding a patient's (and their carers') dignity. For example, there needs to be good communication between the hospital and community teams, involving the patient and their carers' throughout. There also needs to be better service integration so that patients and their carers are not left without care and support when they need it the most, as evidenced below:

> *After caring for [mother] for a month and with just one day's notice, the ICS team withdrew their cover and we were handed over to the Continuing Healthcare (CHC) team ... not able to find a care agency to provide cover at such short notice and we were left with nobody to look after my mother for the weekend.* (Narrative 6[20]).

The narrative above illustrates similar concerns to those raised by Francis (2013), where there is a "culture focused on doing the system's business – not that of patients … [and] a failure of communication between many agencies to share their knowledge of concerns" (p. 4). This patient's (and her carer's) dignity would have been safeguarded had it been for care agencies to prioritise needs of the patient and carers, not the needs of the agencies. Safeguarding the dignity of carers is only possible when their needs are heard and acted on:

> *I constantly [asked for help] from all kinds of sources ... I needed someone to listen, to explain how the system should work, to unravel the endless jargon*

19. Study 5: Co-production and collaborative decision-making (McSherry et al., 2016b).
20. As per footnote 19.

> *everyone talks … most of all to be believed. I have mostly been treated like a drama queen … the word 'sorry' has only been said by one individual.* (Story 3[21]).

The above narratives illustrate the importance of safeguarding the dignity of carers who are looking after a parent. However, there are also instances when parents are also in a position as carers when looking after their children who are accessing a variety of health/social care services. Qualitative findings indicate that *communication, transition between services, assessment and treatment* and *advanced care planning* are all important elements and opportunities where dignity can be safeguarded. Parent carers' stories illustrate the notion that dignity (as an abstract concept) is often inferred through other attributes or key characteristics of care and support. Parent carers reported that having good working relationships with health/social care professionals is a key aspect of feeling valued, respected, and having their dignity safeguarded. Being greeted, included, involved, and empowered are attributes of these collaborations. However, as with the above excerpts, examples of poor communication provided the context by which good communication could be understood and worked towards:

> *[The service] doesn't take your experience [seriously], they just see you as 'oh the parent'. Well, actually I am my children's expert; I live with them 24/7 and know what creates a problem … 'I don't want you to try and make me feel stupid because I'm not'.* (Story 12f [negative section][22]).

> *I am not addressed … I am once more a mere bystander [in the care of my child].* (Story 11 [negative section][23]).

Fortunately, there were examples of good communication within some of the care offered by the above services, where parent carers' dignity was safeguarded:

> *[The professional] allowed us to explain our fears in terms of our previous experience* … (Story 11 [positive section][24]).

> *[We] had constant touch with [the service] … the [responsible professional] was very good, very understanding and showed empathy towards us as a*

21. Study 6: Carers' stories (Boughey & McSherry, 2017).
22. As per footnote 20.
23. As per footnote 20.
24. As per footnote 20.

> *family as a whole, and you could see [they] really wanted to help [the child] and us.* (Story 12f[25]).

The above examples reinforce the importance of all those involved in health/social care actively safeguarding human dignity. They underline the complexity of caring and how safeguarding human dignity in particular involves many individuals, strategies and skills. Crucially, it affirms the importance of health/social care professionals working in partnership, possessing the correct attitudes and behaviours (dispositions) since these have a profound influence and impact upon the cultures, practices and environments in which care is provided. Attitudes and behaviours can either empower and nurture self-worth, autonomy and independence for patients, carers or health/social care professionals; or they can be destructive and debilitating, leading to violations of dignity.

Chochinov (2008), as one of the main pioneers of *dignity therapy* with a specific focus on palliative care, reminds all people involved in care about the importance of dignity by using the mnemonic: A, B, C, D. The 'A' refers to *attitudes* which should always be positive and supportive. 'B' stresses the importance of *behaviour*, which should always be kind and respectful. Dignity conserving care: 'C' concerns *compassionate* attitudes, behaviours and relationships. Interestingly, 'D' is not 'dignity' but in the context of dignity conserving care requires all those involved to engage in *dialogue* and discussions. It is through *dialogue* that we establish trusting and therapeutic relationships, communicate compassion and demonstrate mutual respect, kindness and common courtesy; all of which are fundamental to promoting, preserving and safeguarding human dignity.

SUMMARY AND IMPLICATIONS

This chapter has explored some of the conceptual complexities regarding human dignity in health/social care. Our aim was to reinforce, through reference to our published and unpublished research, how dignity can be promoted, realised and safeguarded in practice. Self-worth was promoted through holistic and person-centred care that respected a person's spirituality and autonomy around making his or her own care decisions. Realising human potential as a key aspect of maintaining dignity was apparent during times of personal vulnerability, health/social care professionals having the requisite knowledge and skills to support themselves and patients, and not just 'caring for' but 'caring about' patients. The importance

25. As per footnote 20.

of safeguarding human dignity was contextualised through the examples of care, which should have been person and family-centred, but often fell short of these standards. Safeguarding human dignity, thus promoting self-worth and creating opportunities to realise human potential, was considered to depend on the development and maintenance of therapeutic relationships based on trust, mutual respect, kindness and common courtesy.

It is important that human dignity is not perceived to be a vacuous concept that is devoid of any meaning and practical relevance. Instead, there should be continued exploration of how human dignity is perceived by patients, carers and by health/social care professionals who have a continued responsibility to promote and safeguard it. Given the immense challenges faced by health/social care internationally, and amid the recent damning reports of failings in health/social care in some countries, there has rarely been a more opportune time to prioritise the dignity and respect of patients and their carers.

AREAS FOR FURTHER DEVELOPMENT

As dignity is understood in the literature and research as an abstract concept, future research of dignity in health/social care should continue to explore the ways in which the concept is expressed both implicitly and explicitly. This could be through the three 'lenses' (promoting self-worth, realising human potential, and safeguarding dignity) that have been outlined in this chapter, or other conceptual frameworks. For example, in their ontological and contextual study of dignity, Edlund, Lindwall, von Post, and Lindström (2013) suggest that the holiness or human worth is contextualised through three dimensions: (1) spiritual (*absolute dignity*), characterising responsibility, freedom, duty and service; (2) psychical (*relative dignity*), characterising the inner ethical dimension; and (3) bodily (*relative dignity*), characterising the external aesthetic dimension.

CONTRIBUTION TO PRACTICE

As the research evidence-base develops, so too will the expectation that this contributes to practice. Health/social care education should continue to prioritise how professionals understand and provide holistic and person-centred care that honours an individual's presence, life situation, along with their bio-psycho-social-spiritual needs. This will help to ensure that individual self-worth is preserved, and human potential is realised during times of vulnerability. Maintaining and developing the evidence base on dignity will ultimately help to contribute to a

culture of compassionate care where dignity is not only safeguarded, but is understood as a way of humans' understanding what Edlund et al. (2013) refer to as their holiness, absolute human worth, and divineness.

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