UNIVERSITY OF HULL

‘I’m a person, you’re a person. We’re not plastic, we’re human beings.’ An ethnographic study of dignity in community nursing.

Being a Thesis submitted for the Degree of PhD in the University of Hull

by

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For Oma and Opa

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Abstract

This study explores dignity and human rights through the experiences of older patients and staff in a community nursing context. Previous empirical considerations of dignity in healthcare focus primarily on hospital-based care, and only a paucity of literature explores dignity and human rights in community healthcare settings. This study assumes a sociological approach, applying a human rights lens to the subject matter which offers an original contribution, as, to date, much of the work in this context has been written from a health or bioethical perspective.

The ethnography on which the thesis reports was conducted over a period of fourteen weeks in which I was located within an urban district nursing team in the north of England. Two methods of data collection were used – observations and interviews. Observations of clinical interactions (n=62) were undertaken between older adult patients aged over 60 (n=40) and members of the nursing team (n=13). Semi-structured interviews were undertaken with staff (n=11) and patients (n=11), which covered some standardised questions about dignity and human rights, plus individualised questions from the observations.

Thematic analysis resulted in three overarching themes: dignity in caring relationships; dignity in caring for the body; and dignity in the home. Dignity does not exist absolutely, but findings indicate dignity is socially (de)constructed through social interactions. Within the caring relationship, nurses and patients can create a ‘dignity encounter’, and if care within the home is managed successfully, an ‘environment of dignity’ ensues.

The study concludes that although dignity is desirable, it is highly complex and has multiple meanings, yet still remains core to community nursing practice. Through investigating routine and ‘mundane’ aspects of community nursing, this study demonstrates how micro-articulations in caring relationships have macro-applications in terms of dignity.

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List of abbreviations

A&E	Accident and Emergency
BAME	Black, Asian and Minority Ethnic
BBC	British Broadcasting Corporation
BMA	British Medical Association
CQC	Care Quality Commission
CPR	Cardio-Pulmonary Resuscitation
DH	Department of Health
ECHR	European Convention on Human Rights
EU	European Union
GMC	General Medical Council
GP	General Practitioner
HCPC	Health and Care Professions Council
HEI	Higher Education Institute
HRA	Health Research Authority
ICN	International Council for Nurses
IRAS	Integrated Research Application System
JSNA	Joint Strategic Needs Assessment
KPI	Key Performance Indicator
LeDeR	Learning Disabilities Mortality Review Programme
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NMC	Nursing and Midwifery Council
np	No page number
QC	Queens Counsel
QNI	Queens Nursing Institute
PANICOA	Preventing Abuse and Neglect in Institutional Care of Older Adults
PPIL	Patient Participant Information Leaflet
REC	Research Ethics Committee
RTF	Rich Text Format

SHA	Strategic Health Authority
SPIL	Staff Participant Information Leaflet
SUCG	Service-User and Carer Group
TV	Television
UDHR	Universal Declaration of Human Rights
UN	United Nations
UK	United Kingdom
UPR	Unique Participant Reference
WMA	World Medical Association
WHO	World Health Organisation

Transcription conventions

…	A short pause of 3 seconds or less.
[…]	Words have been omitted from the re-presentation of the data in order to aid flow, but without changing any context or meaning.
[pause]	A long pause of greater than 4 seconds.
[interrupts]	A person makes an interjection.
_	This topic of speech was broken or interrupted. The speaker interrupts themselves.
[inaudible]	The transcriber was unable to determine what was said.
[Name of nurse]	Identifiable names have been removed. If the person was a participant in this study, their pseudonym has been included. If they were not a participant, then a descriptor is used.
[Name of hospital]	Names of exact locations have been removed and a vague descriptor inserted.
[ ]	Words in square brackets are either an observation, or additional words have been inserted to clarify meanings.

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Chapter 1: Introduction

Background to Study

This study emerged from my social-work practice in the NHS, where I have worked as a safeguarding adults specialist since 2012. Prior to starting the project, my job involved undertaking safeguarding enquiries under the Care Act 2014, devising protection plans and reducing risk for vulnerable people, whilst ensuring safeguarding was 'made personal' (Local Government Association, 2013). All the older adults I worked with had unique life experiences; yet over the years, listening to their stories about encounters with professionals caused me unease, as I investigated many concerns of people in a position of authority or trust (such as health professionals), being perpetrators of abuse or violating other people's dignity.

Although my safeguarding work focused mainly on an adult service-user group that had experienced (or were at risk of) abuse, I recognised that many older adults do not enter the safeguarding system. This might indicate a lack of reporting of safeguarding concerns, but it might also imply that good, dignified care is delivered to many people. I recognised that it was likely to be a combination of both factors that resulted in many older adults not entering the safeguarding arena.

Although there is a growing research-base on adult safeguarding, 'there is little direct evidence for "what works" to prevent abuse in practice' (Faulkner, 2012: 36). This study emerged from my desire to contribute towards the preventative safeguarding agenda. Safeguarding is at the extreme end of an absence of dignity. However, daily care practices framed around giving and receiving dignity contribute to ensuring many older adults are not encapsulated within safeguarding services. It is these normalised and arguably mundane practices of dignity in action that became the focus of this study. I aimed to generate some empirical evidence of what dignity means to older people and how it is understood and operationalised in a community nursing context.[1] This thesis, therefore, partially makes up for an important omission in empirical safeguarding research, as it explores dignity in the context of everyday practice, by considering day-to-day interactions between community nurses and patients and how they construct dignity within their relationships. Through the exploration in this thesis of the everyday and potentially mundane aspects of care, it can be shown how important dignity is for older adults and how it manifests itself in the care they receive from their nurses.

Locating this study within a community district nursing team is significant, as it is a service-area that remains under-utilised by researchers, especially within ethnographic research. The literature review highlighted how existing studies exploring dignity in healthcare focus predominantly on care within institutional settings. Consequently, this study attempted to address a gap by focusing on dignity within care in an alternative, yet important, health setting: community nursing.

'Community nursing' is an umbrella term for care that is delivered outside hospital in the community. This includes district nursing (care in private individuals' homes and delivery of nursing care in care homes), as well as care delivered within clinics, such as practice nursing. I selected community district nursing to be the focus of this study, as it involves professionals entering patients' own homes, rather than patients entering a health clinic. As the service is usually hidden, it is undertaken 'behind closed doors' and outsiders are rarely granted access to observe interactions in these settings, making it an excellent location in which to examine how routine care practices can contribute to dignity. This ensures the study offers a unique contribution to the exploration of the construction of dignity in what is ordinarily a private space.

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[1] It is important to clarify certain terminology used within this thesis from the outset. The phrase 'community nursing' and 'district nursing' have both been used, at times, interchangeably, even though district nursing is just one form of community nursing. However, 'district nurse' is a protected title for a nurse who has undertaken additional training to qualify her in this specific role. Therefore, use of this phrase has been limited accordingly. Nurse-participants who were not qualified district nurses are referred to as 'community nurses', as they were undertaking delegated duties of the district nurse, but they did not have the additional qualification.

The home is a useful environment in which to explore dignity, as it is the place where micro-articulations of relationships take centre stage. Studying nursing care delivered in the home provides the opportunity to cast scrutiny over the intimacies of nursing relationships where experiences are outside hospitals or other institutions in which dignity has been more widely considered and is arguably more easily regulated (including care homes); thus, district nursing care is possibly one of the best settings, and certainly a rarely explored environment, in which to explore the manifestation of dignity.

‘Behind closed doors’: The history and context of community district nursing

Over the years, policy has increasingly emphasised a movement towards community health care models, reducing the demand, where possible, away from hospitals. Despite this political direction, a similar transfer of monetary resources has not accompanied the policy discourse (Charles *et al*., 2018), as funding pressures have impacted community, as well as inpatient, services. Contemporary community district nursing teams are currently experiencing shortages in the workforce. Hence, there is a perception that some community services are at ‘tipping point’ (Charles *et al*., 2018: 8). This lack of additional funding and staff shortages may have an impact on the ability on service-providers to operationalise the *Five year forward view* (NHS England, 2014), which emphasises care in the community and aims to more closely integrate health services.

‘Community nursing’ covers an extensive range of nursing activities and has been described as ‘any nursing care delivered “outside” the hospital setting, such as patients’ homes, or residential care or health centres’ (Spilsbury and Pender, 2015: 129). Community district nursing teams deliver care in people’s own homes and over half of their caseload comprises older adults (Cornwell, 2012). Practitioners within a community district nursing team may consist of support staff, such as healthcare assistants (unregistered staff), community nurses (registered nurses), district nurses (registered nurses who have completed additional training to allow them to use the title ‘district nurse’) and community matrons (senior nurses with advanced nursing skills who assume case management responsibilities for people with long-term conditions or complex health needs) . In the case of the district nursing team being studied in this project, they were also co-located with specialist nurses (such as palliative care or Macmillan nurses, respiratory specialists, diabetes specialists and so forth). The essential criterion of district nursing services is that patients must be ‘housebound’ making them unable to access care at local health centres where staff work in treatment rooms to provide nursing care.

Predecessors of today’s district nurses included the bible nurse, wet nurse, parish nurse, corpse washer, village nurse and handywoman. All of these were terms to describe women who delivered care to people in their own homes; however, it was in 1859, almost 90 years before the establishment of the NHS, that district nursing emerged as a profession (QNI, 2014). William Rathbone recognised the essential role palliative nurses played in caring for his wife at home, leading to him seeking advice from Florence Nightingale before founding the Liverpool Victoria District Nursing Association, along with a training school attached to the local infirmary in 1862, to provide district nurses supervised by a ‘lady superintendent’. A little later, in 1887, the Queens Nursing Institute was established to lead and coordinate district nurse training nationally, which included supplying qualified nurses (QNI, 2014). By 1892 it was a requirement that district nurses received a minimum of one year of training, and it was noted they must be of good ‘moral character’ (Sweet and Ferguson, 2000), a characteristic that remains inherent in modern-day NMC standards (NMC, 2015). By this time, it was also common, particularly in rural areas, for untrained nurses to work under the supervision of qualified district nurses, which is a foundation on which contemporary nursing rests, as qualified nurses continue to supervise unqualified staff.

The nursing role has traditionally been dominated by women, and although men feature within the nursing profession, this is often disproportionately so in senior nursing roles (Davies, 1995). Western historical portrayals of nurses are often polarised into two distinct types. Firstly, there is the angel (or saint-like) status bestowed upon Florence Nightingale following her care of sick and dying war heroes. However, notably, Mary Seacole, a black nurse also undertaking progressive approaches to nursing during the Crimea War, still lacks the prominence in history her white counterpart enjoys. Secondly, there are historical portrayals of the inept and uncaring nurse, for example, Dickens' presentation of the intoxicated nurses, Sairey Gamp and Betsy Prigg, in *Martin Chuzzlewit* (see figure 1).

Figure 1: Harold Copping, 'Sairey Gamp and Betsy Prigg' (1924)[2]

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[2] Image reproduced by permission of the Victorian Web (Copping, 1924).

Both the angel-nurse and the uncaring-nurse remain two significant characters in modern mass-media reporting on nursing. These characterisations also became apparent during fieldwork, when, for example, Michelle, an 86-year-old patient, described her nurses as ‘blue angels’ (referring to the shade of their uniforms), yet later described the very same nurses as ‘slaphappy’, implying an uncaring nature and contradicting her earlier representation of the nurse.

Male nurses are usually omitted from historical constructions of ‘the nurse’. Indeed, the voices of male nurses have not been heard in this study, as the team was all-female, and thus no male staff members could be considered for inclusion. Historically, men in district nursing roles can be traced back to the aftermath of World War 2, in which male soldiers returning to civilian roles began training as district nurses. At the time, ‘men in the district nursing service were often used to deal with cases requiring heavy lifting or the more “difficult” male patients’ (Sweet and Ferguson, 2000: 89). Although men were increasingly being seen in district nursing roles, the work remained gendered, with women taking on the less physically demanding work and the male nurses leading on the more ‘challenging’ male patients. To this day, nursing remains female-dominated. Whereas, historically, male nurses led on the more ‘challenging’ patients, this is now managed through the nursing hierarchy, in which the most senior clinician, in the case of this fieldwork site, the complex case manager, assumed oversight of the more complex patients, delegating certain responsibilities downward to other staff.

Historically, delivering nursing care could be particularly challenging in homes without electricity, hot water or inside toilet. These challenges may not be confined to history, as contemporary community nursing can involve working in the homes of many people living in extreme poverty, where families live in fuel poverty, unable to afford electricity or adequate heating. District nurses need to remain flexible and adaptable to the individual circumstances of each of their patient’s medical conditions, as well as the environment in which they live, as this frames the care that they are able to deliver within the home.

Generally, living conditions have improved for the wider population, and over the years, treatments and nursing interventions have evolved. Medical practices and new drugs have been developed, and these impact on the care people receive. Historically, following housing improvements, the number of patients requiring long-term nursing care in their homes reduced and this had an impact on the work of the district nurse, with the need for frequent visits declining (Sweet and Ferguson, 2000). The introduction of disposable syringes and pre-packed dressings made nursing tasks much quicker (as district nurses did not have to sterilise and re-use nursing equipment in people's homes) and safer (as single-use equipment reduced the risk of cross-infection or contamination). Indeed, during fieldwork, it was apparent how much pre-packaged equipment was used by community nurses, all of whom used their cars as 'mobile storerooms', transporting their wares between appointments and storing sharps disposal boxes alongside clean bandages, syringes and other nursing paraphernalia in their car boots.

The majority of district nursing practice occurs in patients' homes, and 'it is the golden rule of district nursing that the nurse must remember always that, unlike the hospital situation, she is the guest of the patient in his home' (Sweet and Ferguson, 2000: 86). This view was recognised by many nurse-participants in their interviews, who widely expressed views that they were 'invited guests' and thus needed to behave as such. In exploring the changing role of district nursing, Battle *et al.* (1985) indicate that, as nurses visit people in their own homes, a close relationship develops between them, in which patients can participate more equitably in the relationship than when in hospitals, and the nurse does not experience the hierarchical and institutional constraints of the ward environment. Community nurses often practice in isolation from other colleagues. As a result, individual practices may vary more widely in patients' homes than cultural practices on hospital wards, where nurses have continual contact with each other to informally supervise, guide and modify their own and others' practice. When working as a team of nurses on hospital wards, nurses are constantly exposed to a group culture, in contrast to the lone-worker culture of district nursing, making it an area of nursing that is not widely subjected to the scrutiny of other nurses, and, in a research context, a fieldwork location that remains under-explored.

The role of the district nurse has always incorporated educational aspects; historically they would demonstrate or teach family members how to care for relatives in the absence of a nurse, which empowered families to offer care to their loved ones. This educational role remains important in contemporary practice (Maybin *et al.* 2016), with community nurses teaching patients how to self-care (for example managing their own diabetes by controlling their dietary intake and insulin administration), as well as supporting carers and family members to undertake caring roles for people who are unable to self-care. Alongside nurses' responsibilities in teaching patients or their families to self-care, community nurses still maintain responsibility for teaching student nurses – both pre- and post- qualification. During fieldwork, many of the community nurses mentored pre-registration student nurses and one of the senior nurses was mentoring a post-registration nurse undertaking her district nursing training. Student nurses, therefore, remain a consistent part of the nursing landscape, but, as students regularly rotate between nursing placements, they were excluded from participation in this study.

This study focused on one specific community nursing team in an urban area of northern England and in order to understand the social and cultural backdrop to this care, I will now offer an overview of the local context.

The local context of the study

This study was based in a community nursing team in a city in the north of England with a population of approximately 260,000. In 2016, 19.7% of the city's population was aged 60 years or older, and approximately 28% of the population of retirement age were claiming pension credit (JSNA, 2017). It was estimated that in 2017 approximately 5,500 people aged 65–74 years and a further 8,600 people aged over 75 lived alone (JSNA, 2017). In terms of social isolation, it is estimated that 13.4% of adults living in the city aged over 65 may be socially isolated, but this varies dramatically across different geographical wards (JSNA, 2017). Using the Index of Multiple Deprivation, the city is ranked as the third most deprived local authority in

England (JSNA, 2017), and unemployment and low educational achievement feature in the lives of many residents.

To understand the social context in which the community nurses worked, it is helpful to consider the views of a nurse-participant describing, in her own words, the population she served:

> **Nurse-Daisy:** I mean the area we work in… well, we're in a big geographical area but, you know, some of the sort of poverty-stricken areas they're_ where they don't have money and you know they… don't eat… eat and drink as well as they should… and I don't know whether that's because they choose not to, or whether they're not educated enough, but obviously we're there to, you know, provide that education for them and refer them on if we need to, to dieticians but… I think it's the choices that they make as well if, if they're like… non-compliant and they're choosing to go against our advice, that's really difficult and that's_ we find that a lot in their own home, you know when you're in their own homes, but also it's like the area they're in, sometimes it's quite a rough area or… I've been into a few… drug users where they've had people knocking at the door and you can tell that they're doing drugs at the door.

Daisy's comment highlights some of the socio-economic realities of many patients receiving community nursing care by the team in which the fieldwork was based. Many of these realities become apparent in later chapters, where the social conditions of patients are revealed in the ethnographic descriptions

In 2006, *The Guardian* (2006: np) described the city as 'probably the least ethnically diverse large city in Britain'. To this day, the local population remains predominantly White, consisting of many inhabitants whose families have lived in the city over centuries. At the time of *The Guardian*'s article, the city also included a small Chinese population, but otherwise lacked much ethnic diversity, apart from staff and students from the local Universities. Over the years, the city witnessed a slight increase in ethnic diversity through the arrival of Kurdish asylum seekers, Syrian refugees and through other groups being resettled as part of the Gateway Protection Programme, an international programme of support for vulnerable refugees. Economic migration also led to an increase in European populations, particularly people from Poland and Romania, yet, to this day, most residents identify as 'White British' – 89.7% of the local population in the 2011 Census (Porter *et al.,* 2017), and, overall, 94% of the city's population identify as White (JSNA, 2017).

Over recent years the city has witnessed a marginal movement towards greater ethnic diversity as a result of both refugees and economic migrants settling in the city. Data collection began in late Spring 2017, approximately one year after the Brexit referendum, where over two-thirds of the city's residents voted in favour of Brexit. In the British Social Attitudes study, Clery *et al.* (2017) identified concerns over immigration being a crucial influencer in determining people to vote 'leave' in the referendum. Hence, it was unsurprising that immigration featured frequently in the views of participants during data collection

Local health issues provide an interesting context for the delivery of healthcare services. In the city, residents born today have a life expectancy of 80.2 (for women) and 76.5 (for men), which, for both genders, is two years less than the regional average and three years lower than the average for England (Data Observatory, 2017). However, there are marked differences in life expectancy across different localities within the city, as pockets of extreme social deprivation contribute to areas of lower life expectancy. Typically, at the end of their lives, women living in the city experience 24.8 years of ill health and males 20.2 years (Data Observatory, 2017). In 2014, the prevalence of smoking in England was 17.8%, but rates in the study's city are far higher, with the eight most deprived wards having prevalence rates ranging from 37 to 48% (compared to 32% or lower for the remaining 15 wards) (JSNA, 2017). The cost of smoking to the NHS is estimated to be £13.8 million, plus an additional £7.1 million for additional social care required by people who are current or former smokers (JSNA, 2017). The main causes of death are cancer and coronary heart disease (JSNA, 2017), and most deaths registered in the city between 2013 and 2015 occurred in NHS establishments (mostly hospitals) (JSNA, 2017).

This information highlights many local considerations that are indicative of the socio-economic background of residents in the city and the location in which community nursing services are delivered. Inequalities prevail, not simply in terms of the city in overall comparison to other cities within the UK, but it is also noticeable that across the city's political wards there remain significant variations.

The host organisation and community nursing team

The study was hosted within an organisation that officially formed as an independent healthcare provider in June 2010. In 2010, the government published their White Paper *Liberating the NHS*, in which they proposed to create 'the largest and most vibrant social enterprise sector in the world' (DH, 2010b: 36), allowing NHS services to innovate and be more responsive to patients. These changes in commissioning arrangements allowed the host organisation to depart from the NHS and become a social enterprise. Roy *et al.* (2014) undertook a systematic literature review to explore the potential of social enterprises in healthcare; only five studies met their inclusion criteria, and they found limited evidence that social enterprises could build social capital and impact positively on self-esteem and health behaviours that would contribute to overall health and wellbeing. They were unable to find any empirical research examining social enterprises as an alternative model of healthcare delivery. It therefore follows that there remains a necessity for further study into the efficacy of social enterprises in impacting health outcomes, which is beyond the scope of this thesis.

The host organisation was both a social enterprise and a co-owned business in which staff members became shareholders. The nominal shareholder fee (£1) aimed to 'engage staff in the organisation, enhancing their sense of belonging and increasing their ability to have a say in the running of the business'. The organisation offered over 80 diverse health services in a range of urban and rural locations across the north of England, making it one of the largest health social enterprises in the country.

Data collection occurred within one of the organisation's three urban community (district) nursing teams. Patients accessed their services, if they were registered with a GP within their specific geographical area and they were unable to leave the home to attend appointments in a health centre and thus required nursing care in their home. These patients were described as 'housebound', which in itself may be considered disabling, rather than dignity-enhancing or empowering, terminology, as it emphasises a limitation rather than an ability. Although all the GP practices were urban, the community nursing services extended to people living in nearby rural areas if patients were registered with one of the designated GP practices in the city. Nurses reported that rural patients tried to ‘keep hold’ of their urban GP, because services were ‘better in the city than in the countryside’. There was a diverse range of socio-economic households served by the team, including some patients living in some of the more deprived wards of the city, whilst the team also covered some of the most affluent areas of the neighbouring countryside.

Aim and research questions

The overarching aim of the study was to consider staff and older adult patient experiences of dignity in community nursing care practices. This aim was explored by considering the following questions:

1. What does dignity mean to nurses and patients?
2. How do older adults experience dignity in their homes?
3. Are dignity and human rights important to older adults?
4. How might staff deliver dignified care and are there any challenges to this?
5. What factors are needed to promote and influence dignity?

An ethnographic approach was adopted as the most appropriate methodology to answer these questions. The empirical phase of data collection was conducted between July and October 2017, in which I undertook 470 hours of fieldwork, involving a total of 15 different staff members (13 staff observed and 11 interviewed) and 40 patients aged over 60 (40 observed and 11 interviewed).

Dignity and human rights as a conceptual framework

Dignity is important to healthcare delivery. Yet as a conceptual framework, it remains under-utilised. I approached the operationalisation of dignity in practice by applying a human rights lens to the issue, which has not been done before in this context. It is through the lens of human rights that dignity in practice can be better understood, as ‘human rights are a crucial means by which to protect the dignity of the most vulnerable members of society and to enhance respect for dignity' (Koopman, 2007: 177). Human rights are not always easily understood, with scope for (mis)interpretation, which will be evidenced in my later discussions of participants' perspectives of human rights. However, the human rights legislative framework provides statutory enforcement of the overarching principles. The specific population considered within this study are older adults (defined as aged over 60), and by adopting a human rights perspective, I aimed to explore their specific vulnerabilities as a collective, yet diverse group.

Dignity is a contested and complex phenomenon with multiple meanings. This study applied macro-conceptual ideas of dignity and human rights to micro-events – the everyday care practices of community nurses with older adults. From fieldwork data collected in observations and interviews with staff and patients, I will demonstrate how dignity manifests itself differently for people and the ways in which multiple layers of meanings contribute to our understandings of dignity in nursing practice.

An original contribution

This thesis offers an original contribution to the study of dignity in care, specifically by providing an exploration into how dignity manifests between nurses and older patients within district nursing encounters. This study is unique because, until now, an empirical study of dignity has not been undertaken within the specific context of district nursing by applying a human rights lens to the subject matter. The study used an ethnographic methodology, an approach that has not previously been used to explore dignity in patients' homes. Due to the time-consuming nature of ethnographic approaches, the methodology remains under-utilised in health-research and it is also an approach that remains infrequently used when the target participant population are older adults, which also contributes to the originality of this study.

Structure of the thesis

The thesis consists of a total of seven chapters. Chapter 2 offers a detailed narrative literature review, encompassing a range of disciplinary perspectives. Forming the theoretical backdrop to the thesis, its starting point is to highlight debates in conceptual understandings of dignity, and how human rights are an essential medium to offer legislative protections for dignity in practice. Two main bodies of literature are examined to locate dignity and human rights specifically within healthcare practices. The first category comprises policy, guidance and regulatory documents, all of which emphasise the importance of dignity, yet offer limited concrete examples of how this directly manifests itself in practice. Secondly, academic literature (both theoretical and empirical) is considered to offer an additional perspective to the policy and regulatory documents. These studies highlight that care practices do not always reflect the rhetoric of policy. The chapter engages with the literature with a view to identifying significant silences in this important area.

Chapter 3 identifies the methodology and methods of this study. It is presented in two parts. Part I offers a theoretical consideration of the chosen methodology: ethnography. Ethnography is initially considered broadly in its widest methodological application, but this is then narrowed down to consider how ethnographic approaches have been used previously in health research, as well as some of the limited examples of how it has been used in community nursing and when researching older adults as a population. Here, the broad ethics of ethnography are also considered. Part II highlights the specific ethical considerations of the practical implementation of ethnography in this study. Within part II, the study design and implementation are considered, alongside the methods of data collection and thematic data analysis using an inductive approach. The methodology also addresses my own positionality and how reflexivity was, and is, an ongoing and important component of the study.

Constructions and meanings of dignity are presented in Chapters 4–6, highlighting the ways in which participants constructed dignity with each other. The content of these chapters reveals layers of understanding which are inextricably linked together. Thus, although these themes have been structured separately, all three chapters are interrelated. Chapter 4, ‘Dignity in caring relationships’, emerged from the data as the first empirical chapter, because, fundamentally, dignity is socially constructed and (de)manifests within relationships. Through a combination of ethnographic revelation and interview data, this chapter highlights how it is relationships that constitute the dignity experience, which is highly nuanced and personal. The chapter highlights the importance older adults placed on having their dignity maintained, specifically in their encounters with community nurses, but also much more generally, as aspects of ageism threatened and permitted breaches in dignity. In addition to the views of older adults, the voices of nurses remain strong in this chapter, and the associated emotional labour involved in the work of nurses is considered, because, if this is not managed successfully, the stresses caused by emotional burdens can threaten dignity. The fluidity and intangible nature of dignity make it difficult to analyse, but my principle argument is that dignity is embedded, and manifests itself, within interpersonal relationships. Therefore, this chapter’s understanding of day-to-day aspects of care explains how micro-aspects of communication and behaviours between nurses and patients lead to the construction of dignity.

Chapter 5 considers ‘Dignity in Caring for the Body’. The body is a central concern in the manifestation of dignity within community nursing relationships, because nursing tasks invariably involve bodywork, which presents many opportunities for dignity to be reinforced or undermined. As older adult patients decline towards further ill-health, their ill bodies assume heightened importance to them, especially if bodily odour is present, as this leads to a loss of dignity. Issues of continence, bodily leakages and malodorous bodies are identified as crucial mediators of dignity for older adults. Yet, as nurses work with many odorous, leaky, ill bodies, they do not always recognise the significance these issues have with regards to their patients’ dignity. In this study, older adults experienced dignity by expressing agency over their bodies (and homes) when community nurses were present. As I will demonstrate, patient dignity becomes endangered if patients experience a reduction in the control of their bodies (for example, by an ill body not ‘behaving’ as they would like, such as a ‘leaky leg’).

Chapter 6 explores ‘Dignity in the Home’. Receiving nursing care within the home can be problematic for dignity, as this space is traditionally under the control of the homeowner; yet, once community nurses engage patients in these spaces, complex relationships and power dynamics have the potential to highlight the fragile nature of dignity. It is shown how, although many older adults may be time-rich, community nurses are generally time-poor, and this discrepancy provides a potential challenge to their encounters being laden with dignity. Drawing some links with the previous chapter, I will demonstrate how the home becomes a metaphor for the body. As a result, to retain their patients' dignity, nurses must successfully navigate their way through (unspoken) 'house-rules', as dignity can be promoted when nurses treat the home with similar levels of respect as their patient's body. I will explore how, when community nursing patients receive care in their own homes (often over long periods of time as they are living with long-term conditions), the space functions as both 'home' and 'clinic', which has implications for their dignity, as clinical aids, adaptations and daily reminders of their ill-body can challenge their individual dignity. Although the house is traditionally private, the 'home-clinic' is under the medical gaze, and, as individual health declines, patients' homes may be adapted to accommodate their changing needs. However, this can lead to spaces within the home becoming medicalised, and this has an impact on older adults' dignity.

The final chapter offers an overarching discussion of the study's findings, synthesising the entire study by revisiting its aims and considering how each research question has been addressed. In the summary, the limitations of the study are noted and recommendations offered for research, practice and policymakers.

Chapter 2: The Literature Review

Introduction

This literature review outlines the importance of upholding dignity and human rights, making it explicit that dignity and respect are fundamental principles of healthcare. This chapter presents a narrative literature review, considering a variety of sources to explore the legislative, policy and research (theoretical and empirical) context necessary to gain an understanding of dignity and human rights in healthcare.

Some of the literature includes policy and guidance issued to healthcare staff by organisations (such as the Department of Health), professional regulatory bodies (such as the NMC, GMC, HCPC) and voluntary sector organisations (for example, Mencap and PANICOA, a partnership between the Department of Health and Comic Relief). However, they do not offer comprehensive definitions of dignity. Thus, translating these documents into practice may be challenging, particularly as they may offer little in terms of practical strategies for how to demonstrate dignity in healthcare practices.

The substantive literature that will be examined includes both theoretical and empirical work in relation to dignity and human rights in healthcare. These are drawn from a range of disciplines including sociology and anthropology, but also philosophy, bioethics and psychology. Some of these contributions offer theoretical accounts of dignity, whereas others explore what occurs in healthcare practice to promote dignity and respect human rights. It is more common for studies to focus on how healthcare fails to promote dignity and human rights, retaining a focus on abuse, rather than identifying good practice that supports dignity and human rights. In addition to the research evidence, findings from ‘hidden filming’ documentaries are also considered (BBC, 2011, 2012, 2019) and government reports into specific failures in care (Mid-Staffordshire NHS Foundation Trust Inquiry, 2010, 2013).

There is limited empirical evidence on dignity (Lothian and Philp, 2001), and, to date, existing academic literature tends to be written from a health or bioethical perspective (such as Michael, 2014; Häyry, 2004). Sociologists criticise bioethical perspectives for focusing on the individual, rather than challenging assumptions behind the discipline (Nettleton 2013), and thus they uncritically support evidence-based medicine without challenging the ideologies of both societal and health structures. The social sciences have been slow to turn their attention to matters of a bioethical nature, despite bioethical approaches being criticised for their ethnocentricity, lack of context and sterility (Hoffmaster 1992). Gallagher (2009: 145), however, recognises the importance of learning from a wide range of disciplines, noting that ‘understanding dignity and indignity is necessarily an interdisciplinary endeavour’. Therefore, it is time to ensure that the social sciences explore bioethical issues to broaden our understanding and add another dimension to this important area of study.

Prior to the contribution offered by this thesis, there have not been any significant sociological or anthropological considerations of the experiences of dignity and human rights for older adults within community health services, which is significant in the context of charting a rationale for my own study, as

> empirical research and insights from social sciences contribute to theory development and make visible the experiential dimensions of dignity in care from the perspectives of patients, families and nurses, and also contribute to an understanding of factors that support or diminish dignity (Gallagher, 2009: 145).

Black and Dobbs (2014) recognise the lack of research into dignity experienced by community-based older adults, recognising that as life expectancy increases, people are living longer with declining health and other aspects of ageing that may impact on dignity. Unlike my study, empirical studies that do address these issues focus on people’s experiences in acute hospital services (Matiti and Trorey, 2008; Mangset *et al*., 2008; Baillie, 2009; also Zahran *et al*.’s systematic literature review (2016) identifying what improves dignity for older patients in hospitals), rather than offering a perspective from community nursing services, which is the focus of my own work.

Dignity and human rights: A background

Despite being extensively explored by many authors, dignity remains a contested concept. It has been widely considered from Confucius in China to Aristotle in

Greece, as well as philosophers such as Immanuel Kant (1724–1804) and Friedrich Nietzsche (1887).

Kant (1724–1804) locates dignity in morality and autonomy, recognising that, by virtue of being human, everyone is entitled to inherent dignity. Kant (1724–1804) conceptualised the inherent dignity of the person, which is identified within modern understandings of human rights and remains a concept that flows through this thesis. His beliefs about the inherent worth of people provide a standard of human or moral value, which is described by Nordenfelt (2004, 2009) as *Menschenwürde*. Nordenfelt argues there are also other types of dignity, in addition to Kant's notion of inherent dignity, which will be considered shortly.

Dignity is hard to define (Tranvåg *et al.*, 2016), and it cannot be directly measured (Fenton and Mitchell, 2002), even though Horton (2004) suggests that dignity should be a principle of the global health movement. The rhetorical aspects of dignity are acknowledged and debated by writers such as Johnson (1998), who notes the ambiguous use of the word 'dignity', and Agich (2007), who expresses doubts that the concept of dignity can provide practical guidance for choosing approaches to the care of elderly people and recognises the rhetorical as well as the substantive aspects of dignity. Macklin (2003: 1419) describes dignity as 'a useless concept' because aetiologically it has no greater meaning than respect for autonomy. However, Lothian and Philp (2001) differentiate between dignity (which relates to a person being valued by others and maintaining self-respect) and autonomy (the individual retaining control over decision-making). Michael (2014) adopted a bioethical approach to explore the concept of dignity within human rights, indicating dignity is not meaningless but is a 'rich and powerful concept' (Michael, 2014: 13). She describes dignity as the 'foundation of civilized society' (Michael, 2014: 12) and recognises that when dignity is not present, abuse is more likely to occur. Häyry (2004: 7) indicated that, despite the obvious appeal of a simple definition of dignity, this would not capture the true meanings that dignity holds. This led him to pose the question, 'how should dignity, or more fully, *respect for human dignity*, be understood in contemporary declarations and bioethical debates?'

In exploring whether dignity is rhetoric or reality, Tadd *et al*. (2002) note that some of the difficulties of applying dignity in healthcare practice may be a problem ingrained in contemporary society. This is a particularly relevant view, because, ‘if society is the precondition of reason and morality, human beings do not have dignity as such but only under particular societal conditions’ (Lindemann, 2014: 192). Thus, dignity is socially constructed. Different societies construct dignity in their own way, and the manifestation of dignity within healthcare services varies across different societies, cultures and even sub-cultures. Despite different societal constructions of dignity, however, Kant’s (1724-1804) view of the inherent dignity of humans remains relevant over time and across cultures; it is simply how dignity is actually constructed, interpreted and understood that varies.

The inherent dignity of humans is reflected in the belief that humans have certain rights. Human rights legislation provides the legal foundation by which the protection or upholding of dignity becomes lawfully enforceable. The Universal Declaration of Human Rights was adopted by the United Nations General Assembly in December 1948, establishing fundamental human rights that everyone can expect, although critics argue that the UDHR promotes ‘“men’s” rights’ (Howard-Hassmann, 2011). The later European Convention on Human Rights, which came into force in 1953 as a method of implementing the UDHR, was more encompassing of women’s rights (Howard-Hassmann, 2011). Following genocide and other abusive acts committed by the Nazis in World War II, the main purpose of the UDHR and ECHR was to protect vulnerable people from oppressive regimes. Various countries later began to introduce their own legislation to enshrine human rights within the sovereignty of their own States, which, in the UK, became the Human Rights Act (1998).

The Human Rights Act (1998), implemented in the UK from October 2000, applies to public bodies (including the NHS), but does not wholly apply to private providers such as care homes. In YL v Birmingham City Council [2007] UKHL 27, the Court ruled that a privately-owned care home was not performing the public functions within the meaning of the Human Right Act. This gap in legislative protections resulted in s.145 of the Health and Social Care Act (2008), which means those in receipt of state-funded care are now entitled to human rights protection in private care homes. However, these protections are still not extended to those that self-fund their own care.

The Human Rights Act (1998) offers a framework for the legal protections for patients' dignity (with the exception noted above for people who fund their own care in care homes). It contains rights that are *absolute* (which can never be interfered with) and *non-absolute* (which can be restricted under certain circumstances that are determined by the State). The legislation also places three duties on public services: negative duties (not to breach human rights); positive duties (acting to stop abuse); and procedural duties (ensuring systems and processes are in place when human rights are violated). Therefore, as healthcare employees are public servants or agents of the state, they have a duty to act if they know that someone is at risk of harm or abuse. High profile failures in healthcare services have become widely reported in the media, including examples of healthcare staff and services failing to adequately address issues of dignity or implement human rights-based approaches to care, which will form the focus of the later section, 'Human rights and healthcare wrongs'.

Although the UDHR (international), ECHR (European) and Human Rights Act (British) were designed to protect individuals from undue state interference, they were not designed to specifically consider the NHS as a possible violator of human rights. Human rights legislation gives weight to concepts of dignity and respect; however, in terms of prosecutions under this legislation, examples specifically relating to the violations of human rights within healthcare remain absent. Mandelstam (2011: 299) notes, 'it seems odd that one should examine human rights legislation as it applies to healthcare in a modern, wealthy, social democracy'. However, from my own practice as a safeguarding specialist, I understand that it cannot be taken-for-granted that the NHS automatically respects and upholds principles of dignity and human rights. Hence there is a strong argument for the necessity of my own study which begins to explore how community nursing care practices can uphold or reduce dignity and human rights.

Existing academic literature relating to human rights and health focuses on aspects such as: whether there is a human right to health and healthcare (Eleftheriadis, 2012;

Kinney, 2009; Backman *et al*., 2008; Sandhu, 2007); pain relief as a human right (Lohman *et al*., 2010; Brennan *et al*., 2007; Cousins *et al*., 2004); palliative care as a human right (Gwyther *et al*., 2009; Brennan, 2007); and dignity with dying (Johnson, 1998; Hemati *et al*. 2016). Only a paucity of literature explores dignity and human rights specifically in community healthcare settings. One of the limited examples exploring human rights within district nursing practice is Griffith and Tengnah (2009), who base their analysis on a presentation of the legal duties nurses must fulfil to remain compliant with the Human Rights Act 1998. Their work does not draw on any empirical data, and, although the legal situation is explained, it does not directly address the complexities of delivering care based on a human rights approach. A rare example of an empirical exploration of dignity in community healthcare is provided by Muntean *et al*. (2013), who consider the role of the community nurse in promoting human dignity in Romania. They link respect for human dignity with attitudes such as empathy and emotional resonance, which is translated into patients being involved in making decisions about their health.

There are also some explorations into how violations of dignity and human rights can lead to ill health, for example, Mann *et al*. (1999) who link public health to human rights, criticising epidemiology for focusing on individual risk behaviour in isolation from the societal context and societal changes that are required to promote public health. Jonathan Mann, a former professor of health and human rights at Harvard and director of the WHO's Global Programme on AIDS, recognised that the connections between dignity and health are 'simultaneously complex, intuitively powerful and difficult to assess' (Mann, 1998: 32), advocating that clarity of definition is required to enable an advancement in thinking about their relationship. Mann (1998) recognised that dignity violations may also reduce resistance to disease and illness or manifest themselves in health concerns such as depression.

Some people are more vulnerable to dignity violations. De Donder *et al*. (2016) recognised that older women living in the community often live in vulnerable situations where risk factors are increased due to frailty. My study focuses on one particular group of people who may be more vulnerable to dignity violations, simply because of their older age, be they male or female. Pollmann (2011) recognised that everyone does not have equal dignity, arguing that '*because* human beings do not have equal human dignity from the start[…]they all have equal human rights' (Pollmann, 2011: 243). This is a view also acknowledged by the United Nations:

> Human rights are rights inherent to all human beings, whatever our nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status. We are all equally entitled to our human rights without discrimination (Office of the High Commissioner for Human Rights, 2015).

Within this definition, Kant's concept of the inherent dignity of the person remains resolute, and this is also reflected in Article 3 of the *Convention for the rights of persons with disabilities* (UN, 2006), which recognises a principle of the convention as 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'. Despite the wide-ranging international agreement of human rights via the UN, the implementation of human rights may vary across countries. Therefore, critics have argued that human rights may not be universally equitable. Ife (1998), for example, indicates that human rights are relative, applying differently in different cultural contexts, which contributes to the justification of the oppression of certain people (including harmful cultural practices such as female genital mutilation, ethnic cleansing and domestic abuse).

Donnelly (2013: 127) indicates that we are entitled to rights by virtue of being human, and this 'demands respect'. However, it can be argued that only when our human rights are violated do we begin to protest against the (negative) act, rather than acknowledging any positive reinforcement of human rights when our rights are upheld. Claiming human rights may also pose difficulties for more vulnerable members of our communities, as they may feel more susceptible to abuse if they are too vehement in their claims over their individual rights. This is particularly pertinent in healthcare, where, for example, certain groups of people, including older adults, may feel less inclined to challenge healthcare professionals for fear of reprisals.

Whilst our rights are being upheld, they are taken-for-granted, and something will only become labelled as a right (an entitlement) once it has been contravened. This is what the political theorist, Hannah Arendt (1958), came to label the 'paradox of human rights', in which, by claiming human rights, their absence is indicated. This is critical, because, if dignity is present, it usually goes unnoticed, and it is only when dignity is challenged or violated that the lack of dignity (rather than the presence of dignity) is more likely to be identified.

Within existing literature relating to dignity, human rights are not always explicitly acknowledged, but when they are acknowledged, authors tend to focus on violations of human rights, rather than identifying when rights have been promoted (in line with the paradox described by Arendt, 1958). In an attempt to challenge Arendt's (1958) paradox, this thesis begins to address the void of evidence around situations in which dignity and human rights arise and remain unrecognised within everyday nursing interactions. These manifest themselves within patients' relationships with their nurses (explored in Chapter 4) and remain unacknowledged, as they are regarded as regular or routine aspects of care that do not violate dignity and are thus unremarkable. Podnieks *et al.* (2010) recognise that elder mistreatment can be framed as a human rights issue, but this thesis extends this perspective to consider how good care of older adults is also a human rights issue. This study, therefore, focuses specifically on elements that Arendt (1958) considers to be unnoteworthy, by exploring how dignity and human rights are operationalised in daily community nursing care.

Arendt (1958) also regarded morality as an inherent feature of human behaviour, and therefore it is important to consider whether there are universal attitudes that form moral behaviour. Harris and Sulston (2004: 797) indicated that dignity was an 'accepted principle of shared morality', which becomes an important concept in the empirical chapters of this thesis, as it becomes apparent that when nurses and patients enact aspects of a 'shared morality', dignity is more likely to become manifest. When considering morality, it is important to recognise that every human being has a moral position or moral grounding to their behaviour. However, these individual moral positions vary. For example, the legal philosopher Ronald Dworkin (1996) placed dignity at the heart of his moral system, noting that even discriminatory attitudes are based on moral principles: they are simply different principles to an anti-oppressive concept of morality. Hence, it is not a lack of morality, but the lack of a *shared* morality that can lead to contraventions of dignity. Hence, I will argue that when patients and nurses have a shared morality, dignity is more likely to be manifest in their encounters.

In this section, concepts of dignity and human rights have been explored within a broad theoretical and cultural frame. The subsequent sections employ this framework to consider the ways in which human rights and dignity are variously interpreted, understood and operationalised in the context of healthcare in the UK, firstly by considering care of the body.

‘Care’ and ‘caring’ for the body

When exploring dignity and human rights in healthcare, considering the nature and politics of ‘care’ can provide relevant insights. Western contemporary understandings of the word ‘care’ are not consistent with earlier understandings of the term (Dunlop, 1986). Dunlop (1986) distinguished the separate origins of the words ‘care’ and ‘cure’, which date back to the Norman conquest of England when French was the conquerors’ language and Anglo-Saxon became the language of the conquered. At the time, the Anglo-Saxons looked after the pigs to be eaten by the gentry (‘caring’ for pigs), whereas the word ‘cure’ or *curé* (in French) related to a priest; therefore, ‘the higher orders ‘cured’ while the lower orders ‘cared’’ (Dunlop, 1986: 662).

This hierarchy retains relevance for modern medicine, in which those lower in the professional hierarchy offer ‘care’, whilst doctors ‘cure’. Nowadays, doctors may be regarded as ‘the priest of science’ (Lumby, 1997: 122). Twigg *et al*. (2011: 180) note that ‘the power relations of care work form an interesting case, since careworkers do not usually have the authority of doctors, nor do patients have the power typically conferred on people through consumer ideology’. Hence people delivering care and those being cared for remain less powerful than those who ‘cure’. Twigg *et al.* (2011) acknowledge that carers are usually women, often migrant workers, who are often stigmatised due to the ‘dirty work’ they undertake, which ensures that their status is not as elevated as that of a doctor. Their use of terminology based on consumer ideology also introduces the idea that these ‘customers’ have beliefs and expectations associated with the care they receive, even though, as was recognised previously, some people may not feel empowered to be able to challenge poor standards of care (through their own social position or status, including ill-health).

The use of migrant workers to perform caring tasks historically occurred when the government turned to former colonies in Africa and the Caribbean to recruit nurses. In a contemporary context, international recruitment continues as the NHS will become unable to function without the recruitment of sufficiently trained appropriate staff. Migration introduced greater ethnic diversity in the nursing workforce (Likupe, 2015), so, by 1949, recruitment campaigns resulted in nurses travelling to the UK to work in the NHS (Butler, 2008). Many black women were funnelled into training that would qualify them as State Enrolled Nurses, which was a lower-level course, aiming to provide nurses to support the State Registered Nurses (BBC, 2016). In the mid-1980s these qualifications were replaced, but until this time it was only State Registered Nurses who were eligible for promotions, meaning many black women working in nursing roles were barred from entering higher-level positions, due to them being guided into the lower-level qualification.

Bodywork is described as, ‘paid work on the bodies of others’ (Twigg *et al.*, 2011: 171), and it involves direct contact with bodies. This work is often regarded as taboo; therefore, it largely remains invisible (Lawler, 1991). Twigg *et al.* (2011) illustrate how the western demand for bodywork has increased immigration of staff in caring roles who come from countries with less developed caring and bodywork economies. They also recognise that responsibility for caring for the body is highly dependent on classed and racialised groups which reinforce stigmatisation of the body in general and specifically the body that is in receipt of social or community care services. Furthermore, the ill body becomes feminised (Lumby, 1997).

> Many of the positive cultural associations of body work, including touch as comforting or healing, are also seen as feminine, drawing on deeply entrenched patterns in relation to motherhood (Twigg *et al.*, 2011: 178).

Gatrell’s (2006) study of women's careers post-motherhood found that the responsibility for organising housework remained with the mother, rather than father, and those who could afford it outsourced certain domestic tasks. This outsourcing of labour is not a new phenomenon, and increasingly health services have adopted this model, in which certain activities (such as delivering personal care) have been outsourced to lower-paid staff members, usually (although not exclusively) women. People providing hands-on care are perceived to engage in what might be termed ‘unskilled, unqualified and “dirty” work’ (Price and Walker, 2015: 140), and they are paid less money than care-providers working in managerial or supervisory roles who receive higher levels of remuneration for delivering ‘cleaner’ aspects of care. This workforce of people delivering hands-on care remains dominated by women, a large proportion are migrants, and many have lower levels of education. In contrast, the workers that ‘cure’ (such as medical professionals) have higher levels of representation of men, and they are highly educated, although they may be migrants. Women are hugely over-represented in both paid and unpaid care work, and nursing is also recognised as a gendered profession (Twigg, 2000). Thus, we have evidence that nurses (who are generally female) are in ‘caring’ roles, in contrast to doctors (still a male-dominated profession) who are in ‘curing’ roles.

Dunlop (1986) also recognises that ‘care’ has traditionally been the concern of women. Therefore, there is a danger that female ‘deficiencies’ could be held as the reason for failures and abuses in care, especially as power and control within health services remain largely with men. Senior and managerial nursing positions see a disproportionate representation of men. Ranging from politicians determining healthcare priorities, policies and legislation, to the chief executives of NHS Trusts, men dominate these arenas, despite the day-to-day nursing delivery of care continuing to come from a workforce overwhelmingly made up of women. This is not, however, unique to health service structures, as Crompton (1997) recognises the gendered nature of women’s employment, and Singh and Vinnicombe (2004) consider why women are excluded from senior positions in boardrooms, indicating it is not a lack of ambition that excludes women from these positions. Instead they argue that theories of social exclusion can offer an insight.

Western society continues to perpetuate gendered roles in the workplace and specifically in the provision of the care industry; women provide the ‘care’ whilst men are more distant from the direct hands-on work, by engaging in their caring role through the ‘cleaner’ tasks required from a managerial (potentially desk-bound) role. As will be demonstrated in Chapter 4, there are times emotional labour is enshrined in the construction of dignity, and, ‘“emotional labour” maps neatly onto the gendered occupational hierarchies of healthcare, with the privileged, predominantly male professions relegating the emotional work, along with the other “‘dirty work”, to those lower down the pecking order’ (Twigg, *et al.*, 2011: 174). Hence, there is a danger that if dignity becomes regarded as synonymous with ‘dirty work’, it too, receives the inferior status conferred onto bodywork and may also be regarded as the work of women.

Although delivering care can involve emotional labour, tasks of delivering care in district nursing are usually focused around physical health needs. Dunlop (1986) notes that due to the excessive physical orientation of nurses’ work, there are times the psycho-social aspects of care have been emphasised to counterbalance this inclination. ‘Care’ may be more generally associated with the psycho-social domain and not necessarily as a physical or embodied experience, as disembodied care is ‘a ‘cleaner’ form of caring’ (Dunlop, 1986: 665). Therefore, it can be useful to explore two intersectional aspects present within caring relationships: firstly, the intersection between the physical care of the body and the embodied experiences of dignity the care-receiver encounters during hands-on care; and secondly, the care-giver’s own somatic and embodied experiences delivering care in a dignified manner, which are issues addressed in Chapter 5.

There is limited literature exploring the embodied experiences of dignity in care, despite studies into both staff and service-user views (such as Calnan *et al.*, 2005; Bayer *et al.*, 2005; Baillie, 2009; Mangset *et al.*, 2008) that have highlighted how dignity and human rights manifest (or fail to manifest) themselves in the psycho-social aspects of care delivery. Yet, they fail to offer insights into the embodied experience of dignity and human rights in care. Bodyworkers have the potential to embed dignity and human-rights based care through their physical contact with their consumers and not just by achieving psycho-social needs. Consequently, dignity can be regarded as a potentially embodied experience.

In drawing this section to a close, I have demonstrated why it is important to consider the body and embodiment in the context of dignity in healthcare. In the next section, attention will focus on existing knowledge of ‘healthcare wrongs’ and how these link to issues of human rights in healthcare.

Human rights and healthcare wrongs

The National Health Service (NHS) comprises a structure of complex systems and services that deliver healthcare to populations within the United Kingdom. The UK prides itself on the NHS, with 87% of British people being proud of the health service (Smith, 2018). It is important to acknowledge that when exploring dignity and human rights violations within UK health services, despite the arguably flawed NHS, many other countries aspire to have such a national health service. Dignity and upholding human rights in healthcare cannot be taken for granted, as there is evidence that staff are failing to display basic levels of care. Mandelstam (2011) acknowledges that when considering current global atrocities, it may initially appear disrespectful to explore human rights in UK hospitals; however, his exploration of ‘how we treat the sick’ within health services provides compelling evidence that the UK is failing to consistently respect human rights and dignity in health services, despite policy and practice guidance recognising these as essential.

> Dignity is a human rights issue and should be the underlying principle when delivering services (Healthcare Commission, 2007: 9).
>
> It [the NHS] has a duty to each and every individual that it serves and must respect their human rights (Principle 1, NHS Constitution, DH, 2015a: 3).

As shown from these quotations, the dignity and human rights of all service-users should be respected by staff working within the NHS. However, there is some evidence this is not the case, such as the example of Mid-Staffordshire Hospitals Trust, where from January 2005 to March 2009 it was estimated that between 400 and 1,200 people died due to poor care. In 2008, the Trust gained Foundation status, allowing it to manage its own finances. However, it was later cited that cost-cutting measures (designed to achieve the savings necessary to become a Foundation Trust) were the fundamental reasons that poor care was accepted and practised within the organisation (Mid-Staffordshire NHS Foundation Trust Inquiry, 2010; 2013).

Following the media reporting of the events at the hospital, a public inquiry was chaired by Sir Robert Francis QC, resulting in an initial report published in 2010 and the second report published in 2013 (Mid-Staffordshire NHS Foundation Trust Inquiry, 2010; 2013). However, the public inquiry only commenced following the change from a Labour government to a coalition Conservative/ Liberal Democrat government in 2010, as the Labour government had refused to hold a public inquiry, despite public campaigns such as ‘Cure the NHS’, which was initiated by patients, relatives and members of the community lobbying for a public inquiry into the hospital’s failures.

In the first report, Francis contacted 966 patients, recognising that:

> It was striking how many accounts I received related to basic elements of care and the quality of the patient experience, as opposed to concerns about clinical errors leading to death or injury (Mid-Staffordshire NHS Foundation Trust Inquiry, 2010: 49).

This illustrates that patients and their families identified personal experiences and basic elements of care as being important for receiving good care, which are the routine care practices my own study explores. The report recognised that omissions in care led not only to injury, but also a loss of dignity, and it argues that respect for dignity should be a care priority. The report also found that there were chronic staff shortages, particularly nursing staff, and this contributed to a substandard level of care. Many staff felt deterred from taking action because of fears of bullying, and when staff raised concerns, inadequate action was taken. To explore some of the themes that emerged from this investigation and to enable clarity, the inquiry (Mid-Staffordshire NHS Foundation Trust Inquiry, 2010) linked their failures to some of the benchmarks from *Essence of care* (DH, 2003), including failures in continence care, personal and oral hygiene, nutrition and hydration, pressure area care, infection control and privacy and dignity. Notable causes for concern were as follows:

> - Patients who have not been given appropriate assistance with continence issues have been left in a condition which can only be described as degrading.
> - On occasion, patients have been left inadequately dressed or in view of those passing the bedside.
> - On occasion, patients were handled and moved in ways that caused pain and distress without any evidence of a sympathetic approach.

> - Little effort was sometimes made to refer to patients by name, giving the impression that they were regarded as conditions and problems to be dealt with rather than individuals who needed care and attention.
> - Respect for patients as individuals requires those caring for them to engage with them in the way they wish; sometimes this was not done.
>
> (Mid-Staffordshire NHS Foundation Trust Inquiry, 2010: 109).

The above examples illustrate some of the failures apparent in the hospital, highlighting how basic levels of care were not being undertaken. Although some of these issues may have been elevated by inadequate levels of staffing, the fact remains that ‘denials of dignity’ were evident (Mid-Staffordshire NHS Foundation Trust Inquiry, 2010: 10). Priorities of the Trust had been elevated above the needs of patients accessing their services (Mid-Staffordshire NHS Foundation Trust, 2013). Gallagher *et al*. (2008) indicated caring cultures can be damaged when objectives of practice are usurped by the goals of the institution, as appeared to be the case at Mid-Staffordshire.

As has been evident from failures in healthcare services (such as at Mid-Staffordshire NHS Foundation Trust), although organisational failures have been acknowledged by regulatory bodies, these have only been linked to local failures and not systemic shortcomings or problems that may have been averted by political policy. Indeed, accountability for failures often lands with individual clinicians, managers and Chief Executives; however, respect for individual dignity must also be reflected in the health policies aimed at people’s wellbeing (Muntean *et al*. 2013), as well as at an individual level.

Similarly, Mandelstam (2011) notes that high profile cases of criminal healthcare professionals (for example, Beverley Allitt and Harold Shipman) have acted as a smokescreen for what he describes as the ‘greater harm […] that is [the] unbridled execution of policies by chief executives, obediently backed by docile trust boards’ (Mandelstam, 2011: 200), but are these examples of ‘rogue clinicians’ or systematic failures (Mandelstam, 2010)? Mandelstam suggests that ‘in the case of systemic poor and neglectful care, associated so often with government policy and constraints, it would be a great deal simpler and more effective to change the policies and to stop NHS trust boards acting as they do’ (Mandelstam, 2011: 277). He also compares the knowledge of clinicians and politicians, importantly recognising that clinicians have received substantial training in their field and are members of a regulated profession, in which they must practice in accordance with ethical codes of practice. In contrast, the politicians, who are setting healthcare targets, have not received substantial training in any area of clinical practice, and they are not members of a regulated profession, nor is there any ethical code for them to follow. This inherent danger in the politics and organisation of healthcare, requires challenging at both structural and cultural levels, as well as individually, to effectively tackle potential inhumane or neglectful care.

At the time of the concerns at Mid-Staffordshire Hospitals Trust, protective measures for adults were contained within the guidance *No Secrets* (DH, 2000). This guidance was issued following a scandal involving people with learning disabilities placed in services provided by Longcare who were being systematically abused. *No Secrets* defined abuse as ‘a violation of an individual’s human and civil rights by another person or persons’ (DH, 2000: 9), identifying six main categories of abuse (physical, sexual, psychological, neglect, discriminatory and financial), but also acknowledging the potential for institutional abuse. Although *No Secrets* (DH, 2000) was later reviewed (DH, 2009), in April 2015 it was made redundant following the implementation of the Care Act (2014), which placed Safeguarding Adults Boards on a statutory basis. The Care Act (2014) mandates Local Authorities to conduct an enquiry if there is reasonable cause to suspect an adult who has needs for care support is experiencing, or is at risk of experiencing, abuse or neglect, and as a result of those needs is unable to protect themselves against the abuse or risk of abuse. The legislation also recognised self-neglect as a type of abuse, in which the perpetrator of the abuse is also the victim who is neglecting their own needs for care. However, Penhale *et al*. (2017) recognise that the statutory guidance appears to limit the circumstances in which a safeguarding enquiry will be triggered in cases of self-neglect.

Following the events at Mid-Staffordshire Hospitals, it was recognised that despite the existence of human rights legislation, there was an omission in the law to secure individual and corporate prosecutions for abuse and neglect. Although the law offered some protections for children (Children Act 1989, 2004), mental health patients

(Mental Health Act 1983, 2007) and those lacking capacity (Mental Capacity Act 2005), for many of the patients at Mid-Staffordshire Hospitals existing laws failed to offer protection, and the Human Rights Act (1998) was not operationalised. Subsequently, in April 2015, the Criminal Justice and Courts Act (2015) was reviewed to protect people receiving health services, by extending the criminal offence of ill-treatment or wilful neglect (of a person with capacity), to include healthcare workers (s.20) and healthcare provider organisations (s.21).

Mid-Staffordshire Hospitals Trust is not an isolated example of failures in healthcare services and dignity violations. Mencap (2007, 2012) has highlighted how institutional discrimination from health services has led to the premature deaths of people with learning disabilities accessing healthcare services in the UK (Heslop *et al*., 2013), and the LeDeR programme (University of Bristol, 2017) has confirmed that people with learning disabilities continue to die much younger than their non-disabled counterparts. Undercover investigations have highlighted specific locations in which dignity has not featured within care delivery. The BBC programme Panorama has undertaken several high-profile investigative documentaries into failures in healthcare, such as: abuse by staff at Winterbourne View, an inpatient assessment and treatment facility for people with learning disabilities (BBC, 2011); a daughter whose hidden filming of her mother showed abuse by staff at Ash Court, a residential care home rated as ‘excellent’ by the CQC (BBC, 2012); and their more recent undercover investigation into dignity violations by healthcare workers (including registered nurses) at Whorlton Hall, Country Durham (BBC, 2019). These undercover investigations offered emotive evidence to large viewing audiences of how human rights violations and dignity breaches continue to occur in UK-based healthcare services.

This section has summarised some of the main sources of literature on health and human rights. It retained a focus on failures in healthcare, which is reflective of the existing literature and evidence available in this field. All the aforementioned discussions of dignity breaches relate to care delivered in hospitals, care homes or other inpatient treatment facilities. Nursing care delivered in community settings (such as district nursing within the home) is not subject to the public gaze that is present from family, friends and visitors to hospitals. It is much more difficult to gain access to care settings outside institutions, which means out-patient clinics and care delivered in the home remain a neglected area of investigation. Hence, the delivery of care within the home remains hidden. It is often delivered on a one-to-one basis, and, therefore, has the potential to be the site of dignity harms that remain unwitnessed and unreported if the victim is unable or unwilling to report, making my own thesis an important contribution to this area of inquiry.

Before I am able to use my own empirical findings to demonstrate the importance of everyday care interactions to constructing dignity, it is important to consider additional literature. My thesis is based on the notion that dignity does not exist absolutely, but that it is a social construct. The next section explores the existing evidence that indicates dignity is socially constructed, specifically focusing on older peoples' engagement with health services.

Older adults' dignity in health services

As demonstrated so far, the concept of dignity is complex to define and operationalise, but it is arguably both a construction and product of the society and industry in which it is located. Thus, dignity can be socially constructed within healthcare services.

Patients have an innate right to be treated with dignity, whether they are conscious or unconscious, dead or alive (Walsh and Kowanko, 2002). However, 'media, research and anecdotal evidence suggest that patients, families and nurses continue to experience indignity in care contexts' (Gallagher, 2009: 145). When exploring dignity in the care of older people, it is noteworthy that Gallagher *et al*. (2008) coined the phrase 'culture of care' (which has positive connotations) to describe their findings, which were, in reality, examples of non-caring cultures. Jacelon *et al*. (2004) note that, although dignity is discussed in literature pertaining to older adults, its meaning, again, is not always clear. Although problems in definitions have been recognised, dignity must be understood within the context of healthcare and nursing practice (Kalb and O'Conner-von, 2007).

The health and human rights pioneer Jonathan Mann (1998) held discussions with anthropologists, sociologists and bioethicists in which participants were asked to recall a situation in which they felt their personal dignity had been violated, yet again illustrating a focus on Arendt's 1958 paradox of human rights, in which violations are recognised, but the upholding of human rights remains invisible. As a result of these discussions, he offered a provisional taxonomy of dignity violations, illustrating some of the ways that dignity may be violated and recognising that dignity originates in two realms – the internal (how one sees oneself) and the external (how others perceive a person). Mann (1998) recognised that features of the taxonomy include: not being seen; being seen only as belonging to a group identity; invasion of personal space; and humiliation. In his participants' discussions of dignity violations, 'injuries to dignity which occurred decades earlier continued to evoke powerful emotions' (Mann, 1998: 34), illustrating how there can be long-lasting implications when dignity is violated.

Mann's (1998) provisional taxonomy influenced the work of Nora Jacobson (2007, 2009), who is a leader in exploring dignity in health in the Canadian context. Jacobson (2009) utilised grounded theory as her methodology, exploring 75 documents pertaining to dignity in healthcare and conducting interviews with nine experts in health and human rights, in addition to 55 interviews with a wide variety of people, including people who were members of groups marginalised by their health or social status and staff delivering services to these groups. Jacobson (2009) found that violations of dignity within healthcare occurred through various processes, considered below:

- *Rudeness*: exemplified by general disrespect by the healthcare provider. She indicates that a common example is providers who fail to introduce themselves or simply use an elderly person's first name without confirming with them their preferred form of address.
- *Indifference*: participants identified a lack of consideration towards them, which is demonstrated by being left without communication following important medical tests.
- *Condescension*: feelings of being patronised or 'talked down to' by healthcare providers.

- *Dismissal*: when healthcare providers fail to consider the patient's knowledge, perceptions, needs and feelings.
- *Disregard*: described by participants as feeling invisible, illustrated by the example of failing to answer call bells.
- *Dependence*: patients may rely on healthcare providers to act as 'gate-keepers' to other services which may impede their ability to raise a complaint.
- *Intrusion*: the physical environment of hospital care can be intrusive. She cites several examples, such as gowns and curtains that do not fully close.
- *Objectification*: described by many participants as being treated like an object and not a human being.
- *Restriction*: includes limiting people's abilities to direct their own lives, particularly relevant to people under mental health services.
- *Labelling*: use of unhelpful descriptors such as 'bed-blocker' or 'non-compliant' can stigmatise people and harm their dignity.
- *Contempt*: occurs when healthcare staff treat the patient as though they have little or no value, which can occur when the person is engaging in certain stigmatising behaviours (such as prostitution).
- *Discrimination*: occurs when participants are denied care, for example, if they have addictions or psychiatric diagnoses.
- *Revulsion*: when individuals are treated as if they are disgusting.
- *Deprivation*: denying people medical treatment, because they do not have the insurance to cover the costs.
- *Assault*: was a real concern for some participants who identified assaults by hospital security guards; others spoke about over-medication as a form of assault.
- *Abjection*: occurs when patients compromise their beliefs, for example, in hospitals when meals do not respect the patients' religious beliefs, or when patients are left to lie in their own excrement.

Jacobson's (2009) study demonstrates how important 'encounters' are in the construction of dignity in healthcare, as she established that 'any human interaction can be a dignity encounter' (Jacobson, 2009: 1538). The 'dignity encounter' becomes a critical concept within arguments presented within this thesis, as interactions between patients and nurses offer the space and opportunity for the construction of dignity. Jacobson (2009) indicates that violations are more likely to be a result of these encounters when one person is in a position of vulnerability (through illness or confusion in a healthcare context, for example) and the other actor is in a position of antipathy (for example, being impatient or hostile). Whilst Jacobson (2009) notes that all encounters can be ‘dignity encounters’, by contrast, Carlsson *et al*.’s (2006) study of violent encounters in psychiatric settings recognised that patients feared what they described as ‘non-encounters’. Non-encounters were characterised by ‘carers who avoid the presence of their patients’ (Carlsson *et al*., 2006: 291), which makes the patient feel as though they are not worthy of the carer’s presence, breeding insecurity and increasing the likelihood of a violent encounter ensuing. Patients in their study recognised that body language and intonation were important and contributed to ‘stable communication’ (Carlsson *et al*., 2006: 294), which characterised ‘authentic personal care’. This authentic care ensures that patients sense the caregiver’s unrestricted respect for human beings’ dignity, in contrast to ‘detached personal care’ which generates risky encounters that have the potential to lead to violence, because, as Carlsson *et al*. (2006) explain, these aggressive acts are reflective of brief moments of a patient’s empowerment.

Jacobson (2009) recognises that dignity violations are more common when there is a relationship of asymmetry between the actors, in which one person has more power, authority, knowledge or strength (which includes staff working within the health service). Jacobson (2009) explains the factors that underlie ‘dignity encounters’ are gesture, interpretation and response; thus, a social actor makes a gesture (for example, eye contact) which is interpreted by the other social actor, who then offers a response (verbally or by action) based on their interpretation of the previous gesture. She believes it is these interactions that can lead to dignity violations. Within my own thesis, it is the micro-contexts of relationships such as these, that are employed to consider and explore dignity within the various spaces in which healthcare occurs.

There are many factors that may have an influence on how the (powerful) clinician interprets and responds to gestures from the (potentially vulnerable) patient. Kelly and

May (1982) undertook a literature review to explore the construction of 'good and bad patients', which they argue are labels applied to patients as a consequence of their interaction with staff. They indicate there is evidence that patients receive treatment that is variable according to their social class, illness, age and appearance; and they recognise that certain clinical conditions evoke negative reactions from nurses towards patients, citing long-term serious illness, confusion and incontinence as examples. Since their literature review was undertaken, clinical education has developed to include more training and awareness of these issues, and, as there is now an ageing population, long-term conditions, confusion and incontinence may now be more common than when this review was undertaken in the early 1980s. Kelly and May's (1982) analysis is still relevant, however, as the construction of 'good' and 'bad' patients remains important, as the impact of factors such as gender, ethnicity, class and age continue to influence relationships between staff and patients. The construction of dignity for older adults accessing health services may, at times, be based on clinicians' ageist assumptions and attitudes, as ageism in healthcare is well-documented (Beverly *et al*. 2010; Kagan and Melendez-Torrez, 2015; Drennan *et al*., 2018). In particular, Chapter 4 considers the impact of age and gender, but also how other personal characteristics or life experiences may have an influence over experiences of dignity.

When exploring additional considerations of dignity, a substantial body of work explores dignity within palliative care settings. Jacobson (2007) notes that dignity is a well-established concept within hospices and end of life care, as they are grounded in the inherent dignity of individuals (Latimer, 1991; Madan, 1992; Pickett, 1993: Brant, 1998). Some of the existing literature has led to the development of models for practice, such as Chochinov *et al*. (2002) who interviewed 50 patients who were terminally ill with cancer, leading to the development of an empirical model for dignity when working with terminally ill people. Their model proposes three interrelated categories, the first being 'illness-related concerns'. This identifies concerns that are specifically associated with illness, which can influence dignity and which are influenced by levels of independence and symptom distress. The second category is 'dignity conserving repertoire', which refers to internalised skills and qualities that people possess (based on their own world view) and how these are utilised to preserve one's own dignity, despite declining health. Chochinov *et al*. (2002: 438) explain that 'the dignity conserving perspectives may be a reflection of the unique characteristics of patients who are facing their impending death'. The third and final category they offer is the 'social dignity inventory', which refers to social concerns and dynamics within relationships that promote or reduce patients' dignity. They recognise this encompasses how an 'uncaring attitude' might affect dignity, as well as how dignity is influenced when the patient's 'personal environment' is encroached upon in the course of receiving care.

Although there is an established body of literature relating to dignity in palliative care, there are far fewer academic considerations of dignity specifically in the care of older adults. When studies do consider older adults' dignity or human rights, they tend to be located in care homes (such as Hall *et al*. 2014; Franklin *et al*., 2006; Lloyd-Sherlock, 2018), or hospitals (Tadd *et al*., 2011a; Tadd *et al*., 2011b; Baillie, 2009, Webster and Bryan, 2009). This thesis contributes towards filling the gap in current knowledge around dignity in a community district nursing context.

The most comprehensive study of older people and dignity in Europe was led by Win Tadd, which resulted in a number of publications (including *Tadd et al*., 2002; Ariño-Blasco *et al*., 2005; Bayer *et al*., 2005; Tadd and Bayer, 2006: Calnan *et al*., 2005, Woolhead *et al*., 2004; Stratton and Tadd, 2005; Tadd and Dieppe, 2005; Nordenfelt and Edgar, 2005). This project, *Dignity and older Europeans (fifth framework (quality of life) programme),* involved 424 professional participants in focus groups, consisting of medical, nursing, managerial, paramedic and assistant staff from across six European countries. Swedish philosopher, Lennart Nordenfelt, was also an investigator for the project, and not only developed a model of dignity, but applied it specifically to the needs of older adults (Nordenfelt, 2004, 2009). He identified four types of dignity, all of which are applicable to older adults within healthcare services.

1. Dignity of merit
2. Dignity as moral stature
3. Dignity of identity
4. *Menschenwürde* (human dignity)

‘Dignity of merit’ applies to people who have gained a higher status or rank, potentially due to their social position. Nordenfelt (2009) recognised that doctors have a dignity of merit that is associated with their professions, but he states that dignity of merit may also be granted to older adults due to their life experiences and wisdom. Unfortunately, there is no significant evidence that older adults gain dignity of merit due to their age and, for some, their increased years makes them more vulnerable. Mandelstam (2011) discusses John Stuart-Mills’ concept of utilitarianism, in which the needs of a few may be sacrificed to achieve the greatest good for the greatest number, and he acknowledges that there is a danger that older adults will have to endure poor health services for the good of everyone else, thus raising concerns over the dignity of merit.

‘Dignity as moral stature’ is heavily linked to self-respect. It is a type of dignity that is dependent on the thoughts, actions and deeds of the subject – for example, behaving in a ‘dignified manner’. As an example, Nordenfelt (2009) cites Socrates, who was sentenced to death for the alleged crime of seducing young people in Athens. Socrates felt it was more dignified to commit suicide, rather than escape (which it would have been quite possible to do). This remains relevant and transferable to contemporary discussions of older adults’ perceptions of dignity, as will be demonstrated in Chapter 4, in which Jack, an 81-year-old male participant, illustrates why ‘dignity as moral stature’ is relevant to him and his maintenance of dignity.

‘Dignity of identity’ is ‘the dignity that we attach to ourselves as integrated and autonomous persons, with a history and a future, with all our relationships to other human beings (Nordenfelt, 2009: 33). Nordenfelt also links dignity of identity to ideas of humiliation: ‘How can humiliation rob me of my dignity? How can I lose my dignity when I am attacked by people whose moral views I despise?’ (Nordenfelt, 2009: 34). Edgar (2004) has criticised Nordenfelt’s discussions of deliberate humiliation, as this works by undermining the person’s values, damaging them so that they no longer see their own intrinsic worth, thereby reducing autonomy and undermining their personal narrative. This is summarised as follows: ‘where there are gaps in curtains, lack of privacy for examinations, insufficient access to toilets and bathrooms, mixed-sex wards, and drab and shabby accommodation both basic human dignity, or Menschenwürde and dignity of identity are compromised' (Gallagher *et al*. 2008: 8).

One of the most relevant types of dignity to consider in the context of older peoples' dignity in healthcare is the idea of *Menschenwürde*, which is closely allied with Kant's concept of human dignity, which will become apparent in the presentation of the empirical chapters of this thesis. *Menschenwürde* is a German word describing the dignity inherent in everyone by nature of being human. Importantly, Nordenfelt (2009) believes that this cannot be lost as long as the person exists. This type of dignity may also be described as 'inherent dignity', as in Michael's (2014) bioethical perspective which explores two broad categories of dignity – 'inherent dignity' and 'non-inherent' dignity – differentiating the former category as a quality that belongs equally to everyone, which is permanent and inviolable, whereas 'non-inherent dignity' is an acquired condition that is contingent on a person's circumstances and behaviours, and which may relate more closely to Nordenfelt's concepts of 'dignity of merit' and 'dignity of moral stature'. Wainwright and Gallagher (2008) recognise that, for nurses, it is particularly important that they value the intrinsic worth of human life, particularly when cognition is absent as this type of dignity, *Menschenwürde,* is inalienable, and it extends and encompasses everyone. This concept of dignity inherent to humans is returned to frequently in the empirical chapters.

Nordenfelt's theoretical accounts of dignity have been acknowledged as particularly helpful by Gallagher *et al*. (2008). In their literature review into dignity in the care of older people, Gallagher *et al*. (2008) recognise that staff attitudes and behaviours were a strong theme in the literature and this linked to concepts of *Menschenwürde* and dignity of identity. Gallagher *et al*. (2008) identify four themes that could be used to describe concerns about dignity: the environment of care; staff attitudes and behaviour; culture of care; and specific care activities. They establish that the theme of 'the environment of care' is evidenced in empirical work and includes the physical environment of the institution and issues of privacy which may have an impact on dignity. The 'environment of care' and dignity have been recognised and explored with regards to inpatient services (such as within hospitals and mental health and learning disability assessment and treatment units), but it has not been translated to care settings within the home. In the chapters that present the findings from this thesis, the notion of an ‘environment of dignity’ (rather than an environment of care) is used to describe how important environmental factors can aid or hinder the construction of dignity.

Despite this section’s consideration of how dignity manifests itself for older adults during their contact with health services, none of these studies has specifically explored these issues within the context of district nursing care delivered in the home. In their review of both theoretical and empirical literature on dignity in the care of older people, Gallagher *et al*. (2008) recognised that empirical studies have explored the views of older people in nursing homes and in hospital. Similarly, Maybin *et al*. (2016) recognise that, at a national level, relatively little data on community health services is collected, compared with care delivered in hospitals. This, therefore, indicates that there is a neglected area of data collection and a missing evidence base of knowledge relating to people who live in their own homes and access healthcare services in the community, hence the necessity for the contribution made by this thesis.

This section has explored how dignity manifests itself for older adults in health services. There are copious examples of guidance, policy directives and professional codes of practice that emphasise the importance of delivering dignified care in health services. It is these sources of literature that become the focus of the next section.

It's NICE to treat people with dignity and respect

The purpose of the National Institute for Health and Care Excellence (NICE) is to produce guidance and standards to promote the delivery of high quality, safe healthcare services. In clinical guideline 138, relating to patient experiences, quality statement 1 indicates, ‘patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.’ (NICE, 2012: 5). In noting this as a ‘quality statement’, NICE recognise that treating patients with dignity is an indicator of quality, implicitly signifying that dignity is not necessarily regarded as an automatic right. By being recognised as a marker of quality, dignity has been elevated to an ‘optional extra’, rather than a standard element of care, making it NICE to treat people with dignity.

Along with NICE, the Department of Health also publishes policies and guidance documents aiming to promote dignity and human rights. These are addressed widely in *Essence of care*, first published in 2001 (DH, 2001a), revised in 2003 (DH, 2003) and then rewritten in 2010 (DH, 2010a). This document provides benchmarks of good care for healthcare practitioners and defines dignity as ‘being worthy of respect’ (DH, 2003: 7), which has been criticised by Robert Francis QC, who indicated that this definition is not entirely useful as it is a ‘circular’ concept (Mid-Staffordshire NHS Foundation Trust Inquiry, 2010: 108). Dignity is also espoused in the NHS Constitution (DH, 2015a) which establishes NHS principles and values, stating ‘you have the right to be treated with dignity and respect, in accordance with your human rights’ (DH, 2015a: 8). Similarly, the Prime Minister’s *Challenge on dementia 2020* (DH, 2015b: 6) recognises ‘a society where kindness, care and dignity take precedence over structures or systems’.

The British government has led many initiatives and campaigns to improve dignity within health services (Gallagher, 2009). One of these is the *Dignity in Care* campaign, which first began in 2006, aiming to improve standards of care delivered within health and social care services and encouraging NHS staff to become dignity champions by following their ten-point dignity challenge described as follows:

> 1. Have a zero tolerance of all forms of abuse.
> 2. Support people with the same respect you would want for yourself or a member of your family.
> 3. Treat each person as an individual by offering a personalised service.
> 4. Enable people to maintain the maximum possible level of independence, choice and control.
> 5. Listen and support people to express their needs and wants.
> 6. Respect people's right to privacy.
> 7. Ensure people feel able to complain without fear of retribution.
> 8. Engage with family members and carers as care partners.
> 9. Assist people to maintain confidence and positive self-esteem.
> 10. Act to alleviate people's loneliness and isolation.
>
> (*Dignity in care*, 2019)

By promoting these ten values and actions, the campaign aims to raise awareness of dignity for everyone working in health and social care, placing emphasis on improving the quality of care and experiences of service-users.

The Healthcare Commission (2007) found that the profile of dignity increased following the *Dignity in Care* campaign, but it remains unevidenced as to whether this increased profile translated into positive action. *Caring for Dignity* (Healthcare Commission, 2007) was a national report on dignity in care for older people in hospital. It recognised the Human Rights Act (1998) as central to legal discussions of dignity and noted an increased focus on the quality of non-clinical care for patients, which, as I will later demonstrate in my empirical chapters, often provides the opportunity for dignity to become manifest.

In terms of older adults, the *National service framework for older people* (DH, 2001b) describes itself as ‘a 10-year programme of action linking services to support independence and promote good health, specialised services for key conditions, and culture change so that all older people and their carers are always treated with respect, dignity and fairness’. (DH, 2001b: i). Almost two decades have passed since this was published, yet evidence remains that older adults are not always treated with the dignity that this framework promised to deliver. As some UK policies have specifically focused on the dignity of older adults, it may be indicative that the government considers them to be a group at increased risk (Baillie, 2009), and thus they may be perceived as more vulnerable to dignity violations.

In addition to these guidance documents, members of regulated professions (such as doctors, nurses and social workers) must practice in accordance with their ethical codes of practice. Every code of professional practice informs registrants that they must uphold dignity in practice, and Milton (2008: 207) notes that the codes use dignity ‘in conjunction with terms like respect, worth, integrity, uniqueness and human rights’. In 1953, the *International code of ethics for nurses* was developed and updated in 2012 by the International Council for Nurses (ICN). The code states that ‘inherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect’ (ICN, 2012: 1). In addition to these international expectations, they are reinforced by the Nursing and Midwifery Council (NMC), the national regulatory body for nursing professionals in the UK, who indicate nurses must ‘treat people as individuals and uphold their dignity’ (NMC, 2015: 4).

Good medical practice, the equivalent professional code of practice for doctors, indicates that not only must they respect patients’ rights to privacy and dignity, but they must also ‘take prompt action if [they] think that patient safety, dignity or comfort is being compromised’ (GMC, 2013: 2). This is echoed by the HCPC, the professional regulator of most other healthcare professionals (covering paramedics, radiographers, physiotherapists, occupational therapists, social workers and many more), who require that registrants ‘treat service users and carers as individuals, respecting their privacy and dignity’ (HCPC, 2016: 5).

Ideas of promoting dignity are ingrained within the professional codes of practice for all registered healthcare professionals. Other staff working in healthcare may not be members of regulated professions. However, even unregistered staff may also be required to follow professional codes. For example, NHS managers have a code of conduct that states they should ‘respect and treat with dignity and fairness, the public, patients, relatives, carers, NHS staff and partners in other agencies’ (DH, 2002: 4). Similarly, healthcare support workers, must ‘promote and uphold the privacy, dignity, rights, health and wellbeing of people who use health and care services and their carers at all times’ (Skills for Care and Skills for Health, 2013: 2). In addition, the healthcare regulator, the Care Quality Commission cites one of its values as ‘treating everyone with dignity and respect’ (CQC, 2015).

Within all of these professional codes, dignity remains undefined. Accordingly, it is taken for granted that registrants understand what is meant by ‘dignity’. This is entirely at odds with the literature discussed in this literature review, where there is little agreement about what dignity is, other than it being a complex phenomenon. Ariño-Blasco *et al*. (2005) recognise that, despite it being cited in many professional codes and conventions, dignity continues to be difficult to define. In a systematic review of the literature, Cutcliffe and Travale, (2013) note a disconnect between the espoused rhetoric of the importance of dignity and respect in policy documents and its implementation in mental health practice in particular. Woogara (2005) indicates that it was following the implementation of the Human Rights Act (1998) that the UK government published various circulars espousing the importance of respecting the dignity of patients. However, as these guidance documents do not attempt to describe how dignity can manifest itself in clinical practice, the ability of clinicians to apply dignity in care practices is reduced. Schein's (2010) analysis of organisational culture and leadership indicates that there may be 'espoused' values which are the desired values (reflected in the publications examined above), but it can be interesting to compare these espoused values with the observed behaviour of staff, as they are not always congruent (Argyris and Schön, 1978, 1996). Therefore, although this policy framework emphasises the importance of upholding human rights and dignity, the reality of practice may not necessarily evidence the rhetoric of dignity in practice-related documents. This is reflected by Penhale (2010) who calls for further consideration into the mistreatment of older adults, particularly in light of public policy, service provision and the changing nature of relationships between individuals and the state.

Although, as described above, the limitations of the documents are recognised, they remain an important source of knowledge and guidance, as they provide the standards on which health services should be delivered. So, given the existence of Department of Health publications, campaigns such as *Dignity in care*, the professional codes of practice and policy and guidance documents, why does dignity still remain so elusive in the professional practice of many health services? Perhaps considering aspects of the healthcare economy may assist in answering this, which will be the focus of the next section.

The economy of healthcare - 'What price heart surgery and what price a bath?'

Alongside the previous section's focus on the policy context, it is also important to explore the economic implications of dignity in healthcare, which often form the backdrop to policy directives.

Over the years, there has been a policy move to view patients as customers or consumers of health services, as recognised in Twigg *et al.*'s (2011) descriptions of service-users as 'consumers' (described in 'Care and caring for the body'). Choice, personalised care and 'no decision about me, without me' were features of *Liberating the NHS* (DH, 2010b: 3), and Lord Darzi's report *High quality care for all* (DH, 2008) heralded a move away from target-based management to empowering local services based on quality. Along with the roll-out of Personal Health Budgets, these directives indicated a shift in policy, in which patients became viewed as active consumers in a healthcare economy, reinforcing ideas that healthcare services are based on a transaction in which the customer (patient/ service-user) has certain rights.

The NHS was set up in an era when life-expectancy was much lower than it is in contemporary society. Many older adults have a range of co-morbidities, which means they have many complex needs which they manage over long periods of time. Older adults are now living longer, some with long-term conditions, and therefore the health needs of older adults may also be more expensive (as well as more complex) than what the health system was set up to manage. This increasingly ageing population will inevitably result in increased demands on care services (Price and Walker, 2015). With people living longer, increased strains have been placed on healthcare services, despite funding not reflecting these increased demands. Although these challenges are firmly located in the system of healthcare, it is often the older adults themselves who are labelled as the problem, which can contribute to their vulnerability. Older adults will never be on an equal footing with service-providers, as structural inequalities remain evident in the access to, and delivery of, services. They may have other vulnerabilities, not only simply because of their age, but due to possible disability (temporary or permanent) and illness, in addition to any further vulnerabilities related to their socio-economic status, sexuality or ethnicity, for example.

In an age of austerity, the stagnancy of budgets compounded by the needs of an ageing British population has led to increased demands on health services, with fewer staff available to meet those needs. If an absence of dignity and human rights can lead to abuse, Mandelstam (2011) acknowledges that it is too simplistic to suggest that abuse and neglect occur purely from staff shortages, as competence and attitude are also factors. De Donder *et al*. (2016) recognise the multifaceted nature of abuse, which is embedded in environmental contexts, such as loneliness, and macro-cultural contexts, which includes older age. Also, in the first national prevalence study into abuse of adults aged 66 and over and living in private households, O'Keeffe *et al*. (2009) recognise that the prevalence of mistreatment increased with a declining health status. Thus, the most unwell older adults may be more at risk of dignity violations or even abuse. Moreover, frequent patterns of poor care for older adults highlight the presence of ageism in nursing (Kagan and Melendez-Torrez, 2015).

During current times of austerity and resource limitations, clinical staff now assume increased medical responsibilities – nurses now undertake tasks that were previously reserved for doctors (which includes prescribing) and unregistered healthcare staff are now trained to undertake some nursing tasks (such as phlebotomy). Therefore, more complex skills and competencies are expected from lower qualified staff. As a result of an ageing population, there are increased demands for services; effectively meaning fewer staff assume these increased responsibilities. Health services can be criticised for being task-focused: although holistic care is a goal, in reality, clinical interventions may appear to take priority over meeting people's basic care needs (such as washing, toileting, eating and drinking), and these are further alluded to in my own findings, particularly in Chapter 5, where this is demonstrated through my own observations of continence care.

A key skill of nursing is the ability to prioritise. However, consideration should be given to how and what nurses prioritise and to what influences these decisions. As an example, a standard contractual requirement for all hospitals set by the Department of Health is the four-hour waiting-time target for emergency departments which formalises expectations that 95% of patients should be seen within this timeframe. Therefore, for clinicians working in emergency departments, this target will be an important influencing factor in what decisions are made – potentially turning over high numbers of patients will be the priority. The report into failures at Mid-Staffordshire noted:

> The Trust Board placed a high priority on compliance with nationally set targets, and, in particular, the four-hour waiting time target for A&E. The pressure to comply with such targets came from the Department of Health (DH), the Strategic Health Authorities (SHAs) and the primary care trusts (Mid-Staffordshire NHS Foundation Trust Inquiry, 2010: 162).

In 2001, the Department of Health issued practice guidance for nursing staff which gave indicators of dignity. One indicator of dignity was that ‘nurses are active in meeting requests for assistance related to intimate care, in particular, a request to use a toilet is responded to within 5 minutes’ (DH, 2001c: 3). Yet, in contrast to the four-hour waiting time target, this was not adopted by the Department of Health as a contract requirement, remaining purely as guidance. Central government, via the DH, performs a vital role in determining the priorities of the health service and, although they publish copious amounts of guidance and policy pertaining to dignity in healthcare, there is no evidence that this translates into their monitoring and formal targets of dignity, potentially de-prioritising it for healthcare organisations.

Webster and Bryan (2009) indicate that it has been widely recognised that quality healthcare is not only dependent on the actual treatment (usually the elements contained within targets), but also dependent on the way care is delivered (which are not usually included in targets). In a real-life example (described by Mandelstam, 2011), a 93-year-old patient was in hospital with heart failure. She was becoming depressed, as she was dirty and began to smell due to not receiving a bath, shower or full wash for two weeks. When a doctor offered her a surgical heart procedure, she replied that she had lived a marvellous life and did not want to be messed around with at her age, explaining that, actually, a bath would be most beneficial. The doctor left her without any surgery and neither did she receive a bath. This story led Mandelstam to pose the crucial question: ‘what price heart surgery and what price a bath?’ (Mandelstam, 2011: 91).

Essentially, here, Mandelstam (2011) begins to raise issues of beneficence. Every medical intervention has the potential to harm patients. Therefore, beneficence is a concept of western medical ethics, which involves balancing the benefits of treatment against the risks and costs involved. In Mandelstam’s (2011) example described above, although the principle of beneficence will have been applied to the offer of heart surgery, shamefully beneficence was not applied to the woman's request to receive a bath. This vignette, therefore, provides an example of how consumers' ideas of dignity have been usurped by issues that clinicians deem of greater importance, which are often reinforced by government targets. This balance between clinical priorities and patients receiving dignified care also became apparent in my own research and this is considered more fully in Chapter 4, when Margo, a patient-participant, described how the clinical priorities of a nurse were at odds with her own beliefs of dignity. In this regard, my findings also concur with Woogara's (2005) ethnographic study on NHS wards in which she recognised that, 'during the prioritization of patient care, privacy and dignity were often forgotten as they were viewed as less important than receiving medical treatment' (Woogara, 2005: 280). This indicates that healthcare professionals may not recognise the importance patients place upon dignity, where patients may elevate dignity requirements above the importance of their medical treatment.

Nurses may, therefore, prioritise what the government has labelled as more important (as indicated through a target being in place), as opposed to prioritising what may be considered the 'softer' aspects of care (such as dignity), because this is only guidance and not target-led. This may go some way to explain why medical staff are more willing to offer medical interventions, such as heart surgery, rather than give someone a bath.

Thus far, the literature review has explored the legislative, policy and economic context of dignity in care. However, to understand dignity, it is important to gain an insight into people's lived experiences. Hence, the next two sections will focus on studies that offer an insight into views of dignity, from the service-users' perspective and from the perspectives of staff working in care. First, service-users' views of dignity will be considered.

Age-old issues: Service-users' views of dignity

To understand how dignity manifests itself in older people's caring relationships, it is essential to consider the existing evidence base reporting on service-users' views of dignity. Valentine *et al*. (2008) used the World Health Organisation's general population surveys from 41 countries to identify the aspects of clinical care that are most important to people. Dignity was selected as the second most important, with prompt attention being identified as the most important domain. Thus, dignity in healthcare is an important concept for research as well as in actual caring practices. Older adults indicate how certain aspects of their relationships with professionals influence their dignity. For example, communication and listening carefully were identified as important by Anderberg *et al*. (2007), who differentiated 'dignity' (a state of mind) from 'preserving dignity' (which they applied to the context of care). Similarly, on the theme of communication, Bayer *et al*. (2005) noted that older adults frequently cited poor communication (particularly patronising or disrespectful language) as examples of dignity harms, whereas kindness, politeness and listening were valued. Older adults stated they felt invisible, as they were unable to identify many opportunities to participate in discussions and policies that had a direct bearing on their wellbeing and Bayer *et al*. (2005) recognised that dignity could be enhanced by promoting participation and involvement.

Although the experiences of older adults are beginning to be acknowledged in the literature, they are often described as a homogenous group and differences between elderly people are not necessarily being acknowledged (e.g. gender, social class; sexuality). Bayer *et al*. (2005) found that older adults felt excluded from certain aspects of society. For many people, this began when they retired and they identified as problematic the lack of opportunity to perform a 'useful' role. The voices of older adults are not always heard in research. For example, studies such as Rehnsfeldt *et al*. (2014) explore dignity for older adults in nursing care homes, but by gaining the views of their relatives. This is problematic, as these are not the views of older adults themselves, which is reflective of a paternalistic approach towards protecting people, such as older adults, who are automatically deemed 'vulnerable'.

There is some existing literature that explicitly considers the views of older adults, including the largest study, the *Dignity and Older Europeans Projec*t (Bayer *et al*., 2005). This study established that if dignity was maintained, it could enhance self-esteem, self-worth and wellbeing. Following discussions with 391 older people, three themes emerged: respect and recognition; participation and involvement; and dignity in care. Across all the European countries involved, respect and recognition were viewed as fundamental to experiencing dignity, which involved self-respect and respect from others. Participants regarded these as interrelated aspects of dignity, as lack of respect from others could result in damage to self-esteem and self-respect, but they also recognised the reciprocal nature of respect, in which older adults should demonstrate respect for others to receive it. This reciprocal dignity is also recognised by Jacelon *et al*. (2004) and also becomes apparent in my own discussions of dignity in caring relationships (Chapter 4).

Another theme identified by the *Dignity and older Europeans Project* was what was described as ‘dignity in care’, which represented the emphasis older adults placed on being fully informed and maintaining control in making decisions about their care. Taking an active role in decisions about care has been recognised as important by other writers, such as Anderberg *et al*. (2007), who also acknowledged that there is a lack of clarity over what types of caring can lead to the preservation of dignity.

To gain further understanding of dignity, specifically in institutional settings, Tadd *et al*. (2011a) explored dignity in practice as one of the PANICOA studies. They undertook an ethnographic methodology to explore four acute Trusts in England and Wales, using observation and in-depth interviews with staff (including practitioners and managers), older adults (aged 65 plus) and their relatives or carers. They indicated that there were no new findings from the study regarding the meaning of dignity and they were unable to identify any further dimensions of dignity, other than those identified above within the *Dignity and older Europeans* study.

Baillie (2009) undertook a qualitative case study on one ward in an acute hospital, by doing twelve episodes of participant observation and conducting interviews with 24 patients and 26 ward-based staff. She identified that patient and staff views were similar and that patient dignity was comprised of feelings, physical presentation and behaviour. Patients expressed feelings of being safe, happy and relaxed with a lack of embarrassment, also describing feeling valued and cared for. ‘Respect’ was a term frequently used to describe a behaviour associated with dignity, and approximately a third of the patients stated that dignity involved a mutually respectful relationship.

Respect was also identified in Webster and Bryan's (2009) exploration into older people's view of dignity, in which interviews were conducted with ten participants aged 73–83 following an unplanned admission to hospital. The participants perceived that ageism was still evident and that this contributed to a lack of respect. Interestingly, the researchers note that three participants used the term 'geriatric' to describe patients that were incontinent, had dementia or were immobile, and six of the participants stated that they did not want to be associated with these traits. Thus, it is possible that the participants were demonstrating ageist attitudes through a lack of respect for their more dependent peers. However, Webster and Bryan (2009) note that these participants provided examples of how they assisted less independent patients, which may indicate that their actions came from concern, rather than criticism of their less autonomous contemporaries. Importantly, the participants also acknowledged that maintaining dignity was easier for people who could express their needs and make them known to hospital staff.

Matiti and Trorey (2008) conducted interviews with 102 patients in three UK hospitals to identify patients' views of what factors contribute to maintaining their dignity whilst in hospital. They identified six themes that contributed to the preservation of patient dignity: privacy; communication; confidentiality; choice and involvement; respect; and decency. The respondents accepted that whilst in hospital they would lose some autonomy. However, having opportunities to make choices about their care and having staff understand their standpoint were important issues for patients.

Mangset *et al*. (2008) undertook a qualitative study on the satisfaction with rehabilitation for elderly stroke patients, by undertaking semi-structured interviews with twelve service-users. They found that a core factor in patient satisfaction was 'to be treated with respect and dignity (Mangset *et al*., 2008: 825). This overarching factor could be further broken down into five subcategories which included: being treated with humanity; being acknowledged as individuals; respect for autonomy;

trust and confidence in professionals; and dialogue and information exchange. This echoes Høy *et al.*'s (2007) findings that dignity comprised autonomy, identity and worthiness in the practice of care providers in hospitals. Mangset *et al.* (2008) noted that when respondents were satisfied, they made more general statements. However, where dissatisfaction prevailed, they were more detailed with descriptions of situations that caused their dissatisfaction (in line with Arendt's (1958) articulation of the human rights paradox).

Age-old issues: Professionals' views of dignity

In addition to service-users' views, to understand dignity in the caring context it is important to consider how professionals involved in the caring industry conceptualise and understand dignity.

As part of the cross-country analysis of the *Dignity and older Europeans Projec*t, dignity was understood as an inherent part of being human (*Menschenwürde*), and this was closely linked to respect (Ariño-Blasco *et al.* 2005). Factors that were acknowledged as essential to providing dignified care included: promotion of autonomy and independence; a person-centred, holistic approach; maintenance of identity and encouraging involvement, participation and empowerment; and effective communication and respect. Older people's care was identified to be a 'Cinderella service', which was not prioritised and regarded as being of low status. Across the six European countries involved in this project, the authors noted that 'participants were unanimous in their criticisms of the system, claiming that deficits affected their ability to provide dignified care' (Ariño-Blasco *et al.* 2005: 34).

Calnan *et al.* (2005) state that there is limited systematic evidence about dignity and its importance in healthcare. In their study, Calnan *et al.* (2005) explored the meaning of dignity for healthcare professionals via their primary method of data collection, which was a set of focus groups involving 52 participants, across a range of professions including: care assistants, nurses, physiotherapists, social workers, care home managers and geriatricians. Most professionals were located within hospitals (n=42) or residential homes (n=7), and only three participants were based within the community. Therefore, although this study offers some useful insights into healthcare professionals' perceptions of dignity, it does not really explore the concept of dignity for practitioners working in community healthcare services. As my own research will demonstrate, there are clear differences between delivering dignified care in a hospital environment, as opposed to in the home. Through the focus groups, Calnan *et al.* (2005) identified a range of ideas about dignity, including: meanings associated with independence and autonomy; the individual's identity (including respect for privacy); and the right to confidentiality and equal treatment. Interestingly, the authors only explicitly acknowledge that the final category (confidentiality and equal treatment) links to human rights, failing to draw the links between respect for privacy (which may link to Article 8, rights to a private and family life) and independence and autonomy (linking to Article 5, rights to liberty). The authors note that the different occupational groups generated different answers. However, all groups recognised privacy and respect as a shared meaning of dignity. They also acknowledge that there are different levels of training about dignity, indicating that care assistants receive no official training, in contrast to physiotherapists who reported that dignity was prominent in their training, while also citing one physiotherapist who explained that they were failed on practical examinations if they forgot to cover someone over. Calnan *et al.* (2005) also recognise the task-orientated culture of the health service in which issues such as dignity are not highly valued, with greater emphasis placed on getting the job done. They believe this may be due to staff regarding 'problems' as easier to resolve than focusing on 'people', and they acknowledge that there is a gap between what professionals would like to deliver and what they are able to offer. In conclusion, Calnan *et al.* (2005) indicate that older people do not consistently receive dignity in care.

Chapter Summary

This chapter has offered a wide-ranging exploration into existing literature that is relevant to issues of dignity, human rights and older adults' experiences of healthcare. By exploring policy and legislation, in addition to theoretical and empirical evidence, I have demonstrated that dignity remains a complex, but strongly desirable and, arguably, essential aspect of care.

It has been shown how current academic considerations of dignity in care focus largely on experiences within hospitals, rather than community-based settings, and it indicates that within the existing literature, dignity is rarely related to the specific experiences of older adults. Additionally, applying a human rights approach to dignity is not frequently undertaken by existing literature. Thus, there is a clear rationale for my own study in which these important omissions are considered by exploring older adults' experiences of dignity and human rights in district nursing care.

The next chapter will outline the methods adopted within this study, along with the rationale for the methodology and methods employed.

Chapter 3: Methodology and methods

This chapter describes the methodology and methods used in the study. It is divided into two parts. Part I explores the theoretical basis to ethnography, describing the key markers of an ethnographic methodology and discussing how others have used this methodology, before concluding with some reflections on potential ethical issues associated with ethnography. Part II explores how I implemented ethnography in practice, by noting my own ethical approvals, through to describing the study design, methods used and how data were collected, stored and analysed. I also present a critical reflection on how my own positionality influenced the research.

Part I: The theory

A Qualitative methodology

Qualitative methods are particularly useful to explore experiences when the people involved require, ‘time and space to construct their own stories in which meaning and values gradually unfold’ (Roseneil, 2006: 6). To explore peoples’ experiences in this way, naturalistic inquiries gain an understanding of the social world through observation, description and interpretation, which relies on the researcher as the primary instrument of data collection (Lincoln and Guba, 1985; Britten, 1995; Patton, 2002). To counteract possible claims that qualitative research is not generalisable and is biased, Guba (1981) proposes credibility, transferability, dependability and confirmability as epistemologically appropriate criteria by which to assess the trustworthiness of qualitative methodologies.

As this study considers people’s experiences and understanding of dignity and human rights within community nursing services, a qualitative methodology was employed as the most suitable approach to appropriately answer the research questions, rather than attempt to quantify people’s experiences. In the context of this study, to gather data that was credible, transferable, dependable and confirmable (Guba, 1981), ethnography was regarded as the methodology best suited to achieve this. To understand this rationale more fully, the use of ethnography as a methodology will now be explored.

Ethnography as methodology

It was the seminal writing *Argonauts of the Western Pacific* by Bronislaw Malinowski (1922) that firmly established ethnography as an accepted anthropological methodology which has subsequently been embraced more widely across the social sciences and other disciplines. Yet, some disagreement and confusion remain over what ethnography actually is (Savage, 2006). Willis and Trondman (2016: 5) describe it as 'a family of methods involving direct and sustained social contact with agents, and of richly writing up the encounter'. Hammersley (1994, 2006) defined ethnography as a methodology, but Lillis (2008) distinguished ethnography as a methodology, method, or a tool for deep theorising. However, she notes that when ethnography is used as a methodology, there are 'richer opportunities for developing contextualised studies of academic writing' (Lillis, 2008: 362).

Despite there being a variety of interpretations regarding what ethnography is and is not, it is accepted that the primary tool of data collection is the researcher themselves. Attempting to gain an insider's emic perspective may be a goal of some ethnographic research; however different schools of thought have contrasting ideas about whether this is actually possible. Although there may not be a clear consensus on many aspects of an ethnographic methodology, Savage (2006: 385) notes it is

> the way in which ethnography makes links between the micro and macro, between everyday action or interaction and wider cultural formations [which] makes it particularly valuable for researching healthcare issues.

In my study, an ethnographic approach was used to focus on everyday interactions between nurses and patients to re-present micro-descriptions of the operationalisation of dignity in care. A central precept of ethnography is that individuals' experiences are socially organised (Hardin & Clarke, 2012). By employing an ethnographic methodology to my own study, it enabled a means of understanding the micro-processes of individual carriers of the rules and systems (nurses and patients) and how these were reflective of macro-considerations of dignity and human rights.

Ethnography can be regarded as ‘both a process and a product…the name for ‘doing ethnography’ is ‘fieldwork’’ (Agar, 1996: 53–54). Fieldwork should be ‘an especially deep, extended and interactive research encounter’ (Clifford, 1997: 54), which is a view that indicates prolonged participation in a culture is required. However, Crabtree *et al*. (2012: 77) note, ‘rather than conduct extensive periods of fieldwork, it is often more effective and productive to conduct short periods of fieldwork that are well aligned with and respond to the needs of design’. There are, therefore, divergent views over the length of time required to conduct an ethnography. The quality of ethnographic encounters may be enhanced if researchers ‘put aside his or her notebook and participate’ (Grimshaw, 2001: 55), which may allow cultures to reveal themselves in shorter periods of time, therefore, it is not always the length of time spent in the field, but the quality of engagement with participants that contributes to the trustworthiness of the study.

Grimshaw (2001) distinguishes between ‘exploration’ and ‘revelation’, noting that revelation is central to Malinowski’s model of ethnography. Simply exploring a culture or society will not present the thick descriptions that can be gained from the revelations made through ethnographic practices (Grimshaw, 2001). Similarly, Ghodsee (2016) argues that ethnographers should ‘show’, rather than ‘tell’ their reader ethnographic details, which helps to sustain a rich experience for readers. In this thesis, ethnographic revelations are used to illuminate participants’ experiences by using their own narratives, and at other times utilising thick description gained from observations to engage the reader in the world of community nursing care practices with older adults.

Ethnography in health research

Ethnography is under-utilised in health research (Savage, 2006). Although ethnography is appropriate for a wide range of research topics within healthcare, there continues to be a ‘general lack of research employing this methodology’ (Goodson and Vassar, 2011: np). Even when health literature recognises the positive use of ethnography, the methodology is often related to educational aspects of health or medicine (for example Leung, 2002; MacKenzie, 1992).

The use of ethnographic methodologies in health research has been criticised when researchers fail to draw upon knowledge gained from observations (a key component of an ethnographic methodology). For example, Ruchti (2012) undertook approximately 800 hours of observation in a hospital setting, yet her discussion of how nurses manage intimacy with their patients contains

> virtually no analysis of such observations. What we are treated to is extracts from interviews with the nurses[…]we are left wondering how nurses manage themselves and their patients in order to achieve certain kinds of work while avoiding other kinds of intimacy (Atkinson, 2015: 75).

Counterbalancing this possible criticism, my own thesis re-presents both quotes from interviews, as well as thick observational descriptions, ensuring one type of data has not been more favourably represented than another.

Hospitals remain important venues for anthropologists to conduct fieldwork (Long *et al*. 2008). Classic examples of how ethnography has been used to offer insights into inpatient care are Goffman's (1968) exploration of 'asylums' and Roth's (1963) exploration of how inpatients with tuberculosis negotiated an early release from a 'sanatorium'. Bridges *et al*. (2010) presented a systematic review of older adults' experiences in acute settings. In this study, out of the 42 primary studies eligible for inclusion, only four stated they used ethnography as the methodology, which indicates that ethnography remains an under-utilised approach to the study of older adults' experiences in hospitals, despite having advantages, such as being able to offer a rich source of data that can reveal previously unarticulated issues and provide detailed findings that capture behaviours and emotional experiences. However, Bridges *et al*.'s (2010) systematic review only considers examples of ethnographic research in institutional settings. There are far fewer examples of the methodology being used in community healthcare, an issue that will now be considered in a little more detail.

Ethnography in community nursing

As previously noted, although ethnography has been used to explore hospital cultures (such as Woogara, 2005; Tadd *et al*., 2011b; van der Geest and Finkler, 2004; Allen, 2004; Davis 2001), it has been used less widely to explore community nursing services. Existing studies that cite ethnographic approaches to study community nursing are provided by Kennedy (2004), McGarry (2008), Drew (2011) and Walshe *et al*. (2012), all of which will now be considered more fully.

Kennedy (2004) used an ethnographic design to research district nursing assessment practices, with data collected in the observations being used to provide a focus for in-depth interviews with participants. McGarry (2008) undertook an ethnographic approach to a community nursing team to explore the nature of care relationships within the home, becoming what she describes as a 'partial participant' (McGarry, 2008: 85), as at times she would carry equipment and complete minor tasks to assist the staff. In exploring professional identity and the culture of community nursing, Drew (2011) undertook an ethnographic methodology utilising methods of participant observation and semi-structured interviews, explicitly indicating 'respect for autonomy, beneficence and justice' as ongoing ethical processes throughout her research (Drew, 2011: 127). She explained that 'community nursing is poorly articulated and appreciated outside the cultural group' (Drew, 2011: 130), and thus further research into the cultures of community nursing is beneficial. Finally, Walshe *et al*. (2012) adopted an ethnographic methodology within their longitudinal study of district nurses' work with palliative patients, in which they observed seventeen encounters and undertook 23 post-observation interviews with patients, carers and district nurses. They recorded both observations and interviews, undertaking iterative data analysis to investigate the role of the district nurse in the provision of palliative care.

Although these studies are located within community nursing services, there are currently no ethnographic studies specifically exploring cultures of dignity and human rights within community nursing teams. Contributing to the originality of this thesis, the study adopted an ethnographic approach, which offers a perspective via a rarely utilised methodological perspective in the context of care within the home. An ethnographic methodology is useful to study complex societal and cultural interactions and relationships that cannot be quantified, such as experiences of dignity in community nursing care. Employing ethnography can also highlight views and perspectives of cultural groups that may not be from the dominant culture and are, therefore, in danger of remaining unheard (such as older adults).

Ethnography in research with older adults

There are limited examples of ethnographic methodologies being used within community nursing teams, but there are even fewer examples of ethnography being used as a methodology for the study of older adults. In the 1970s Keith (1979: 5) recognised that

> exploration of this territory by ethnographers of age and ageing will be a key step in the transformation of our old alliance with the aged into systematic contributions to both anthropology and gerontology.

Existing studies that indicate ethnography has been used in their study of older adults include Dobbs *et al*. (2008), Tadd *et al*. (2011b), Skilbeck *et al*. (2017) and Taylor *et al*. (2015). Dobbs *et al*. (2008) studied residential care and assisted living facilities for older adults in Maryland over a period of four years. Their methods involved observations and semi-structured interviews with over three-hundred participants, using multiple researchers to collect data.

Similarly, Tadd *et al*. (2011b) adopted observations and semi-structured interviews in their ethnographic study of dignity in the acute care of older people. They undertook 617 hours of non-participant observation in sixteen wards in four acute NHS trusts and interviewed recently discharged older adults and their relatives/ informal carers, alongside a range of healthcare staff including people delivering frontline care and managers.

Following Dobbs *et al*. (2008) and Tadd *et al*., (2011b), Skilbeck *et al*. (2017) also used non-participant observation and semi-structured interviews in their ethnography to explore the experiences of older people living with complex health problems. They observed up to six episodes of care between ten older adults and their community matron over a period of between four and eleven months, in addition to conducting semi-structured interviews with participants in their own homes.

There is one systematic review of the use of ethnographies focusing on older adults. Michel *et al.* (2014) reviewed studies submitted to Brazilian HEIs between 2004 and 2011, where a total of eleven studies met the criteria of being an ethnographic methodology with a participant group of older adults. In concluding why ethnography is an appropriate methodology for the study of older adults Michel *et al.* (2014: 355) summarise as follows:

> ethnography has been used as a methodology for studies which seek to deepen the knowledge of the culture through detailed descriptions of the daily life of the older adults. The choice of the ethnographic research strategies is explained by the need to obtain a closeness to the understanding of the objects studied, in a contextualized form, and based in the culture.

Therefore, ethnography is a suitable methodological approach for my study because it seeks to interpret and understand the daily lives of older adults receiving nursing care in their home and how this influences their sense of dignity.

Although all the previously described studies employed ethnography, Taylor *et al.* (2015) described their study of nurses' experiences of caring for older adults in the emergency department as a 'focused ethnography' (Knoblauch, 2015). They explained the rationale for adopting a focused ethnographic approach was to 'focus on the particular rather than the general' (Taylor *et al.* 2015: 186), and they note that because the researcher held a position within the emergency department she had 'insider' status, and therefore her familiarity with the context of the research enabled a focused ethnographic approach.

'Insider' and 'outsider' or 'betwixt and between'

A polarised perspective, such as that indicated by Taylor *et al.* (2015), implies that the ethnographer may approach their study from the position of 'insider' or 'outsider'; however, an alternative is to adopt a non-binary position, which regards the ethnographer as both 'betwixt and between' (Turner, 1967: 93). Any of these positions ('insider', 'outsider' or 'betwixt and between') will have an impact on the research process, as this will influence the ethnographer's interactions and relationships with the social actors under investigation. Considering the ethnographer's insider/ outsider status offers reflexive insights into the study and enhances transparency and credibility. My own status will be considered in my positionality discussions in Part II of this chapter.

Bonner and Tolhurst (2002) recognise that, as a nurse researcher, there are both advantages and disadvantages of being an ‘insider’ and ‘outsider’. Davis (2001) undertook fieldwork to explore the use of computers in different wards and areas of a hospital. Due to the environment’s culture of using computers and taking notes, recording her fieldwork observations remained unobtrusive as this was in the realms of ‘insider’ behaviour. Allen (2004) promotes a rigorous and theoretically informed approach to the conduct and reporting of ethnographic research in healthcare settings. She notes the claims that only ‘insiders’ immersed in the field can produce an authentic account, whereas ‘outsiders’ offer an etic perspective without the biases from what she describes as ‘being native’. She also recognises that ethnographic practices can involve ‘detached observation’ or ‘embodied understanding’ (Allen 2004: 16). However, it is also possible that the ethnographer’s position may not remain static and they may move between these two domains during different phases and interactions in the research experience.

Mulemi’s (2010) reflections on his ethnography of cancer referrals in a hospital in Nairobi considers the ‘native’ and ‘outsider’ roles: ‘the hospital ethnography process was a venture of continuous negotiation to access the lifeworlds of the other social actors in the cancer treatment centre and ward’ (Mulemi, 2010: 8). Davis (2001) discusses her lack of nursing or medical training and how her ethnographic role sat somewhere between what Gold (1958) describes as ‘participant as observer’ and ‘observer as participant’, recognising the complexities of managing herself whilst moving between these roles by acknowledging the emotional labour associated with an ethnographer’s (involuntary) engagement with emotion work. I will address my own positionality in the second part of this chapter which explores the practical implementation of the study.

Methods

> Qualitative research aims to generate in-depth accounts from individuals and groups by *talking with them*, *watching their behaviour*, and *analysing their artefacts* (Kuper *et al*. 2008: 405) [my emphasis]

This quote from Kuper *et al*. (2008) identifies the three methods of data collection that will effectively facilitate the gathering of relevant data in ethnographic enquiries, which are worthy of further theoretical discussion before I identify the methods specifically used by this study in part II of this chapter.

'Talking with them' (Interviews)

Ethnographic interviews are used 'as a way of shedding light on the personal experiences, interpersonal dynamics and cultural meanings of participants in their social worlds' (Heyl, 2001: 372). Interviews may be structured (consisting of a pre-determined fixed interview schedule including many closed questions), semi-structured (some questions may be pre-set, but using open questions or prompting is allowed) or unstructured (in which there is no formal interview schedule), or may consist of focus groups, which can be regarded as a group interview. The type of interview used will be dependent on the topic under consideration, the type of data required and resources available; however, for this research, semi-structured interviewing was deemed most appropriate to elicit the most credible and dependable data.

Although interviews are the ethnographer's most important tool of data collection (Fetterman, 1989), they may also be considered 'friendly conversations' (Spradley, 1979), or indeed a 'professional conversation' (Kvale, 1996: 2). When using an ethnographic methodology, a more relaxed and informal approach to interviews may be undertaken, and content from unstructured interviews often forms part of the 'thick description' of ethnographic narratives (Geertz, 1993).

It is important to acknowledge that the interviewer will influence the interview process (Oakley, 1981). This can be illustrated by Harris and Guillemin (2012) who suggest that, by developing sensory awareness, participation may be enhanced. They cite an example of a research interview relating to people's experiences of being in hospital in which the interview had been stalling. As a result, the interviewer modified her questioning strategy which was based on practical task-based aspects of acute care, to ask, ‘how did your hospital bed feel?’ This question enabled the participant to offer a revealing account of ‘blood-stained, pale grey sheets; cranked up beds and creaky mattresses’ that left the participant feeling ‘like an accident waiting to happen, like I could leak at any moment’ (Harris and Guillemin, 2012: 689). By using questions that evoke sensory memories, participants may offer deep explanations, useful for the thick description of ethnography.

Wenger (2003) explores some issues that are specific considerations when interviewing older adults, whilst also recognising that ‘most older people are just like everyone else, except that they have been around longer’ (Wenger, 2003: 128). She recognises that it can be difficult to gain access to older adults living in the community, as family members may act as gatekeepers and may try to avoid the involvement of their oldest family members, which can also be a concern when attempting to gain access to a potentially abused or neglected older adult (Norrie *et al.*, 2018). However, as nurses acted as gatekeepers within my study, it was their trust (and not the trust of family members) that I needed to gain to enable access to older adults.

‘Watching their behaviour’ (Observation)

> Nothing is stranger than this business of humans observing other humans in order to write about them (Behar, 1996: 5).

Hammersley and Atkinson (2007: 2) describe participant observation as a ‘cognate term’ for ethnography. However, participant observation is used as a tool of data-collection in other methodologies such as grounded theory (Glaser and Strauss, 1967). It is important to recognise that although participant observation is not always an ethnographic method, it is a ‘staple’ in anthropological (and particularly ethnographic) studies (Kawulich, 2005). DeWalt *et al.* (2010: 259) also recognise participant observation as ‘accepted almost universally as the central and defining method of research in cultural anthropology’.

Clifford (1997: 188) describes participant observation as a prolonged period of ‘deep hanging out’, which is not entirely straightforward, as ‘hanging out is a skill’

(Bernard, 2011: 277). This can be even more pertinent when observing people who are potentially vulnerable or frail, and thus ethical issues must adequately be considered and addressed before any observations begin.

Atkinson (2015: 25) describes participant observation as at the ‘heart of the ethnographic tradition’. However, he also prefers to describe this method as ‘fieldwork’. In contrast, DeWalt *et al*. (2010) note that, while fieldwork involves participating and observing people, as a method, participant observation includes the recording and analysis of the data for the purpose of social sciences. Participant observation involves potentially long periods of time ‘in the field’ which provides ‘an especially deep, extended and interactive research encounter’ (Clifford, 1997: 54). Bonner and Tolhurst (2002) authored a paper describing their experiences of conducting participant observation, which illustrates its potential as a method to gain valuable research data from nursing teams:

> Participant observation allows the researcher, therefore, to observe nurses’ actions and interactions, together with their antecedent and consequent conditions (Bonner and Tolhurst, 2002: 8).

Participant observation has advantages over other methods, including that it generates data that can offer ‘thick descriptions’. It provides a method of reporting on unscheduled events and can enable access to ‘backstage culture’ (DeMunck, 1998: 43). However, when combined with other ethnographic research methods, participant observation may become most useful, as it may help identify any discrepancies between what people do (participant observation) and what people say they do (interviews) (Agar, 1996), which was a means I also employed when triangulating my own findings.

‘Analysing their artefacts’

There may also be a difference between espoused values (desired behaviours) and observed behaviours (Argyris and Schon, 1978, 1996), and, through processes of artefact analysis and participant observation, it may be possible to identify discrepancies between these. Schein (2010) believes it is dangerous to infer deeper assumptions from artefacts alone, because the researcher's interpretations are a projection of their own feelings or reactions. However, this criticism may be directed to many methods of qualitative data collection where the researcher is the primary instrument of data collection.

Schein (2010: 26) described artefacts as ‘easy to observe and difficult to decipher’, and it may, therefore, be useful to undertake a semiotic deconstruction of artefacts found in an ethnographic study to reveal the multiple meanings behind what may be considered common objects. ‘Semiotic anthropology’ was first noted by Singer (1978), whose writing ‘contains a theory of how systems of signs are related to their meanings, as well as to the objects designated and to the experience and behaviour of the sign users’ (Singer, 1978: 224). Exploring semiotic understandings enable ‘systematic analysis of symbolic systems’ (Manning and Callum-Swan, 1994: 466), and thus a more detailed understanding of the complex healthcare environment can be achieved. Within my study, the use of clinical artefacts and their symbolic representations became apparent. For example, at face value, a commode may be a clinical aid to enable patients to access toileting facilities, which may be perceived as more dignified than using incontinence pads. However, as will be demonstrated in subsequent chapters, a commode is so much more than this; it becomes a symbolic marker of an ill or ageing body, a body that is demonstrably out of the person’s control, which is representative of patients’ internal power struggles and changing narratives, as they come to terms with their declining body.

Ethical concerns with research

There are ethical considerations when conducting any research, and the ethnographic tradition is no exception to this. The Association of Social Anthropologists (2011) and the British Sociological Association (2002) also provide guidelines for ethical research practice, and the ethnographer must act with integrity, ‘in terms of both complying with institutional ethics policy and being morally and ethically responsible’ (Halse and Honey, 2005: 2142).

When undertaking research with humans, particularly those who may be considered vulnerable, it is the role of an ethics committee to ensure vulnerable older people are not approached by unscrupulous researchers (Wenger, 2003). This reinforces the principles of the Nuremberg Code of Ethics (1947) and the Declaration of Helsinki (WMA, 1964). In part II of this chapter, I will now describe how I adopted an ethnographic methodology, firstly by considering ethical approval for the study.

Part II: The Practical implementation of the study

The study comprised fourteen weeks of fieldwork in 2017, involving observations of 62 clinical interactions between nurses (n = 13) and patients (n=40), and 22 interviews with both nurses (n=11) and patients (n=11).

Ethical approval

Ethical approvals were received from the University of Hull, Faculty of Arts and Social Sciences on 23/6/16 and Yorkshire and the Humber – South Yorkshire NHS Research Ethics Committee on 13/3/17 (Ref: 17/YH/0009. IRAS ID: 21677, shown in Appendix A). Once ethical approvals were received, the host organisation invited me to attend their Research and Development group on 11/4/17. Prior to this meeting, members had been sent copies of the ethics approvals, research protocol, risk assessments, data management plan, participant information leaflets and consent forms. I attended the meeting and answered their questions. Following confirmation of HRA approval (received on 28/4/17), the Research and Development Group gave their approval on 11/5/17, issuing their site confirmation, which remained in place until 31st December 2017.

Also contributing to ethical considerations is my own position in relation to the research. Therefore, before explaining how the study was implemented, it is also ethically essential to explore my own positionality and how this influenced the study design, implementation and analysis.

Positionality

Positionality enables researchers to be accountable for the position they occupy (Gatrell, 2006). As ethnographic research is experiential by nature, boundaries between discussion of the ethnographic research data and the ethnographer's existence or being may merge. Through a process of participation and observation, the ethnographer immerses themselves in the activity, not to produce the data, but to experience being, making them part of the data themselves. The position of the ethnographer, therefore, is a crucial component in understanding any data generated, and it is important for researchers to consider their own position within an ethnographic project, as gender, ethnicity, social class and other factors will be used (especially by critics of the methodology) to challenge methodological integrity by raising claims of bias and subjectivity, leaving the work being considered, at best, self-indulgent or, worse, not credible and thus meaningless. Through reflexive processes, the trustworthiness of the findings can be maximised, and criticisms of the methodology can be counter-balanced.

England (1994) believes that the researcher's biography and positionality influence fieldwork. Hammersley and Atkinson (2007: 11) recognise that when researching familiar settings, the ethnographer must treat the environment as 'anthropologically strange' and thus, although I have worked within the health service for eight years and some aspects of the environment may be somewhat familiar, it was important that I did not make any cultural presuppositions or take anything for granted. Okely (2012: 107) notes, 'learning about difference beyond the familiar and the avoidance of ethnocentrism, are a living challenge for anthropologists in the field'. Therefore, my status must be explored reflexively to enhance the research and counter-balance potential claims of bias and ethnocentrism.

When considering my position, I feel that it is important to disclose some of the precipitating factors that prompted me to undertake this particular topic of study – some of a more personal nature and other, professionally-related influences.

During this research, shortly before fieldwork commenced, my grandmother ('Oma') died at the age of 90, after a relatively short phase of acute-illness. Over the last ten to twenty years of her life, I saw a gradual decline in her health, mainly associated with age-related illnesses, which were interspersed with episodes of acute health needs, involving short admissions to hospital. As a granddaughter, I not only adored and loved Oma, but I also recognised both her individual vulnerabilities (due to various health conditions and her age) and structural vulnerabilities (resulting from her interactions with a health service that did not view her with the love and affection I did). My experience navigating aspects of the health system as a granddaughter and my professional role (which will be described shortly) influenced my choice of topic for this thesis, but also undoubtedly influenced the design, implementation and analysis of the project.

In terms of my professional influences, I am a qualified social worker, registered with the HCPC. As a registered social worker, I am bound to follow my professional code of practice (HCPC, 2016), which indicates that 'you must make sure that the safety and well-being of service users always comes before any professional or other loyalties' (HCPC, 2016; 7.4). I, therefore, held a dual-role when undertaking this PhD, firstly as student-researcher and secondly as a social worker. Thus, in my researcher role, I was bound by my professional and ethical code, which I was aware could potentially mean that I would need to intervene or act if I witnessed harmful practices. During his fieldwork, Norris (1993) observed police violence towards detainees; however, despite ethical considerations of what he would do, he chose to write up his findings without taking any further action. Norris was not a member of a regulated profession. By contrast, if I encountered a potentially abusive scenario, I knew would be unable to remain the passive ethnographic researcher (such as Norris), but would need to undertake some form of intervention. In reality, I was fortunate that I was not placed in a situation where this occurred, as although there were some dilemmas and challenges, such as my own perception (which was not shared by participants) of minor potential infringement of dignity (as described in 'A bum thing' and 'Amber's story'), these were not significant enough for me to necessitate my departure from the passive ethnographic role to undertake immediate or direct intervention.

From 2012, I was employed within the host organisation as their full-time Safeguarding Adults Specialist. I performed this role until September 2015, when I reduced my working hours to one day per week, to undertake a full-time PhD. Whilst I was still writing-up the thesis, in December 2018, I left the organisation to take on a different post as a designated professional for adult safeguarding within an NHS

Clinical Commissioning Group. This change in job role (moving from working in a provider to a commissioning organisation) also broadened my understanding of the phenomenon of dignity, as my practice experiences began to broaden away from the operational delivery of care towards some of the commissioning aspects of care.

As a member of staff in the host organisation, I had worked in this particular 'field', but I had not previously undertaken fieldwork at this site, which is an important distinction for Wolcott (2004), who notes that, without 'intent', being 'in the field' is simply an experience. I had been employed within the organisation for over eight years, and during this time I worked alongside some of the participants as colleagues. This included working in my role as a Practice Learning Facilitator, in which I supported nurse mentors with failing nursing students, and also undertaking home visits and attending Multi-Disciplinary Team meetings within my safeguarding role. I also previously led a safeguarding enquiry into care delivered by one member of the nursing team, and a couple of years prior to my fieldwork I led a major enquiry into a care home where nurses from this team raised significant safeguarding concerns. This history meant that some of the participants had worked alongside me as a practitioner, and I was not entering the field as a totally unknown person, which had both a negative and positive effect. The staff who knew me will undoubtedly have had preconceptions about me based on their former relationships with me. However, I felt my pre-existing relationships with staff were positive, which ensured I was able to fairly rapidly gain access to their 'backstage' and 'hidden' worlds. This became apparent in the second week, when one nurse secretly smuggled a sample of pink gin in a sputum pot to me which she covertly concealed from 'management' for me to sample when I got home.

During fieldwork, my safeguarding specialism was a blessing and a curse, as on several occasions concerned nurses would approach me with safeguarding issues, leading me to believe that I was never completely regarded as a researcher or ethnographer, as they were so accustomed to perceiving me in my specialist role.

My role, therefore, cannot be defined in binary terms of 'outsider' or 'insider', as I found myself in a liminal state, occupying 'the space between' (Dwyer and Buckle, 2009: 60). Although at times I felt an 'insider', there were significant factors that also revealed my ‘outsider’ status. I have no nursing training and, at times, my clumsy use of clinical and medical terminologies would have betrayed my outsider status to genuine insiders. I also asked nurses questions that they took for granted, which, at times, resulted in receiving strange looks from participants, as they must have wondered why I was asking questions that, to them, had ‘obvious’ answers.

Therefore, in this context, I do not offer a polarised perspective from an ‘insider’ or ‘outsider’, as my position is somewhere between the two. Perhaps it is more appropriate to think of myself as entering the field with an open mind, which, as Atkinson (2015: 58) states, is not the same as having an ‘empty mind’.

In the context of ethnographic research, although the emic perspective is valued more highly than the etic (Olive, 2014), a culture can be best understood by engagement and interaction in that culture, and I tried to fully engage in the nursing culture. In terms of my position, I am neither a nurse nor an older adult as defined by this study. An etic perspective may therefore be an inevitable consequence of my position, which may not necessarily be a disadvantage, as my perceptions have not been influenced by the experiences of being an older adult or community nurse.

The study design and implementation

The study design and implementation were governed by the research protocol, involving fieldwork (between July and October 2017). Fourteen weeks of fieldwork were mutually agreed by my supervisors, the host organisation and me, to be sufficient to generate high-quality, meaningful data which would enable revealing accounts of the experiences of older adults and community nurses, whilst remaining workable for staff and service-users within the service.

Following a period of observation, semi-structured interviews were undertaken with nurses (n=11) and patients (n=11). Nurse-participants ranged from a junior healthcare assistant to the most senior nurse within the team – some of which had been observed, and some had not. Patient-participants were both male and female aged between 60 to 93 years old, all of whom had previously been observed. The interviews offered the opportunity to ask standardised questions, for example, ‘what does dignity mean to you?’, but also presented the opportunity to directly question participants about encounters that had previously been observed.

The first two weeks were allocated to setting up the study. This involved briefing the nursing team about the aims and objectives of the study, answering any questions, seeking consent from staff-participants and supplying them with participant information leaflets to pass onto appropriate patients on their caseload who they identified as meeting the inclusion criteria.

The week before fieldwork commenced, I attended a community nursing meeting to outline the project, answer any questions and provide staff with information about the research, giving them the opportunity to consider if they wished to be involved. Staff were made aware that they were not required to participate and that they could withdraw at any time without having to give a reason. They were given the opportunity to ask questions, in addition to being given a Staff-Participant Information Leaflet (SPIL – shown in Appendix B). SPILs were also left in every team member’s pigeonhole, ensuring everyone was informed about the study, even if they did not attend the meeting or volunteer to participate. After the initial meeting, one community staff nurse immediately volunteered and requested a copy of the consent form, which I supplied, but I insisted she take time to consider before signing. At this point, a senior nurse shouted over, ‘I’ll do it as well. We are on the same team, so you might find it helpful to observe both of us’. Again, she was given a consent form to take away with the reassurance that she should take time to reflect before signing.

Over the fourteen-week period, I spent a total of 470 hours in the field, using two research methods: observation and interviews. Weeks two to fourteen consisted of observations between staff/ patients, and interviews commenced in week eight, whilst observations were still ongoing. The rationale was that conducting the interviews following a period of observation would yield richer data which could be informed by earlier observations.

The fieldwork followed an iterative, circular process in which: I observed interactions between staff and patients; recorded these observations in my fieldnotes/ reflexive journals; read research papers or articles that I felt related to my observations; informally spoke to participants to check out my thoughts; and then recorded further thoughts and reflections as a result of this. The process then continued *ad infinitum* allowing many different issues and ideas to emerge.

Research sample

Across qualitative studies, there is a wide divergence between sample sizes and sampling strategies. Mason (2010) examined sample size and saturation in qualitative interview studies of PhD students and found that the smallest samples were one (for a life history), while the largest sample was 95, but the median number of interview participants was 28. Bertaux (1981) indicates that fifteen is the smallest acceptable sample, although Ritchie *et al*. (2003) outline factors that further influence sample size, including the budget and resources available.

Taking all of these factors into consideration and because this ethnographic study involved two research methods (observation and interviews), the ethics committee agreed that overall sample size of participants was an unlimited number of patients and nurses to be observed, with a maximum of twelve patients and twelve staff to be interviewed. In reality, I interviewed a total of eleven staff and eleven patients. A full breakdown of all participants can be seen in Table 1A (patients) and Table 1B (staff).

Table 1A: Participant characteristics – patients

	Pseudonym	Age (if disclosed)	Gender	Tick if observed	Tick if Interviewed
1	Olive	60	F	✓	✓
2	Martha	62	F	✓	
3	Amber	63	F	✓	✓
4	Vera	64	F	✓	
5	Eve	67	F	✓	
6	Alistair	68	M	✓	
7	Warren	69	M	✓	✓
8	Don	71	M	✓	✓
9	Lucy	71	F	✓	
10	Doug	76	M	✓	
11	Barbara	77	F	✓	✓
12	Flora	77	F	✓	
13	Poppy	79	F	✓	
14	Jack	81	M	✓	✓
15	Alison	82	F	✓	✓
16	Justin	83	M	✓	
17	Millie	83	F	✓	
18	Beth	83	F	✓	
19	Antonia	83	F	✓	✓
20	Michelle	86	F	✓	✓
21	Margo	87	F	✓	✓
22	Cora	88	F	✓	
23	Maude	88	F	✓	
24	Rose	90	F	✓	
25	Winnie	91	F	✓	
26	Lizzie	91	F	✓	
27	Judy	93	F	✓	✓
28	Dora	94	F	✓	
29	Bill	94	M	✓	
30	Pru		F	✓	
31	Mabel		F	✓	
32	Brenda		F	✓	
33	Peter		M	✓	
34	Violet		F	✓	
35	Patience		F	✓	
36	Ruth		F	✓	
37	Viv		F	✓	
38	Betty		F	✓	
39	Simon		M	✓	
40	Ada		F	✓	

Table 2B: Participant characteristics – staff

	Job Role	Pseudonym	Age (if disclosed)	Gender	Tick if Observed	Tick if Interviewed
1	Case Manager	Denise	48	F		✓
2	Complex Case Manager	Nieca	48	F	✓	✓
3	Community Staff Nurse	Rina	47	F	✓	✓
4	Healthcare Assistant	Anya	46	F	✓	✓
5	Case Manager	Ivy	44	F	✓	✓
6	Healthcare Assistant	Chloe	34	F		✓
7	Community Staff Nurse	Daisy	31	F	✓	✓
8	Community Staff Nurse	Victoria	30	F	✓	✓
9	Community Staff Nurse	Mary	30	F	✓	✓
10	Community Staff Nurse	Sheila	29	F	✓	✓
11	Community Staff Nurse	Sapphire	25	F	✓	✓
12	Case Manager	Ella		F	✓	
13	Community Staff Nurse	Fiona		F	✓	
14	Bank Nurse	Jane		F	✓	
15	District Nurse	Claire		F	✓	

Inclusion and exclusion criteria

Staff sample:

To participate, staff members had to meet three criteria:

- Aged 18 or older

All staff were aged over 18 and thus were eligible for inclusion. However, the rationale for this lower limit was that there are times when apprentices, aged under 18, may be based within the team.

- Based in the community nursing team

The staff member had to be based within the specific community nursing team in which fieldwork occurred – this ensured all clinical job roles within the team were eligible for inclusion, ranging from healthcare assistants to senior nurses.

- Willingness to be involved in the study

The final criterion was a willingness to participate in the study, and, voluntary informed consent was essential. This was an opt-in study, and, people were not included without their consent.

Patient sample:

To participate, patients had to meet the following criteria:

- Aged 60 or older

As the study focused on the experiences of older adults, all patient-participants were required to be aged 60 or over.

- Under the care of the community nursing team

Patients needed to be under the care of the community nursing team. There were no eligibility criteria around the length of time they had been under the team. Participants' experiences varied from only a week to many years, or even decades, of receiving nursing care within the home.

- Mental capacity and willingness to consent to involvement in the study

Patient-participants needed to have both the mental capacity and willingness to give informed, voluntary consent to involvement in the study.

- Not living in a residential care home

The study focused on the experiences of older adults receiving care in their own homes. People living in residential care were purposefully excluded, as this is beyond the scope of this research due to there being a separate body of literature that examines these people's experiences.

- Ability to communicate in English

The final inclusion criterion was the ability to communicate in English, as there was no scope to use any translation services.

Data Collection: Benefits and incentives

There were no direct benefits for the participants who volunteered for this study. No incentives or rewards were offered, and this was clearly explained in the PPIL/SPIL (shown in Appendix B). The main benefit cited would be that their involvement could potentially lead to published accounts of community nursing care practices.

Participants

40 patients participated in observations.
11 patients participated in interviews (all of these had all been observed).
13 staff participated in observations.
11 staff were interviewed (9 of these had been observed).

The job roles of staff-participants spanned six clinical gradings which are known as 'bandings'. These included: healthcare assistant (bands 2 and 3), bank nurse (band 5), community staff nurse (band 5), case manager (band 6), district nurse (band 6) and complex case manager (band 7). Regardless of their specific job role, the generic terminology of 'nurse' has been adopted to describe all the staff participants in the empirical chapters, as their hierarchical position does not add any value to the presentation of the data, but, when it becomes relevant, their individual job role is noted.

Patient-participants were not ethnically diverse – all were White British. There was some ethnic diversity within the nursing participants, but further ethnic information will not be shared as this may potentially disclose their identity. In order to maintain confidentiality, where participants discussed their own experiences that may make them identifiable, I have not included their pseudonyms, reducing the likelihood of their identification.

Biographical narratives of patient-participants have been included where this has offered important contextual information or 'thick description', but this has been done in a manner that will not make them identifiable. Where relevant, or to offer background understanding, I have offered some discussion on the clinical intervention undertaken by the nurse, again in a manner that should not make anyone identifiable.

All nurse participants were female: the pronoun 'she' has been consistently used to describe nurses throughout this study.

Recruitment, sampling and informed consent

Staff members self-selected by volunteering to be involved in the study. Over the initial four weeks, staff usually approached me face-to-face to volunteer, but I also had one initial contact via email.

Once staff members had given consent to be involved, it was the staff members themselves that determined patient eligibility for inclusion. Each staff participant acted as 'gatekeeper' to patients. Once staff members signed a consent form (Appendix C1), I supplied them with copies of the PPIL to distribute to people on their caseloads that met the inclusion criteria. Wenger (2003) recognises that bias occurs when samples are generated through professionals approaching patients; however, this was the only way that I would be able to access patients as the ethics approval would not allow me to approach any patients directly.

Patients were given sufficient time to consider if they wanted to be involved, which, for most, meant they had at least a week to discuss this with family and ask questions before being asked for their decision. In advance of my first attendance at a visit, the nurse gained initial (verbal) consent from each patient-participant. During my first visit, I sought their agreement to participate in the study by requesting their signature on the consent form (Appendix C2 – consent for observation), and if any family members remained present, they were also asked to sign a consent form for their own participation (Appendix C3).

Ongoing consent was sought from the participants and, on my arrival at every visit, I asked each patient if they were willing for me to enter and to remain, reinforcing that they could ask me to leave at any time. I was never asked to leave any observations once they were underway. Patients who consented to interview were asked to sign a consent form prior to their interview (Appendix C4 – consent to interview).

The full process of consent seeking is explained in two flowcharts shown in Appendix D. To ensure the safe storage of personally identifiable information, as soon as participants signed consent forms, I allocated them a ‘Unique Participant Reference’ (UPR), which could not make them identifiable to others. I had a password protected spreadsheet containing a list of the participants’ UPRs linked to their allocated pseudonym. Minimal personal information was collected on the consent form – only the participant's name and signature. Completed consent forms remained stored in a locked filing cabinet, and they will be destroyed twelve months after the completion of this project.

At the request of the Health Research Authority, completed consent forms were also supplied to the host organisation for them to store on the patient’s medical record.

Method: Observation

During fieldwork, I observed 62 clinical interactions between members of the nursing team and patients. The length of time for each of these contacts varied. However, most of these visits lasted between fifteen minutes and one hour.

When travelling to appointments, I generally travelled in a car with the staff member undertaking the visit, which meant there was the opportunity to engage in purposeful conversations with staff during our journey. During the times that I was not undertaking formal observations between staff and patients, I situated myself in the nursing office, so I was regularly on-site, easily contactable and visible within the team. Many informal and unstructured conversations occurred within this environment (some conversations included me and some did not), and, although ethical approval was not gained to undertake formal observations in the office, some of the ‘office-chatter’ was helpful to inform some ensuing staff interviews.

There is no agreed definition of participant observation (DeWalt *et al.* 2010), but Agar’s (1996: 9) writing, *The Professional Stranger*, describes it as ‘more about observation than participation’. I am not qualified to assume a clinical role; thus, I did not clinically participate in any of the interventions. However, I cannot describe myself as a purely non-participant observer – it was far more complex than that. I found that whilst the nurses undertook their clinical business, many patients would either directly talk to me, or they would smile and initiate eye contact, displaying signs within their body language that indicated they wanted to talk to me. In these situations, I would respond accordingly, which, on many occasions, involved engaging in conversation, mainly listening, but using appropriate verbal interjections, such as ‘aha’, ‘right’, ‘tell me more…’ and ‘why’s that?’ which would encourage them to speak. I did not feel comfortable with simply ‘hanging out’ or being a voyeur of people’s complex healthcare interventions. I believe it is a privilege to be invited to observe nursing care in an older adult’s home, and I felt it would be rude to ignore any obvious attempts to engage me in conversation. Therefore, it is inarguable that I had an influence on the interactions between nurses and patients. Behar (1996) recognises that an observer will never make an observation that would have occurred without them being present, and indeed this has been the case in my study. As a result, in many of the ethnographic encounters described in the later chapters I firmly locate myself in the observation, speaking in the first person.

Sandelowski (2002) regards participant observation as an embodied encounter, and Pink (2009) notes it has been widely recognised that ethnographers share the sensory world of their participants. However, although I shared the physical space, I did not share a fully embodied sensory experience with patients whose care needs were being fulfilled. Similarly, I did not share the embodied experience of the nurse-participants as I did not participate in any ‘hands-on’ activities. Although I did have one embodied ethnographic experience of indignity, which I describe in ‘A bum thing’ (Chapter 5), generally the embodied experiences I had as researcher differed considerably from that of the participants.

Method: Interviews

Interviews were undertaken after some observations had occurred and also following a substantial amount of time building rapport during the fieldwork. Rapport is, ‘commonly used but ill-defined’ (Oakley, 1981: 35), yet it is also ‘an essential component of the interview’ (DiCicco-Bloom and Crabtree, 2006: 316). However, building rapport can lead to ‘ethical and emotional difficulties’ (Duncombe and Jessop, 2012: 112), if friendships are faked. Many of the nurses had existing relationships with me from my professional safeguarding role (and I made use of our existing rapport), but other nurses did not know me. None of the patient-participants were known to me before fieldwork commenced, which necessitated the swift development of rapport with them. Interviews were undertaken with both nursing staff and patients, and thus building rapport was a necessary preliminary aspect of my engagement, as ‘people will talk more willingly about personal or sensitive issues once they know you, once rapport has morphed into trust’ (Glesne, 2011: 144). Rapport is not only necessary for interviews, but it is also required for effective participant observation (Kawulich 2005), and it is developed over time in ethnographic practice (DiCicco-Bloom and Crabtree, 2006). Wenger (2003) notes that many older adults may equate an interview with a ‘test’, particularly if the researcher identifies themselves from an academic institution. When I invited people to interview, I clarified the situation by describing it as ‘a conversation that I record’, but I noted that one nurse said, ‘I feel like this is a job interview’ during the early stages of our interview, before we had both relaxed into the conversation.

A semi-structured interview schedule was used to offer some structure and consistency in the questions (see Appendix E). However, just as Kennedy’s (2004) ethnographic study of district nursing assessment practices used observational data to inform interviews, I used the knowledge gained from my observational data to ask supplementary questions and explore issues in more depth with participants.

At interview, participants were recorded using an audio recording device, making this data initially available in MP3 format. I then transcribed each interview recording into a Word RTF file and ensured that the written form was of a high quality, while ensuring that confidentiality was retained. For example, during transcription, if the participant named another person or an organisation, I removed names from the anonymised transcript and inserted a vague descriptor, such as ‘family member’, ‘nurse’ or ‘hospital’, so that specific individuals and places remained anonymous.

Interviews commenced in week eight, by which time I had undertaken sufficient observations to inform and assist my interview questions. Prior to the start of each interview, I usually engaged in general conversation, either about the weather, what a person’s day had been like or what they were planning to do at the weekend. I found this relaxed them a little and ensured they were receptive to a conversational style of interviewing.

To avoid influencing the respondent and to maintain a degree of objectivity, I tried not to share my own opinions, but there were times that I was asked directly for my view, or other occasions where I was unaware I had offered an opinion until later, when I transcribed the interview. If directly requested, I shared my opinions at the end of the interview when participants had their opportunity to ask me questions. In my re-presentation of the data I made the decision not to include quotes from participants if, on reflection, I felt that I had asked leading questions or that my words may have directly influenced their replies.

The interviews generally lasted around an hour. However, the shortest interview was approximately 45 minutes and the longest took nearly two and a half hours (although this included a number of short breaks).

Ideas began to emerge during the period of the interviews. Consequently, I adopted an iterative approach in which I checked out my understanding with subsequent participants, although this relied upon my memory, as I did not manage to transcribe each interview before conducting the next interview. I conducted a maximum of two interviews per day, and where possible I only undertook one interview. This allowed me to focus purely on the individual participant, without any distractions reflecting on other interviews on the same day.

Although ethical approvals allowed me to interview up to twelve nurses and twelve patients, I only managed to undertake eleven interviews with each group. I had scheduled interviews for twelve participants in each category. However, due to situations beyond my control, I was unable to complete the remaining two interviews. Nurse-Claire was due to be interviewed but, due to service-demands, she cancelled this twice at very late notice, which made our one-to-one unfeasible. The patient who was scheduled to be interviewed, but did not proceed, was Lizzie, who was 93-years-old and required palliative care. However, on the day I arrived to interview her, I found out that she had been hospitalised the night before, and thus I felt it was inappropriate for me to make further attempts to undertake our interview.

Data Collection: Unanticipated problems, ethical issues and methodological modifications

As fieldwork commenced at the start of school summer holidays, many staff members had annual leave during the first six weeks. Others were on maternity leave or became ill during fieldwork. As an example, the first staff member who agreed to be involved in the study quickly went off sick and did not return during my fieldwork, meaning she was never observed, nor interviewed, so I withdrew her from the study. I had not accounted for staff absences resulting in increased workloads for the remaining nurses, and it was apparent that having a researcher with them could slow down their work further. This resulted in occasions when I remained in the office, as no one was available or willing to take me out with them. At times, I felt the pressure of the team, and there were occasions when I acted as ‘taxi-driver’, taking one nurse to undertake her insulin visits when she had a flat tyre and collecting another nurse when she telephoned to say her car had broken down and she was stranded. There were several occasions in which the nurses said it was, ‘a shame you can’t sling on a uniform’. Thus, in an attempt to be a team player, I made myself useful to them in other ways, where possible, even though at times that simply meant walking to the local shop to buy some milk for their drinks. Undertaking these tasks allowed me to develop a rapport with the nurses and demonstrated my commitment to ensuring the smooth running of the team, rather than simply making demands on their time.

Prior to starting fieldwork, the operational manager suggested I may also like to wear a uniform ‘to blend in’. I declined her offer, as I felt it may imply I was there in a clinical role, and, as I was not permitted to undertake any clinical interventions, I felt wearing a uniform may be deceptive and unethical. Therefore, during the fieldwork, I wore my own clothes, which marked my appearance as different from genuine ‘insiders’.

None of the patient-participants were known to me prior to the research, and they knew very little about me, other than I was a researcher and PhD candidate. Therefore, I felt they initially treated me as a ‘friendly stranger’. On one occasion during my fieldwork, a nurse referred a patient-participant into the safeguarding team in which I worked, and whilst I did not disclose to my work colleagues my pre-existing relationship with this person, I ensured I did not manage his safeguarding case. I also made the decision not to invite him to interview, as I felt the potential conflict of interest could be problematic and, ethically, this felt the most appropriate action to take.

In contrast to my relationships with patients, some of the nurse-participants knew me as a colleague, with some shared histories. However, many of the other nurse-participants formed a new relationship with me, purely based on my role as a PhD researcher from the University. During the nurse interviews, one participant who had known me for years, became tearful and upset when openly discussing her work, which posed the ethical dilemma of whether to proceed with the interview. At the time, I made the decision to offer to halt the interview on several occasions, but each time, she said she wanted to continue, although there were times I chose to stop the audio recorder to allow her to speak ‘off the record’. As this nurse was my colleague prior to undertaking fieldwork, we had an existing professional relationship, but we were not personally connected. Roer-Strier and Sands (2014) recognise the interviewer’s position is central to interview dynamics, and my relationship with this nurse enabled her to move beyond the ‘official story’. I was aware that she was sharing deeply personal accounts with me, because we had built a good rapport with each other and she trusted me. Therefore, she felt able to reveal the burdens, pressures and emotional labour involved in her work. Thus, notions of relationship and emotional labour are important, not purely as thematic concepts. They also had methodological implications for the study, as without building trusting relationships with participants, it is doubtful that the quality, range and depth of data would have been collected. I also engaged in my own emotional labour during the study, which will be considered under the section ‘Transcription’.

Data management of fieldnotes

When in the field, I ensured that everything I wrote was anonymised at source (by using the participant’s UPRs). This ensured that if I ever misplaced my site journal (which I never did), the information would not contain any personally identifiable data, nor break any participant’s confidentiality.

My fieldwork journal comprised a filing system (akin to a Filofax) in which individual pages could be moved into different sections. At the end of each day, I transferred my handwritten notes into a ‘master’ journal which was safely stored in my home office (again to minimise any losses if the journal was misplaced). As the physical journal was so versatile, I could use it to record my observations in addition to my reflexive accounts and personal reflections. The thoughts and reflections I noted in my journal formed part of the data analysis, as they also assisted with the reflexivity that is necessary for a trustworthy qualitative study, and thus reflections are purposefully foregrounded in the empirical chapters.

During fieldwork, most fieldnotes were written contemporaneously. Picken (2013: 344) recognises the complexities of ethnographic enquiry: ‘you also need to be able to simultaneously – or nearly simultaneously record all your observations and write about them.’

There were three main physical locations where I wrote fieldnotes.

1. The nursing office

In her hospital ethnography, Davis (2001) explains how she used her computer to blend into her surroundings. Similarly, I found that when I was in the nursing office, docking my laptop and working from a computer screen enabled me to blend into the office environment. Without the laptop as my ethnographer’s aide, there would have been an obvious difference between myself and others in the environment.

2. In cars

As I travelled between visits in the staff members’ cars, I handwrote notes in my journal. This meant that, as nurses spoke to me, I was able to jot down keywords and phrases that I could later expand on. On occasions, I waited in the staff member’s car if they were seeing a patient who was not participating in the study, and this also provided a valuable opportunity to write down notes from previous observations, whilst my memories were still vivid.

3. At my home office

When at home, I would type up hand-written notes from the field and I would write reflexively about my thoughts, my ever-changing position and the influence I was having on the study. On some days, when my brain was working faster than my fingers would type, I used Dragon® software to aid swift recording and transcription of my thoughts, which was later edited manually to more accurately record my observations.

Transcription

Fieldnotes, observation notes and reflective notes were typed up, either in the field (at the office) or in a timely manner. On one occasion, when my time was severely limited, it was 48 hours after the observation that I first had the opportunity to write up my notes, but all other notes were written more promptly. This meant that at the end of my time in the field, all observational and reflective notes had been typed and no further transcriptions were required for these datasets.

However, data generated from the 22 interviews all required transcription. Once fieldwork had come to an end, I produced individual verbatim transcripts. In line with Braun and Clarke (2013), I am unwilling to label the transcripts ‘accurate’ (as this is subjective), but instead I focused on ensuring the transcripts were ‘thorough and of high quality’ (Braun and Clarke, 2013: 162).

Although Agar (1996: 153) notes that ‘transcription is a chore’, rather than view transcription in this way, I valued it as an essential part of data analysis. It was a lengthy and time-consuming process. However, it allowed me to familiarise myself with the interview data and assisted with the formulation of ideas. It laid strong foundations which ensured I was subsequently able to recollect much of the content of the interviews, as well as recall which participant said what.

To transcribe, I initially used Dragon® software; I listened to the interviews via headphones, whilst simultaneously speaking aloud the words allowing Dragon® to notate. This did not supply a high-quality transcript, but it was a starting point from which I returned many more times to manually edit. Speaking aloud the words of my participants was a hugely powerful experience. On occasions, I uttered words that had never passed my lips, nor have done since, and at times I found this to be both tiring and emotionally laborious, but it left me connected to participants’ stories, and ensured I was thoroughly familiar with the data.

Whilst transcribing the interviews I also maintained reflexive notes, which I referred to throughout and which supported the development of my analysis as my understanding deepened. Formal analysis of the interviews began through extensive reading and re-reading of the interview transcripts, as I noted down further emerging concepts and ideas.

Approaches to data coding, analysis and synthesis

From day one in the field, data analysis followed Braun and Clarke (2006, 2013), making it continuous and ongoing until the submission of the thesis.

The analysis was iterative and ongoing, in line with qualitative and ethnographic analysis. During fieldwork, analysis began through documenting observational notes, which offered detailed descriptions of events; as well as reflexive fieldnotes which monitored my positionality and factors that were changing and influencing the study. I also maintained theoretical and methodological notes throughout the period of data collection, and these were used as reference points, as concepts emerged and my ideas developed. In the course of fieldwork and beyond, I was looking not only for patterns but also aimed to identify any exceptions to these patterns.

All data; fieldnotes, observational data and interview transcripts were stored on QSR NVivo where ‘complete coding’ (Braun and Clark, 2013: 206) occurred. Coding was applied to individual words, sentences or paragraphs, and many codes overlapped. Codes were a combination of what Braun and Clarke (2013: 207) describe as ‘data-serviced codes’ and ‘researcher-derived codes’. These two types of codes meant that codes were allowed to emerge from the data (data-derived codes), but I was also able to add my own interpretations (researcher-derived codes).

Through the data coding process, ideas began to increase, and these were then clustered into appropriate overarching categories. These categories of data were reviewed, evaluated, written and rewritten, and existing literature or theory was being incorporated to form an essential aspect of the analysis. Once the themes were drafted, overlapping issues were apparent, and thus working and reworking the overarching themes continued until I and my supervisors were satisfied that all elements of the data had been appropriately explored and analysed. The data fell into one of three overarching categories or ‘themes’ – ‘Dignity in caring relationships’ (Chapter 4), ‘Dignity in caring for the body’ (Chapter 5) and ‘Dignity in the home’ (Chapter 6).

‘Writing down’ fieldnotes and ‘writing up’ findings

Once data had been coded and analysed, came the task of writing-up findings. Fabian (1983) differentiates the ‘writing-down’ of fieldwork from the ‘writing-up’ of a monograph. Transforming notes from the field into a comprehensive account of the phenomenon under study presented a major challenge to select the most appropriate data to present in the thesis. I had produced over 300,000 words of fieldwork notes and interview transcripts, which resulted in many potential examples of the same phenomenon. When selecting appropriate data, Guba’s (1981) criteria to assess the trustworthiness of qualitative methodologies was considered in terms of it being credible, transferable, dependable and confirmable. However, I had also attached my own value to much of the data, as I had formed close relationships with many of the participants who shared highly personal stories with me, leading to many hours being spent battling with my feelings that some stories were too precious to omit from my ethnographic re-presentations. Hesse-Biber (2007: 344) recognises that ‘writing involves ethical, moral and personal decisions’, and many hours were spent deliberating how to re-present some of the highly intimate and personal accounts of my participants in a way that remained faithful to their original, yet did not reveal their identity through my descriptions.

When writing up the thesis I felt it was important to balance data gathered from observations with data gathered during interviews to demonstrate how both methods produced meaningful and complementary information. To illuminate the emotional experiences of participants, many narratives have been presented in the participants’ own words, whilst I have firmly ground myself within the ethnographic detailed experience of my own direct encounters during observations.

Braun and Clarke (2013: 233) explain that as data generates no single ‘true’ story, it is important to tell a story that is faithful to the data. Therefore, the empirical chapters have been presented in this manner, in which the content remains faithful to the data without claiming to represent a single ‘truth’. As Geertz (1993: 9) summarises, ‘our data are really our own constructions of other people’s constructions’, or as Stanley and Wise (1993: 6–7) note,

> the researcher is an active presence, an agent, in research, and she constructs what is actually a viewpoint, a point of view that is both a construction or version and is consequently and necessarily partial in its understandings.

Thus, an ethnographic representation is the researcher’s re-construction of their participants’ interpretation of reality. As the data is offered as an ethnographic account, based on my personal experiences, encounters and observations in the field, it was important to consider how to present the data. Van Maanen (1988) indicates three options for data to be presented. First are ‘realist tales’, in which the data is objectified, as the ethnographer is absent from the account which is written in the third person. Second are ‘confessional tales’, written in the first person and depicting the ethnographer’s personal experiences within the field. Finally, ‘impressionist tales’ explore both the actions of participants and the ethnographer's thoughts. Most of my re-presentations fall into Van Maanen’s latter two categories, ‘confessional’ and ‘impressionist’ tales.

Trustworthiness of study

In seeking to establish the trustworthiness of a qualitative study, Guba (1981) uses the terms credibility, dependability, confirmability and transferability, arguing that the trustworthiness of qualitative research should be assessed by evaluating these aspects. To demonstrate the trustworthiness of this study I have evaluated all four components.

Credibility

Contributing to the credibility of the study is my use of two methods (observations and interviews), allowing data to be triangulated. Initial ideas gained through observations were checked out during interviews – some early theories held up to further scrutiny, whereas others did not and thus were not included. Credibility is enhanced by offering transparency over consent processes, interview schedules and open reflections of how my own positionality influenced the study.

Transferability

The study's transferability was enhanced by explaining the context of the research and offering detail of the process and types of data collected. The study provides thick ethnographic descriptions, to reveal people's lives, demonstrating how this can be applicable to people living in other areas, but in similar social situations, making it transferable to other contexts.

Confirmability

Confirmability is evidenced by following Braun and Clarke's (2013) approach to data analysis, which provided an objective framework for analysis. Observations have been re-presented reflexively to enable the reader to assess for themselves any researcher bias in operation. At times, these descriptions are written in the first person in which I firmly locate myself in the observation, making the narrative my own. Through consideration of my positionality, I have remained transparent in my motivations, beliefs, background and influencing factors.

Dependability

The study's dependability is apparent because the research process has been detailed – methods of data collection have been made explicit, the semi-structured interview schedule has been supplied and the process of data analysis and use of NVivo for coding has been discussed. The two research supervisors did not undertake a formal enquiry audit, but they examined and challenged aspects of data collection and analysis and offered feedback in order to ensure findings were better articulated and arguments were strengthened.

Time and the ethnographic present

Through the analysis of data, it became clear that 'Time' was an important constituent to themes within my work. Consequently, I feel there are methodological issues that require consideration in order to explain how I have represented time within the empirical chapters.

In my discussions, I have deliberately avoided the ethnographic present (the convention of presenting ethnographic research in the present tense) to reflect that cultures are not static. Giddens (1979) is critical of anthropologists who effectively develop their own version of time which negates the intrusion of temporality. In recognition of Giddens' (1979) perspective, I regard my re-presentation of data as an historical account. 'Synchronic studies raise fewer problems than diachronic ones' (Lévi-Strauss, 1972: 291), and thus the thesis is synchronic, offering descriptions of a nursing culture that continues to evolve, both organically, and in response to political and structural changes. Therefore, my thesis describes what *was*, and not necessarily what *is*.

In his *Confessions IX*, St. Augustine (1912) considers time in terms of the construction of memories and anticipation. He identified time as the past, present and future, acknowledging that the present cannot be broken down into smaller units; otherwise, it would not be the present, but an eternity. The past survives in memory, the future pre-exists in our anticipation and time is transient between the past and the future. Yet, these are not fixed points that can ever be reached. St. Augustine's *Confessions* remain relevant and applicable to dignity in community nursing in the 21st century because, in this study, all participants (nurses and patients) drew on their memories to describe past experiences, either of care in the home or in hospitals, and many participants also expressed views of how they perceived their future lives, including reflecting on their (potential) care needs. On many occasions, it appeared difficult for patient-participants to discuss the present. For people experiencing ill-health, dwelling on current difficulties may lack appeal, and, during our interviews, patient-participants may have found speaking about past or future events more appealing. For older adults receiving nursing care in their homes, reminiscing through memories of the past is an effective method of enhancing psychological wellbeing (Bohlmeijer *et al*. 2006). However, living in the present may be more meaningful to older adults than thinking about the future (Clarke and Warren, 2007).

Fabian's (1983) seminal writing, *Time and the Other*, recognised the coevalness of fieldwork and the allochronism of writing. I perceived that temporal distancing may be an issue for my work because 'fieldwork implies a sharing of time with the Other, but, when written about, the Other is placed in a different time from that in which the anthropologist places herself' (Hastrup, 1990: 51). Giddens (1979) also recognises that the study of social activity involves the elapse of time, and therefore static analysis cannot be undertaken. There were great challenges in reflecting time within the empirical findings, as they were not structured in a chronological manner and time had inevitably passed from my experience of an event to my writing-up of my account into this thesis. As 'Time' was one of my sub-themes (largely explored in Chapter 6), I felt it was particularly important not to distance myself temporally from the findings, and an acknowledgement of the passage of time between fieldwork and the conclusion of writing up the thesis required reflection in my language. As a result, my findings chapters are written in the past tense.

Introduction to fieldwork findings

The next three chapters present the trilogy of findings from fieldwork – 'Dignity in caring relationships' (Chapter 4), 'Dignity and the body' (Chapter 5), 'Dignity in the home' (Chapter 6). These chapters present analyses gained from observational data, interview data and reflexive journal entries. Observational data is often presented as an ethnographic narrative, and, at times, these are highly reflexive accounts of my observations. Rather than attempt to distance myself from the data, I was integral to each observation. Therefore, many of the observational scenarios are written in the first person. These reflexive insights assist the reader's understanding of how my position influenced the data and its re-presentation.

When presenting interview data where direct quotations are included, these have been indented and the pseudonym of the participant has been included at the start of each quote. All quotes are presented *verbatim*. The generic prefix 'Nurse' has been used if the participant was a staff member. Where there is no prefix to participants' names, the speaker is a patient-participant. Where quotes are from a patient-participant, their age (if known) has been placed in parentheses following their pseudonym.

Chapter 4: Dignity in Caring Relationships

Central concerns

This chapter begins to illustrate micro-aspects of relationships between patients and nurses that mirror macro-considerations of dignity and broader issues of social order. To consider dignity in action, the chapter adopts some specific terminology that is necessary to facilitate learning in this area. For example, nurses and patients are recognised and, at times, described as ‘social actors’, representing their agency, but acknowledging that this is restricted by internalised societal and cultural expectations that influence their actions. The chapter explores how behavioural expectations placed on people labelled ‘nurse’ and ‘patient’ are an influencing factor in how dignity can be constructed or deconstructed within professional nursing relationships.

The ‘dignity encounter’ was first identified in the literature review, in which it was noted that ‘any human interaction can be a dignity encounter – an interaction in which dignity comes to the fore and is either violated or promoted’ (Jacobson, 2009: 1538). This chapter adopts Jacobson’s terminology of the ‘dignity encounter’ to describe how two or more people in the nursing relationship have the ability to (de)construct dignity through their relationships with each other. The ‘dignity encounter’ then remains an important feature of subsequent chapters of this thesis.

This chapter considers dignity in relation to age, gender and choice. It demonstrates how (older) age is a risk-factor, allowing possible violations of dignity, explaining how, and why, patient-participants recognised ageism as a specific threat. Furthermore, the relevance of gender becomes apparent when the ‘dignity encounter’ is (de)constructed between male patients and female nurses, at times also inducing emotional labour. By scrutinising day-to-day aspects of community nursing care with older adults, it will be shown why ‘dignity in caring relationships’ is a central finding of this research.

This chapter reveals that dignity is a fluid and dynamic concept, which does not exist absolutely, but rather manifests itself through relationships as a socially constructed phenomenon. As social actors, nurses employ tacit or intuitive knowledge to create dignity within their relationships with others, making relationships critical mediators of dignity. This chapter explores the everyday practices of community nursing care to illustrate how dignity operates in practice, by considering how minute micro-articulations have the ability to (de)construct dignity within professional relationships.

Dignity: The impact of ageism and age

> **Judy (93)**: You try to keep your dignity, no matter how old you are.

Given that all patient–participants were drawn from an older adult population of people aged between 60 and 94, a common theme was that dignity remained important to them; or, dignity was *especially* important to them as a result of their age. Many of the patient-participants, however, identified their older age as a potential risk-factor for dignity. This was noticeably emphasised by some of the oldest patient-participants, such as Judy, aged ninety-three, who indicated why dignity was particularly important at her age.

> **Interviewer**: Is it important for you to keep your dignity?
>
> **Judy (93)**: Oh definitely […] not to be treated like an elderly person, as though I don't know what's happening, kind of thing. Cos some people act_ talk to you as though you don't know anything.

Indicative of societal perceptions that the value and worth of people diminish as they age, Judy's comment illustrates the presence of ageism when people communicate with older adults. Ageism 'is a form of oppression which results from individuals being discriminated against purely on the grounds of age as an indicator of competence' (Thompson, 2005: 5), and, as adults move towards the later stages of the life-course, ageist attitudes may feature in their interactions with others, including their engagement with health services. This is significant in terms of patients' interactions with their nurses, as barriers to dignity immediately occur if ageist beliefs underly their relationships. Ageism is often overlooked, or even socially condoned (Butler, 1969; Palmore, 1999; Nelson, 2005), and ageism continues to contribute to the poor healthcare of older adults (Kagan and Melendez-Torrez, 2015; Angus and

Reeve, 2006; Allen, 2015). As a result, older adults may also be more at risk of dignity violations than their more youthful counterparts.

Linking aspects of ageing to dignity was a common dialogue across the patient interviews. Their views indicated an assumption that some people perceive dignity as being less important for older people, which participants were keen to indicate was not the case, with dignity actually appearing to become *more* important the older participants were.

> **Margo (87)**: Dignity is…acknowledging people, listening, whatever their age.

Margo's words recognise that age should be irrelevant when it comes to dignity, yet many older adults described occasions when, due to their increased years, some people spoke to them in a manner that they felt was inappropriate, threatening their dignity. Margo was receiving community nursing care for leg dressings, but she had other health issues which were being managed by her GP and the hospital. She emphasised that to maintain her dignity she needed health professionals to listen and understand, not just simply hear her words and potentially discard what she said. This was prompted by her experiences with healthcare professionals when she was involved as a research participant in a clinical trial. During our interview, Margo explained:

> **Margo (87)**: They [clinical research staff] said, er, they thought I needed angioplasty and a [heart] bypass. Anyway, I got this thirteen-page letter… and, asking me, er, telling me about this project: 600 patients throughout the country, 300 were going to be given angioplasty, 300 were going to be given bypasses. And of course, there's no choice and it's anonymous. […] So, I was reading all this report and then I read it a second time and I thought, 'I'll ask about this'. So, there was a number and I rang. And I said, 'I've agreed to go into this scheme'. I said, 'however, I'm just a bit concerned'. I said, 'if I have angioplasty, it said I'll have 24 hours [in hospital], occasionally two nights'. I said that I can cope if there's no problem. I said, 'if I have a bypass_' I said, 'I phoned up_', I said, 'what will happen?' So, she said, 'you've got a pacemaker, so you'll be given an epidural and it is_ possibly you could be in hospital for ten days'. I said, 'Sorry'. I said, 'that I cannot do!' I said, 'I'm entirely on my own.' So, they said, well, you know. I said, 'NO! I mean I am ON-MY-OWN. I have_ who's

> going to bring me clean underwear, nightdresses, take home dirty underwear and wash? Nobody. There's nobody to do anything.'

This description evidences how clinicians and patients evaluate dignity in different ways, and how different priorities may affect dignity outcomes. It is Margo's concluding comments that begin to illustrate the issues she identified as important to maintain her dignity. Essentials were clean clothes and washing, which were challenges that remained unrecognised by the clinical trial staff, who did not understand the significance that a longer stay in hospital would have on her. Margo was an articulate woman, and from her explanation of this encounter with research nurses, it was apparent that she did not feel that the staff working on the project listened to her worries about the social aspects of her care. Nor did these professionals value Margo's concerns above their clinical priorities, concurring with Mandelsam's (2011) observations, considered previously in the literature review and expressed in terms of the question: 'what price surgery and what price a bath?' Important dignity concerns are suspended when nurses remain focused on applying beneficence to clinical issues, rather than considering wider aspects of care and how these issues retain significance for older adults' dignity.

The example from Margo is illustrative of the differing concepts of dignity that nurses and patients may hold, and, as experienced consumers of nursing services, it is unsurprising that patient-participants emphasised the importance of dignity within their relationships with nurses, expressing their specific vulnerability to dignity disruptions in terms of their older age. If dignity is conceptualised differently by nurses and patients, it will be more challenging to make it manifest, as there is no 'shared morality' (Harris and Sulston, 2004). As discussed in the earlier literature review, Harris and Sulston (2004) regard a 'shared morality' as a precondition for dignity, which is a perspective that will be revisited later in this chapter and subsequent chapters. Morals and concepts of dignity may be influenced by ageist associations, which Michelle recognised in terms of how care manifested itself from nurses, implying that it was due to her ageing years that the nurses were a little nonchalant, or hurried, in their care for her.

> **Michelle (86)**: Just because people are old, just because they're ill…it doesn't mean you can, erm…how would you say… slaphappy always comes to my mind [laughs].

Michelle explained that recently her care had been transferred to a different team of nurses. She preferred her first team of nurses as they took time to explain things to her and she felt that the current team were more rushed (or 'slaphappy', as she described it). Michelle's words were symptomatic of much broader systemic issues in healthcare, where there are increasing pressures placed on clinicians to spend less time with patients, as Levy and Banaji (2002) argue, discrimination against the elderly is likely to increase. This begins to pose issues of how time and temporality impact on dignity. The manifestation of dignity within the nursing relationship may be dependent on differing expectations of time. Thus there may be difficulties in the co-creation of dignity, if older adults are 'time-rich', whilst nurses remain 'time-poor' – challenges that will be considered in greater depth in Chapter 6.

Time limitations in the delivery of nursing care may make relationships (and interventions) hurried, meaning the pleasantries of conversations may be rushed or indeed absent. For older adults with ill bodies, it is not always the 'nursing' that is important to their dignity, as participants explained how their existential experiences of dignity manifested themselves, rather, through the relationship with their nurses. Smith (2012: 99) recognised that older patients are not usually popular with nurses because, as one student nurse from her study implied, 'physical demands of working with the elderly left little time for considering their individual feelings'. However, it is not always the physical (nursing) intervention *per se* that influences patients' experiences of dignity. Instead, for older adults in this study, dignity manifested itself in terms of their 'feelings' by evoking an emotional response to their relationship with the nurses, as explained by the patient-participants below.

> **Alison (82)**: Well to me personally they [the nurses] treat you as a person. They don't treat you as someone just laid there and they're doing their job. They have a little chat with you, they make you feel so much better, just by chatting, to me they do anyway they do.

> **Antonia (83)**: When I'm talking to 'em like I'm talking to you, I, I don't feel as old as I am. Or as old as I look, I just feel…all right

> inside […] They are very, make me feel like, like they should. That I'm, you know, I'm the one when they're here and they're doing everything for me.
>
> **Don (71)**: They make you feel so comfortable.

These comments illustrate broken bodies and existential dignity issues, as well as the role of relationships in creating dignity. When social actors interact, dignity can be socially constructed, or socially deconstructed through their interactions, making dignity both a constructed and embodied experience in community nursing relationships. Older adults experienced the social construction of dignity through emotional responses (their feelings), which was manifested via their relationships with nurses which left them feeling valued, cared for and acknowledged. Conversely, as illustrated in a quote from Antonia, dignity is quickly deconstructed when relationships do not manifest positive emotional responses.

> **Antonia (83)**: One time I think I told her [the nurse] about something and she said, [sharply] 'I know what I'm doing'. So, to me that was a real blunt reply.

It is micro-articulations of words, bodily movement and behaviours that can disrupt, or indeed, aid, the creation and construction of dignity. As was the case for Antonia, it may not be the actual words spoken by the nurse, but it may be her vocal tone that harms the relationship and undermines the possibility of the presence of a 'dignity encounter'.

It is a highly nuanced activity to construct dignity within community nursing relationships, based on social actors generating positive relationships with each other in order to create the essential conditions in which dignity can be co-created. Identity, complexity and contradiction are all determining factors when nurses and patients come together within their professional relationships, providing the basis for the (de)construction of dignity in their relationships. Understanding who people are, their individual circumstances and context, makes dignity more likely to manifest itself. For community nurses accessing patients in their own homes, this environment enables nurses to have greater knowledge and empathy of their patient's individual circumstances than when care is delivered in a hospital (which will be discussed at length in Chapter 6).

To enable the possibility of dignity becoming manifest, nurses employ tacit knowledge to navigate through complex relationships with multiple patients and their families, modifying and adapting their own behaviours in response to each individual. Although there may be some commonalities in terms of understanding what dignity means, people retain different subjective experiences and interpretations of dignity. Thus behavioural adaptions between each individual nurse and patient are necessary to reinforce dignity. At times, this is largely an unconscious act for the nurse, rather than being carefully planned and prepared for.

If individual differences between nurses and patients are not managed effectively, conditions are created in which dignity disruptions may occur. Dignity can be enhanced when nurses and patients interact with each other by enacting mutually acceptable behaviours – these behavioural expectations are not overtly negotiated, but usually manifest themselves informally through tacit knowledge or ‘trial and error’. As a result, problems may occur, and dignity disruptions may arise when mistakes (or misjudgements) are made in patient/ nurse relationships. When nurses adapt their behaviours between patients, this may be an unconscious act, but by doing this, they can ensure they meet the social and behavioural expectations of each patient, and these scenarios allow dignity to unfold. Illustrating this point is the ethnographic consideration of routine community nursing practice with Jack, an 81-year-old man under the care of district nursing for bilateral leg dressings.

Jack: Dignity, standards and respect

> **Jack (81)**: I think dignity is terribly important. It’s helping the disabled person in the hospital bed to be clean, washed, hair combed and sat up, so that they’ve got some self-respect. And they get their dignity back. Rather than just leave them lying there in squalor. And then again we come back to the nurses, don’t we? Cos them nurses need to realise that.

Jack remained seated on his sofa. Beside him lay a crumpled newspaper, the creases exaggerated by a magnifying glass lying over the text, next to a dirty fork strewn across various remote controls. A mobile phone, pliers and a scrunched-up tea towel were also on the sofa within Jack’s arms-reach. The cluttered sofa mirrored *the fullness of the lounge where there was limited space for District Nurse Claire to manoeuvre. The spiralling pattern on the Axminster carpet was covered in hair and crumbs. As a result, although Claire knelt on the floor to perform Jack's leg dressings, she began clearing newspapers off a nearby pouffe, which she instinctively regarded as cleaner than arranging her 'sterile field'*[3] *on the floor. Whilst she unpacked the necessary equipment, Claire spoke to Jack, discussing his future holiday in Wales, asking him about exactly how much vodka he planned to drink whilst there.*

Much later on, outside this observation, Claire explained to me, 'Each time I visit, I specifically look down the side of his sofa as that's where he hides his bottles of vodka.' As Jack continued talking to Claire about his love of cars and driving, Claire listened intently, paying little conscious attention to unpacking her nursing equipment, spreading the dressings haphazardly over the pouffe in no particular order, focusing her attention on Jack's words. Claire's unsystematic 'aseptic technique' was noteworthy, as it was unlike the careful unpacking I had observed when other (more junior) community nurses undertook preparations of their 'sterile field' – there appeared an inverse proportionality between the rank of the nurse and the care she took in laying out her equipment. In contrast to her *laissez-faire* approach to unpacking, Claire very carefully and gently unwrapped the bandage from around Jack's leg.

Under and over; under and over; under and over. Calmness ensued as she meticulously unwound the outer dressings. After removing the bandages, she discarded her soiled gloves to one side and replaced them with a new (clean) pair, before she interrupted the silence with a formal question:

'Are you experiencing any pain in your leg?'

'Yes – right here.' Jack pointed.

'Mhm'

---

[3] A sterile field is an aseptic area free from microorganisms. This is the space that nurses arrange the equipment they require to undertake their clinical work. This aseptic and sterile environment is necessary to reduce risks of infection and to protect the health of patients during clinical interventions.

The quietness resumed as Claire slowly began re-bandaging Jack's leg, whilst he silently looked on. Once finished, Claire picked up Jack's nearby drug card, checking what pain relief had been prescribed.

'That's quite a lot!' she exclaimed, before continuing, 'As you're still in pain, I'll speak to the GP for a medication review.'

Jack nodded. 'Can you get my socks that are drying on the radiator in the hallway?'

As Claire left the room to collect the socks, Jack turned to me and asked me to tell him more about my study.

*'I'm interested in dignity_' I began, but before I could say anything further, Jack interrupted_*

'_When you start dropping your standards, that's when your dignity goes.' (Jack was a retired military man)

'Standards are dropping terribly,' he continued. 'The whole world revolves around standards'.

I asked whether these opinions came from his military service and he reflected,

'I don't know whether that's where it stems from, or whether it was always there and the military's helped bring it out.'

Claire returned to the room and began placing a sock on the foot of Jack's newly dressed leg.

'That's better!' Jack confirmed as Claire settled herself back onto the floor to continue her work on his other leg.

This was the only occasion I observed Jack and Claire together, but, despite the silences, their positive working relationship was apparent. This was a routine, unremarkable interaction, but the mundaneness and unexceptional content of their encounter contributed to it being dignified. This was marked by long, but comfortable silences, by Claire's smiles and questions about Jack's holidays and by the careful, tender bodywork with which she engaged whilst undertaking his leg dressings. Dignity was not manifested from the 'sterile field', nor directly from the task of the leg dressing, but it was constructed in the relational aspects of their interaction.

During our interview, Jack revisited his views on the links between dignity and maintaining standards, recognising that as his health was declining and he lived alone, it was not always easy for him to maintain the standards that were so important to him.

> **Jack (81)**: Er. I'm afraid that my standards can drop occasionally. Er, but generally speaking I like to be up, washed, shaved and dressed. I mean because of my current circumstance, I find it easy to fall back into, er, being a sloth… Er, it's easy. It is so easy just to sit here with the television on, and a bowl of porridge.

This offered some explanation as to why Jack's sofa was encumbered by many objects. Jack was finding motivation difficult and as a result, was not making as much effort with outward appearance (personal and home) as he wanted, which appeared to be somewhat at odds with his longstanding beliefs that appearances matter. Randers and Mattiasson (2004: 64) recognise that when 'cultural conditions disappear there is a risk that relative dignity will also disappear'. Therefore, a declining social position has the potential to challenge an individual's ontological security and dignity, as their individual narrative requires reconsideration to reflect a potentially changed social position. This may have been the case for Jack, who had retired from the military. Thus, his military culture had been usurped by a civilian culture and lifestyle which, alongside matters of ill-health, contributed to Jack being no longer able to fully achieve the standards that had influenced his life for so long.

Jack reinforced his notion that dignity was related to standards:

> **Jack (81)**: I am a very big believer in the fact that second class standards are set by the receiver and not by the giver. Because if you put up with rubbish that's all you'll get.

Jack really emphasised the importance of this belief, instructing me to 'quote me on that'. From his statement, it is clear he believed that individuals have the right to self-determine what is acceptable and what is not, in terms of their own dignity standards. Jack's view implies that people should assert their agency to ensure that they receive dignified care because, if it falls short of their standards, they (the 'receiver') are responsible for challenging the professional (the 'giver'). Jack was staunchly independent and highly assertive; thus, his view is entirely in line with his own external presentation of his lifeworld. Other people, however, may be unable to assert their agency due to illness, disability or other factors (such as those lacking the independence and assertiveness of Jack), which makes them even more vulnerable to potential dignity violations, if, as Jack suggests, dignity is dependent on the patient's own ability to accept or challenge nurses' standards. Jack's view indicated that by asserting agency, people will receive higher standards of care if they challenge undignified care. By extension, patients get what they settle for in their relationships with nurses, and dignity is about not settling for anything less than one's own standard of nursing care. Yet, it must also be recognised these remain grounded in peoples' variable wider social expectations of standards and acceptability.

Jack's belief that dignity was linked to the maintenance of standards was reinforced by some of the nurse-respondents,

> **Nurse-Rina**: Dignity is, is you know… holding up someone's standards to what they believe their standards should be.
>
> **Nurse-Nieca**: [Dignity] It's embedded all the way through the NMC… Standards for us… er, dignity and respect… and that a new one out isn't there? Don't ask me the name of policies [laughing] […] I think you need to follow those standards. I don't necessarily agree with all the elements of the NMC… erm, but I think the standards are there for a reason and while the standards are there, I think we do follow them. I think we do try and abide by them. It's embedded throughout nursing isn't it? The NMC standards… erm, and there's all the white papers and within the white papers there is_ they refer back to the NMC, don't they, our standards.

Nurse-Rina agreed with Jack's view that dignity was achieving each individuals' standards. However, standards of care can reflect many varied expectations. For example, if someone has not been treated favourably throughout their life, their expectations may be far lower than a person with privilege who has become accustomed to higher standards and thus expects this as the norm. In contrast to Rina's opinion, Nieca emphasised that standards were set externally by bodies such as the NMC, indicating that it was these agreed standards (not patients' individual standards) that should guide the construction of dignity in nursing interventions. Dignity involves subtle behaviours and actions that become manifest through nurses' relationships with their patients. Therefore, dignity is such a complex phenomenon that it is arguable whether this can be achieved simply through adhering to reductionist NMC standards.

Although standards were an important feature of Jack's relationship with his nurses, he also linked dignity to self-respect.

> **Jack (81)**: Erm… I'm afraid I'm one of the old school, erm, I would always stand up if a lady came in the room …and …gone are the days when you stand up on the bus to give a lady a seat. They went out wi' the Vikings I think. But…that gives you self-respect as well. Doing it. It's… yes, it's something that you feel yourself [clears throat]. But don't forget I'm of a different generation to most people [clears throat]. I mean when I was a lad you would stand at the curb edge of the road in respect of a funeral that went past. They don't do that nowadays.

Jack's description is illustrative of the type of dignity Nordenfelt (2009) described as 'dignity as moral stature', in which the subject's actions reflect dignified behaviours. I asked Jack to explain a little more about self-respect and he clarified as follows:

> **Jack (81)**: Well it's something you earn, isn't it? You've got to earn self-respect.

During our interview, each time I asked Jack about dignity, his answers related to dignity in a broad context, rather than focusing on the district nursing care he was receiving, which is reflective of dignity being grounded in social experiences and expectations, rather than simply being linked to the NMC standards nurses follow when delivering care. As Jack did not directly link dignity and self-respect to the care he received from the nurses, to redirect his focus I decided to ask him whether he thought anything from my earlier observation with Nurse-Claire related to dignity. He responded:

> **Jack (81)**: Claire was dignified because she's got self-confidence, she knows exactly what she's doing. I was dignified because I was treating her with respect.

This is illuminating, as it offers an example of how dignity is created in the space between nurses and patients where their individual relationship lies with each other. It highlights how, for Jack, the nurse's display of self-confidence reflected *her* dignity, but, for Jack, *his* dignity was directly linked to the way he treated his nurse – i.e. with ‘respect’, which indicates that respect is a core feature of a dignified relationship between nurses and patients. According to Jack, Claire gained dignity from within, but he gained it externally as a result of his outward displays to the nurse. Jack perceived Claire as dignified, as she knew her trade and performed it well (i.e. to Jack’s own standards). Jack indicated that he and Claire both had standards and self-respect, and the enactment of these shared beliefs ensured their relationship supported dignity. Therefore, in this context, to enable a ‘dignity encounter’, social features of their relationship displayed their shared understanding of standards. Hence, within their interaction, they did not cause offence or embarrassment to each other, which supports Harris and Sulston’s (2004) explanations of a ‘shared morality’ being a necessary condition for dignity. It is when one person causes offence to another (whether intended or not) that dignity disruptions may occur, as will be illustrated shortly in the example of ‘Don and his nurses’, which sharply contrasts with Jack and Claire’s relationship.

Along with respect being an essential feature of dignified relationships, Jack’s next comments illustrate how micro-moments of dignity are manifested in individual relationships between nurses and patients,

> **Jack (81)**: I’m not talking about the nurses; but you can get people, in some walks of life where as soon as you see them you know they don’t care. [Pause] But nurses are different. They seem to have a dedication. Er…they ah, you just feel right when they’re there with ya.

Jack’s assertion illustrates how difficult it is to explain dignity and how intangible it really is. The positive emotional reinforcement Jack gained from his nurse led to experiences of dignity. The ‘dedication’ he refers to is the tacit knowledge, the skills, values, attitudes and approaches nurses adopt with their patients in order to co-construct a ‘dignity encounter’. Conversely, if a patient does not experience validation, their dignity becomes fragile in their exchanges with the nurses and there is greater potential for an undignified encounter.

Jack could not recall exactly how long he had been receiving community nursing care, but indicated it was somewhere between 20 and 30 years, during which time he had encountered many nurses. Although I had only observed one appointment with Claire, during our interview he explained how each individual nurse had a slightly different approach.

> **Jack (81)**: Some of them [nurses] are extremely…old hat. If you know what I mean.
>
> **Interviewer:** Tell me what you mean.
>
> **Jack (81)**: Starchy…er, professional nurse. Er…nothing wrong with it…old school. They do things the established old way…Then you get some nurses that are really laid back… and er [pause] they have a softer approach. But all in all, all of them do the job in their own way and they achieve the result which is what matters.
>
> **Interviewer**: Okay. So for you, it's more about, not how they do it, but about the result at the end?
>
> **Jack (81)**: I think that's most important, yes.
>
> **Interviewer**: Okay.
>
> **Jack (81)**: And I think, think this is the nub of the matter. It's the end product that matters.
>
> **Interviewer**: And for you, what's your end product then?
>
> **Jack (81)**: Feeling good after they've gone. And I always do. They always manage to, ugh, they always manage to lift me [Pause] […] Er. I think one of the reasons for that is because I'm stuck in here all day on me own and the very fact I've been [inaudible] someone. I've been getting an interchange of dialogue. Helps to make me realise there is a big world out there...

This excerpt from Jack's interview further indicates how dignity manifests itself through interpersonal relationships between patients and nurses. He expressed a typology of nurses, identifying them as 'professional', 'old hat', 'laid back' and 'softer'. Yet for Jack, it was not these different approaches that influenced his dignity, it was the 'end product' (his feelings once they had gone). It is important to recognise that Jack's 'end product' involved positive feelings once his nurses had departed, which is a much softer target than the goals of nurses and other medical professionals whose expectations are based around targets of reducing hospital admissions, controlling symptoms and healing patients. This presents another example of how clinicians and patients may perceive dignity outcomes from entirely different perspectives, understanding and evaluating the quality of the ‘dignity encounter’ in very different ways. Jack continued:

> **Jack (81)**: I think the way that you treat people does reflect on yourself. [Pause] And I believe that if you treat people with dignity, they will respond in a like manner.

Jack’s idea of reciprocity in relationships is important – if one treats another with dignity, it will be returned. This view was echoed by Olive, who stated:

> **Olive (60)**: If they’re polite to me, I’ll be polite to them. And that, yeah, yeah. If they’re funny with me, I can be funny, I can be funny back.

The reciprocity of politeness was also a feature of Olive’s description. However, as Olive would only grant politeness if she had first received this from the nurse, Olive highlights how the responsibility for politeness remains firmly in the realm of the professional, as it is the nurse who remains responsible for creating the appropriate conditions for dignity to flourish. Although Jack and Olive view dignity as a reciprocal concept, the subtleties of power relationships inherent in any patient/ nurse relationship remain, and respectively, dignity may not always have a mutually co-dependent status (as will be demonstrated in the next section, ‘Don and his nurses’, in which Don’s dignity remained intact, but the dignity of his nurses’ was fragile).

Jack and Nurse-Claire had managed to co-create a relationship in which they understood each other and shared an understanding about standards of acceptable behaviours within their relationship. Dignity can be enhanced when nurses and patients have shared beliefs in terms of how to interact with each other, but if one person finds the other person’s behaviours to be at odds with their own expectations, this may lead to embarrassment or shame and can cause the person’s dignity to become disrupted. It is when one person causes offence to another (whether intended or not) that dignity disruptions can occur. This fragility of dignity will now be illustrated through the example of ‘Don and his nurses’, in which it was the nurses’ dignity that was more delicate than their 71-year-old patient.

Don and his nurses – Challenges for the delivery of dignified care

Twice a day, nurses visited Don to administer his insulin. He was one of their first visits each morning and one of the last patients they attended every evening before returning home. For around four years, a small team of three nurses accommodated most of these appointments.

‘Drive safely,’ bellowed Don from his chair, as Nurse-Mary closed the front door behind us. Now outside his flat, we trundled down the flights of stairs. Mary turned towards me and whispered,

‘I find him tiresome’.

Despite her soft tone, these words echoed around the stark concrete stairwell. She grimaced as I smiled and nodded, unwilling to answer in case my words bellowed like Mary’s. We silently walked down the remaining stairs and, as we left the building and approached her car, I simply asked her the question,

‘Why d’you say that?’

She beeped her key to unlock the car door and looked up at me,

‘He tires me out, and it’s only my first visit.’

Mary casually picked up her diary from inside the car and opened it on the right date, as she flung herself into the driver’s seat. She began studying the long list of patient names written under the list of her tasks for the day, and, whilst avoiding my gaze she replied,

‘I know it’s bad, but when he does this, I just think he’s a pervy old man… [Name of nurse] just administers his insulin in silence, she says although it’s awkward it’s better than having to talk to him – that’s how she copes with it.’

So, what prompted such a strong reaction from the nurse, especially after receiving such a fond farewell from her patient telling her to ‘drive safely’? This was a twice-daily occurrence for her – the salutations were both genuine and routine, but so were the interactions that preceded them.

During our visits, Don always remained seated on his sofa in skimpy boxer shorts and a T-Shirt. He regularly told Mary,

'Oh, you're so beautiful, you're lovely…and you have such lovely eyes. If I were 30 years younger, ha, ha, ha…Come back here tonight, I've got plenty booze, we can have a party and then you can tuck me into bed…'

Don showered Mary with these words on most visits. All his 'compliments' focused on Mary's looks and attractiveness, not her skills or nursing abilities. Sexual overtones resonated in his words. He flirted with her, and although she responded politely and engaged in small-talk, Mary did nothing to encourage his libretto, choosing to ignore any innuendos. During our interview, Don told me he enjoyed a 'joke' with the nurses, which at times included 'pretending' to refuse his insulin, which he described as, 'having a laugh'. However, when I observed this in action, from Mary's reddening cheeks and audible sighs and tuts, it was apparent that this made her feel vexed, and at 8: 40 in the morning she always faced a long day ahead. I noticed that Don's behaviours had a detrimental impact on Mary – she would begin his visits with zest and enthusiasm, but by the time she departed, she was quieter and more subdued. In the later stages of my fieldwork, I visited Don with Daisy, another of his three 'regular' nurses, and he showered her with almost identical compliments. Just like Mary, Daisy also chose to ignore his words.

'Did I tell you I had to call the paramedics the other day?' Don asked.

'No.'

'I passed out. They told me if it happened again they'd have to admit me.'

'Was it your heart?' queried Daisy.

'Yes. I told them I'd go in voluntary as long as my two lovely and gorgeous nurses come too...'

Daisy bit her lower lip as Don continued,

'They asked me 'which nurses?' and I told them, Mary and Daisy. I told them I'll let them do anything except one thing…A bed bath. I don't want you doing that. I'll get embarrassed.'

'Can I have your finger please?' Daisy interjected.

Daisy required Don’s finger to administer the pinprick that would check his glucose levels, but, by ignoring his previous comment, she swiftly refocused the conversation to the task in hand, whilst simultaneously being able to take back control of the situation as a mechanism to restore equilibrium to her own dignity.

As Don moved his hand towards Daisy, he turned towards me and chuckled. ‘They [the nurses] make my day. I worry about them and tell them to look after themselves. I keep saying to Daisy, ‘if I was 40 years younger’!’

During their visits, both Daisy and Mary showed empathy and compassion toward Don. Their outward displays did not challenge his conduct, which effectively colluded with him and perhaps suggested to Don that they tolerated and accepted these behaviours. However, when outside Don's flat, each nurse would shake their head, raise their eyebrows, sigh or tut, which illustrated signs of emotional labour and revealed the frustrations they felt as human beings, as women. When I asked the nurses about Don, at times they offered justifications for his behaviours: ‘he’s lonely’, or ‘he’s just that little bit odd’. At other times, they recognised that although Don regarded his behaviours as a ‘joke’, to them it was ‘far from being a laugh’, but they also explained how he was ‘creepy, but not scary’. When alone with me, both nurses readily admitted his flirtations were inappropriate and made them ‘weary’. However, both Mary and Daisy were resigned to this being part of their relationship with him, indicative of the emotional labour inherent in nursing relationships. Mary explained how Don’s behaviours were ‘subtle’, which made them difficult to challenge, as Don was able to rationalise and minimise his behaviours:

> **Nurse-Mary**: [Don] would maybe be able to tell by my response… even if it was still jovial… that he would then immediately back-up something, ‘oh I’m joking, I’m joking’ because maybe he didn’t get what he thought he might have got out of it… but it’s all very subtle, it’s not like having to turn round and say, ‘you’re being out of order, don’t say that to me’.

Outwardly, Don showed little awareness of the impact that his sexualised words had on the nurses, and, if he recognised any signs of discomfort in his nurses, he chose to ignore them. The way in which Don had historically embodied his own masculinity became apparent during his interview when he explained:

> **Don (71)**: I enjoy teasing and, and having a bit of fun, do you know. Cos I've always been like that. You know. I mean my late wife, she used to say to me 'I wish you would stop it Don, cos some people may not appreciate it' and I said 'well…Tough'. Tough. If they don't like it…well, they know what to do.

The relationship between Don and his nurses was complicated, as they lacked consensus over what were acceptable and unacceptable behaviours within their relationship. Giddens (1991: 36) describes a 'shared, but unproven and unprovable framework of reality', and although Don regarded his communication as acceptable, the nurses did not. Therefore, it was the times his dialogue veered towards a sexualisation of the nurses that tensions arose, which led to potential disruptions to his nurses' dignity. Through the nurses' failure to directly challenge or address the issue with Don, he appeared to remain unaware of the effect he was having on them.

During her interview, Mary explained:

> **Nurse-Mary**: Personality-wise he can be sort of quite hard work and test boundaries a little bit… erm…but I think if you have sort of a professional relationship with him, but it's boundaried in that you can still be sort of_ […] You know, to be able to get him to open up to you if he didn't feel too well, or if he had a hypo or you know… He's recently sort of been having DnV [diarrhoea and vomiting] quite a lot and he said, 'oh I don't tell anybody else apart from you' and I thought that is because of how we get on.

Don clearly experienced his relationship with Mary positively, as he felt able to disclose his diarrhoea and vomiting. However, their relationship remained unsatisfactory for Mary, who showed no indication of directly expressing her displeasure with Don's sexualised remarks.

Jacobson (2009) explains that dignity violations occur as social actors create meaning in their interactions through the sequence of gesture, interpretation and response. In this context, there were no readily apparent breaches of Don's dignity, yet Mary's dignity remained highly fragile in her exchanges with Don. When social actors engage each other, it is their individual subjective experiences, framed in societal expectations, that enable them to attribute meaning to each other's physical and social markers. Thus, through the sequence of gesture, interpretation and response, relationships are formed, and this can lead to a dignified encounter, or, alternatively, result in a dignity-reducing encounter. Language crafts power relations, and although verbal dialogue facilitates the level of dignity within the spoken encounter, to ensure the manifestation of dignity in the social encounter, it is also important to avoid 'unmeant gestures' (Goffman 1959). Unmeant gestures are sources of embarrassment or disruption to the performance, and Don's 'unmeant gestures' (his 'jokes') resulted in disconnection in the dignity relationship between patient and nurse. It was the occasions Don's unmeant gestures were interpreted by the nurses as 'odd' or 'pervy', that the nurses' dignity was potentially violated, or, at least, the dignity of the nurses was highly fragile.

By virtue of their profession, nurses are in structurally powerful positions. However, patients may retain social power or gain power from their individual status. Despite the structural power of nurses, the nurse's individual power or their ability to assert their agency may be minimised, because, in situations such as when working with Don, it may be more difficult for the subject of a dignity-reducing encounter to respond assertively. Additionally, for many women, it is perhaps a more rehearsed response to ignore, rather than challenge, unwanted sexual attention, especially when confronted with Don's behaviours, many of which were clear expressions of his masculinity. Hence the intersection of a range of personal factors, including gender, ethnicity and age, all impact on individual relationships between nurses and patients, and these are mediated by each individual's structural, positional and individual power. These complex dynamics all play a role in how relationships manifest themselves between nurses and patients and, if managed successfully, can result in a 'dignity encounter'. Yet if these differences are not successfully negotiated, disruptions to dignity might occur.

Don's relationship with his nurses was complex, and, along with some behaviours that challenged the nurses, he clearly had many endearing qualities. His regular valediction, 'drive safely' came from a position of genuine care and regard, which he explained during his interview,

> **Don (71)**: I may be wrong but I think they like that [I tell them to ‘drive safely’]. Because it shows that, that I like them and I respect them […] I care about them, er, and I have a lot of respect for them. Cos every time they go out, I always say to them, ‘you drive carefully’.

Don appreciated the care he received from Mary and Daisy. He recognised his arthritic hands no longer had the dexterity to self-administer the insulin he needed, and he was reliant on nurses to provide this care to him. The ‘caring’ aspect of their relationship was reciprocal: the nurses provided physical care to him by administering insulin, and, in return, Don expressed his ‘care’ for the nurses by telling them to ‘drive safely’ and ‘joking’ with them. In the previous discussion of Jack, it was described how he regarded dignity as a reciprocal relationship. However, although from Don’s perspective the ‘care’ within his relationships with the nurses is reciprocated, it is evident from Daisy and Mary’s discussions that they did not entirely share this view. Therefore, dignity was not experienced reciprocally by the nurses, even though Don himself believed he treated his nurses with dignity. Therefore, when dignity is (de)constructed through relational aspects of care, these are subjectively (and not necessarily mutually or simultaneously) experienced.

The nurses internalised Don’s farewell salutation (‘drive safely’) differently from his flirtatious words, which threatened their own dignity. ‘Drive safely’ was recognisable as Don’s way of showing that although the nurses cared for him, he also cared for them. In contrast, during the times he spoke in sexual innuendos, it was more difficult to identify aspects of care in his words. Don outwardly justified these occasions as ‘joking’. However, if humour was his intention, the nurses did not interpret and construct meaning in this way.

In this exploration of Don’s relationship with two nurses, it has been demonstrated how Don (inadvertently) caused offence to Mary and Daisy and how this potentially disrupted their dignity, whilst Don’s dignity seemingly remained unaffected. The ethnographic account of Don and his nurses began to introduce notions of emotional labour, in terms of how Mary and Daisy engaged with Don. This manifested itself through their mental preparations in advance of entering Don’s flat, the maintenance of what they regarded as a professional demeanour during their interactions with him, and then, after their visits, being able to unburden themselves by using more authentic language when describing their experiences. In the next section, emotional labour will be considered further in the context of nursing care, which is especially significant in terms of gendered relationships. It will be shown how nurses identify that emotional labour is necessary to allow them to create dignity in their relationships with some patients.

Gendered relationships, dignity and emotional labour

Steinberg and Figart (1999) indicate that most work activities involving emotional labour do not necessarily intersect with sexuality. However, on many occasions, the emotional labour of nurses is firmly located in their sexuality or gender, as was described in the aforementioned example of Don's nurses Mary and Daisy. Whilst it is important to recognise that patients may also engage in emotional labour, the focus of this section remains on the emotional labour that nurses undertake when working with patients and how this aids, or undermines, dignity.

Hochschild (1983) first conceptualised emotional labour in terms of the work of flight attendants in the aviation industry. However, it is widely recognised as a feature of other service-industries or vocations, such as nursing. Hochschild and Machung (1990) explored work in the home by focusing on the lives of two-job couples and their division of domestic labour, concluding that the work of the home is devalued by society and remains largely within the scope of women. The diminished value of this work has consequences for staff working in community nursing teams, which largely comprise of women delivering care within the home. Smith (2012: 28) also recognised that 'professional care work undertaken in the home may be similarly devalued', which indicates that community nursing care in the home may assume a low status. Jobs involving large amounts of emotional labour are likely to be female-dominated occupations (Smith, 2012), as exemplified by nursing, which is clearly a female-dominated profession. Indeed, the staff-participants in this study were all female, reflective of the all-female staff team in which they were located.

Regular engagement with emotional labour can not only have implications on nurses' relationships with their patients, but can also influence nurses' own family lives, as in the example of Nurse-Denise, who described how emotional labour as a consequence of her profession, manifested itself within her personal life.

> **Nurse-Denise**: When you're on your own and you take these things home and you've got the kiddies…majority of times, when, and I have openly thought, 'I'll have a glass of wine' – that wine's gone into a bottle when you've had a bad day at work, which i'n't always a good thing to do…

Nursing activities involve large quantities of emotional labour (Smith, 2012; Theodosius, 2008; Delgado *et al.* 2017). In the quote below, Nurse-Sapphire uses a simile to emphasise the importance of containing emotional labour to maintain professional relationships, which she implied could have disastrous consequences if released.

> **Nurse-Sapphire**: Say you're having a bad afternoon, you sort of have to keep it in and we all have to do [it] when we're having a bad [day]. We can't portray that [it's a bad day], but sometimes in this job I feel as though the pressure's immense and I think… you're like a ticking time bomb.

Emotions are symptomatic of the emotional labour which nurses are engaged in; hence the 'ticking time bomb' described by Nurse-Sapphire threatens the dignity of both the nurse and patient, as unregulated or uncontrolled displays of emotion from the nurse can reduce the likelihood of a 'dignity encounter'. This ability to control the 'time bomb' and conceal emotions may be more challenging when delivering care in the home, than when working in a hospital, as Nurse-Ivy explained.

> **Nurse-Ivy**: I know this is supposed to be the community isn't it? It's not a hospital ward-based…. it's the community it's the home… but then you know, like, do you know what I have to try and do? I have to… when I get like this [tearful], I have to stop the way I feel here inside [places hand on heart] and I have to put a persona on and it's hard.

Nurse-Ivy recognised she used a 'persona' to manage her emotional labour, which was necessary to enhance relationships with patients and support the development of a 'dignity encounter'. As emotional labour involves 'the management of feeling to create a publicly observable facial and bodily display' (Hochschild, 1983: 7), by achieving this successfully, conditions are created in which patients' dignity can remain intact. People are socialised into norms that guide emotional expressions in different contexts. Hochschild (1983) indicates emotional labour consists of 'feeling rules' involving two types of behaviours to manage emotions – 'surface' and 'deep' acting. Nurse-Ivy's 'persona' included 'surface acting' which involved consciously changing outer expressions to ensure internal feelings were not displayed outwardly, which Yang and Chang (2008) indicate is inauthentic. When 'surface acting', 'nurses modify and control their emotional expressions' (Yang and Chang, 2008: 883), and this may produce mistakes or dissatisfaction (Hochschild, 1983) due to the lack of authenticity. By contrast, 'deep acting' may produce satisfaction (Hochschild, 1983; Yang and Chang, 2008), and this involves expending effort to regulate emotions as the person actively invokes memories, images and thoughts to facilitate changes to their internal feelings to match outwardly projected facial displays. This means that nurses may need to present many faces (Bolton, 2001), allowing them to adapt to individual circumstances and situations. Therefore, nurses have been described as 'emotional jugglers who are able to match face with situation but not necessarily with feeling' (Bolton, 2001: 86), which was echoed in Nurse-Sapphire's next comments.

> **Nurse-Sapphire**: We're human beings and I feel as though in this job, in particular, you can't express how you feel, which I understand you have to keep your… emotions intact and you have to act as a professional, but how long can you keep hold of that?

This quote from Nurse-Sapphire concurs with Bolton's (2001) view, recognising that it is not always appropriate to express internal feelings outwardly towards patients. It follows that professional characterisations must remain uninterrupted, despite the times when contrary emotions may remain at odds with outward displays, which is, in itself, an act of emotional labour.

Yang and Chang (2008: 880) indicate that 'emotional labour requires that one expresses or suppresses feelings that produce an appropriate state of mind in others; that is, a sense of being cared for'. To ensure dignity remains intact, there are times nurses undertake 'surface acting' to conceal their own feelings. However, it remains important that they are not perceived as robotic or mechanical in their relationships with patients, resulting in an inevitable tension between displaying authenticity and being robotic.

> **Nurse-Mary:** [Nurses should] show [patients] that you're human, you're not a robot, you're not just coming to do this intervention […] I think sort of being able to… relate in an appropriate way as well. To a degree… without sort of giving too much away about yourself or your personal life…erm… I think a real lot of it is letting people realise that you're human and you're not just… like a machine who's just coming round to do this and then that's it.

From Nurse-Mary's words, it is important that nurses show their human side whilst remaining professional, which illustrates the potential for effortful 'deep acting', in which more genuine emotional displays are possible within nursing relationships. Damasio (1994) indicates that work devoid of emotions is poor, and, thus, as Nurse-Mary's quote implies, it is necessary for nurses to display some emotion, as nursing devoid of emotion will not create dignity. Steinberg and Figart (1999: 9) explain that emotional labour emphasises 'relational rather than the task-based aspect of work found primarily in the service economy'.

However, the emotional labour of nursing stems not only from their relationships with patients but also through undertaking tasks during their care of ill bodies that may be highly distressing, such as Nurse-Victoria's description of how, with one particular patient, it was important for her to regulate and control emotional displays.

> **Nurse-Victoria**: This chap, erm, I wasn't aware of his history and he…erm… unfortunately had cancer, but he had a craniotomy and they'd taken way a lot of the bone flap, so it was an open wound, so you can see like some of the… erm… it was just a really like nasty open wound really, erm, quite deep as well into his head so erm… and it was really icky, it was just everything you wouldn't want a wound to be. […] I undid his dressing to check his wound erm… and was so quite surprised by it. But luckily I was stood behind him, because I wouldn't ever want a patient to see [my reaction]_ I don't think it's professional, or just [not] nice to see any_ to register any sort of shock at something on someone's body, you know, I just think it's just not… it wouldn't be good, so I was just sort of glad that he didn't… register that anyway, you know.

Although emotional labour is often described in terms of being a by-product of relational aspects of a job, Nurse-Victoria's description exposes how bodily malfunctions and clinical crises managed by nurses can also involve emotional labour and regulation. As Leidner (1999: 87) notes, 'scripting of speech, movement, and body language is an especially common approach to regulating emotion work', which describes the challenges Nurse-Victoria recognised above. Failure to script speech and manage movement and body language may cause discomfort or embarrassment, and these feelings of discomfort or embarrassment have the potential to lead to a disruption of dignity. Nurse-Victoria appeared acutely aware of this in her interaction with her patient who had a head wound. Indeed, she recognised concealing her shock was necessary to preserve his dignity (and also potentially reinforcing her own dignity by regaining her composure). As human rights legislation imparts legal responsibilities on nurses to ensure their encounters with patients retain dignity (a legal responsibility not bestowed upon patients), nurses such as Victoria may work hard to conceal their emotions if they believe displaying their true emotional responses may disrupt their patient's dignity. Similarly, patients also acknowledged that nurses should maintain professionalism and not allow personal issues to affect them whilst at work.

> **Jack (81)**: you've got to remember… that the nurses are terribly overworked, overstretched. That they have their personal problems same as we have, but they can't allow them to overflow and influence their work…

Jack recognised that nurses have high workloads, which also reinforces Smith's (2012) argument that nurses now have little time to do anything other than meet patients' physical needs. This highlights one of the issues that will be dealt with more thoroughly in Chapter 6, in which issues of time become important in the consideration of dignity in the home.

Jack expressed his expectation that nurses should not display emotional responses to personal issues and the following quote from Nurse-Anya concurs with this view, illustrating how 'the nurse', like many other professions, becomes a persona in which personal issues remain concealed from others.

> **Nurse-Anya**: They [patients] don’t care what your day’s like. They care that you’re there to do their legs, have a chat with them, and brighten their day. They don’t care if you’ve just had a_ if someone’s just broke into your car or you’ve just been given another 50 visits, they don’t want to hear that. They’re the most important person at that time.

Nurse-Anya’s explanation indicated some of the emotional regulation she undertook to sustain relationships with her patients. Other nurses described examples of emotional labour, and these were often related to their (female) experiences of managing relationships with (male) patients.

> **Nurse-Nieca**: From another perspective [of] dignity, men! Sometimes we've had some really, really… erm… Awful situations where they’ve been sort of, erm….there’s been sexual, sexual elements to it where they’ve sort of you know been… pervy.
>
> **Nurse-Denise**: We’ve had some gentlemen that think it’s OK to touch your boobs, your bottom, or to give you a cuddle when we’re not there for that. It’s mainly, the erm, the gentlemen, the older ones.

The sexualisation of nurses, as described in the quotes above, is not a new or surprising finding in this study. Yet, it remains relevant when considering how relationships between nurses and patients influence the construction of dignity. Relationships are integral in professional nursing practice (Pierson, 1999), and gender is a rehearsed act (Butler, 1988; 1990; 2004). Therefore gendered performances, and any associated emotional labour, influence relationship displays, which can aid or hinder the construction of dignity in community nursing care. Butler (1990) views performances as both the result of individual identity and simultaneously a source that formulates identities. As a result, gender is socially constructed through performative acts of speaking (*parole*) and nonverbal communication (gestures). In this study, all nurse-participants were women, and in the context of this research, it became apparent that gender was an important consideration in how dignity was manifested (or failed to be manifested) in community nursing relationships, as well as how their gendered relationships with patients involved emotional labour.

Nursing remains a feminised profession. Although, as social actors, nurses retain structural and positional power from their profession, their social position and experiences as women also influence and shape their professional relationships with others. Throughout their lives, women become accustomed to managing everyday sexism, which transfers and extends into their professional careers as nurses. Nieca was one of the longer serving nurses, and she discussed some of the ways nurses were sexualised. Although at the time of her interview she held a senior role, Nieca recalled a patient she cared for when she was in a more junior position.

> **Nurse-Nieca**: Erm, yeah I've had a patient where when I walked in and he constantly_ he used to have pornos on, pornographic videos on and it was horrifying erm…

As an example of how she engaged in emotional labour, Nieca continued to explain that she responded to the situation by ignoring the issue (also in line with the strategy Mary and Daisy adopted of ignoring Don's sexualised language). Nieca said she did not acknowledge what her patient was watching and explained she would casually say, 'I've come to do your leg, can you just switch the TV off?' Nieca's actions concur with Dan *et al*.'s (1995) findings that nurses commonly respond to harassment by ignoring the behaviour or avoiding the harasser. Through their interviews with nearly 2,000 Canadian women about their experiences of public and workplace harassment, Gruber and Smith (1995) also found that women adopted non-assertive responses to harassment. In their study, they found that women generally responded non-assertively if the harassment was deemed not severe, as appeared the case for Nieca. Although Nieca chose to ignore the issue, she described the scenario as 'horrifying', demonstrating her distress and offering a clear articulation of the emotional labour required to manage the professional/ patient relationship in situations, which clearly constitute dignity-reducing encounters for the nurse.

Nieca disparagingly categorised certain patients as 'not the really older men, the midlife crisis men'. She generalised these as male patients who displayed unacceptable behaviour when nurses delivered catheter-care, which included the inappropriate revealing of genitalia to the nurses, or one specific patient who 'used to put furry handcuffs on top of the care plan when we had paper care plans, so you'd have to move that'. Placing furry handcuffs on the care plan may be regarded as 'low-level' sexualised behaviour; subsequently, the response from Nieca (removing the handcuffs) was proportionate to an isolated incident. However, as women regularly encounter sexism and harassment, they develop tacit knowledge of how to manage such situations. The nurse-participants in this study were able to articulate their methods of managing male advances in the professional context of their nursing relationships with patients, but these approaches were based on tried and tested methods they had rehearsed within their normal day-to-day lives, as women. Because low-level sexual harassment is routinely experienced by community nurses within their relationships with patients, and as each individual incident may be minor, it can be easily dismissed. However, cumulatively, being subject to these behaviours may result in significant emotional labour, stress and pressure, which is something that remains unrecognised in the training, supervision and ongoing support of nurses.

Every nurse-participant identified examples of sexualised behaviours they had encountered professionally. Therefore, during the interviews, I asked all nurse-participants if they had ever received any training on how to deal with these behaviours. No-one was able to identify any specific training they had received (from their training as student nurses to their current roles as qualified nurses), which suggested the sexual behaviours of patients remain unacknowledged within the nursing curriculum. However, this is clearly something that remains a routine feature of nurses' work and the wider social experiences of women.

During their interviews, nurse-participants spoke freely about having to manage the sexual behaviours of their patients, and whilst some linked this to a threat to their dignity, others felt it did not impact their dignity.

> **Nurse-Sheila**: Oh yes…erm…there's a few patients I can think of [laughing]…erm… that are quite rude to the nurse. They'll be quite sexually…erm, I mean… now I can sort of take it …and some patients will have a bit of a laugh and a joke and they'll say, 'oh I wanted the blonde one to come today', and I know they're only kidding, but then… like some of them will comment, 'oh you're married?' and then they'll start being quite rude and sexually … like inappropriate and… I mean… it doesn't affect my dignity. I just tell them that it's completely inappropriate and they shouldn't be speaking like that, but I

> could imagine that some nurses_ I mean maybe four years ago if somebody did that to me in the community, then I would feel like… quite undignified and embarrassed, but now… it's, it doesn't bother me.

Sheila linked embarrassment to being undignified. She was an experienced community nurse who indicated the sexualised behaviours of patients did not affect her dignity. However, she recognised this may have had a different impact on her when she was newly qualified, which may suggest that increased professional exposure to these situations can lead to desensitisation of one's own dignity, leading to the minimisation of certain scenarios to ensure they are no longer identified as a challenge to dignity. Throughout their lives, women become accustomed to low-level harassment and sexualised behaviours – they often become normalised and viewed as a part of life, rather than being identified as social, cultural or gendered issues requiring challenge. Sheila indicated that her responses to these behaviours involved asserting her agency by challenging patients' unacceptable behaviours, providing an example of how, in practice, a nurse enacted Jack's previously noted view that 'second class standards are set by the receiver and not by the giver […] If you put up with rubbish, that's all you'll get.'

All nurse-respondents linked sexualised behaviours to male patients. When asked if they had experienced sexualised behaviours in female patients, none were able to identify any examples of this. During the interviews, all nurse-respondents were asked if they accepted sexualised behaviours as a 'normal' part of the job. Interestingly, none of them said they *accepted* it, but most identified it was a behaviour that they *expected* to encounter. Nurse-Rina offered her explanation for these behaviours.

> **Nurse-Rina**: It's not something that you accept but… it_ there is certain scenarios that you… That there is a very, very massive old school, you know it does come from the 'Carry On' films, that, you know_ throughout my career it's, there's always been those, those seedy bits in it and I think it does stem back to you know sort of the, the good old British postcard.

The humour of *Carry on Nurse* (1959), was based on gender and nursing stereotypes, which were left unchallenged in the middle of the 20th century, which was also true of the 'British postcard'. However, by the 1970s, the 'saucy postcard' was beginning to decline as the humour became at odds with changing social attitudes (Donald McGill Museum, 2018). Many older adult patients may have been heavily exposed to these stereotypes throughout their lives (particularly in their younger years where these were much more prominent). As a result, they may regard it as acceptable to reflect these attitudes in their own behaviours towards their nurses. Social and cultural experiences of social actors are therefore important, as, for example, when a younger (female) nurse encounters an older (male) patient (the ‘old school’, as Rina described), their understandings of acceptable boundaries of humour and behaviour may be at odds. Hence, they lack a ‘shared morality’ (Harris and Sulston, 2004), which was also exemplified in the discussion of Don and his nurses, where Don’s sexualised ‘humour’ threatened the dignity of his nurses.

Although changing societal attitudes may now lead to these views and behaviours being challenged, it does not mean they are absent within contemporary society, as exemplified by the #MeToo movement. As an example of the persistence of sexualising nurses, in 2010, Procter & Gamble released an advertising campaign called ‘don’t you just love moments like these?’ for ‘Head & Shoulders’ shampoo. The TV advert portrayed ‘nurses’ singing and dancing beside a man washing his hair in the shower. The ‘nurses’ wore white PVC figure-hugging uniforms, including the redundant nursing cap, whilst black seamed stockings emphasised the red stilettos on their feet, and crimson manicured nails caressed the head and chest of their showering ‘patient’. It was an unashamed sexualisation of nurses, exemplifying how advertisers marketed what is essentially a consumer product (shampoo) by broadly linking it to sexualised women in healthcare. Thus, although ‘Carry On’ and the ‘British postcard’ may initially appear outdated, contemporary examples of the objectified and sexualised nurse remain. Therefore, professional boundaries can be difficult to reinforce if social actors have internalised sexualised perceptions of the nurse. If an individual patient’s actions and behaviours reflect these perceptions, the nurse’s dignity becomes undermined and threatened, which illustrates how nurses are potentially recognised as unworthy of dignity in the macro, as well as the micro, context of the professional relationship.

When nursing boundaries become blurred and patients transgress into sexualised or other inappropriate behaviours, Nurse-Rina described this as being 'unbusiness-like'. Indeed, retaining professionalism may be essential for dignity to be manifested. If there are no boundary transgressions, dignity may remain intact, but if one actor oversteps this (invisible) marker (which is not static and varies for each individual), the dignity of the other social actor may be disrupted, violated or abused. Dignity, therefore, remains very much at the core to all patient/ nurse interactions, and it can be undermined or upheld depending on the nature of the interaction, as is evident from the following scenario from my own fieldwork.

Rina had been a nurse for 25 years. She allowed me to observe her work and interview her after several weeks. I observed one of her visits to Bill, aged 94, to administer a B12 vitamin injection and to check his pressure areas.[4] During our car journey to his house, Rina provided a little background to her patient, just as she did before my first visit to all her patients. She explained that, as a result of his carers failing to get him out of his chair, Bill's skin had broken-down into a grade four pressure ulcer (full thickness of skin loss). This had been reported as a safeguarding incident as potential neglect, because pressure ulcers acquired in the home may be symptomatic of systems failures or poor care (Manthorpe and Martineau, 2017).

Rina also explained that, a while ago, she had requested for Bill to be removed from her visits, but now he had appeared back on her list. She said she was pleased I would be attending her first return visit because, during her last visit, she rolled him over to check his pressure areas, and 'Bill's hand landed on me [sic] bottom'. She frowned and said that it made her feel uncomfortable, but she was not one hundred per cent certain that it was not an accident. Due to her unease, and in accordance with Dan *et al.*'s (1995) findings that women in nursing manage scenarios by avoiding their harasser, Rina asked her senior to remove her from visiting Bill in future. She explained that she did not formally report the incident as she was not completely certain that it had been a deliberate act, even though she felt uncomfortable. Rina

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[4] Areas where bones are close to the surface and under the most pressure, making them at greatest risk of developing pressure ulcers.

explained that she had also discussed the situation with her husband who warned her to ‘be careful’, as he felt if she did not return to Bill, the patient may lodge a complaint against her. Subsequently, it caused Rina concern that she might be the subject of a complaint, and thus she raised no objections when re-allocated Bill.

> **Nurse-Rina**: I felt that he [Bill] was becoming really, really attached to me […] Whether there was anything behind that, other than… just attachment, I don’t know, but I didn’t want to put myself in that scenario and… he’s, he’s a vulnerable adult but so was I, at that_ I felt vulnerable at that moment in time so, I think to be fair to both of us, it was better to just, you know, keep, keep the distance, let somebody else go in […] So, just for the sake of not going for probably about four or five weeks, it, it went back to… service as normal, if you like. Un-business-like, if you want really.

Rina described both herself and her patient as ‘vulnerable’. She recognised that the age and frailty of her patient made him vulnerable, but, as a lone-worker undertaking care with patients, and as a woman, she too was vulnerable. Therefore, retaining and reinforcing a ‘business-like’ relationship remained important to her, which was also indicative of the emotional labour she was engaged in to sustain her own and her patient’s dignity in their relationship.

Community nurses, like all nurses, engage in emotional labour. However, a key difference is that community nurses form relationships with patients in their own homes, ensuring that they have direct experience of their patients’ social and living situations, as opposed to nursing undertaken in designated clinics or inpatient settings, in which staff do not directly encounter patients’ private lives in their homes. The significance of this is considered further in Chapter 6, which also recognises patients’ engagement in acts of emotional labour when their homes require clinical modification or adaptations.

By considering examples such as *Carry on Nurse* (1959) and ‘Head and Shoulders’ marketing campaigns, it has been demonstrated how the nursing uniform is used to sexualise nurses and that this permeates societal values and expectations. Paradoxically, during their interviews nurse-participants expressed how their uniforms were useful in aiding their mediation and regulation of emotions, and how the nursing uniform was actually helpful in mediating dignity within relationships, an issue that will now be considered further.

Uniform as mediator and reinforcer of dignity

McNally (1990: 51) noted, ‘forget staff shortages, clinical grading and the poll tax…nothing gets nurses more worked up than their uniforms’. Thirty years later, the poll tax has disappeared, but the influence and significance of the nursing uniform remains. Respected by patients and cherished by nurses, the uniform is symbolic of the profession’s identity (Shaw and Timmons, 2010). As a semiotic marker, uniforms identify power (Pearson *et al*. 2001) and offer nurses and patients confidence in the profession (Sparrow, 1991). Through their interviews with nurses, Hayward and Tuckley (2011: 1511) recognised that nurses’ professional personas involved emotional boundaries, which they described as ‘akin to putting on their uniform’. The uniform allows nurses to mask their emotional labour and suppress personal beliefs that may be contrary to their expected professional behaviours, at times enabling nurses to offer a dignified response that may be at odds with their personal reactions.

> **Nurse-Denise**: When someone speaks to you in a certain way, I’m glad this uniform is on because it stops you saying some things and reacting the way you would if you was outside of work.

Laing’s (1960) exploration into existential psychiatry and psychology recognised that the ‘self’ was not a unified body-subject but comprised an ‘authentic’, private-self and a ‘false-self’ people display to the world. The uniform provides the ‘costume’ that enables the ‘professional self’ to present itself to the outside world. Nurse-Denise’s observation indicates she would behave differently in some scenarios if she was outside of work, and she was grateful that she wore a uniform, as this enabled her to differentiate between her two characterisations (‘personal self’ and ‘professional self’).

The uniform may be helpful to aid the nurse modify and mediate the behaviour of her ‘personal self’ during her relationships with patients, thereby facilitating a dignified approach. However, there may be limitations to the protections a uniform offers the nurse from her patients' behaviours.

> **Nurse-Anya**: Patients respect the uniform, but not always the person.

Anya differentiated how respect gained from wearing the uniform was not always applied to the underlying person. Patients may respect the symbolic identity of the uniform, but they do not always demonstrate that respect to the human wearing the clothes.

Within the host organisation, it was policy for clinical staff to wear uniforms, and even the administrative staff wore a (non-clinical) uniform. In the nursing team, it was only the senior managers that were not uniformed, offering a readily observable indicator of hierarchical superiority – the further away from the delivery of care, the less likely a nurse was to wear a uniform. The uniform itself also offered visible indicators of hierarchy, as the more senior the nurse, the darker her uniform became. Student nurses wore white, and uniforms were then graded from pale to darker blue dependent on the seniority of the role, with the highest grade of clinical nurse wearing dark navy blue with different coloured piping edging their collars (again colour-grading indicated specialisms or seniorities). Nurses may be highly aware of the hierarchical implications of the colours of their uniform, but patients may be less familiar with the specific symbolism, status and identity each colour brings, especially as the symbolism of the colours varies across each NHS Trust.

When nurses wear their uniform, it aids in creating their 'professional' character, offering a visible differentiation between their 'personal self' and 'professional self'.

> **Nurse-Denise**: I'm not [dressed] like this when I'm at home, believe me [laughing], I stay in me onesie all day, but this is me as a nurse.

Denise's words, 'this is me as a nurse', illustrate how wearing a uniform allowed her to distinguish between the nurse-as-human-being (the 'private self') and nurse-as-professional (the 'professional self'), facilitating her nurse-performance and mediating her relationships with patients. Denise's comment illustrated how her two ‘selves’ became identifiable through what Twigg (2007: 286) described as the ‘vestimentary envelope’. In this context, the nursing uniform both contains and presents the body, aiding in mediating nurses’ interactions in the social world of work. The ‘vestimentary envelope’ supports the manifestation of the ‘nurse’ persona and facilitates them delivering convincing displays of professionalism. Denise’s ‘private self’ existed when she wore her ‘onesie’ in the privacy of her own home, in contrast to her ‘professional self’ which existed when the uniform was worn publicly.

Ironically, at times nurse-participants described wearing a uniform in a manner that indicated they gained some level of ‘protection’ from it, or they implied that the uniform was a shield to deflect undesirable elements of the job, which contrasted with their simultaneous views that there were times the uniform served to sexualise. Nurses regularly espoused methods they used to differentiate their ‘personal self’ and ‘professional self’, explaining how each day they transformed into becoming the nurse.

> **Nurse-Denise**: When you put this uniform on [touches her tunic] and you tend to act. You have this role that you do perceive as a nurse. A professional role. I have a different role when you’re at home but as soon as you put this uniform on it’s like [you have] this barrier that you act a certain way.

Denise explicitly stated that once the uniform was worn, an ‘act’ ensued. She continued to explain how the uniform also ensured she suppressed the behaviour of her ‘personal self’, enabling her ‘professional self’ to remain in control. She recognised that the uniform had a silencing influence on her, which aided in maintaining the ‘professional’ character and assisted in negotiating the effects of emotional labour.

> **Nurse-Denise**: When I get angry I cry and it is hard when someone’s saying…not nice things to you, it’s good to look down and see that I’ve got this [uniform] on and [I] don’t do anything, [I] don’t provoke, [I] just don’t say anything.

Denise’s comment suggests how displays of her ‘professional self’ involved suppressing behaviours – not showing emotion (anger or tears) and being submissive (not doing anything, not provoking) when she felt challenged. She was able to maintain her own, and her patients', dignity by regulating and modifying her behaviours, and these were made easier to regulate by wearing her uniform. Her words also explained how her experiences with others influenced her responses, recognising that wearing the uniform prevented her from behaving in the ways that were more natural for her 'personal self'. Thus, the uniform regulates behaviours, simultaneously being silencing and protective, as it enables the nurse to remain distant at a personal level, if derogatory comments are made.

The uniform offered a level of protection for Denise, but also potentially protected her patients who were not subjected to behaviours from Denise's 'personal self' (which were implicitly more destructive than those she displayed as a 'professional' nurse). This, therefore, ensures a dignified environment can be maintained, as the nurse's emotions remain firmly regulated and controlled with assistance from the uniform. From Denise's description, her 'personal self' consisted of crying and anger, which may be deemed by some to be 'unprofessional'. However, they are not atypical human responses to feeling angry or upset. Therefore, donning a uniform reinforces expectations of 'professional' behaviours required from the nurse, rather than encouraging the enactment of 'personal' behaviours, which also aids in concealing any associated emotional labour. In this sense, and in line with Goffman's (1959) dramaturgical analogy, the uniform is not simply a mask, it is the professional costume that allows the nurse to continue in character, for her performance to remain uninterrupted, and potentially facilitating a dignified encounter.

Although uniforms may be regarded as professionalising nurses (Newton & Chaney, 1996), they can also serve to depersonalise. There is a danger the wearer becomes perceived as the objectified nurse, rather than an individual with agency. Thus, when undertaking the 'nurse' performance, there are risks that the person themselves becomes invisible, as exemplified by those nurses who said they had to 'put aside' parts of their personalities when working with patients. In clinical interactions, it is the nurse persona (the 'professional self') that assumes prominence over parts of the authentic self (the 'personal self') which must be placed to one side, so that the performance of the professional 'nurse' is maintained. The human side of the nurse (the 'personal self') often remains invisible, as a metaphorical mask is worn.

Nursing relationships are shaped by the theatre of the home (as opposed to the theatre of the hospital), as homeowners have licence to do things differently in their relationships with the nurses when their performances are located on the stage of their own home. Nurses don their uniform and enter the 'home-theatre' to undertake their performance as the 'nurse'.

Although the uniform can be used to aid the characterisation of 'the nurse', it is limited in the protection it affords in nurses' presentation of their gender. Nurse-Rina recently moved into community nursing after working in hospitals for many years and she explained:

> **Nurse-Rina**: It's only until I've moved here actually that I started wearing dresses again [as my uniform]. I stopped wearing dresses, I didn't wear them for years and years because I had_ I worked on a elderly medical [ward] and I had a patient lift up my dress with his erm walking stick […] to see if er, the nurse had suspenders and… a [suspender] belt on…erm, totally unacceptable.

Due to her patient's actions, Rina modified her choice of 'vestimentary envelope' (Twigg, 2007). Although the patient was the source of Rina's loss of dignity, the dress had become symbolic of this loss. Without being able to assert control over her patient's behaviours, Rina's response was to reject dresses and instead wear gender-neutral trousers and tunic, which were deliberately worn to deflect male attention and served to ensure her legs remained concealed, aiding in de-feminising her body – her sartorial modifications exemplifying how gender is rehearsed (Butler, 1988; 1990; 2004). Rina perceived that this change would potentially reduce the risk of future scenarios like this. However, it was achieved only by compromising the clothes that her 'personal self' was most comfortable wearing; thereby suppressing expressions of the 'personal self' in order to protect and maintain the dignity of the 'professional self'. Suppressing the 'personal self' and presenting as a 'patient' or 'nurse' is particularly hard work, because individual relationships not only require successful navigation, but they also involve the enactment of expectations associated with their specific role. In the next section, some of these expectations will be explored in greater depth.

Expectations when navigating relationships

The data presented so far suggests that the construction of dignity occurs through the development and management of community nursing relationships, featuring strong elements of emotional labour. As nurses and patients manage relationships with each other, it is through their interactions that dignity can be reinforced or undermined. These relationships are defined by the roles which each social actor is performing, whether that of ‘nurse’ or ‘patient’, and both roles involve expectations. Firstly, there are expectations placed on nurses:

> **Olive (60)**: They come in happy, erm. They’re jolly. We have good fun together, a good laugh together, er, yeah, I think, erm…they help you out as much as they can.
>
> **Alison (82)**: They understand what they’re doing to start with. They’ve got to understand what they’re treating and what the best medication is.
>
> **Nurse-Anya**: I’ve always got a smile on my face for my patients because I think you have to, because I could be the only person they’re seeing…and I think as long as we have that in the back of our heads, that you could be that only contact… to that patient… I think that makes you a good [nurse].

Secondly, there are expectations placed on patients:

> **Nurse-Anya**: There’s a few patients out there that no matter what you do for them, they’re not gonna be happy… we could… but I think a lot of that has come from their upbringing, their environment and things like that, the way they’ve been brought up… erm, and then you’ve got others that are just so, so happy that you’re there.
>
> **Nurse-Sheila**: I mean you get the non-compliant ones that’ll never listen to you… but that’s them […] There’s the ones that don’t… comply and you think, ‘oh God, I’ve got to go there again because… when I get there she’ll just have her dressings off’, do you know, and these are the ones that really frustrate you, because the NHS is ploughing all this money into trying to get their legs better or whatever, and they just, they’re just taking them off and they don’t care.

If these expectations are not met it is unlikely to result in a ‘dignity encounter’, as preconceived ideas are strong indicators of what is necessary for dignity to manifest itself in a relationship. During the participatory encounter, dignity is manifested when feelings of being valued and worthwhile are evoked. The elusive nature of dignity necessitates its renegotiation at every visit, relying on the nurse's ability to adapt and respond quickly and appropriately to the social cues of their patients. Nurse-Chloe underpinned the importance of negotiating individual responses to patients, stating that she often felt under-prepared for some of the situations she encountered.

> **Nurse-Chloe**: It's how you deal wi' it and how you talk to someone can often change the way that they are. You can either make 'em worse… by what you say, why you're trying not to_ why you're trying to do the opposite… but sometimes I don't know, I don't think we've had training on things like that. You know, because you're going into people's mental health issues, forms of dementia, people who are alcoholics… all these different people that all behave in different ways and I don't_ I just_ going in and if there is like confrontation, trying to… be diplomatic, trying to be kind but not_ I don't know if it's the right thing or not.

Nurse-Chloe's hesitation over whether 'it's the right thing or not' illustrates that what may be 'right' for one person, may be wrong for another. This demonstrates the problematic conceptual nature of dignity. Diversity of individuals requires nurses to be skilled and adept at renegotiating their relationships with individual patients. If this is successful, then a 'dignity encounter' may occur. Nurse-Victoria explains how the more frequently this negotiation is undertaken, the easier this becomes for nurses.

> **Nurse-Victoria**: I think the more you deal with people, the better you get it. It's like anything… and you get better at reading people and just meeting so many types of different people in this job and you've got to deliver that same standard to every personality, every person, you know… everybody's got different considerations so you do get used to like reading [people] that I think. Everybody gets it wrong sometimes cos everybody's human and… maybe personalities don't always gel or whatever, but for the most part, I think you do get much better at reading people… and just feeling what they might like or not like and just reading between the lines as well, it's not always what somebody verbalises, it's in their like, body language and just their demeanour, how comfortable are they?

Nurse-Victoria recognised that every individual has 'different considerations', which is indicative of her tacit knowledge in determining how to construct a 'dignity encounter' with each individual patient. It can be challenging to ensure language, communication and relationships reinforce dignity according to every individual's nuanced preferences, by mediating and moderating words, language and behaviours in different contexts with diverse people. Thus, constructing dignity in community nursing encounters can be highly problematic. It is not simply adherence to legislation (such as human rights), guidance (such as NICE) and professional codes (such as the NMC) that generates a 'dignity encounter'; it is the daily conversations, actions and relationships with patients that manifest dignity.

Within these routine interactions, clinical interventions require consent from the patient, and thus negotiating consent retains significance in terms of how dignity is manifested within the nursing relationship. The next section will focus on issues of choice and consent, which is presented in the context of Smith's (2012) assertion there are some patients nurses would rather care for than others.

Maintaining dignity through choice and consent in patient/ nurse relationships

> **Nurse-Nieca**: You don't have to be…. a super nurse, do you, with your cape on, going around giving injections and treatments, sometimes it's just about sitting and listening and just making sure that person gets their wishes at the end.

Here, Nurse-Nieca recognises that non-clinical aspects of a nurse's care ('sitting and listening') can ensure dignity remains intact, but it is also important the 'person gets their wishes at the end', concurring with Jack's aforementioned preferences earlier in the chapter, in which he indicated his end wishes were 'feeling good' once the nurses left. For someone to 'get their wishes', issues of choice and consent are paramount. This is expressed by the government as 'no decision about me, without me' (DH, 2010b: 3). These semantics of dignity are indicative of shared decision-making, in which clinicians assume a partnership approach with their patients, actively involving them in decision-making over their care, recognised by Coulter and Collins (2011: vii) as 'an ethical imperative'.

Shared decision-making involves negotiation and agreement, but it is based on patient choice. Nurse-participants frequently used the word ‘choice’ when discussing dignity. For Nurse-Denise, it was the responsibility of the nurse to supply patients with relevant information allowing them to make an informed decision. However, she noted that there were times when this informed choice was not concordant with the nurse’s views.

> **Nurse-Denise**: It’s about giving them as much information to make an informed choice and sometimes, that informed choice …in’t the informed choice we [smiling] would like them to go down and it, it’s hard then to accept it. But when you do accept it, you do; but you still worry. You do still worry. We don’t think it’s in their best interest, but they want it.

Nurse-Denise recognises that patients have the right to choose, but, when they make choices that are not in line with nurses’ views, this can be difficult for the nurses to accept, as they believe an alternative option is in the patient’s best interest. Thus, there may be occasions when nurses must put aside their medical knowledge and training and adapt to patients’ wishes. As an example of this in practice, Nurse-Sapphire spoke about how she modified Judy’s leg dressings.

> **Nurse-Sapphire**: She finds compression painful, so we do it how she likes. But she’s not getting the full benefit […] We’re not meeting her needs.

There is an evident disconnect here, because, as a nurse trained under the medical-model, Nurse-Sapphire believed that she was not meeting her patient’s needs, as slackening the compression bandages made them less clinically effective. However, this adapted approach was in line with Judy’s wishes; it was implemented with her consent and clearly met her needs in terms of choice and control, making it a dignity-enhancing approach to care. If needs are determined by the patient, this approach met her needs, but if they are defined by the nurses, Judy’s (clinical) needs were not being met. Nurses have responsibilities to deliver healthcare in line with evidence-based practice, but this must be through shared decision-making and consent. Western medicine is based on ‘evidence-based practice’ in which (largely through clinical trials), it is evidenced how body-objects respond to specific clinical interventions. These beliefs of body-as-object (which will be explored further in Chapter 5) result in all bodies being regarded as identical, failing to recognise the impact differing narratives, subjective experiences and expressions of agency have on health and wellbeing. This is exemplified by Nurse-Sapphire failing to acknowledge the dignity benefits Judy was experiencing through receiving care in this manner. Adapting compression bandaging reinforced Judy's dignity and human rights, allowing her to receive the dressing in the manner that she wanted.

Patients such as Judy were often described by nurses as 'non-compliant'. This label was applied when nurses described people who did not conform to their treatment plans or patients who asserted their agency, at times making decisions against the advice of the nurses. The danger is that patients who do not fully adhere to nurses' instructions become stigmatised through this process of labelling. The following examples offer insight into how the label 'non-compliant' was operationalised.

> **Nurse-Daisy**: A lot of patients are non-compliant, so you know, as much as we explain… that does get in the way sometimes.
>
> **Nurse-Nieca**: Sometimes they're just non-compliant with medicines and sometimes that's just education and sometimes that just means that we need to go in two or three times to reiterate, to explain, what the medicine's for, erm, maybe get people involved such as medicines management, it might be just something really simple like a nomad system, just to remind them.
>
> **Nurse-Sheila**: I mean you get the non-compliant ones that'll never listen to you… but that's them.

The pejorative nature of using terminology such 'non-compliant' to describe patients, reinforces bioethical beliefs that patients 'ought to do what healthcare professionals recommend' (Cody, 2003: 289). This exemplifies the powerful position of nurses and, in itself, is a perspective that is at odds with maintaining dignity, as consent and the right to self-determination become usurped by the nurses' control. Smith (2012) recognised that nurses would rather care for some patients than others, and it was the older adults given the label 'non-compliant' who were least desirable to appear as names on the nurses' caseloads. In a further example to highlight how nurses had preferred patients, Nurse-Denise explained how she modified her interactions with those she described as 'horrible' patients.

> **Nurse-Denise**: Even when you get the horrible ones [patients] it's still a privilege because they're like a challenge, are the horrible ones. Cos in the end, they become lovely and we sort of 'district nurse' them to be …in a [laughing], in a certain way. [Smiling] Cos when you go in every day and you're really happy and nice and when someone's horrible, they, it changes them as well. It's like a little bit of fairy magic, it changes. And it's lovely…

Demonstrating an example of nurses' positional power, Denise's description illustrates how she used 'district nurse' as a verb to describe how nurses can cause patients to behave in a certain way. Although Denise used the benevolent terminology of 'fairy magic', her words essentially describe the power inherent in nursing relationships, in which patients react and respond to their nurses, modifying their own behaviours accordingly. This is not to say this is a one-way adjustment, as nurses, too, adapt in response to their patients.

Nurse-Denise described certain people as 'horrible' patients, a category she used for people who do not automatically comply with or acquiesce to nurses' instructions. Issues, therefore, arise in terms of how dignity manifests itself when the nurse and patient disagree over the management of a health issue or the implementation of a care plan. It is perhaps the issue of consent which sits at the heart of the 'dignity encounter' in this context. Nurse-Nieca, for example, acknowledged that ensuring dignity was about 'having that conversation' to gain consent from her patients.

> **Nurse-Nieca**: Just having that conversation right from the beginning. We do these things but we don't necessarily think about them… [it's about] going in, having that conversation you know, [asking] 'what would you like? How would you like to be treated? What's your, what do you want? Do you want to be laid on the bed with a_ or would you like a dignity sheet over you?'

Nurse-Nieca's comment indicates that dignity is about treating patients how they would like to be treated, rather than treating patients how you *think* they would like to be treated; it means having conversations with them to clarify their wishes. She also acknowledged the use of a 'dignity sheet' in nursing, which is used to cover parts of the body regarded as private (to be considered further in the next chapter).

Nurse-Victoria was also clear that dignified nursing care was not simply about ‘doing the job’, but that informed consent was paramount.

> **Nurse-Victoria**: [You] portray dignity in how you do your job, like making sure you’re giving, that you’re getting really good informed consent and not just doing the job that … that they understand it, do they want it, you know…

Clearly, dignity cannot exist without informed consent. Victoria noted that informed consent involved the person being able to ‘understand’ and express if ‘they want it’, which means dignity will not feature without these elements in a nursing interaction. Indeed, if these elements are absent, what should be ‘care’ might actually manifest itself as abuse.

> **Nurse-Anya**: [It is about]…not forcing anything on somebody and listening to what they have to say, and how they want it to be done, and if they want it done a certain way, respecting that, because… they might have a reason behind that, they might have had a bad experience, you know.

Although consent did not feature heavily within the patient interviews, both Michelle and Olive indirectly linked the consent-seeking process of the nurses as making some contribution towards maintaining their dignity. These aspects may contribute to a ‘dignity encounter’.

> **Michelle (86)**: Well…dignity… I mean, not erm…being asked to do something you know like to, to sit in your chair […] Er, not being you know, ‘Get into your chair then’, sort of thing.
>
> **Olive (60)**: The nurses don’t come walking in. They turn round and say, ‘is it all right if I come in and do your insulin?’ and I say, ‘yeah’.

Although they did not use the word ‘consent’, essentially both Michelle and Olive identified this concept as important, and thus their dignity was maintained by gaining their consent for the subsequent action to occur. To gain consent, language and communication are important, as they each offer a medium through which dignity can be enhanced or reduced. Professionals’ language must be accessible and clearly communicated, and information should be available in different formats to suit individual needs. Without these, manifesting dignity within a professional nursing relationship may be problematic, as choice and consent remain essential prerequisites for it.

Summary

This chapter has shed light on how dignity can be constructed, mediated and rehearsed through nurses' relationships with their patients. In the context of this study, dignity exists as a set of relationships which are socially constructed and mediated through perpetually renegotiated relationships during every nursing visit. Everyday encounters between nurses and patients also generate possibilities for dignity to be (de)constructed. Their interpersonal relationships can lead to a 'dignity encounter', or, conversely, dignity can be disrupted, or even eradicated, if relationships are unsatisfactory. Supporting and maximising the possibility of dignity being manifested in practice relies largely on the informal knowledge nurses gain through life experience.

The chapter demonstrated how patient-participants identified ageist assumptions and ageism as a potential threat to their dignity, making older adults particularly vulnerable to dignity violations or infringements. All social actors have different understandings of dignity, which are based on their own world-views, individual life experiences and knowledge. By virtue of being 'older' adults, patient-participants in this study had many more years of life experience than the nurses who cared for them. Importantly, they recognised that, as older members of the community, ageism was a major threat to their dignity, and as age is irreversible, this is an inevitable threat that will only worsen as time progresses. The potential of this discriminatory context is highly important when considering how dignity is (de)constructed in nursing relationships.

Dignity is fragile. This vulnerability was recognised by considering the ethnographic account of 'Don and his nurses'. Although Don intended to display care and kindness to his nurses, they interpreted his words and behaviours as dignity-reducing, highlighting that there are times when nurses may also experience dignity-reducing encounters. Through their relationship with Don, nurses very much engaged in emotional labour, concealing their frustrations when in his presence, but venting their emotions at other times. Thus, emotional labour is a critical element of nursing work and features heavily in the construction of dignity in nursing relationships. There are times nurses use their uniforms to aid them in moderating their behaviours, to mask emotional labour and to ensure encounters with patients remain dignified, by allowing them to differentiate personal reactions from their professional responses. Dignity involves older adults being given choices about the care they receive and giving consent to treatment, and this is undertaken through their relationships with nurses, which is where dignity also becomes manifested.

Nurses' views of dignity are created not only through their life experiences but also during their professional training, both of which shape their views of dignity within the professional context. Trained under the medical model, nurses are taught to recognise successful treatment through clinical markers of care and healing, rather than acknowledging that interventions may be successful because they are meeting older adults' dignity needs. As exemplified in this chapter's discussion of choice and consent, there are times that nurses regard themselves as failing to meet patients' needs, because their work is less clinically effective, failing to recognise that their work may achieve patients' dignity needs and fulfil their dignity standards.

Both patients and nurses related dignity to the maintenance of standards, but, as a collective, each group had different understandings of this terminology. Whereas patients, such as Jack, emphasised how dignity was related to their personal standards, nurses, such as Nieca, linked dignity to professional standards that were set by the NMC. Although dignity may relate to standards, as a concept, this varies from person to person, each with different life experiences and expectations by which they measure standards. Therefore, although this chapter considered the views of 'older adults' and 'nurses', both of these groups of people comprise diverse individuals who may have some shared understandings of dignity, but there remain individual idiosyncrasies where dignity is concerned. Thus, manifesting dignity is difficult. It requires nurses to continually renegotiate dignity at every visit, as dignity changes; it evolves over time, and dignity considerations may be abruptly transformed when someone's health deteriorates as illness descends.

Relationships are an essential aspect for the experience of dignity for older adults within their participatory encounters, as they must feel valued, worthwhile and respected by their nurses. There are two other crucial, broad factors that are necessary for dignity to thrive in older adults’ engagement in community nursing care: firstly, the role of the body, and secondly, the specific nature of receiving care in the home. As dignity is constructed, enabled and played out in the context of nurses’ relationships with their patients, it is also constructed through interactions between two bodies. It is the place of the body in the dignity relationship that takes centre stage in the next chapter, as Chapter 5 explains how dignity manifests itself in the care of the body.

Chapter 5: Dignity in Caring for the Body

Central concerns

There are times that the human body, particularly the ill body, can disrupt or betray Kantian concepts of inherent dignity, described as *Menschenwürde* by Nordenfelt (2004, 2009). At times, ill and out-of-control bodies can be a source of shame, as they may not present externally as anticipated, nor behave within the parameters of usual standards of social acceptability. Therefore, when previously healthy bodies become ill, embodied identities can become disrupted and the lack of bodily control often associated with an ill body fails to outwardly reflect an internalised sense of dignity.

This chapter considers how two ontological views of the body may influence experiences of dignity. The first view, grounded in Descartes' mind-body dualism, regards the mind as separate or disembodied from the body. Dualist beliefs are founded on problematic assumptions (Williams and Bendelow, 1998) as mind and body do not exist independently; yet Cartesian perspectives of a mind-body dualism continue to inspire medical approaches (Leder, 1992). In the second ontological view, the mindedness and embodiment of human life are inseparable (Merleau-Ponty, 1962, 1965), as this perspective rejects the belief that subject (the mind) and object (the body) exist as separate entities. The body is the physical embodiment of a person with agency and it reflects their personality. Yet, social and cultural expectations are placed on the body to 'behave' in a certain way. This chapter will explain how a 'dignity encounter' can occur when social actors share similar beliefs about the body, because what Harris and Sulston (2004) describe as a 'shared morality', contributes towards appropriate conditions for a 'dignity encounter' to occur.

Embodiment remains central to this chapter, through a consideration of the physical body and its relationship to self and others. The body is both object and subject. Perspectives on the body as object/ subject began in the 19th century: as Foucault (1973) explains,

> paradoxically, in relation to that which he is suffering from, the patient is only an external fact; the medical reading must take him into account only to place him in parentheses. Of course, the doctor must know 'the internal structure of our bodies'; but only in order to subtract it, and to free to the

> doctor's gaze the nature and combination of symptoms, crises and other circumstances that accompany diseases. (Foucault, 1973: 8)

Reductionism, in which clinicians diagnose and treat a 'body', without taking into account the body-subject experience, and Foucault's ideas of the clinical 'gaze' are both considered further in this chapter. Certain parts of the body and certain nursing tasks may be more likely to inhibit the construction of dignity and these issues are explored, particularly in terms of social codes of touch.

This chapter also recognises the importance of how spoken language influences the construction of 'dignity encounters' because speaking is embodied, deliberate and intentional. This chapter reveals dialogues from the observational phase of the research to illuminate the powerful impact language has on the dignity of older adults through their daily conversations with nurses.

A key finding of this chapter is that bodily odours are an important mediator of dignity. This begins to be introduced in the opening of this chapter 'Anya's "passion"'. During fieldwork, I spent many occasions observing Anya's practice, as well as conducting an interview with her. The 'passion' she referred to was her work that involved 'getting people dry'. Continence is a critical mediator of dignity, which was identified not only by Anya, but by many patient-participants; indicating this is crucial to embodied experiences of dignity.

Anya's 'passion': 'Nobody should be wet'

> Bodywork can be dirty work; and this links to the tendency for it to be demeaned and to be of poor status. Bodywork trades tend to come low in the occupational hierarchy, and often with an element of stigma attached to them. Twigg (2006: 135).

Anya had responsibility for delivering continence care within the nursing team. In line with Twigg's (2006) argument, Anya was low in the occupational hierarchy, employed as a healthcare assistant, four clinical grades lower than the senior nurse in the team. Anya was in her late forties and, as she began nursing when only a teenager, she was one of the longest-serving nursing staff members. With nearly 30 years' experience, Anya explained to me, 'I hate being described as untrained as we may not be qualified, but we are trained'. This reinforced how she jostled for her own status with the qualified nurses (many of whom had fewer years of experience in the caring industry).

Anya consistently demonstrated her passion for continence care. As well as undertaking work with bodily waste, she also used it as a descriptor of some of the less agreeable aspects of nursing, as well as using it to describe how her role was viewed by her seniors.

> **Nurse-Anya**: We're just this entity [healthcare assistants], which is_ this little entity that goes out and the does all their [the nurses]… shitty jobs, the more shitty job sometimes.

Anya was towards the lowest end of the nursing hierarchy, and thus the 'shitty' jobs (meant both literally and metaphorically) came to her. Anya's employer allocated her one day per week, 'protected time', for incontinence work, but on some of these days, Anya's seniors asked her to prioritise other visits. When this occurred, Anya was vocal in her annoyance:

> **Nurse-Anya**: No, you're not taking my continence visits off me, I'll manage them, you know, I'll do your leg dressing but… I'm still gonna go and do this [incontinence assessment].

Anya explained that there was no independent continence service locally. Therefore, this work was combined within her caseload of what she described as 'normal' visits. Even her choice of the word 'normal' indicated that Anya did not regard continence as a routine part of her role, but because she valued the impact of this work, she ensured she was able to allocate time to do it each week, attempting to protect the time, even though her senior colleagues did not. Anya's 'passion' was the part of her work that involved 'getting people dry'.

> **Nurse-Anya**: I feel the best care is when I get a message saying, 'you've changed my life, I'm now going out, I went to London with my family, I was dry, I didn't have any worries', so going from being trapped in a house, not wanting to have her family around her, because she was incontinent, to… putting_ taking that time and effort and getting a pull-up authorised and getting her dry, has changed that lady's life. You know so…. That, to me, is the best care I could possibly get and the best feedback I could possibly get, you know, so and I think… What I found with continence is if we get good continence, we relieve a lot of

> pressure on other services because they're not falling, because they're not rushing, because they're confident that they don't have to rush, because they've got something in place, erm less infections because they're not peeing everywhere, erm, social isolation, you get rid of that, so they're not, you know, you're reducing a lot of things and they become more independent, they want to go out again. But we don't give it its credit, we don't give continence the importance. I think a lot of nurses go, 'oh, it's only continence, put it to the back-burner', but actually, no… to that patient it should be treated_ it's exactly the same as… a leg, a wound, a blood, because to that person, it's the most important thing ever. And that's how we need to, we need to respect that.

She further explained,

> **Nurse-Anya**: I would never think, 'oh God look at him smelly twat', you know, you wouldn't. We shouldn't do that, because nobody knows the circumstances, you can't judge somebody and nobody should feel, and I'm really passionate that with continence no one should feel that they're the only person that has this problem.

Poppy, aged 79, had been referred to Anya for an incontinence assessment. We sat in her conservatory overlooking her garden whilst Anya asked Poppy some general questions, such as her age, existing health conditions, and other generic supplementary questions, noting down the responses.

'How much alcohol do you drink?'

'I like a martini'

'What? Do you have one a week?' smiled Anya

'One a day, a large one.'

They both chuckled.

As they spoke, Poppy's husband slowly moved between the kitchen and garden, which involved walking past our seats in the conservatory to gain access between both areas. He avoided eye contact with us, but his regular movement between these spaces indicated he may have been interested in his wife's conversation, but also illustrated how daily life continued whilst health issues were being discussed in the same space.

In anticipation that he may at any point appear again, and to maintain Poppy's dignity, Anya lowered her voice to forewarn,

'The next three to four questions are quite personal'.

Poppy nodded.

Silence.

Anya paused to allow Poppy's husband sufficient time to move back through the conservatory and enter the garden. Anya recognised her next questions were sensitive and therefore delayed asking them when Poppy's husband was temporarily present. Once Poppy's husband was out of earshot,

'Do you have any discharge?' Anya enquired.

'Erm…No.'

Almost on cue, Poppy's husband moved back past us in the conservatory and entered the kitchen. Anya remained silent, looking at her papers.

The assessment slowly continued as Anya interspersed questions around the man's movements, and from Poppy's responses more questions ensued,

'Do we wet our knickers?'

'No', replied Poppy.

'Do we need to change any of our underwear?'

'No'

'Do we wet the bed?'

'No'

I was immediately struck by Anya's choice of the word 'we'. I assumed Anya was not incontinent and even if she was, when asking these questions, the appropriate pronoun would be 'you'. After around 45 minutes, at the end of the assessment, Anya concluded that Poppy was not eligible for further incontinence support, so she took great care to signpost Poppy to appropriate pads that were commercially available, even finding photographs on her phone to show what the packaging looked like.

A short while after this visit I interviewed Anya and asked her about her choice of the word 'we'. Anya expressed surprise that she had done this, but then slowly reflected on her use of words.

> **Nurse-Anya**: I think… I don't know… I don't think, I don't want anyone ever thinking they are alone […] cos they're not alone, lots of people wet their knickers you know… it's… They're not alone and they should never feel that it's only them… it's, you know… I don't know, I don't know. I didn't realise I'd said it, but… I think that's how I always feel I don't ever want anyone thinking they're in isolation, that they're the only person… Because that's not the case, lots of people… have a problem and they're one of many [people] and we shouldn't be embarrassed about it. It's not something we have to hide. We just need to manage… and there's ways of managing things. Nobody should be wet, nobody should be shrinking in a corner thinking, 'I can't do this because I'm gonna wet my knickers'. Because lots of people wet their knickers, lots of young ladies wet their knickers, you know, lots of older ladies wet their knickers, lots of men do. So I don't know. I don't know, maybe because it's that, because of how I feel, and it came out that way.

Using the word 'we' was indicative of Anya's attempt to be inclusive in her discussions around 'wee'. However, it was simultaneously infantilising and patronising. I undertook several observations with Anya of what the nurses described as 'inco-visits', but even this terminology placed the emphasis on the loss of the body's ability to control the release of waste matter (incontinence – dignity-reducing), rather than focus on the person's ability to contain waste (continence – dignity-enhancing).

My first visit to Lizzie was with Anya. She lived alone, in her own home in an affluent suburb of the city. The nurses described Lizzie as 'a palliative patient, refusing treatment', which was language that reduced her to being a 'refuser', language that was clearly not dignity-enhancing. Prior to her retirement, Lizzie held a senior nursing role in a national organisation. She spoke to me about working in Westminster alongside Margaret Thatcher to make changes to nurses' working conditions (which she proudly told me resulted in a pay rise), and she still maintained a keen interest in what was happening both locally and nationally in nursing and healthcare. At 91 years old, Lizzie was very content with the life she had led. She was thankful for her opportunities and was refusing cancer treatment. However, she continued to allow the nurses to visit and she clearly enjoyed regaling them with stories of when she was a nurse, as well as questioning them about changes and developments in nursing.

The first time I met her, Lizzie proudly declared,

'If I need something, I will buy it!'

Lizzie used this as a justification to Anya for buying incontinence 'pants' from her local chemist. Despite Anya's explanation that Lizzie was entitled to free incontinence pads, Lizzie protested that she never had anything for free from the NHS and,

'I do not need anything free now!'

Anya patiently listened whilst Lizzie shared her views and then when there was an appropriate opportunity, she asked,

'So, how have you been getting on with the [incontinence] pads I gave to ya?'

Lizzie described how she wore her own incontinence pants from the chemists and placed Anya's incontinence pads inside them.

Anya's face grimaced before she clarified to Lizzie that there was no need to buy pants as the pad could go in her knickers and 'do the same job'. Anya explained this to Lizzie in at least three different ways. Each time Lizzie's reply remained constant,

'Yes, but I don't want to smell!'

After several iterations of this statement, and perhaps as a response to her frustration, Lizzie turned to me and barked,

'You've been near me – do I smell?'

I felt fortunate that I was quickly able to offer an honest and reassuring response.

'No, you don't smell,' I replied.

Lizzie grinned in satisfaction that my words essentially confirmed the effectiveness of her 'double-padding' approach to continence care.

I remained silent and Anya remained undeterred, continuing with her attempts to persuade Lizzie to use the incontinence aids as clinically recommended.

'My pads have something in them that just draws in the urine, so it won't leak and won't make it smell. So, *you don't need to buy any more pants.'*

'But I don't want to smell. That's why I sometimes wear the pads, pants and *my* knickers. *I've changed my knickers twice today already.'*

I glanced towards her clock. It was 11:20am.

Anya continued,

'You won't smell and you don't need to change your knickers so often. My pads draw in the smell.'

Lizzie responded,

'I don't want to leak on my sofa. I made all the covers for my sofa, and the erm, pillows, um, I mean cushions. And I don't want to smell!'

Their conversation had reached an impasse.

Lizzie had taken control of her own incontinence; she was managing it in the way she felt was best for her, in a manner that enabled her to feel as though she was maintaining her own dignity. Lizzie had been subjected to Anya's (critical) clinical 'gaze' (Foucault, 1973), and Lizzie failed to conform to established medical conventions on how to manage continence. Foucault (1973: 8) explains how medical staff place the patient in 'parentheses' to 'free to the doctor's gaze' the physical illness and its treatment. Illustrative of this were Anya's persistent attempts to persuade Lizzie to use the incontinence pads in accordance with the clinical instructions. For Foucault, the body is 'more than the locus of subjectivity; it is the very condition of subjectivity' (McLaren, 2002: 83). Yet, Anya's determination to impose a clinical view of dignity onto Lizzie did not recognise her subjective experiences. Anya's view was solely based on understandings of how incontinence pads should be used for maximum clinical effectiveness on the physical body-object, without acknowledging the embodied agency of the body-subject, which may manifest dignity in a different manner. As a retired nurse, Lizzie must have, a least at some stage in her life, 'bought into' the foundations of her profession, grounded in western medical 'evidence-based' knowledge. Yet now, by asserting her own agency which conflicted with this knowledge, she was apparently rejecting her previous training in the context of her own bodily experience, to reinforce her own dignity by managing her continence how she wanted, and this included departing from textbook continence-care to keep her body clean.

This indicates there may be a conflict between medical knowledge of the effective treatment of the body-object and the body-subject experience of dignity, as these may not be mutually dependent. Therefore, individuals may have to decide whether to prioritise ‘evidence-based’ care of the body-object or the maintenance of their body-subject dignity, as in Lizzie’s case example. Lizzie prioritised body-subject dignity over medical ‘evidence’ of what works best for continence care, and thus she managed dignity in her own way. Although her self-management of her incontinence signalled the expression of her own agency and control over how she wanted to experience dignity, this was also reflected in her refusal of any treatment for cancer, which, as she explained to me later, was based on her desire to ‘die with dignity’.

Despite the impasse in their conversation, Lizzie continued explaining to Anya:

‘Every time I go to the toilet I change it [the incontinence pad]...even if they’re clean, they still have germs, so I change every time’. ‘I would hate to dribble [urine] in my bed. I hope I don’t stink...I’m so frightened.’

In contrast to Lizzie’s physical slightness, she usually spoke with such authority and agency, but these words began to reveal her frailty and anxiety. They also highlighted how the nurses’ application of the label ‘refuser’ did not recognise Lizzie’s position of vulnerability and the place her emotions had in underpinning her decision-making. Although the nurses regarded ‘non-compliance’ as a challenge to their work, Lizzie’s body was not behaving as she would have liked, and asserting her agency in this manner was, therefore, a direct challenge to her body’s non-conformity.

Before we left, Lizzie confided,

‘Only you two and my cleaner know [I am incontinent].’

These were powerful words, as they showed another rare moment of vulnerability for Lizzie. It dawned on me how privileged I was to have been involved in observing her interaction with Anya. Lizzie admitted incontinence made her feel ‘frightened’, and she concealed this part of herself from others. Yet she permitted me, a stranger, entry into this part of her life, which left me feeling humbled and honoured, but also apprehensive about the responsibility of how to manage this within my research. Her words were not simply ‘data’. They amounted to more than this; they were a reflection of Lizzie’s self and her inherent dignity. As a researcher, I felt it was also my duty to retain her dignity in my discussions and accounts of her ‘data’, which I aimed to achieve by revealing her story in a manner that accurately re-presented not only her dialogue, but reflected her beliefs, values and agency.

My second observation of Lizzie was with Nurse-Claire, who was undertaking a palliative care visit.

During this visit, Lizzie insisted that we enter her conservatory to see her wardrobe. From her seat in the kitchen, Lizzie shouted, 'open the [quadruple] cupboard doors'. Once opened, these revealed incontinence pads from top to bottom – hidden in plain sight. We both audibly gasped at the number of pads, before closing the door and then returning to join Lizzie in the kitchen.

'Two hundred pounds that [wardrobe] cost me…who on earth buys a wardrobe to go in their conservatory?' Lizzie asked, but without waiting for an answer she continued,

'But I needed to store my [incontinence] pads somewhere.'

The wardrobe contained vast amounts of pads, which made me wonder if Lizzie was simply storing Anya's supplies whilst instead using her own 'pants' from the chemists.

As a social worker, I wanted to ask this question. However, in my role as observer and researcher, I recognised this was not appropriate, so I remained quiet. Claire did not ask this either. However, as a district nurse, she was relatively high in the nursing hierarchy, so Claire's responsibilities for continence had been delegated to staff members hierarchically lower than herself, and continence was not specifically the remit of her visit on this day. As described by Twigg (2000), the further up the hierarchy, the further away from waste and dirt a professional remains, and, concurring with Kelly and May (1982), incontinence did not seem of interest to Claire, the qualified nurse.

On my final visit to Lizzie, she was very frail, and her neighbour was there checking if she was well. Her breathing was laboured and she was clearly in a great deal of pain. During this observation, she told me, 'You're born with dignity and, my God, you should die with dignity.' As a former nurse, she had insight into her prognosis, knowing that her time was limited. Therefore the time she had left needed to culminate in a dignified ending. Lizzie wanted me to interview her, and, although she was busy the next day, she asked me to return the day after for an interview, which I readily agreed to. However, on the morning of our appointment, after ringing her doorbell, the neighbour I met at the previous visit beckoned me over from across the road. I walked over to the neighbour's bungalow where she told me that an ambulance had arrived the previous night and Lizzie had been hospitalised. Sadly, I did not have another chance to interview Lizzie formally and I never saw her again.

Lizzie emphasised that maintaining her dignity was important, and this manifested itself in her actions to ensure she did not smell. Concerns about malodour were echoed by many other patient-participants, who also regarded smell as dignity-reducing. Anya's 'passion' for continence remained closely aligned with patient concerns around smells and dignity. Although Anya was low in the nursing hierarchy, her work remained towards the top of any dignity hierarchy, as she was able to reconcile the conflict between incontinence smells and a loss of dignity by enabling access to resources that would restrict the flow of urine, which in turn reinforced dignity through the presentation of a clean and socially acceptable body.

The relationship between smells and dignity has begun to be acknowledged in this section, and I will return to discuss this later in 'Addressing distressing dressings'. Before considering this, the next section will explore how the process of leg dressings (a routine and regular task of community nurses) can aid in the construction of dignity.

Deconstructing dressings and the manifestation of dignity

Deconstructing the process of leg or foot dressings can offer an insight into how these routine tasks of clinical care can contribute to the construction of a 'dignity encounter'. Although they may not be as 'intimate' as other parts of the body, feet are private, usually remaining covered in public spaces; even within the home, slippers conceal the body beneath. The feet and footwear have many meanings, interpretations and symbolic identities. The study 'If the shoe fits' by Hockey *et al.* (2018) explores changing identities throughout the life course through the specific consideration of shoes. Yet, more generally in sociology, attention to the feet remains largely absent.

Across cultures, the feet remain taboo. For example, in Thai culture, it is considered disrespectful for feet to be pointed towards another person or towards Buddha. In China, the historical practice of binding women's feet for cosmetic and beauty purposes was only prohibited in the twentieth century. In Western societies, women's feet become sexualised through the wearing of stiletto heels: thus feet are the source of fetishes for some people, and, in 1992, the Duchess of York made international headlines for an incident in which she participated in 'toe-sucking'. Some people have an intense dislike of feet; others detest their feet being touched or, in extreme cases, experience podophobia. Feet, therefore, are inherently controversial.

During my fieldwork, I observed that leg dressings were a core component of community nurses' work. During the leg-dressing process, nurses began by laying out their 'sterile field', often on the floor, but sometimes on nearby furniture, if available. During the procedure, patients remained seated on a chair, or sometimes sofa, whilst nurses sat at the feet of their patients. Although most nurses knelt, Mary chose to sit cross-legged, which she described as 'like sitting as a child in assembly'. Their body position offered a physical marker of the nurse's submission and subservience, which contrasts to the bodily manoeuvrings of a hospital nurse, in which her body position remains higher than her patient as she looms over the hospital bed to access the body, retaining a physical dominance over her patient. As a consequence, embodied power relationships differ visibly when nurses interact with patients in hospitals and their own homes.

Once nurses are seated on the floor and the 'sterile field' is laid out, in a display of servitude, they begin to wash the feet and legs. Despite there being a long history of foot washing that precedes Christianity, the washing process evokes religious connotations to Christ washing the feet of the disciples, indicative that the task was not beneath him, a task which at the time was reserved for slaves. Therefore, when washing feet and legs, nurses are engaged in a task that has a long ritualistic history; it is only comparatively recently that this has also been a task for nurses to perform.

Although not grounded in historicist beliefs, by washing feet and legs in the present, nurses are recreating historical acts, whilst also generating future history, as nursing evolves and develops over time.

Washing was a soothing and caring activity. Usually peaceful, patients would relax as their nurse’s arms moved slowly and gently up and down, cupping water in their hands, which they poured over their patients’ legs. This presented opportunities to engage patients in conversation, most usually about their daily lives, their families, the weather or anything else the patient chose to talk about. In their consideration of careworkers dressing people with dementia in residential homes, Buse and Twigg (2018: 350) state: ‘rather than an activity to be rushed, the act of dressing can be an opportunity for “being with”, a time for one-to-one interaction, sensory engagement, and a practice of supporting identity.’ Although in their context, Buse and Twigg (2018) refer to the application of clothing to the body, this is equally relevant in the context of nurses dressing legs with bandages.

When nurses wash their patients, washing becomes a clinical interaction and thus it is medicalised, distancing the action from something that may be considered a routine behaviour for most people. In daily life, the primary purpose of washing may be to maintain cleanliness and hygiene. However, a secondary outcome is the sensory pleasure gained from soaking in a hot bath or allowing water to cascade around the body in a steaming hot shower. Nurses stopped washing patients’ legs when they were cleaned to their own sense of satisfaction, which was determined without any consultation with their patients. When nurses wash a patient’s leg, the primary purpose of washing is retained (to become clean), but this medicalised washing fails to acknowledge the secondary purposes of washing gained through the sensory pleasures of physical human contact and touch.

After washing the exposed body part, nurses softly patted the leg dry with a towel, sometimes (but not always) before massaging cream around the leg, not over the wound, but around other ‘healthy’ areas of the leg which also remained concealed by the dressing. This process also involved pleasurable sensory experiences, for which some patients had developed their own strategies to ensure this was sustained for as long as possible, as explained by Antonia.

> **Antonia (83)**: ...they get the cream out, you see, and they start rubbing it on my leg and rubbing it under me foot and, ooh, it's so lovely. So lovely. And erm, they do it a bit more when you say it's nice [laughs].

As a widower, Antonia had limited physical contact with others. During leg dressings, her body was engaged in a sensory experience, and this was especially important because this part of her body was restricted by bandages. The occasions the nurses washed her leg were the only opportunity for it to be touched. Antonia's body was receptive to her nurse's touch, and she learnt that if she expressed her appreciation, nurses were more likely to spend more time doing this. Thus, to sustain her pleasure for longer, Antonia expressed sounds such as 'ooh' and 'ah'. Although this benefitted Antonia, it indicated that, alongside the nurse, she, too, was engaged in emotional labour to gain her reward. As women, emotional labour is a part of life, because women have the 'job' of 'creating the tone of social encounters' (Hochschild, 1983: 20), and Antonia recognised that if she created the 'tone' of the encounter with her nurses, her corporeal pleasures may be sustained for longer.

During a leg dressing, two bodies interact through fleshy inter-corporeality, but it is nurses who retain the power to initiate physical contact. The patient's body remains passive from the outset, in that it awaits the nurse's instigation of physical contact when she actively touches the foot or leg. Husserl (1913) describes the 'double sensation' of a person using one hand to stroke their other hand, but, in the nursing context, the sensations differ. The nurse's 'touch' is an active act (which is 'felt' by their hand through the barrier of clinical gloves), whereas the leg 'feels' the touch, experiencing this sensation passively, as 'being touched', rather than actively 'touching' the (nurse's) hand.

Although much of the nurse's 'touch' is gentle, there may be times this becomes more aggressive as the cleaning process can involve descaling dead skin. This was described by the nurses as 'picking', and while some nurses thoroughly enjoyed this aspect of their work (such as Rina), others simply endured it as part of the job, but gained no pleasure from doing it (Sapphire). If they enjoyed this process, nurses described themselves as ‘pickers’, also describing the descaled skin as ‘cornflakes’ or ‘cornflakes in milk’ when a cream was also present. Patients may also ‘pick’, but this is not the ‘clinical picking’ of the nurses; Nurse-Mary revealed that some patients would pick their legs when they were close to healing, so that the nurses did not discharge them. This was not the ‘picking’ that is an established clinical process to promote healing, as, although it involves the same physical act, patients used this to slow down the healing process, thereby sustaining contact with the nurses for longer. Hence, the same professionalised activity had been simultaneously de-legitimated. ‘The things people will do to stop being lonely’, Nurse-Mary explained.

> **Nurse-Sheila**: I’ve had patients in the past that are lonely and they don’t want their wounds to heal, and… you might go one day and you’ll be like, ‘it’s nearly healed – great! We’ll be able to discharge you soon’ and then you’ll go the next week and it’ll be as bad as ever […] you’ll get the ones that’ll actually like sabotage their wounds do you know, because they don’t want the district nurse to stop coming, because they don’t have anybody else, and it’s really sad.

Leg dressings were observed as core work of community nurses’ care with older adults. The following section continues discussing observations of leg dressings. However, it focuses on the sensory experience of smell and how this relates to dignity, particularly on the occasions when nursing stinks!

Addressing distressing dressings and the right of redress: Sometimes nursing stinks!

Undertaking dressings is a common part of the community nurse’s job and as a significant number of my own observations involved nurses undertaking dressings, it would be remiss not to address dressings here. The word ‘dressing’ is commonly used to describe the process of adorning clothes. However, in the nursing context, it is also commonly used to denote the process of bandaging a part of the body (e.g. ‘I’m doing a leg dressing’), or it can refer directly to the item used to cover the ill body (e.g. ‘the dressing covered the wound’) or, in reductionist usage, it can denote an entire person (e.g. ‘they are a bilateral leg dressing’). Despite these multiple meanings, all of these involve essentially the same processes: the concealment and containment of a part of the body, the ill body. Undertaking a dressing is not simply a dressing, it can also involve other things, such as ‘addressing’ (communication):

> **Nurse-Denise**: [Interrupts] I still make my_ I go in, before I do anything. I go in and say, ‘have you had a drink today, do you want me to put kettle on?’ I go put kettle on ‘we’ll put kettle on, we’ll do your dressing and I’ll make you a cup of tea’, it’s that little thing of_ that means the world to somebody. And we are a nation of, ‘oh cup of tea, cup of coffee’ solves everything and just that little chat and it’s that chat while you’re doing a dressing to somebody. Just chat and ask them questions.

Echoing Nurse-Denise, a patient who was under district nursing care for leg compression bandaging said:

> **Judy (93)**: I look forward to them coming [laughing] cos we have a little chat, you know while they’re tending my leg we have a little chat and that.

Nurse-Denise extended her explanation of why a cup of tea and chat was so important during a dressing.

> **Nurse-Denise**: The crux is communication, if you can’t talk to somebody then you’ll not be able to nurse them properly cos you’ll not be able to tease anything out. You don’t have to have a tick list you can find lots of information just by sat having a conversation.

Denise did not view leg dressings as a single simple task. She viewed it as an opportunity to interact and engage with her patients, which she initiated by offering a ‘cup of tea’ and having a ‘chat’. During these interventions, interactions unfold to create meaning, which ‘means the world’ to older adults and is reflective of British culture where a cup of tea solves everything. Hence, an unintended consequence of undertaking dressings is to provide a potentially lonely, or isolated, patient with the opportunity to engage with another person.

There are, however, times when undertaking dressings do not match the tea-drinking ideals described by Denise, as there are times when dressings can be distressing.

> **Nurse-Daisy**: It was the cancer that was kind of eating away his abdomen and it was really smelly and I managed to sort of get the smell under control with the dressing that helps with smell…

Throughout my fieldwork, the relationship between bodily smells and dignity began to unravel. It was not solely issues of continence that caused older adults anxiety about smell; sometimes the source of the smell was from wounds or ulcers. These too required regular bodywork from nurses to promote healing, but, through the successful containment of the odour/smell, dignity could be stabilised. As described in 'Anya's "Passion"', malodour, or even the threat of potential malodour, caused disruptions to Lizzie's dignity, and, during interviews with other patients, many (female) patients identified malodour as a challenge to dignity. Therefore, understanding the lived experiences of people who express concerns about 'smell', can aid in understanding how to promote dignity in nursing.

Leaky bodies smell. Nurses undertake bodywork to heal, but also to contain necrosis and malodour. In their description of patients with hypoglycaemia, Mol and Law (2004: 54) explain how the body 'becomes untrustworthy and embarrassing', which was a view also reflected in conversations with patient-participants. Throughout their younger years, women are expected to manage and conceal menstruation, and for the female patient-participants, all were post-menopause, yet managing and concealing their leaky ill-bodies remained an important and rehearsed act. The management of a leaky body is a social obligation and a necessary prerequisite for engagement in the outside world.

Leakages must be hidden, they should not be observable by others, nor should odour accompany the leakage, otherwise dignity is endangered. The unbounded body requires re-binding in bandages as nurses stem the tide. As bodyworkers, nurses focus 'directly on the bodies of others: assessing, diagnosing, handling, treating, manipulating, and monitoring bodies.' (Twigg *et al*., 2011: 171). Bodywork is 'dirty' work, involving emotional labour, as discussed in the previous chapter. Even if a body smells, the nurse's embodied reaction must not indicate any discomfort. Leaking bodies are cleaned and bound to inhibit the leakages. Leaking bodies are abject. If you are the owner of a body that leaks, it can be regarded as something to be despised, detested and a source of shame. Dignity is the avoidance of shame.

Bodies ‘allow us to act, to intervene in, and to alter the flow of daily life[…]acting people are acting bodies’ (Shilling, 2005: 8). Understanding the body can aid a sociological understanding of human agency, as the two are interrelated, as will be explained now by considering the example of Antonia. For eighteen months, Antonia had received daily nursing visits for a leg dressing to cover an exposed tendon. During one of my later visits to her, I met Nurse-Sapphire at Antonia’s bungalow. As I knocked at the door, Sapphire opened it, already dressed in her gloves and ‘pinny’, indicating to me that either Sapphire was early, or I was a little late and the nursing had commenced. The previous day, Antonia had been to a specialist to remove her blackened tendon and Sapphire was there to re-dress the leg, just as nurses did every visit. Antonia told me she had not seen Sapphire for quite some time and the warmth in her smile made it apparent she was genuinely pleased to see her again.

Whilst Sapphire began laying out her ‘sterile field’, Antonia began unwrapping her own leg – this was usually a task for the nurse to undertake, but Antonia liked to assist. Antonia began grumbling that she did not understand why, after removing the tendon, the specialist had bandaged her leg in this way – it was not applied in the usual manner, and this clearly displeased her. Antonia was always vocal with the nurses, and after eighteen months of receiving their input, she appeared confident in informing them how she liked her dressing done, and during all my observations the nurses readily obliged. It was important to Antonia that the nurses allowed her to direct them, which enabled her to demonstrate her agency and retain some control over her body. This is particularly important for ill bodies that are, ostensibly, ‘out of control’. She told me:

> **Antonia (83)**: I could quite easily wrap me leg up meself [sic] cos I’ve got all the equipment and I know exactly what they do [laughs] but, er, and I would if it was absolutely necessary.

Also reinforcing her sense of agency, Antonia explained how one time a ‘blunt’ nurse did not take kindly to Antonia explaining how she liked things done.

> **Antonia (83)**: Well…she was erm…she didn't talk, and…when, you know, when they're doing my leg, I would say 'will you just put a_' and she would go, 'ugh, ooh, ugh – don't touch! You'll get infected!' I'm not gonna touch, I'd never touch. I'm just showing you where I want it to be. But that, she always blew up if I tried to do that and erm, then one time I think I told her about something and she said, 'I know what I'm doing'. So, to me that was a real blunt reply. She didn't want me to be taking part.

For Antonia, it was important to be permitted to participate in the process of her leg dressing. Perhaps this normalised the 'dressing' process, as people generally dress themselves when able to do so. This was Antonia's body and she wanted an active role, not passively allowing the bandage to be done *to* her – it should be done *with* her. The 'blunt' nurse's attempts at dissuading Antonia from 'touching' illustrated how Antonia's body no longer belonged to her. It was now under the direction of the professional: Antonia's control of her body had been displaced to the nurse's jurisdiction, raising issues of who assumes ownership of the body in these scenarios. The nurse had dictated what was appropriate (her own 'clinical' touch) and inappropriate (touch from Antonia, which could result in infection or harm). This nurse had appropriated control of Antonia's body, preferring the patient to keep out of her bodily business, and in turn, this disrupted Antonia's dignity.

Antonia explained that, shortly after, she had mentioned the incident to Nurse-Anya, who explained she had rights of redress through complaining to the manager of the team. This essentially gave Antonia permission to make a complaint, so she telephoned the manager to explain her annoyance. As a result, the 'blunt' nurse had not returned, and Antonia was pleased with this outcome. Antonia had her preferences and enjoyed assuming an active role in the process of dressing her leg, which affirmed her agency and independence. Thus, when the nurse discouraged her independence by preventing her participation in the process of leg dressing, she felt a lack of understanding, which disrupted her dignity.

During my visit with Sapphire, Antonia's dressing was yellowed by serous leaking from the leg. Knowing that she would be unable to unwrap the leg without dampening the dressing, Sapphire squeezed a vial of distilled water over it. Whilst this was in progress Antonia revealed, ‘I am really conscious of smelling.’ Her pained expression slowly softened as Sapphire reassured her that there was no smell. I was seated significantly further away, but I could smell Antonia’s leg. In fact, so strong was the malodour, I could taste the necrosis in my mouth. Therefore, I assumed Sapphire’s words were displays of her ‘professional self’, reassuring her patient, despite contrary indications of malodour. As Sapphire denied the presence of smell, she was able to maintain an illusionary dignity-encounter. Her choice of words (denying the smell) served to reinforce Antonia’s dignity, who appeared satisfied with the answer, despite the aroma of rotting flesh. This cannot be described as an authentic ‘dignity encounter’, as Sapphire’s words were based around something that cannot be objectively regarded as a single truth (the significance of words will be considered further in ‘The Segmented Body’, later in this chapter). Through their mutual collusion, by failing to acknowledge the smell, both Antonia and Sapphire had constructed, and could maintain, the illusion of a dignified encounter.

Malodour is often a consequence of necrotic tissue and even the potential threat of malodour caused distress to Antonia. ‘I always want perfume so I can make myself smell nice because I know you don’t always smell nice when you’re not very well.’ Antonia used perfume as an attempt to mask smells from her ill body. She was conscious that she might smell offensive and this caused her concern, threatening her dignity. Although the necrotic leg tissue was the main source of any potential smells, Antonia, like many other patients, ensured her entire body was prepared for the nurse’s arrival. Entwistle (2000: 11) draws on Mauss (1979) when describing the act of ‘getting dressed’ as a body technique ‘preparing the body for the social world’. For Antonia, her preparation involved a ritual of getting ‘washed’ and becoming ‘clean’ which made her ‘ready’ for the nurses. ‘[I] always try to get washed and be nice and clean ready for when they come.’ The regular nursing visits dressed Antonia’s leg, to conceal and control her bodily leakage. The ill body was only exposed when Antonia’s leg was unwrapped and re-dressed by the nurses; it remained bound and hidden all other times. Thus, when Antonia washed prior to the nurses’ visits, her bathing did not involve cleaning the part of the body that was ‘ill’ (the leg). Yet her words above indicated that she still placed importance on the remainder of her body being ‘clean’ and ‘ready’ for the nurses, even though these were not the sites on which bodywork occurred. Getting washed and ‘ready’ is part of a process of preparing one’s body for engagement with the mediated social world, by ensuring its public presentation is acceptable, reinforcing Antonia’s identity and outwardly displaying her social acceptability. Being clean and remaining odour-free reinforced Antonia’s dignity.

I asked Antonia about whether the nurses supported her dignity and she related this back to smell. She explained:

> **Antonia (83)**: I sometimes say to them, when they’re unwrapping me leg and I’ll say, ‘oh my God!’ and they’ll say, ‘Antonia everywhere we go, people have things like this and we don’t smell it. We don’t smell it. We don’t notice it. It’s just there, but you just don’t bother’, and erm, so you know, and it calms me down a bit cos I think it is bad... But they never, ever refer to anything […] I just thought, [whispering] ‘oh my God is that what the nurses have to smell every day?’

Antonia indicated bodily odours were of concern to her, but she was reassured when the nurses indicated they could not smell anything, which assisted in maintaining her dignity. Even though I could smell necrotic tissue, Sapphire told Antonia at our visit that she did not smell. During our interview, Sapphire recognised the detrimental effect malodour could have on her patients, as it ‘has a lot of effect on their personal life, on themselves really’. She spoke about a different patient:

> **Nurse-Sapphire**: […] I could smell leakage. If there’s a particular scent that you could have, wet legs, shoes fully wet, feet swollen, infection […] [I] saw her about week after… erm…lovely, swelling had gone down, leakage, less leakage… not smelly.

Sapphire also described another patient she encountered in the treatment room:

> **Nurse-Sapphire**: We had a gentleman who worked night shifts and it was just a normal job and you wouldn’t even think when he rocked in, there was something wrong, that he had a wound. He had a really, really nasty gaping wound on his left leg and it never healed. I think it was a surgical wound and it was really nasty and he was embarrassed about the smell.

Nurses may be reluctant to inform patients that they smell. It may be deemed to be embarrassing, insensitive or indeed potentially perceived as unprofessional to acknowledge.

Sapphire explained a little more about this from a nurse's perspective:

> **Nurse-Sapphire**: Sometimes, you see things and you wanna vomit or… it makes you gurge [sic] sometimes, don't it, like the smell of wounds or like certain things, they do, but you've just got to, you've just got to keep it hidden.

This explains how the nurse's 'professional self' conceals her own embodied response to odours, so that her performance makes no acknowledgement of the emotional labour she is engaged in. Sapphire recognised that smells must remain 'hidden'; as they are invisible, they can be ignored. Even if a patient directly asks if they smell, it may be perceived to be rude to confirm this, which was why Sapphire denied the presence of smell to Antonia. Malodour is an affront to dignity.

> **Nurse-Chloe**: You just think, 'urgh!' Like I'm there trying to act like it's normal… because it's normal to them, but like if it smells_

Chloe's words indicated that smells are not "normal", and thus her emotionally laboured performances should not betray the irregularity of malodour.

There was one solitary occurrence in which I briefly observed a nurse acknowledge bodily odours to a patient. In this observation, Nurse-Rina unwrapped Michelle's leg dressing.

'This leg smells a bit,' Rina remarked.

'Don't say that!' Michelle hastily retorted, and the conversation was over.

The atmosphere immediately became frosty and Michelle's tensed muscles and rigid frame visibly demonstrated her embodied reaction to feeling embarrassed. Michelle had made a '*faux pas*' (Goffman, 1959: 204), as she had unwittingly made a statement that destroyed the image of an odour-free scene. This halted, if not shattered, the construction of a 'dignity encounter'.

A short while later, after having time to reflect, Rina began backtracking, saying she felt sure it was the INADINE™ dressing causing the odour, even though the clinical aroma of INADINE™ is unmistakable compared to the smell of necrotic tissue. Deflecting the smell away from Michelle’s ill-body and onto the dressing seemed to offer some reassurance to the patient, who quickly agreed, ‘Yes, it is the INADINE dressing that smells!’

Goffman (1967) considered embarrassment to be related to unfulfilled expectations, and if embarrassment is a challenge to someone’s dignity, minimising embarrassment and reducing any shame will move the encounter towards one in which dignity becomes stabilised. Thus, through Rina and Michelle’s mutual collusion, dignity was restored. As smell is invisible, it can remain ignored, an unspoken secret that assists in maintaining a dignified encounter – it is when spoken language confirms the presence of malodour that disruptions to dignity are likely to occur, as will be considered in the following section.

The segmented body: Reductionism and the significance of language

On a daily basis, conversations between patients and nurses involve clinicians providing technical medical explanations to patients, but problems may arise if this is not done well, making dignity fragile and easily shattered through spoken words.

> **Margo (87)**: Medical terms, it’s speaking in tongues isn’t it.

Inaccessible language when clinicians use medical terminology may be a barrier to patients’ understanding. Margo recognised there were many occasions when clinicians spoke to her and she had difficulty understanding the meanings of their words. Words and language are powerful, and they can have long-lasting effects. People’s intended meanings may be reinterpreted by other actors involved in the dialogue, and this can result in someone experiencing the manifestation of dignity, the absence of dignity or the violation of dignity if words are belittling or abusive.

Reductionism aims to make complex concepts more intelligible. However, by eliminating certain elements of these descriptions, there is the risk of oversimplification and lost meanings. In medical and nursing contexts, reductionism is commonplace – this was recognised in the previous chapter where nurses reduced certain patients to the labels of ‘non-compliant’, and earlier in this chapter where Lizzie was described as a ‘refuser’. Beresford (2010) recognises that evidence-based medicine is grounded in reductionist methodologies, in which problems are heavily simplified and complex entities are reduced to measurable units so that statistical methods can be applied. Thus, it may be unsurprising that there are times when reductionist principles permeate into professional practice.

When considering reductionism in nursing, it can be helpful to consider the role of spoken language in terms of how it can express some reductionist perspectives held by nurses. During fieldwork, reductionism was most likely to occur when staff were not in the company of patients, either in the office or travelling in their cars, where they used reductionist terminology to describe their patients. There were also many occasions when nurses would refer to patients by their names (which occurred when they were communicating with another nurse who knew the patient); however, it was often when speaking to a nurse who was unfamiliar with the patient that their language reduced that patient to their diagnosis or nursing condition. Thus, in the nursing office, it was commonplace to hear reductionist descriptions of patients. As examples: Judy was ‘a compression’; Jack was ‘bilateral legs’; Amber became known as ‘a bit of self-neglecter’; and Lizzie was ‘a declining palliative’ (‘declining’ because she was refusing treatment, but holding a dual meaning as her bodily functions and abilities were also ‘declining’ as a result). Labels such as these can lead to stereotyping and can be powerful in reinforcing or reducing dignity. Minimising people to diagnoses, interventions or body parts is a short-hand method of communication (giving the recipient of the communication a quick comprehension of the diagnosis or potential intervention). However, it does not describe the complexities of human beings and can lead to preconceived professional expectations based on the label, ultimately resulting in professional responses being predetermined. As Foucault (1973: 59) explained,

> the patient is the *subject* of his disease, that is, he is a case; in this clinic, where one is dealing only with *examples*, the patient is the accident of his disease, the transitory object that it happens to have seized upon.

Reductionism regards people as a ‘case’, failing to acknowledge the holistic body and the existence of personhood. It simply segments one part of the body (the ‘ill body’, rather than the ‘healthy body’) making the patient synonymous with their (ill) body-part. Through this process, patients become depersonalised, as they become the embodiment of illness. In these scenarios, dignity is absent, as it remains inherent only in humans and cannot exist within the isolation of a disease or illness.

Language influences dignity outcomes both through the spoken word and also in how it is operationalised in the production of clinical records, offering what Foucault (1973: xvi) described as ‘commentary’ on professionals interventions with patients. During her interview, Nurse-Rina drew on her 24 years of nursing experience to discuss dignity. In our discussion, she described a scenario in which a doctor had recorded something she felt was inappropriate on a patient record (the ‘file’). This scenario related to one of her bariatric patients whom she cared for during her time working on the wards.

> **Nurse-Rina**: In [name of nearby city]…they had everything… in one file so, your files could have been picked up [by patients or relatives]... and in this particular patient’s notes the doctor had requested erm, a chest X-ray and he’d wrote in it, erm, ‘please enquire with local zoos’ and he wasn’t being malicious but the only X-ray machine that would hold her would be one at a zoo, but that was really, really undignified…To know that you’re so obese that they’re wanting to check with the local zoos it’s… and it was something that_ it wasn’t malicious… but maybe that could have been worded differently, just in case somebody did see that… but what if she died and they wanted to get those notes back_ and I’m not saying… hide things, because we’re not allowed to do that, but it could have been worded differently… and it’s not just caring about the patient, it’s not just the physical care that you give to a patient, it’s everything that surrounds it. It’s the way that you refer a patient, it’s the way you talk about a patient or document about a patient. You know, it’s all got to be… maintaining their dignity so, I can’t, you know_ when we try to explain what does it mean to you, I can only do it by sort of sharing those experiences but… it’s all those things that have made me, made me very, very passionate about dignity. I, I… absolutely hate disrespect in anyway.

Rina indicated dignity is not simply about the physical care that a patient receives, but it is ‘everything that surrounds it’, including the language professionals use when recording patients notes. Rina found it undignified that the doctor had used the terminology, ‘enquire at local zoos’, which she felt was dehumanising. Importantly, it was the language used to express this situation that Rina felt was undignified and not the specific act of sending an obese patient to a zoo for an X-Ray. Although Rina acknowledged that they cannot conceal things from patients, in this example, she believed dignity could be maintained through a more appropriate choice of words. Thus, for Rina, it was the terminology used to describe nursing actions and processes, but not the act itself, that can cause a breach of dignity. As an aside, it still remains unclear as to whether the NHS uses equipment in zoos to scan humans, as there are ‘claims, counterclaims and outright denials’ about the practice (Meikle, 2013).

This section has shown the importance of spoken language in maintaining dignity and how there are times when clinicians segment the body linguistically into individual parts to describe patients, which is an approach at odds with maintaining dignity. The next section builds on the concept of the segmented body to consider aspects of nursing care with more intimate parts of the body and the implications this has for dignity.

It’s ‘a bum thing’: Working with the intimate body

Nursing in the community encompasses interventions that involve physical intimacy, including the manual evacuation of faeces, applying vaginal creams and catheterisations. Indeed, in these intimate procedures, some degree of a ‘performance’ is required from both the patient and nurse (recognised previously in Chapter 4) to retain a sense of ‘normality’. This aids and facilitates the interaction, especially if it involves transgressing the usual social codes of acceptable touch.

To create and maintain a dignified encounter, all parties must understand the boundaries of acceptable behaviours in each specific clinical interaction.

> **Nurse-Denise**: When you recatheterise, it is [intimate]. They’re exposed. It is an intimate_ and when you’re doing a breast

> dressing or, you're packing somebody's scrotum or their sacral dressing. That is very intimate because you are, it is intimate dressing. You don't expose your bottom, or your breast, or your genitalia to anybody and it is very intimate the things that we do, but that doesn't give them the right …to cuddle and to touch and to say, quite…not nice things.

Denise explained that when engaging in intimate procedures, there were times patients interpreted this as an indicator that they can 'cuddle and touch' the nurse, confusing the patient/ nurse boundaries. Nursing relationships involve unequal bodily transgressions, in which nurses are permitted to touch intimate areas of their patients, yet patients must not reciprocate. When performing clinical interventions, nurses transgress wider social codes of touch, but these remain boundaried by their professional codes of conduct. Although patients should not reciprocate by transgressing social codes of touch, according to experiences expressed by the nurse-participants, it seems at times, they do.

In line with Gallagher *et al.*'s (2008) recognition that 'specific care activities' have the potential to help or hinder dignity, when body-working on intimate areas, creating 'dignity encounters' assumes increased significance, as there are more opportunities for dignity to be violated when intimate areas are exposed. In describing dignity, in this context, Nurse-Victoria explained:

> **Nurse-Victoria**: Making sure somebody…erm… like if you do an intimate procedure, that they feel covered up, that they feel comfortable you know…

Some parts of the body are less intimate and therefore are more publicly viewable than others. These notions of more public and private parts of the body echo discussions in the next chapter, which explores how different spaces within the home are more public than others, and this, too, has implications for dignity. In terms of privacy of the body, an example can be found in nurses' administration of insulin which requires exposing the injecting site – an upper arm, upper leg or abdomen. To avoid lipohypertrophy,[5] injecting sites are usually rotated. These three bodily sites

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[5] The accumulation of fat around the injecting site which affects the absorption of insulin.

also form a hierarchy of bodily exposure and intimacy, in which the upper arm is the least intimate (and most public) area, the upper leg is more intimate than the arm but less intimate than the abdomen, and then, finally, the abdomen is perhaps most intimate of all, as it is the least likely area to be publicly displayed (other than on a beach).

During nursing visits, the exposure of body parts is often anticipated. Both nurses and patients assume responsibility in determining what area of the body can be exposed in what specific area of the home, illustrating the overlap between dignity in caring for the body (Chapter 5) and dignity in the home *(*Chapter 6*)*. For example, administering an insulin injection usually occurred in patients' lounges, at times when family members were also present. Yet, this did not lead to either nurse or patient identifying any breach of dignity. However, if an injection is required in a more intimate area, such as a depot injection in the bottom, it is more likely that the interaction will be undertaken in a more private space, such as the bedroom. Thus, exposure of more intimate bodily parts may result in the patient moving into a more 'private' area of the home, regardless of whether anyone else is present. This indicates that there is a relationship between privacy levels of the body and the home, with more public parts of the body being revealed in more public areas of the home, and more intimate areas of the body being more likely to be exposed in the bedroom, a more private part of the house. This is considered further in the next chapter.

> **Nurse-Chloe**: [I ask], 'do you mind having it done in front of so-and-so or would you like them to go out? Do you want to move to your bedroom?' or if it's a bum thing, 'oh do you want to go in your bedroom to change your dressing on your bum?'

In the context of bodywork with the more private areas of the body, both dualist and monist discourses retain relevance. Cartesian perspectives of duality regard the mind as a non-physical and non-spatial phenomenon, separate from the body; in which the body is an appendage to the mind. Prior to the emergence of dualism, Christian views of the mind-body relationship hindered the development of medical science. Body and soul were one. Thus, for the Christian soul to reach heaven, the body needed to remain intact, resulting in a religious prohibition on anatomical learning through dissecting the human body (Mehta, 2011). Descartes' dualist perspective enabled segregation and separation between body and mind, which reconciled religious beliefs that the mind and body were one. Therefore, once a person died, the soul was free to leave the corpse and enter heaven, whilst the cadaver remained available for dissection under the scalpels of medical science. Following an ontological turn towards monism, the duality perspective was rejected so that the mind and body were viewed as one. Hence, the view was that people do not possess a body, they *are* their body (Merleau-Ponty, 1962). However, it can be argued that the dualist perspective still dominates medical practices, despite its repudiation from health practitioners and philosophers alike (Mehta, 2011, Joubert, 2014).

The presence of this Cartesian duality became apparent in one of my observations between a patient, Brenda, and her nurse, Nieca. Prior to our visit, Nieca described her patient as 'bedbound', and, when we arrived, Brenda's husband guided us to their bedroom where Brenda lay in bed. The room was disproportionately small for the furniture it housed: dominated by an enormous bed, there was only just enough room for us to squeeze around the side so that Nieca could sit on a commode next to the bed, whilst I perched on a chair beside her with Brenda's husband remaining standing.

As part of her assessment, Nieca asked to check Brenda's pressure areas. Quickly, without further discussion, Brenda lowered her pyjama trousers fully exposing her bottom. Whilst sat on the commode, Nieca began typing on her laptop without looking up whilst Brenda remained exposed. I looked away, maintaining eye contact with Brenda's husband whilst he spoke to Nieca, whose eyes remained firmly fixed on her laptop and thus I was unsure if she was aware Brenda's bum was still on view. I deliberately avoided looking towards Brenda as my peripheral vision could only see a bottom.

Nieca continued to type her notes.
Brenda's bottom was exposed.
Nieca remained seated on the commode typing.
Brenda's bottom was exposed.
Brenda's husband was talking.
Brenda's bottom was still exposed

The commode, a bottom, the commode, a bottom, the commode…
…I felt somewhat panicked.

I was uncomfortable, slightly embarrassed, but wanted to ensure my own discomfort remained concealed. My eyes locked on Brenda's husband's face, but as he spoke, I failed to hear or process his words. I was unable to avert my gaze as I was aware that any slight eye movement could result in me viewing something that felt inappropriate. I sensed my cheeks redden, yet my stoic gaze remained on the man, hoping (more than anything) that the whole situation would be over as quickly as possible.

After what felt like an eternity, but what must have only been perhaps a minute or two, Brenda's husband told her it was 'all right' and she could cover herself, which she then did. It was at this point that I became aware that I must have been holding my breath, as I quietly gasped for air, safe in the knowledge I could now, once more, breathe…

Although this part of our encounter lasted only a matter of minutes, two elements were striking. Firstly, Brenda readily allowed me to view an 'intimate' part of her body. These viewing rights may be willingly granted to nurses because of the nature of their profession, but in my primary profession as a social worker I am not automatically bestowed these privileges, and I would consider it unusual for a service-user to expose their bottom to me. As a researcher, this was my first encounter with a naked part of the 'private' body. My embodied response manifested somatically in my limb muscles tensing, in a quickened heartbeat and in me holding my breath, and although I could not see myself, I sensed a reddening of my cheeks, whilst I continued to stare intently at Brenda's husband. My ethnographic reality had become what Allen (2004: 16) describes as 'embodied understanding'.

Brenda was obviously so accustomed to having her body displayed during interactions with the nurses that exposing her bottom was automatic; it was acceptable and was not a big deal. Her body was public, and I was now among the 'public' that could view. Hence, Brenda's body had become 'specimen' (Jones, 2011). Whilst the body-subject remained 'private', the body-object was created during this clinical encounter, in which it became ‘exposed and publicly displayed’ (Mol and Law, 2004: 43).

The second significant consideration of this encounter was whether any violation of dignity occurred, because an intimate body part was exposed for what may have been an unnecessary length of time. My embodied reaction during the event, and my personal reflections after the encounter, led me to believe there may have been a transgression of dignity. It was not simply Brenda’s naked bottom that caused a potential breach of dignity, as this was necessary to check the pressure areas, but it was the length of time that she was exposed that became most relevant in determining whether dignity was absent. During this observation, my experience of time had decelerated – I experienced the exposure as an ‘eternity’, yet realistically it could only have lasted a few minutes. Thus, if dignity is violated, it may be felt temporally through changes in the experience of time. As illustrated by this example, time considerations are important, and these will be considered in more depth in the next chapter ‘Dignity in the home’.

Although I felt there may have been a lapse in Brenda’s dignity, from their subsequent interactions, it was apparent that neither the nurse, the patient, nor the husband shared my perception. This example demonstrates how dignity is not universally understood and experienced the same way, which accounts for my own perception that dignity was absent, whilst my participants’ experience appeared to differ from my own. It is possible that they had become desensitised to the exposure of this ‘private’ area of the body – decades of medical interventions had ensured their frequent experience with bodily exposure in this context, and it was me alone who had not experienced this history. Perspectives of mind-body dualism can potentially explain how they were able to normalise the encounter without it being a dignity violation. Despite being problematic, if the duality doctrine is accepted (by the nurse and her patient), inherent dignity can remain intact, because dignity can remain ‘of the mind’, whilst the somatic body may be exposed or be subject to a breach of dignity.

In this scenario, the participants had all normalised an objectified body as something that required observation and assessment, which did not influence the dignity of the body-subject. Thus, through their shared understanding (their ‘shared morality’ – Harris and Sulston, 2004), they maintained a ‘dignity-encounter’. Every social actor has their own understandings of the world, and it when there is a disruption to the actor’s ontological security that dignity may be absent. In this scenario, my own (monist) beliefs that ‘I am my body’ (Merleau-Ponty, 1962: 321) meant I may have identified a breach of dignity, as internal dignity cannot remain intact if the outward body is offended. Hence, ontological perspectives of mind and body are essential in determining whether dignity remains undamaged or violated. When nurses and patients enact shared moralities, dignity violations should not occur, as their views harmonise, but transgressions of dignity may occur when people hold contrasting views. In this context, remaining mindful of the two theories of the body (dualism and monism) is useful, as social actors may be interacting with each other based on two different perspectives of the body, and this increases the potential for dignity disruptions.

I failed to ask Nieca about this observation during our interview. However, the significance of this encounter only became apparent much later, during my subsequent data analysis. I failed to question her about it during our interview, as I had minimised the encounter, and its complete significance was not in my consciousness at the time. However, during our interview she noted,

> **Nurse-Nieca**: what one person perceives as privacy [another doesn’t]…and it goes hand-in-hand with dignity doesn’t it?

She recognised that notions of privacy may be contested, which may explain my differing interpretation of the scenario involving Brenda’s naked bottom. As a social worker, naked bottoms are unusual, but for nurses they are much more routine.

Bodily waste: Excrement

The previous section considered working with the intimate body, specifically by exploring an observation involving the exposure of a patient’s naked bottom. Attention will now focus more specifically on dignity relating to matters of bodily waste-matter: urine and faeces.

Bodily waste is normal, but it is ‘dirty’. In wider society, excrement generally remains absent from social interactions. Yet, during my fieldwork, when nurses interacted between themselves, there were indicators that these discussions were normalised. Sitting in the staff room over lunch, conversations about faeces, urine or ulcers would occur between the nurses. They appeared unaware of the contradiction between placing food in their mouths, whilst discussing the process of bodily excrement – two bodily activities that usually remain distinctly separate. As bodyworkers, nurses undertake dirty work and their descriptions of this, even during mealtimes, indicated an evident professional desensitisation.

The body’s removal of excrement is inherently related to dignity. For a healthy body, the removal of excreta is generally a private matter, undertaken behind the closed doors of a bathroom, often behind a locked door to ensure even family members cannot invade or interrupt this activity. However, this view is based on assumptions that people live in a home and have the resources of a bathroom at their disposal. Nurse-Daisy offered an account of some care she gave to a patient who was homeless. Infection control was Daisy’s priority, but she had to balance this against the patient’s differing priorities. She did not recognise this dichotomy, nor did she recognise this was not solely an issue of infection control. Actually it was an issue of dignity.

> **Nurse-Daisy**: Well, he was erm… homeless, but obviously living in [name of local hostel] for_ temporarily, he was an alcoholic and we, me and [name of nurse] was called to_ well it was like a referral for a new catheter. So we went in to_ just assesses it, make sure they’ve got stock of catheters, erm… make sure he’s using it properly and you know, and give him like hygiene advice if he needs it. So I’d noticed… [Name of nurse] was doing all the laptops, and I was just checking he had it secured to his leg, because obviously if it’s not secured it will pull on his penis and it can cause bypassing and blockages and then trauma… and then I noticed the tap was hanging down… out of his trouser leg… so I said, you know, ‘are you, is there any reason…’ because some of the catheter bags are longer than the others, so that’s another thing I thought, ‘is it because the tubes are really long, that he’s been ordered?’ so I asked him if he wanted any shorter ones ordering, he said, ‘no I like it like that, because I can just empty out on the street when I’m outside’, so I said, ‘well you know we wouldn’t really advise

> that, because when you open the tap you're letting in bacteria especially if you're opening it out on the floor outside' and he just decided he wanted to continue like that so… we just allowed him to because we gave him the advice and he decided_ he had capacity to make the decision and accept the risks involved… so he carried on with the long tube catheter and just allowed it… hanging down.

Daisy was concerned about reducing the likelihood of infections (on the body-object) caused by a lengthy catheter tube, but she failed to recognise her patient's differing priorities. During the day, the hostel required all residents to vacate the building and Daisy noted that each day the man would 'walk the streets'. However she failed to recognise this limited his opportunity to access toilets or another private space in which he could manage his catheter. The only other alternative would be to publicly lower his trousers to enable him to release the urine, which may not only be undignified but also potentially perceived as a criminal act with legal consequences. Thus, although the catheter tube was longer than clinically necessary, the patient's dignity was maintained as he could 'empty out on the street' without revealing himself and potentially being criminalised as a result. Bury (1982) recognises how chronic illnesses can lead to biographical disruptions due to the intrusion of illness prompting a re-evaluation of the self, which can result in disturbances of routine behaviours. In this example, Daisy's suggestions to change the management of the catheter may have interrupted the patient's ontological security and biographical flow. Over his time living on the streets, he had rehearsed solutions to manage his continence and when Daisy suggested an alternative, this did not fit with his lifeworld experiences, as it was routine and habitual to open the tap at the bottom of his trousers to drain the urine. This was embedded into his everyday life.

Daisy's example of her homeless patient, along with the earlier discussion of Lizzie's continence care, illustrates how dignity is inherently intermingled with the effective management of bodily waste. Hence, to ensure dignity, care must be managed in line with body-subject experiences and not simply grounded in nurses' knowledge of the body-object which is devoid of agency and subjective experiences.

Bodily waste is linked to dignity, but waste matter can also become 'symbols of defilement' (Sibley, 1995: 127).

> **Nurse-Nieca**: …oh I did once get trapped in a flat with a patient erm…and he was an absolute horror and he used to have dirty protests and er faeces_ and he used to open his catheter bag and trail round this_ because it wasn't it was like a, it was like a rehab place er, so it wasn't his own house. And he used to open his catheter bag and just wee all over… the flat and all over the building and the nurses_ the carers were absolutely pulling their teeth, pulling their hair out, [they asked us], 'can you just come and have a look at this catheter I don't know whether he's done it cos he's got a problem with it', so… and they just sort of… they'd sort of… to get us to go, what they said was for the referral was, 'his catheter's leaking' […] So I'm thinking, you know, bypassing catheter and when we got there it wasn't the catheter, it was the leg bag and there was pee everywhere and it was in the flat and he trapped me in the flat, in the corner and I couldn't get out, and the carers were saying, because he had an electric wheelchair and they're really heavy, and he'd sort of [inaudible] me in the corner and I was due to go off duty, and oh my god and the carers rang the police… erm, they just come and tasered him […] They come and tasered him. He went into… cardio failure and the paramedics had to come and do CPR [laughing] […] And [he was] admitted to [name of local hospital]. They [police] don't take no messing. So we were pandering around him, trying to sort of get to the better side of his nature and they just went chush [mimicking tasering sound].

This scenario was not a 'dignity encounter'. Despite her laughter, Nieca offered a detailed description in which it appears that dignity was entirely absent for all parties involved in the interaction. From her description, Nieca explained her anticipation that the visit was to correct a bypassing catheter. However, on arrival, she was confronted with an unexpected scenario in which the patient had deliberately used his own bodily fluids as part of what she described as 'a dirty protest'. Nieca believed that this behaviour was prompted by the man failing to have a sense of ownership over his flat, implicitly indicating that if this was his own home, he would not have behaved in this manner. This patient would 'just wee all over… the flat and all over the building'. In an analogy to an animal marking its territory, this behaviour may have been indicative that he had no sense of ownership over the environment, which was demonstrated through a deliberate (loss of) control over his body and an enactment of agency, which can reinforce dignity. This ownership of the home environment is important when considering dignity in community nursing care and is the focus of Chapter 6 in which dignity in the home is examined.

The body in space: The ‘incomplete’ body in public and private spaces and ‘plastic bodies’

Before reaching the end of this chapter, attention will focus on how dignity can be influenced when people have ‘missing’ body parts or ‘incomplete’ bodies. Through a consideration of Barbara’s situation, I will demonstrate how there is an evident intersection between the body and space, as Barbara adapted her use of prosthetics in public and private spaces to create and maintain her own dignity.

Barbara was 77 years old and lived with her husband in their home in the city centre. She had been receiving daily insulin injections from the community nurses for three and a half years. As a result of health issues (other than diabetes), Barbara’s legs had both been amputated and it was her legs (or lack of them) that were central to her challenge of retaining dignity. She explained:

> **Barbara (77)**: [I] just keep smiling all the time. I do. And when I talk to people I don’t talk_ I just talk to ’em like I’ve got my legs, just natural. And when they say, ‘oh hello [name of participant], how are you?’ and I go, ‘oh fine, same as yesterday’. So I never let them know. And if I was badly I still wouldn’t let ’em know…

On my first visit, Barbara was sitting bolt upright on a daybed, her long grey hair reflected in the gilded mirror behind her. She was dressed in a white lacy negligee that did not quite cover the bottom of her knees, which marked the end of her legs. Although Barbara was sitting on a daybed, it was positioned in the lounge, which also served as Barbara’s bedroom (when someone is ill, rooms have multiple uses, which is considered further in Chapter 6). The room was bursting with Barbara’s collections: floral Chinese rugs covered the carpeted floor, whilst teddy bears and frilly dressed porcelain dolls gazed blankly at cross-stitched tapestries adorning the walls.

Barbara’s prosthetic legs featured heavily in conversations with Nurse-Sheila, and this was mirrored in her interview, in which Barbara focused on the necessity of being seen *with* legs to maintain her dignity. Barbara was concerned about other people’s perceptions, and there was clearly the potential to disrupt Barbara’s dignity if people saw her without legs. It was not necessarily other people's perceptions *per se* that led to a disruption in Barbara's dignity, but her preconceived beliefs about other people's perceptions that led her to anticipate a possible lapse in dignity. Barbara had a pair of (prosthetic) legs, but she wanted new ones as she described her current legs as 'horrible'. Barbara explained they were uncomfortable, despite being visually appealing,

> **Barbara (77)**: When they made them I said, 'make sure you put me slim ankles', so when I'm in a wheelchair you think I've got me legs, proper legs.

When in public, it was important to Barbara that people remained unaware that she had prosthetic legs as her own experiences of retaining dignity meant being able to display a complete (not partial) body. This raises implications for the politics of disability, as well as having broad dignity implications for people with physical disabilities, who may be perceived by society as worthy of pity and lacking dignity if they are viewed in this manner. Although she was proud of her 'slim ankles', Barbara still described her legs overall as 'horrible'. Slimness, or, more generally, appearances, can be an influential consideration for women, and this can be at odds with an ageing body, in which body-parts inevitably begin to droop and sag. Thus, having slim ankles was a point of pride for Barbara. To maintain her dignity, she wanted other people to believe her prosthetics were 'proper legs'. She explained:

> **Barbara (77)**: Cos when I'm out people don't realise they're fake legs, so when I'm in my wheelchair they don't stare and make me feel like everybody else.

For Barbara, having dignity was about being the same as 'everybody else', and not displaying her difference. Barbara normalised having two legs and being seen with her prosthetics made her feel like everyone else, thus her dignity was maintained. Barbara used the words 'proper' and 'fake' when describing legs, and to retain her dignity she needed to be viewed as possessing 'proper' legs. This 'properness' of legs is reflected in Jones' (2011) anthropological consideration of embodied ethics. In this paper, Jones (2011) discussed Magritte's famous painting (shown in figure 2), 'Ceci n'est pas une pipe' (translated – 'this is not a pipe'). The painting is merely a representation of a pipe; it is not a 'real' pipe itself. Similarly, Barbara's legs were not real (‘proper’), they were manufactured representations of legs (‘fake’). However, as long as people perceived her legs as ‘proper’, Barbara’s dignity remained intact, even though they offered merely an illusion of reality, not reality itself (as per Magritte’s ‘pipe’).

Figure 2: René Magritte, ‘Ceci n'est pas une pipe’ (1928/29)[6]

When I interviewed Barbara, she said it was very important to her that people did not identify her legs as ‘fake’, because she didn’t ‘want to be looked on as disabled’. Barbara did not want pity and she regarded disability as being something evoking this response from others. Barbara always used a wheelchair when she was out, but the wheelchair did not elicit the same negative reaction from her. Whereas the (prosthetic) legs were part of Barbara’s embodied identity, the wheelchair was not; thus it was not a mediator of her dignity, despite being a clear marker of disability. Maintaining a sense that her body was complete meant Barbara felt she was able to avoid a reaction

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[6] Image reproduced under an Attribution-NonCommercial 2.0 Generic licence. Available from: https://www.flickr.com/photos/xwl/4936781806/ [Accessed 21/08/18].

of pity in others, so that the (‘horrible’) prosthetics bestowed dignity. It was the missing body part that caused Barbara concerns she may lose her dignity, but wearing the prosthetics meant they both remained intact (her body and her dignity). However, Barbara’s dignity was incomplete because her body was incomplete. A complete body could ensure complete dignity.

When Barbara went outside she wore ‘sparkly Michael Kors [shoes], so people don’t stare at me’. Her legs may have been ‘fake’ but her Michael Kors shoes were not. Much contemporary research into shoes and older adults focuses on the prevention of falls, rather than shoes being a fashion item for older adults. Thus, studies such as Menant *et al*. (2008: 1167) indicate that, to prevent falls, ‘older people should wear shoes with low heels and firm slip-resistant soles both inside and outside the home’. This fails to recognise the importance that fashion may play in an older person’s life, nevertheless, although this may be the practical choice of footwear (for people of any age), just because someone is older does not mean they do not want to be fashionable. Findings from the sociological project into shoes by Hockey *et al.* (2018) indicated that many older women express dismay at no longer being able to wear shoes in styles worn during their younger years. Barbara still wore the shoes that she enjoyed wearing as a younger woman. However, her shoes served purely aesthetic (and not functional) purposes, as she had no concerns of falling as she always remained in her wheelchair. The shoes did not serve the functional purpose of offering the foot any protection, but their aesthetics (and ‘realness’) were able to reinforce Barbara’s dignity. There is a juxtaposition between the ‘properness’ of Barbara’s shoes and the ‘fakeness’ of her legs, which shows the importance of displaying the prosthetic body in a certain way, dressing it in shoes that pleased Barbara. The Michael Kors shoes drew attention to her ‘slim ankles’ and this may, in fact, focus other people’s attention onto the very area of her body that she stated she did not want others to view as ‘different’.

Barbara consistently linked her dignity to being seen with legs in public spaces. However, she never wore prosthetics for visits from the nurses, which indicated that her dignity must have remained intact in the home, despite an absence of legs. The prosthetics bestowed dignity to her in public spaces, but they remained unnecessary in the private space of her home, including when nurses, or even outsiders such as I, entered this space. At the interview, I asked her about how her nurses treated her.

> **Barbara (77)**: They treat me like I've got legs. Cos they say, 'I wish we had something to write down Barbara, can't you just say you don't feel very well today?' [Laughing] But they're so lovely.

Barbara retained her dignity in her home, reflected by her acknowledgement that the nurses treated her as though her body was whole. Her home environment offered her a space in which dignity could be manifested without the necessity of prosthetics. Yet, to maintain her dignity in public spaces it remained essential to conceal visible indicators of ill-health and display the whole body by wearing prosthetics. This indicates that dignity can manifest itself differently in public and private spaces, which is a key argument in the following chapter. Barbara demonstrated power and agency in her own home, and thus her dignity remained intact without the need for the addition of prosthetic legs. I only observed Barbara once before interviewing her, but on our second meeting she called her husband to hand me one of her legs so that I could have a good view of it and 'feel the weight'. I cannot imagine Barbara being this open with other people, or strangers such as me, highlighting how my position as a researcher offered a position of privilege, enabling access to the ordinarily hidden.

It is not just prosthetics that raise issues of how dignity manifests itself when bodies are partly artificial. Consider a quote from Lizzie:

> **Lizzie (91)**: I'm a person, you're a person. We're not plastic. We're human beings.

Lizzie was introduced at the opening of this chapter in 'Anya's "Passion"' and it seems appropriate to return to her now. Before her retirement, Lizzie had worked as a nurse for many years, so her views were based on her experiences both as a nurse and as a patient. Despite her retirement, Lizzie continued to hold the dual persona of 'nurse' and 'patient', because 'once a nurse, always a nurse'. Retirement did not stop the nurse-persona from being a part of who she was. For Lizzie, recognising people were not plastic was fundamental, as somatic bodily experiences cannot be compared to those of a ‘plastic body’. This was reinforced during my second visit to her in which I sought her views on contemporary nursing.

> **Lizzie (91)**: The problem was when nurse training started in universities. Nurse training should be done in hospitals. Not with plastic [mannequins]. You know, with real people.

Again, she made reference to ‘plastic’. On this occasion, it was within the context of the plastic models that feature in clinical skills laboratories used by most student nurses during their training. Use of plastic ‘bodies’ in this way is not an entirely new phenomenon. However, it does not offer the complete nursing experience that is gained from interacting with a living, breathing human being. By nature of being plastic, a mannequin cannot possess *Menschenwürde* (Nordenfelt, 2004, 2009) and thus it cannot experience a violation of dignity.

Resonating with earlier discussions of Barbara’s prosthetic legs and how these offer similar representations to Magritte’s ‘Ceci n’est pas une pipe’, we can surmise from Lizzie’s views of plastic mannequins that ‘this is not a body’ (even though they are supposed to represent a body-object). Mannequins may *represent* bodies, but they can never *be* bodies. Lizzie emphasised human beings are not plastic and they behave quite differently from the models used in nurse training. When something is plastic, it cannot experience emotions, it lacks agency, nor can it engage in a participatory relationship with human beings. Plastic bodies have training value, as in many scenarios it would be undignified and unethical for trainees to practice on humans. However, mannequins cannot respond like humans, and thus they have limited use in training nurses to conduct themselves in a manner that will lead to a dignified encounter with their patients. There is no intersubjectivity between a nurse and a plastic mannequin, and Lizzie’s words emphasised that human beings should not be treated as inanimate body-objects.

Summary

Although dignity is an abstract concept, the body is a critical medium through which dignity is enacted, felt, reinforced or reduced. Dignity cannot exist without a body. Dignity is embodied. Dignity is a feeling experienced by a lived-body; different body-subjects enact different responses to the same stimuli, depending on the individual's ontology, lifeworld and lived-experiences. When considering dignity, all bodies do not respond identically (body-object). For this reason, aspects of dignity can be best understood through qualitative methodologies in which body-subject experiences can be revealed.

In community nursing, dignity violations usually occur when two or more bodies are in close proximity, but, without the 'gaze' of another, dignity can remain intact. Dignity is constructed through intersubjective relationships between bodies; these interactions can either construct or damage dignity. 'Dignity encounters' are most likely to occur when social actors have shared understandings of the body, which reduces the potential to offend dignity. Dualists will defend their position that although a body may have been outwardly offended, inner dignity can remain intact, whereas monist theorists will regard a violation of the outward body as a violation of inner dignity. As long as all social actors are interacting based on shared beliefs of the body, however, (regardless of whether it is dualist or monist) it reduces the potential for the actors involved in the encounter to perceive a violation of dignity as they are enacting a 'shared morality' (Harris and Sulston, 2004).

Sociological consideration of the body is helpful in understanding dignity in a nursing context, as I have demonstrated how dignity is socially constructed when two or more bodies are in proximity. This chapter has identified the intersection between body, space and time. Some parts of the body are more public than others; similarly, some parts of the home are more public than others. As all patient-participants received nursing care in their homes, the use of space is important in the creation of an 'environment of dignity'. This will be considered in the next chapter. However, time too is 'inextricably bound up with the body' (Urry, 1996: 372), and this is a concept that will be given greater consideration in the following chapter.

Chapter 6: Dignity in the Home

Central concerns

This chapter explores the place of the home in health care and why this environment is central to discussions of dignity, specifically within district nursing care. Policy has increasingly moved the locus of care towards service delivery in the home. With this in mind, by considering micro-aspects of care in the home, alongside the flow of daily life in this environment, it will be demonstrated how geographies of care influence dignity outcomes.

Receiving care in the home is such a unique environment that it calls for a different understanding of space, as it does not function in the same manner as a hospital or outpatient clinic, and, as noted throughout this thesis, manifestations of dignity vary in the home and in hospitals. Examples from fieldwork will demonstrate how Bourdieu's (1979) concept of habitus is reflected through place and the home, and these reflections of habitus cannot be supported in a hospital environment. Due to the structure and organisation of hospitals, systems ensure staff retain control over the management of space, but in the home, nurses must adapt to each household.

Community nurses can only undertake their work once they have been allowed entry to the home. The home is a sanctuary, in which the dictum, 'an Englishman's home is his castle', holds true. In this location, the home-dweller is King or Queen of their own Kingdom (the home). In 1760, Pitt the Elder stated:

> The poorest man may in his cottage bid defiance to all the force of the Crown. It may be frail, its roof may shake, the wind may blow through it. The rain may enter. These may enter. But the King of England may not enter (Johnson, 2009: np).

This emphasises the sovereignty of every homeowner in determining who can access their home. Thus, community nurses cannot assume they will automatically be granted entry, and they can only undertake their work once they have crossed the boundary into the home, as without being granted passage, nursing care cannot occur.

Within the confines of the home, nurses are in the patient's territory (or 'Kingdom'). This is the patient's environment and nurses must recognise the patient's increased control in this context.

When older adults receive district nursing care, the home functions as both domestic space and workplace, therefore negotiations over the use of space can contribute to experiences of dignity. Therefore, this chapter introduces the concept of the 'home-clinic', which is a label I have applied to describe the space in which nursing interventions occur within the home. The phrase reflects the dual use of the space; primarily as the home, whilst also recognising that, at specific times, the same space assumes a clinical purpose. The 'home-clinic' is significant because patients informally designate an acceptable space in the home in which the nurse is allowed to perform her duties, but this is also the space in which dignity is likely to (de)manifest itself.

Respect for the home is arguably directly related to respect for patients' dignity. Social obligations and cultural scripts shape people's expectations of behaviours in the home. Thus, I have described codes of operation in the home, 'house-rules', which are a key concept in this chapter. When nursing care is delivered in the home, there are expectations that staff will follow the homeowner's 'house-rules', which provide socially and culturally constructed norms, adopted by each household and establishing standards of behaviour that are acceptable. Every home has its own 'house-rules', in which residents are socialised into familial norms. Although these rules of behaviour are unwritten, there are expectations people will follow them, and these expectations extend to guests within the home, even if they have not been formally introduced to these established codes of social behaviour. 'House-rules', are not universal, and, although some underpinning values may be shared across different households, wide variations remain, including differences between how transgressions of the rules will be understood and managed. As community nurses enter many different households, there are infinite numbers of 'house-rules' they must adhere to, but it is impossible for each patient to induct nurses into their individual standards. Therefore, in order to show dignity and respect, nurses must navigate their way through complex cultural scripts. There are consequences if nurses disobey these codes of operation, regardless of whether this is inadvertent or deliberate, and disruptions to the patient’s dignity may occur when these ‘house-rules’ are broken or transgressed.

Chapter 4, ‘Dignity in caring relationships’ first introduced the concept of nurses as social actors. Similarly, aspects of ‘staging’ within the home contribute to the arguments presented in this chapter, in which nurses’ behaviours become mediated and moderated in different areas of the home. This chapter also begins to consider how it is the nurse’s clinical role as ‘agent of the state’ that allows them access to the home. Adopting the phrase ‘agent of the state’ recognises the inherent power in nurses’ positions, highlighting how, at a broader level, their actions are under state direction. As previously discussed in the literature review, as agents of the state, nurses have legal obligations to safeguard their patients’ dignity by promoting human rights. Hence, this chapter begins to consider how macro-structural considerations such as these inform and underpin dignity at the micro-level of community nursing relationships in mundane spaces and through geographies of care within the home.

Use of the home and the organisation of the ‘home-clinic’

Certain areas of the home are more public than others, just as certain areas of the body are more public than others (as considered in Chapter 5). Rooms in a house are ‘zoned both spatially and temporally’ (Urry, 1996: 382), although this may vary across countries and cultures. Whilst working within the home, the spatial freedom of nurses is restricted, unlike in a hospital where it is patients who have greater spatial restrictions than nurses.

During my observations, nurses’ movements were limited to certain areas of the home. To facilitate the delivery of clinical care, accessing downstairs areas was generally acceptable. However, except for a few limited circumstances which will be considered shortly, accessing upstairs areas generally remained forbidden. When I observed multiple visits to the same patient, it was usual for patient/ nurse interactions to occur in the same area of the home – I have described this space, the area in which care occurred, as the ‘home-clinic’. If the patient was not already in this location, on the nurse's arrival, without any verbal acknowledgement of what they were doing, patients would hastily position themselves in this area to allow nursing to begin. The ‘home-clinic’ was an essential feature of space as there are certain areas of the home where it was implicitly preferable for nursing care to occur than others – lounges, for example, were much preferred to kitchens or bathrooms, possibly because these other spaces have a designated purpose that is less acceptably contravened.

On arrival in the home, the nurse's use of space begins passively as she moves her way into the ‘home-clinic’, which is the space that she can begin to assume greater control over. It was accepted that nurses required spatial movement during clinical tasks, so they were given relative freedom to conduct their business within the area functioning as ‘home-clinic’. Once the clinical intervention commences, nurses begin to appropriate more control and ownership of space. The ‘home-clinic’ is revealed when nurses unpack bags of clinical paraphernalia in the room, creating what the nurses describe as their ‘sterile field’ or ‘aseptic area’. This involves laying out a sterile sheet and then placing the necessary clinical tools and equipment on the top of this. If the intervention is a leg dressing, the ‘sterile field’ was usually created on the floor, so that all equipment was close to the nurse for ease of access. At times, particularly if the floor was not as clean as the nurse desired, I observed them requesting to use a pouffe, hearth or small table, which they then appropriated to create their ‘sterile field’. If a patient received care in their bed, the clinical space was formed on the mattress, alongside the patient. Once the ‘sterile field’ was created, this specific space now belonged to the nurse, as no-one else was permitted entry or the ability to touch anything in this space. Although it was commonly understood that no-one else may touch this area, the nurses recognised there were times where circumstances beyond their control caused disruptions.

> **Interviewer**: What do you do in those houses where you can’t set up a ‘sterile field’?
>
> **Nurse-Victoria**: You just have to do your best with what you’ve got really… erm…and hope that… a cat doesn’t come and jump on your dressing pack at some point or something, cos it’s happened so…
>
> **Interviewer**: That sounds like you’ve had a cat jump on the dressings?

> **Nurse-Victoria**: Yeah…and you're like, 'oh, right'…bin it all off and start again. So you just try and open your dressing pack and make sure you keep that part that you're using as sterile as possible and you know…think ahead about when you're gonna do, what you're gonna do and… erm, where you're gonna put things and just try and be prepared. But that seems to get easier with experience.

Victoria indicated her nursing experience made these challenges easier to manage. Whilst the creation of the 'sterile field' is to ensure cleanliness, and hygiene and to reduce infection or cross-contamination, it also aids in the creation a medicalised care space (or 'stage') in which actors are able to understand and perform their role of 'nurse' or 'patient' (see Chapter 4).

Despite this spatial freedom, nurses' movements were directly under the patient's gaze, but this apparent lack of restriction did not extend to allow the nurse access to other areas of the home without prior permission, nor did it extend to permit objects to be touched, other than those designated necessary for the provision of nursing care. 'Houses are lived through one's body and its memories' (Urry, 1996: 390): thus, the home might be perceived as a metaphor for the body. Nurses must gain consent to undertake bodywork, and, similarly, they must gain permission to move out of the 'home-clinic' into another area, or indeed touch an item that does not belong to them. Whilst nurses continue to seek consent to move outside the 'home-clinic', patient dignity can remain intact. There is a danger that if nurses simply move around the home without gaining the permission of the patient, there is a potential to disrupt their patient's dignity, as the patient is no longer in control of how 'their' (home) space is being used.

From my observations, it was common for the nurses' first point of entry to be through a front door into a 'hallway' – either the communal hallway in a block of flats or the individual hallway of a house. The hallway was liminal. It was a transient space, not a space for nurses to dwell in, but it was a passage leading to the space in which the patient was seen (the 'home-clinic'). If patients lived alone, and on the occasions when nurses gained entry themselves (for example via a keypad), once they entered transitory spaces such as the hall, they were able to begin their creation of the 'nurse' character without being subject to the patient's gaze. Thus, the hallway was neither front of stage nor backstage, and, at times, it was the space in which the transformation of ‘the nurse’ would occur. In contrast, if a patient or relative opened the door, the nurse performance began immediately, before she had even set foot into the home.

Occasionally, nurses gained entry at the back of the house, which only occurred when a patient was known to the nurses and their point of entry had already been previously negotiated and agreed with their patient. If a backdoor was used to gain entry, it usually opened directly into a kitchen. The kitchen is traditionally the domain of women and in heterosexual older couples, it is typically the woman that orders this space, controlling actions in this area, but the kitchen was not generally the place where patients were nursed. It only occasionally functioned as the ‘home-clinic’, most usually when other people were occupying the lounge or if the patient was already seated in the kitchen and had no desire to move. The kitchen was used to store certain medications, especially those that required refrigeration, and so there were times when nurses would require entry to this area. Kitchens were also used by nurses as areas to access water, either to wash their hands or to fill bowls of warm water to clean their patient. It was a space used to gather resources needed for nursing interventions, but it was not generally the place where these interventions occurred. There appeared to be unspoken, yet agreed, expectations that kitchens were not the appropriate space to care for leaky bodies, possibly because at other times the space was used to prepare food, so that the ‘home-clinic’ required locating elsewhere.

Nurses did not go upstairs. The exception occurred when they attended patients who were being nursed in an upstairs bedroom. There was only one occasion in which I went upstairs with a nurse. Some patients lived in flats or bungalows, making all the rooms accessible without the use of stairs, but, regardless of whether people lived in a house or single-storey dwelling, in general, bedrooms were considered out-of-bounds for non-residents of the home. Bedrooms are intimate spaces, associated with sleep, which is when we are at our most vulnerable as we are unable to protect ourselves from potential threats, but they are also the space associated with sex. As both sleep and sexual activities are highly personal acts, the designated space in which they take place also becomes private.

Only a few visits made use of the bedroom as the 'home-clinic'. One example of this occurred when visiting Alison. The nurses usually found her somewhere in her open-plan living area, but as soon as the nurses entered the house, without any verbal negotiations, Alison would begin moving towards her bedroom and the nurses would automatically follow whilst they engaged in small-talk. They shared an understanding that Alison was unwilling to be nursed in the more public living space and, in this context, the privacy of the bedroom functioned as the 'home-clinic'. This was interesting because no-one else was ever present in the house, as Alison's husband would always remain in the large garden during the nurses' visits, only entering the home when invited by the nurses – quite a role-reversal, as in this scenario he, the homeowner, waited for an invitation inside by a nurse.

Alison was blind, and she described her husband as 'my eyes'. At the start of each appointment, after Alison entered her bedroom, she lay down on the bed, removed her stockings and raised her skirt just high enough to allow the nurses to unbandage and then re-bandage her legs, but without exposing herself unduly. Once her lower legs were exposed, Alison would always ask the nurse to invite her husband into the room to examine her ulcers, apparently valuing his perspective more than any feedback the nurses could give her. The nurse would go to the garden and invite him inside, where he would readily oblige and offer his gaze to Alison. After this inspection, Alison and her husband would have a short conversation about whether the ulcers looked better or worse than the last time, and, once this was over, her husband would quickly leave the bedroom and return to the garden. The nurses never began dressing Alison's leg whilst her husband was present, only continuing once he left the area, thereby ensuring Alison's privacy and dignity in the space that functioned as the 'home-clinic'.

I asked Alison about the use of her bedroom as the 'home-clinic', and, when asked about dignity, Alison's answer offered an interesting insight into why she used the bedroom as this space, away from her husband's view.

> **Interviewer**: I wondered what dignity means to you?
>
> **Alison (82)**: Erm, dignity. I don't mind at all if it's females, with me being female but if it comes to a man even [name of husband] my husband, I don't like him to look at my body, er if

> I’ve got anything wrong with it and if I say, ‘is that a bit scurfy down there?’ things like that I don’t like and I know it’s odd.

Alison’s husband was allowed to view her body purely with a clinical lens, which he only possessed when her body became medicalised in the presence of the nurses in the ‘home-clinic’.

Other patients received nursing care in their beds. These patients were what the nurses described as, ‘bed-bound’ – patients whose illnesses left them requiring full bed-rest, or more usually the inability to leave the bed, which is symptomatic of the care of many end-of-life patients. At times a radical reordering of the home is necessary when illness descends. Thus, when ‘bed-bound’ patients did not live in single-storey accommodation, the lounge was often transformed into a ‘bedroom’, whilst simultaneously retaining functions of a living area as well. When the nurses undertook their work, this space also became the ‘home-clinic’, so essentially it was a room functioning with a triple purpose (lounge, bedroom and ‘home-clinic’), although the primary function altered at different times, adapting to needs or according to the presence of different social actors. Sometimes telehealth equipment was used to monitor aspects of health, so that patients could be monitored from afar. As a result, the clinical gaze continued to follow patients, changing the landscape of their home (Liaschenko, 1995). Realigning space in this manner ensured the clinical gaze remained a constant presence in the home, even in the absence of nurses.

When the lounge is transformed into a triple-purpose space, it becomes a hybrid area remaining an unsatisfactory space for all, as the overall purpose of the space has broken down. The actual use of the area differs from its intended function, making it unboundaried, an aesthetic disruption to the home. In the nurse’s presence, the room has meaning as it immediately transforms into the ‘home-clinic’. However, when nurses are absent, the space becomes a ‘nonplace’ (Augé, 1995) or a ‘noplace’ (Lawton, 1998), as any definition is lost, functional boundaries are blurred and the area remains confused and ill-defined, resulting in an environment in which it is difficult for dignity to flourish. Illness (and the ensuing clinical paraphernalia) can cause disruptions to the home environment as there is the continual threat that the functions of daily home life become usurped by illness in the household. Thus, for dignity to thrive, these spatial disruptions require careful management by the homeowner.

Artefacts that make a lounge recognisable, such as television, sofa and family photographs, were often present in patients' homes, sometimes displayed alongside clinical equipment such as commodes, hoists, oxygen cylinders and wheelchairs. Structural elements of rooms also remained, such as windows and doors, but even these fundamental features were used in different ways at unexpected times. For example, in the homes of people whom many nurses described as, 'the poorlies' (patients that are particularly unwell and thus their clinical needs require prioritising over other patients – they are often end-of-life patients), doors would remain ajar – neither open, nor closed. The ill-person was given a degree of privacy, but not contained totally away from others. Doors that are neither open nor closed are symbolic of the bodily limbo experienced by the palliative patient who is waiting to die. In these spaces, regardless of the time of day that we visited, it always felt like dusk to me, which was possibly a metaphor for the stage of life that many of the palliative patients, 'the poorlies', were facing.

At times, a profiling hospital bed dominated the space, and if a television was on, it was either muted or the volume was extremely low, making it difficult to hear. Similarly, curtains or blinds would be drawn across windows during the day, preventing daylight from invading and leaving the room in a perpetual state of twilight. Seasons may pass, yet windows slightly obscured by curtains did not allow the patient to view the weather, nor witness other symbolic indicators of seasons changing and the movement in time. Time becomes suspended, as the relevance of clock-time is no longer important when eternal twilight prevails. The sad irony is that, for patients at the end of life, the significance of time may be even greater, as they are acutely aware that they are running short of time, and yet they are inhabiting a space in which time is effectively suspended by the absence of markers of the passage of time (day and night).

As well as the occasions when lounges were used as bedrooms, traditionally, this room functions as the 'family' space within the home. It is also commonly the space used for entertaining others, and thus it is perhaps seen as one of the more public areas of the home. However, when this space functions as the ‘home-clinic’, the multiple uses of the room can cause spatial tensions within families, where some relatives want to continue to use the space as a living area, but the patient desires rest or sleep in the same room. One of the nurses explained,

> **Nurse**: It’s not like the hospital when we strip ’em of their clothes and shove ’em in a bed. We have to deal with palliatives where they need a hospital bed downstairs and the family say ‘no, we don’t want our home looking like a hospital’. It’s really hard sometimes.

She articulated a difference between nursing in a hospital, in which actions are described as potentially abusive (‘stripping’ and ‘shoving’), and community nursing, where skills include being able to ‘deal’ with patients and their relatives through negotiation. There is no dignity inherent in her language as she stated a generic description of end-of-life patients as ‘palliatives’.

To many families it is important that their home does not look like a hospital, as people do not necessarily want visible reminders of the illness that has descended on their household. Thus, maintaining dignity in the home may involve concealing the presence of illness – there may often be resistance towards the reordering of the home to accommodate illness in the family. Even though, in essence, the ‘home-clinic’ is used to conduct activities in a similar way, or even identically, to those in a ward, the lounge often remains central to social activities and family practices. Although the function of a hospital ward and lounge may be similar, to maintain dignity within the home, the outward display of these spaces should be different.

‘Environments of dignity’: Total institutions and the home

A hospital is an example of what Goffman (1968) compellingly describes as a ‘total institution’. Total institutions comprise a closed social system in which established norms and behavioural expectations are reinforced by staff behaviours. Patients are ‘managed’, and staff are the ‘managers’. In hospitals, patients’ lives merge into the routines of the institution, and they lack opportunities to demonstrate their individual agency, as they are expected to adapt to the routines and practices of the institution and accept their status within the ‘sick role’ (Parsons, 1951/91). In contrast, when undertaking care in the home, it is the nurses themselves who must adapt to the routines and practices that are established or accepted within each individual’s home.

In her *Notes on Nursing,* Florence Nightingale observed: ‘Nurses often do not think the sick room any business of theirs, but only the sick’ (Nightingale, 1859: Appendix No.26). Nightingale acknowledged that to support wellness, patients needed to be placed in the best conditions for this to occur, but that a consideration of ‘the sick room’ (space) was absent in nursing until this time. In contemporary practice, the environment has gained nurses’ attention, as they focus concern on infection control in clinical areas. Thus, issues of spatiality are recognised in nursing practice, albeit with a focus on health and safety concerns, rather than viewing the use of space as an essential component of delivering care with dignity.

Through careful and considered use of space, ‘environments of dignity’ can be created. Total institutions are organised in a manner to suit staff needs. Even though some nurses may believe the hospital is a patient’s ‘home space’ (Gilmour, 2006), hospital wards remain the domain of nurses, as they control and organise space. Patients have no control over which bed they are placed in, nor control over where and how equipment is stored, over when they will eat and even over the times their families may visit. Patients are passive beneficiaries of their environment. Generally, with minimal complaint, patients conform to institutional regimes (by accepting and adopting the cultural scripts of ‘hospital rules’). Residents’ ability to personalise their individual rooms in care homes adds to a sense of ownership over the space (Emmer de Albuquerque Green *et al*., 2018), but this personalisation of space is not granted to those in hospital provision. Social obligations vary between care in hospitals and care in the home, as variable relationships of power across these two settings lead to patients having different expectations of themselves and others.

Nurse-Nieca had worked in district nursing for 15 years. The geographies of care become apparent, when she differentiated between patients’ expectations of dignity in their own home, in comparison to hospital-based care.

> **Nurse-Nieca**: There’s a big difference in the community with dignity than there is in hospital, I think patients’ perception of dignity is very different as well. I think people expect to lose their dignity when they’re going into hospital, but I think when they’re at home, they expect to be able to maintain their dignity.

Therefore, in hospitals, patients accept that space is used in a certain way which they cannot control. In the home, nursing occurs by compromise and agreement, and this includes negotiation over how certain spaces are used when a person is ill. This directly contrasts to total institutions in which negotiation may be lacking and agreement may be minimal.

The difference between how spaces are used in hospital and the home, means power differentials between staff and patients present themselves differently within their interactions. Power differences remain. However, whilst total institutions can disempower residents by making them conform to institutionalised routines, people retain more power, agency and control over routines and behaviours in their own homes. Nurse-Daisy explained a scenario that was not uncommon for community nurses to encounter.

> **Nurse-Daisy**: I have been into an actual palliative patient who we’ve got on the syringe driver[7] and he started to smoke whilst I was there and then his son started smoking_ to light up a cigarette, and his wife said, ‘oh come on, the nurse is there’, and the son said, ‘oh it’s *his* house, he can do what he wants in it’ and I was just like, ‘oh’. I nearly said to them, ‘do you just mind, while I’m just doing this?’, but he said that and I was like [thinking], ‘oh, I can’t say anything now’, but I could have done, but then it might have caused a bit of…you know, upset, so I just thought to keep it easy.

Despite organisational policy indicating patients should not smoke when nurses are present, this may still occur when patients enact their agency at home. Daisy’s words indicated that she felt that there was little room for her to challenge the smoking without risking ‘upset’, once the son had said, ‘it’s *his* house, he can do what he

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[7] A portable battery-driven pump that administers medication subcutaneously over several hours, often used in the management of pain for palliative patients.

wants'. This comment clearly marked the boundaries of behaviours that were acceptable (to the residents) within the home.

Whilst similar situations may occur in hospitals, smoking is clearly against the rules which are enforceable through systems and structures that expel anyone failing to conform in this manner and that are enacted by the use of security or, force, if necessary. In scenarios like these, it may be difficult for community nurses to challenge families, especially when multiple family members are present, which may intimidate the nurse who is a lone-worker in the home. Hospital patients and their families are more likely to follow the rules of total institutions, but smoking may be a marker of how agency is expressed within the home. In their own home, patients feel greater empowerment than in hospital.

> **Nurse-Victoria**: Now I think there is more of an empowerment to_ for people to like voice their concerns and ask questions and know like why you're doing what you're doing.

As power is internalised more freely within the home environment, patients are more likely to exert control over what happens to their body – they gain strength from being in their own homes, and it becomes easier to 'voice their concerns' than when receiving care in a total institution, meaning the patient experiences greater empowerment.

Power is an important element of all patient/ nurse relationships, but displays of power differ in hospitals and the home. The physical manifestation of the nurse's power through her body was considered in Chapter 5, 'Dignity in Caring for the Body'. However, nurses also gain positional power from their profession, as considered in Chapter 4. When community nurses enter the home, they renegotiate the scope of their power, although their structurally powerful position remains. McGarry (2003) recognised that community nurses viewed their status as a 'guest' in the home, so that nurses negotiate from the position of being both a professional in their workplace and acting as a 'guest' in the home.

Nieca believed community nurses held a position of privilege as they entered people's homes (their private spaces) and this enabled them to hold a greater understanding of people's lives.

> **Nurse-Nieca**: [Hospital] nurses don't see them as a person in their own home, they just see them as a patient in a bed. Actually when you go into somebody's house… you see… what… how they've contributed to society in the past, you know, you get these amazing people who are old and frail, and if they're put in a hospital bed [they] don't look like anything but actually when you… go in…in to their home…

As Nieca explained, nursing a patient at home means that their personhood is easier to identify and potentially uphold, than in the depersonalising hospital, where a person is a medicalised 'patient'. When delivering care in the home, nurses can more readily perceive the entire person, as they can appreciate the context of their patients' lives. Photographs adorn walls, personal artefacts and objects remain displayed, and, together with conversations with family members and friends, these all contribute to nurses' increased understanding and enhanced perceptions of their patients. Thus, the space in which people are nursed becomes important in terms of constructing environments in which dignity may flourish, as this is more achievable in the home. However, a possible danger of delivering care within the home is that it is more likely to lead to relationships of dependency.

> **Nurse-Rina**: …people can become very dependent on you […] Erm… they do almost see you as, not quite as a nurse, although you are a nurse, you are… part of their little circle.

The long-term nature of patients' health conditions and the resulting long-term relationships they form with the community nurses mean that their bonds are formed differently to those in their (brief) hospital encounters. The dependencies formed in these two environments differ, and thus it may be important for community nursing patients to include nurses within 'their little circle', particularly if they are experiencing loneliness or social isolation. Many community nursing patients live alone, and as they are defined as 'housebound', meaning there are reduced opportunities for social interaction. Yet for most human beings, contact and socialisation with others is an important aspect of mental health and wellbeing, and hence, for many older adults under their care, visits from nurses can be an important opportunity for social interaction.

There may be occasions when nurses attempt to create an ‘environment of dignity’ in areas other than the hospital or home. Nurse-Sapphire, for example, explained how she had also delivered community nursing care to someone whilst she had been at the hairdressers, which begins to alter our understanding of the possible spaces in which community nurses function. She described a recent visit to administer insulin for a woman residing in a supported living facility which had on-site facilities, including a restaurant and hairdressers.

> **Nurse-Sapphire**: Dignity means, erm… it means, it doesn’t just mean like when a patients_ me checking the pressure areas, it_ dignity can maintain you know, like I went in to see a lady about er…an insulin, [I] walked past her because she was at the hairdresser's, now I gave her her insulin where she was, but she didn’t want people seeing even a tiny bit of her belly, to get the needle in, so she wanted the door shut and I said, ‘that’s absolutely fine’.

This scenario raises issues of how a public space can function as a ‘home-clinic’. Although Sapphire recognised that the patient still wanted a degree of privacy, maintained by closing the door, as a public space, the door could have readily been opened by a stranger. Thus, to conserve the patient’s dignity, Nurse-Sapphire was required to navigate the complex boundaries of creating a ‘private’ space to perform the function of the ‘home-clinic’ within a ‘public’ hairdressers’ salon.

‘Environments of dignity’ evidently exist differently in total institutions and the home. Due to the structures of hospitals, staff retain control of the management of space, contributing to the (de)construction of ‘environments of dignity’. Patients have limited control over space within hospital environments, as even the bedspace is governed by rules, such as whether flowers are allowed and the number of visitors that can sit in the area, which means patients cannot assert their own individuality and agency in these spaces. When acutely unwell, patients may lack agency as they may feel scared, frightened, or too ill to be able to assert their autonomy. Returning to wellness is their focus: thus, hospital rules are generally accepted and taken for granted as how things must be. In contrast to receiving care in total institutions, when patients receive care in their own homes, despite illness, they are more likely to feel empowered and may be more inclined to display their agency. Being able to exhibit their own agency in their own home, in turn, reinforces their dignity. It is through showing respect to the home that nurses can create an ‘environment of dignity’.

In the next section, ‘Amber’s Story’ considers one specific patient under the care of the community nurses. Amber lived in a social situation that was not reflective of societal norms and expectations, and she wanted this to change, but the way she displayed her agency was to refuse social care staff entry into her home, which, as will be explained, left her dignity in a highly fragile state.

Amber’s story

Amber had been referred to district nursing by a doctor following several falls in her home. She lived in a ground floor flat provided by the Local Authority, and although she walked confidently around her home, she admitted to having fallen a number of times, which meant she no longer left her home without being in a wheelchair. Amber’s husband died around fifteen years ago, and she lamented how much she still loved him, describing their relationship as ‘a very good relationship, unlike my sister’s husband who beat her up.’ Amber was a former nurse who cared for her husband and mother before their deaths.

I first visited Amber with complex case manager, Nieca, who expressed reductionist language to describe her as ‘a bit of a self-neglecter’.

After Nieca rang the doorbell, Amber slowly came to the door wearing baggy cat-print pyjamas, her long black hair dripping onto the floor. Whilst ushering us into the lounge, as we walked over unsanded floorboards, littered with clumps of cat hair and dust, Amber explained she had just got out of the shower. Dense, tobacco-filled air fell heavy in my lungs, as I observed bare plaster walls stained heavily with nicotine, water streaming inside broken windows and high piles of unidentifiable papers covered in a dense coating of cigarette ash. Unpainted walls highlighted *gouges and cracks in the nicotine-stained plaster, which could only be the result of many, many years of heavy smoking.*

Amber smiled warmly and pointed towards a small sofa, telling us to sit down. Nieca and I perched next to several plastic bags containing boxes of medications, surrounded by piles of ash-laden papers. I could see no open fire, but the pungent stench of tobacco led me to assume the thick ash-blanket was most likely from cigarettes.

As we settled, Amber smiled at us and chuckled,

'I've burnt my hair off with a fag before.'

She physically moved her body forward to demonstrate how her long hair fell over her face.

'I've had long strands of hair burn off into my hands_'

'_You've made yourself a fringe before, 'an't ya...' Nieca interjected.

As she peered towards the yellowed ceiling, Nieca continued,

'...I can see you've got smoke alarms – that's good.'

The fire-risks posed by piles of ash-laden papers ran through my mind, as I glanced up towards the nicotine-stained smoke alarm, wondering if the alarm was working and if the battery had ever been replaced.

Amber explained to Nieca her main priority was to get rehoused. She knew her flat was in a poor condition, and she consistently mourned the cleanliness of her home. After a previous visit, Nieca had referred Amber for support from the Local Authority, but Amber cancelled their visit, explaining to us,

'I don't want them in my house until I get it sorted.'

Nieca made a thinly disguised attempt to validate Amber by telling her the flat was looking better than before, as she no longer had 'empty Carling cans littering the house'. So, on the one hand, Nieca tried to reassure Amber that her house was 'looking better', but the judgemental reference to alcohol negated the preceding validation and reinforced the perception that Amber's home did not conform to socially accepted standards. Like all human beings, Amber had inherent *Menschenwürde* (Nordenfelt, 2004, 2009). However, the presentation of her flat did not offer a congruent outward display of her internal dignity, which caused her upset, and was potentially reinforced by Nurse-Nieca's approach.

People carefully stage-manage their environments, and Amber had not yet managed to present her home to a standard that she felt was acceptable for outsiders to view. To achieve her dream of moving, the (private) home required public viewing by social workers and Amber was not yet ready to allow this, because the 'public', in this context, are not without judgement. Amber's emphasis on getting her flat 'sorted' was important, as this would result in a home environment reflecting social norms, and this, in turn, would offer an external display of her inner dignity. The way Amber spoke disparagingly about her home and self, indicated she lacked the self-esteem and self-respect Sandman (2002) states may be necessary for contingent dignity. Thus, she remained locked in a perpetual state where she wanted to move, but was unwilling to allow the very professionals into her house who could assist her in doing this.

During my second visit to Amber, which was with Jane, a bank nurse, her task was to inform Amber that she was going to be discharged, as Nieca had assessed that there was 'no clinical need' for Amber to remain under the community nursing team, because her needs were 'social not health'. Nieca's bifurcation of care needs that were 'social' and care needs that were 'health' placed responsibilities on professionals other than herself, because, even though nurses must practice holistically, it is only 'health' needs for which they retain accountability. Labelling Amber's needs as 'social' meant that Amber did not meet nursing criteria, making her ineligible for their support, even though Amber obviously not only had care and support needs, but was also willing to allow nurses (but not social workers) into her home.

The opportunity to comprehensively assess Amber's needs had already been granted to 'the State', as Amber has allowed nurses access to visit her in the home. The movement towards integrated working between health and social care is essential for the NHS to meet the demands of care for the 'oldest old' (Iliffe and Manthorpe, 2018: 77). However, professional boundaries and limitations placed on the design of individual services mean tasks are designated to specific 'agents of the state' and thus in this scenario, care is not about meeting the needs of individuals, but about policy directives. In this case, Amber's needs were 'social', so it had to be a social worker meeting these, and, as a nurse, Nieca was the 'wrong' agent of the state to undertake this, even though she was the one who had been granted access. In this circumstance, the State had missed an opportunity to offer Amber the care and support she needed. Amber found it acceptable to allow a nurse and me, a researcher who she knew was also a social worker, entry to her home, but she did not want to allow entry to a social worker, who was the gatekeeper to her attaining her goal. Missed opportunities such as these continue to leave people vulnerable. Once access to the home has been received by one agent of the state (regardless of which professional it is), it cannot be assumed that access will be given to another professional on a different occasion. Thus, at the time access to the home is granted, working across professional boundaries or across boundaries of health and social care may assist in ensuring holistic support is offered to the person.

Nationally, there is a move towards greater integration between health and social care to avoid people being passed from 'pillar to post', as this can inhibit effective intervention and treatment. Yet, in this example, Amber had been told that, despite her long-term medical conditions, she was not suitable to receive support from community nursing. Thus, she was discharged as there was 'no clinical need' for her to remain on the nurses' caseload. During our interview, I asked Amber to explain why she had been discharged.

> **Amber (63)**: [The nurse said] that I seem to be getting by and that, so you know, there's no real need for us [the nurses] to be here.

Amber indicated she was managing and this was the reason she was discharged. The rejection from the nurses had the potential to lead to feelings of abandonment, but Amber suggested that it was not her fault, because she herself did not request input from the nurses.

> **Amber (63)**: I don't know what they [the nurses] expected to, to find… I mean lying on my back or whatever, you know, I mean, I didn't ask for these nurses to come – it was doctors.

The nurses had discarded Amber, and perhaps she was also concerned social workers would reject her too. Amber had seen a nurse several times before I interviewed her, and during our interview she stated:

> **Amber (63)**: There were some times when I was a little bit scared of these nurses and I don't know what they want me to say. You know [say] to them. I try to put on a bit of an act, you know, I try to be happy when they come. But it's not always how I'm feeling, you know, and it obviously isn't how I'm feeling.

Amber acknowledged the performative aspect of her relationship with the nurses when she described how she would 'put on an act', whilst acknowledging her outward display was not a true reflection of her feelings. As Amber was so vocal about the unsatisfactory nature of her home environment, I asked if she felt respected by the nurses in her home. From her response, it was evident that Amber extended respect for herself to respect for her home.

> **Amber (63)**: I can't really expect a lot in this room [laughs], cos it needs doing, like it does, I can't expect too much, but it's not my fault, normally my house has been immaculate, but I just can't do anything what I've needed to do.

Amber's response indicated that gaining respect from the nurses was contingent on meeting socially accepted criteria. Amber showed an awareness that her home did not meet these criteria (paralleling her failure to meet nursing criteria) and thus she could not 'expect a lot' from the nurses. Amber was also quick to explain it is 'not my fault' that the house is not immaculate, and thus she absolved herself of responsibility for this.

A person's home becomes interrelated with their whole being and sense of self; it is the environmental manifestation of their identity and can be a reflection of what Bourdieu (1979) describes as their 'habitus'. Created by social processes, the habitus represents the way people demonstrate agency by reflecting and reproducing social structure. People decorate and furnish their homes in a manner that displays their own individual style. This can reflect their habitus and agency, which hold possibilities for reinforcing dignity. However, for some people, such as Amber, expressing one's agency through the home can provide a challenge, and as Amber spoke in a selfdepreciating manner about herself, this was reflected in her home space. Structural positions shape the habitus; therefore, when people assert their agency, they simultaneously reflect and reproduce social structures (Bourdieu, 1979). Consequently, although it is not currently recognised in existing literature, any disrespect for the home has the potential to result in a disruption to the patient's dignity. When people become unwell, health issues dominate, and, as their focus turns to the management of a health condition, other aspects of daily living can lose priority. Successfully managing and controlling the ill body may take precedence over successful management of the home. Hence, there are times when the home may not be viewed as an 'environment of dignity', something which is constructed on subjective opinions. Amber's story illustrates how she did not experience her home as an 'environment of dignity', and neither did her nurse.

The home is traditionally a private space, a space where people are unobserved by the outside world, remaining free from the critical gaze of others. Entry into these highly private spaces is controlled, as homeowners carefully stage-manage their environment before the arrival of visitors. As was the case with Amber for fear of judgement, most people ensure their house achieves certain standards of social acceptability before allowing outsiders access, displaying the image they would like outsiders to view. The next section will consider further issues of relevance when the 'private' home is made 'public' through nursing interventions.

When 'private' becomes 'public' in the home

> **Nurse-Anya**: Dignity… just respect that you're in someone's house, it's their house… respect it, they've invited you in.
>
> **Nurse-Rina**: I think it is very, very hard because you are going into somebody's space, they're not coming into yours.

To some people, 'home' may be a place of comfort, safety and security. However, for others, it may be a place of danger, imprisonment or violence. For many women, home is the domestic workplace and for older adults who have lost a spouse or child, it may be an important reminder of previous relationships. When people require nursing treatment in the home, domestic space and the spaces of formal service provision merge. Patients may receive nursing care in the same location within the home in which they sustained the injury requiring nursing input. This may especially be the case for older adults who have fallen in their home (such as Amber), who are now receiving nursing care as a result. In these situations, the site of the ‘accident’ later becomes the ‘home-clinic’, in which nurses deliver their care. This space may, therefore, hold dual meanings for the patient – as both a site of harm and a site of healing. Bachelard (1994) argues that the home is not purely a physical object, but memory traces are inherently embedded in it. Memories of an accident or injury in a certain location may evoke anxiety and apprehension, yet new memories of healing may also be constructed if nursing care is delivered in the same space. It is the paradox of this duality that may pose a potential threat to dignity, as conflicts occur between the associations of both harm and healing in the same space.

Symbolic of global issues in the wider world, spaces within the home may hold multiple conflicting meanings. Access to the wider outside world is severely limited for district nursing patients, who are ‘housebound’. These patients are armchair observers, who no longer have the ability to actively enter and fully participate in the ‘outside’ world. Thus the home becomes representative of the wider world when these environments are no longer accessible.

> **Nurse-Denise**: It’s the best job ever. It’s better than any hospital. Cos you’re going into their home…they’re letting you into their world and it’s an absolute privilege.

Denise recognised her privileged position meant gaining entry not just into patients’ homes but also into the patients’ worlds with which their homes were synonymous. Entering into the world of the patient is regarded by community nurses to be a privilege, and, therefore, respect for their home is paramount.

Warren was not only restricted to remaining in his home. He also explained how he was confined to sleeping in his chair and how it was only through access to the internet, television, or through contact with family and friends that he was able to gain glimpses of the outside world.

> **Warren (69)**: The only time I see what [name of city]'s like, is when I see it on the telly. I've never been in town, for 30 years.

As the home is now the patient's 'world', it may be significant for them to retain control over what, when and how things occur in this environment. It is through outsiders showing respect for the home that, by extension, this also displays respect for the person.

> **Nurse-Victoria**: In the community, you'd maintain dignity by, like you'd knock before you_ if you didn't know somebody you don't just walk into the house, you'd wait to be invited.

Victoria explained how it was respectful to knock before entering the home of a stranger, but implicit in these words (and concurring with fieldwork observations) is that if a patient is known, it is often acceptable for a nurse to simply enter the home, removing the prerequisite of knocking.

When inside the house, family members often continue with their tasks of daily living whilst the community nurse goes about her business in the home. However, some patients may live alone and may see their nurses more frequently than close family members or friends.

> **Nurse-Anya**: Even if I'm having a really bad day I've always got a smile on my face for my patients because I think you have to, because I could be the only person they're seeing…and I think as long as we have that in the back of our heads, that you could be that only contact… to that patient… I think that makes you a good [nurse].

To some, visits from the nurses may be regarded as a disruption to daily routines, but, to others, it may be perceived as integral to the routine of the patient that is 'housebound' and a core component of their social activity.

As nurses visit a home regularly, they begin to build and retain memories of the space. This may include examples such as remembering where the patient stores their medication or the specific location that has been designated the 'home-clinic', as both the nurse and patient mutually create a shared understanding about where this will occur. Through regular attendance and through the nurse's development of memories of these spaces, she becomes increasingly accustomed to each home environment. Thus, over time, the unfamiliar becomes familiar, and even though this is not *her* home, the nurse may begin to ‘feel at home’. As a result, she may begin to relax and modify her behaviour as she becomes more comfortable in these spaces. Her everyday movement around the home assumes a ‘habitual’ nature without her being conscious of her body’s actions (Seamon, 1980). Although during the clinical encounter, both nurse and patient share the same physical locality, the space ‘belongs’ to the patient. If the nurse temporarily ‘forgets’ the home is her workplace and not her home, there is a danger that she could undermine the patient’s dignity, if she fails to treat the environment as belonging to another.

Complex dynamics come into play when someone’s home becomes another person’s workplace. Boundaries of what is public and what is private begin to merge as the sacred and private space known as ‘home’ becomes a ‘workplace’, which outsiders can view and interact with. In a clear example of the house becoming workplace, I witnessed Nurse-Mary appropriate space within Olive’s flat where she adapted a walk-in cupboard to use as her own office space.

Olive was a 60-year-old woman who required insulin twice a day. After administering Olive’s insulin, Mary had to document the details of her visit on the patient record using software known as ‘SystmOne’,[8] which was accessed via her laptop. Inside the flat, the only place she could gain an internet signal was when standing inside a walk-in cupboard. Thus, on every visit after the insulin was administered, Mary opened the cupboard doors, stepped inside with her back towards Olive whilst she inputted the information on her laptop. Mary’s navigation of Olive’s flat to appropriate the cupboard for a digital purpose was only necessary because the remainder of the home was an internet void. In this case, the cupboard, which usually remained closed to guests, now became a digital and clinical report writing space, something which neither Mary nor Olive regarded as unusual.

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[8] An electronic medical record used by community nurses to document their work.

The progress of modernity, in which electronic signals allow data to be almost instantaneously available to people occupying other spaces at the same time, means that as soon as Mary saved her notes on SystmOne, they became visible for other users of the programme. This documentation is an example of 'reversible time' (Levis-Strauss, 1972), because, once written, they exist in each future moment and in past moments across both time and space. Through the nurses' contemporaneous use of SystmOne, time and space were effectively accelerated or even merged, making patient records omnipresent and accessible to any authorised user, anywhere in the world (provided they have the software and appropriate access permissions). Across spatial distances, there is now an immediacy in the record. With the advent of the electronic care record and community nurses' mobile working, information travels across space much more quickly than the temporal gap necessitated by the exchange of paper-nursing notes.

Using SystmOne to record patient's notes in the home was part of 'mobile working' and had been part of working practice for less than a year. Prior to this, handwritten notes were stored in the home, and these nursing records had an entirely different relationship with time and space. As handwritten notes were single copies, they could only exist in one location at any one time (the patient's home). Historically, if other professionals needed to view the community nursing notes, this would involve a delay between someone identifying the need to view the notes and gaining access to them, as the single copy of the record required physical transportation across space, which took additional time. However, technology no longer allows distance in space to govern temporal distance, as SystmOne means the temporal gap is substantially reduced.

Further observations of Mary's and another nurse's interactions with Olive highlighted how space also assumed relevance in terms of how aspects of dress, in this case shoe covers, were used. In 'Addressing dressings' (Chapter 5), earlier discussions considered how feet are markers of power and control: here in Olive's home, nurses' feet became symbolic markers of important dignity considerations, through the use, and non-use, of shoe covers. By exploring this example, it will be demonstrated how this is not simply a matter of shoes, but is illustrative of the place of the home in health care, the sociology of place and relationship, and how it becomes a signifier of the challenges in the geographies of dignified care.

Immediately inside Olive's hallway was a 'bin' containing plastic shoe-covers. As soon as Nurse-Mary entered the hall, she placed these covers over her shoes before entering the lounge where Olive remained seated. In contrast, during my visits with Nurse-Daisy, she always strode into the lounge without covering her shoes. Mary and Daisy's differing behaviours were representative of the many different behaviours nurses adopt when entering patients' homes, indicative also of different cultural scripts, or the 'house-rules' people apply to their own homes. Tensions may occur when nurses enter the private realm of the home, if they misread these cultural scripts. When entering Olive's flat, these two nurses adopted two different rules of behaviour – one wore shoe covers and the other did not, which is indicative that their behaviours were under their own control, rather than the jurisdiction of the patient. The removal of shoes is regarded as respectful in some cultures, but may go against some patients' social behaviours or against the 'house-rules' of others. Shoe covers are symbolically significant when considering how dignity can be maintained for patients, when the nurse (who, as an employee, is required to follow organisational policy) is expected by their employer to behave in a manner that may be at odds with the patient's 'house-rules'. In these scenarios constructing an 'environment of dignity' can be challenging, if not impossible.

During my interview with Mary, it was apparent she had reflected on wearing shoe covers, as she explained this was a conscious act to show Olive that she respected her property. By extension, showing respect for the flat extended to respecting Olive's dignity. However, Mary also noted that even by wearing shoe covers there was also potential that this could be perceived as 'rude'.

> **Interviewer**: So working_ doing community nursing and delivering care in patient's homes, so you going into their home, do you think that can have any influence over dignity?
>
> **Nurse-Mary**: …Yeah because it's their personal environment […] I quite often, sometimes cringe a little bit to myself when I go in someone's house and we're not allowed to remove our shoes… and if they don't sort of_ if they're not a known person

> to us and we [don't] have shoe covers… sometimes I kind of think, 'do I look rude?' And I feel like I need to say… erm, 'do you mind if we come in with my shoes on?', even though I'm sort of half walking in… and I feel like I need to kind of address it… because it's like manners as well. I sometimes sort of think, if someone walked into my house and just started walking through on the carpets, I'd probably be like you know [said in a sarcastic tone], 'keep your shoes on if you like'. It's a bit rude I think, so… sometimes that makes me feel a bit… cringy.

When in patients' homes, Mary behaved in a way that she found acceptable for outsiders entering her own home. Essentially, she adopted the doctrine of treating others as she would like to be treated herself –hence she followed her own 'house-rules' when entering Olive's home. However, the act of wearing shoe covers was not based on any dialogue with Olive, but was based on Mary's assumptions that this was why shoe covers were present in the hallway and that this is what she would expect in her own home. Although Mary and Olive may have shared similar expectations about (not) wearing shoes in the house, Daisy's actions indicated she did not. During my visits with Daisy, she never covered her shoes: thus, she was potentially violating Olive's 'house-rules', which may have disrupted Olive's dignity as her own values and standards of behaviour in the home could have been violated in this instance. However, I never observed Olive ask Daisy to cover her shoes. This may have been due to a lack of ability to express her own agency. If these were part of 'house-rules', they remained unspoken. Therefore, if any dignity disruption occurred, it was not addressed or acknowledged by either party.

On a separate, but related, occasion, a group of nurses were discussing how they reacted when patients asked them to remove their shoes. One nurse suggested they should be given shoe-covers, but this was promptly dismissed by another who said, 'they're a trip hazard and against company policy'. This highlighted that Mary was breaching organisational regulations (the company's 'house-rules'), in order to maintain an 'environment of dignity' by following Olive's (contrasting) 'house-rules'. In the same conversation, another nurse commented frankly, 'I tell the patients, if I can't keep my shoes on, I'll just go'. This meant company policy had been adhered to, but it placed patients in a position where they potentially had to decide whether to allow a nurse to violate their own 'house-rules', or whether to forego their care, which may have consequences for dignity. These scenarios are complex, as to receive nursing care in the home, essentially patients may have to compromise aspects of their dignity. On a separate occasion, on a heavily rainy day, another nurse told me that she had been taking her shoes off all day when entering patients' houses, even though she knew this was 'against the [company] rules'. She explained that if she did not remove her shoes, 'I'd get a wet bum from kneeling down on the floor.' Thus, for her, the removal of her shoes was not a selfless act to respect her patients' dignity: it stemmed from her own self-interests rather than thinking about the consequences of walking wet shoes through her patients' homes.

The (non)use of shoe covers is symbolic of the dilemmas that nurses experience when attempting to navigate their way through scenarios in the home. Mary chose to 'circumvent' organisational policy by wearing shoe covers to display respect for Olive's home and to maintain a dignified environment, whereas Daisy strictly adhered to organisational policy in this regard. Maintaining dignity can be achieved partly by demonstrating respect for the patient's home, yet when organisational policy prohibits an act (i.e. wearing shoe covers), the foundations of the 'dignity encounter' rest on unequal power relationships, in which nurses can refuse to deliver care if the patient does not grant her entry on the terms of their employer. Although shoe covers may initially appear a trivial matter, their significance and relationship to dignity were noticeable because, in the context of Olive's care, shoe covers became artefacts of power. The significance of these, and other artefacts, will be the focus of how dignity is constructed in the next section.

Artefacts in space and time

Artefacts, such as shoe covers can be symbolic indicators of (in)dignity. Constructing an 'environment of dignity' can be challenging, as the introduction of nursing equipment marks the passage of time and denotes the decline of the functioning of the body, making spaces medicalised and less homely. Considering geographies of dignity in terms of the organisation of the home, including how the home is adapted when illness descends, can offer an insight into how (in)dignity is displayed in the home.

During my observations, it was usual to quickly notice indicators that a person was receiving nursing care. I became accustomed to identifying plastic bags of clinical paraphernalia in individual ‘home-clinics’. On their arrival, nurses would rifle through these bags to locate exactly what they required for their visit, and at other times they would bring additional materials to leave in the bags, ensuring supplies were sufficient for the next visit. For Warren, keeping nursing ‘stock’ in his home was a source of both comfort and distress. When stocks were at a level that was acceptable to him, he expressed contentment. However, at times when supplies were ‘low’, it became a source of anxiety. Under this circumstance, these supplies were also artefacts of power – their absence promoted anxiety, whilst their presence was a positive influencer of wellbeing and contentment. During all my visits, Warren remained seated in his bariatric chair, which, he explained, he also slept in overnight, as going to bed was no longer a viable option for him. An oxygen cylinder remained at his feet, while, at times, his grandchildren ran around him, avoiding the bags and boxes of clinical dressings stored in the room. When Warren’s clinical resources were lower than he wanted, he wrote what he described as a ‘shopping list’, which he gave to the nurses to replenish his supplies. The nurses also spoke to me about Warren’s ‘shopping lists’, explaining that there were times that their own nursing supplies were not always large enough to be able to fulfil his requests. Thus, one nurse told me that Warren’s ‘stock cupboard’ was, on occasions, potentially better equipped than the depository at the nurses’ office.

Clinical artefacts, specifically bandages, were highly visible within Warren’s home, and most other homes I visited also contained indicators of illness such as these. Lucy was the only patient I visited where there were no observable nursing artefacts on display, and, from looking at her home alone, it was impossible to identify that she was under nursing care. Lucy received regular dressings for an abdominal wound, but, unlike many patients, it was her bedroom that transformed into the ‘home-clinic’.

As Nurse-Sheila and I entered her bedroom, Lucy motioned for me to sit on her velvet Louis XV Bergère chair, located in between an antique Cheval mirror draped in pearls and a walnut dressing table displaying vintage art deco perfume bottles. My *eyes scanned the room for Nurse-Sheila's equipment, but I could not see anything other than a luxurious bedroom reflecting impeccable taste. As Lucy lay on her bed, Sheila opened the French blanket box at the end of the bed, gracefully painted with pink roses.*

'Aha, I wondered where your stuff was!' I remarked.

'I encourage them to store everything in a box – it makes it so much easier than being in a bag' replied Nurse-Sheila, while Lucy remained silent and still.

Sheila found the blanket box to be a more satisfactory storage solution than the plastic bags that were most commonly used by other patients. She recognised that the box meant she could find her equipment more quickly and efficiently than rummaging through noisy plastic bags that often ripped and tore, dropping the contents. The benefits of the box were far greater than simply the ease it offered Sheila. This beautiful box concealed all evidence of any nursing artefacts, hiding them from view, ensuring the bedroom retained 'normality' in its primary function as a bedroom, thus creating and maintaining a visible 'environment of dignity'. The dual role of the space (bedroom and 'home-clinic') was completely concealed, so, to outsiders looking in, it presented as a bedroom and only revealed itself as the 'home-clinic' temporarily in the presence of the nurse. Furthermore, it was easier for 'normality' to resume once Pandora's clinical box was closed and the nurse departed. When Sheila finished her work, the intrusion was minimised by hiding evidence of the 'home-clinic' in the box, ensuring its concealment until the next appointment. Although Lucy's body bore evidence of her ill-health through her stomach wound, she did not have a constantly visible display in her bedroom reminding her of her health condition. That was packaged away in an attractive French blanket box, much like her stomach-wound which was visibly concealed by dressings.

If, as Bourdieu (1979) suggests, taste functions as a marker of class, Lucy's bedroom represented aesthetic standards of good taste, social acceptability and cultural capital. 'The idea of taste, typically bourgeois, since it presupposes absolute freedom of choice, is so closely associated with the idea of freedom that many people find it hard to grasp the paradoxes of the taste of necessity' (Bourdieu, 1979: 177). Lucy had sufficient social and cultural capital to ensure that the 'home-clinic' remained fully hidden when nurses were not present. However, cultural capital is inequitably distributed and, thus, she was one of the privileged few who was able to achieve this standard (unlike Amber who did not have the cultural capital of Lucy). Bourdieu (1979) recognises that different conditions of existence and lifestyles produce different habitus, also indicating that the body is a socially produced expression of the person. Along with the body, the home is also a socially produced expression of personhood, in which the lived environment reflects the social and cultural position of the inhabitants.

Although Lucy had sufficient capital to conceal the artefacts that visibly demonstrated her illness, some patients could not easily conceal these artefacts, and therefore, for some patients, it may have been preferable to simply refuse them. This was the scenario I encountered when observing Betty and Nurse-Nieca. Betty had some mobility issues and she had been prescribed Frusemide, which is a diuretic that can increase the need to go to the toilet. Betty’s only bathroom was upstairs, a significant distance from where she sat downstairs during the day, and it had proved difficult for Betty to get to the toilet in time. Nieca suggested getting a commode, but Betty quickly declined, and the vehemence of her refusal indicated great displeasure at this suggestion.

Betty’s response of protest was an automatic and, perhaps, natural reaction to being offered a piece of equipment that she did not associate with her sense of self. After Betty’s refusal of the commode, in what was possibly an attempt to minimise embarrassment, Nieca hastily acknowledged that Betty was obviously a ‘proud woman’, despite the offer of a commode. This recognition served as a much softer, dignity-enhancing statement, recognising Betty’s independence and self-efficacy. It also implicitly acknowledged the stigma attached to commodes, but, equally, it effectively closed down opportunities for Betty to accept one in the future, as agreeing to a commode would now be associated as a counterpoint of being ‘proud’.

Offering patients commodes may be a fairly routine and regular occurrence for nurses, but for others, it is neither routine nor regular. In fact, using a commode is quite irregular and symbolic of a declining body, a lack of mobility or a body that can no longer be fully controlled. It may also symbolise the passing of time and potentially serve as a reminder of years gone by, when illness had not invaded the person's biography or narrative. Even though in practical terms, a commode would have made Betty's ability to self-manage her continence easier, this benefit was outweighed by the dignity-reducing messages inherent in accepting the artefact.

Betty's refusal of a commode also ensured that visible signs of illness remained absent in her house – a commode is an obvious indicator of illness, a key example of an artefact that holds both power and stigma. However, interestingly, Betty had only recently been discharged from hospital, where she admitted she regularly used a commode. Thus, for Betty, it was acceptable to use a commode in hospital, but this was unacceptable in the home. Hospitals are littered with clinical artefacts, and thus patients are more accepting of them, but, introducing clinical artefacts into the home is a different matter. Discharged back into her own home, Betty now felt her dignity would be jeopardised by the introduction of a commode, hence her refusal. Patients' acceptance of care within the home is based on different behavioural standards to those they adopt when care is received in a total institution, as people modify their standards and expectations according to the differing environments in which they may receive care. Thus, whilst it may be acceptable to use a commode in hospital, for this patient it was not acceptable at home. The hospital may be the domain of the nurse, but the house is the domain of the patient and retaining a sense of normality for as long as possible is desirable. As the home is the environmental manifestation of the patient's identity or habitus, depersonalisation of the home through the introduction of nursing artefacts, can result in a gradual erosion of the patient's identity and dignity.

Michelle was one of the patients who had a commode in her lounge. However, it was carefully hidden behind a door, and thus it was only when I went to interview her that I sat in a different position and was able to gain a glimpse of it, peeping out from behind the door. We discussed the commode during our interview, and Michelle acknowledged her initial resistance to the commode, but now she was enjoying the benefits it gave her.

> **Interviewer**: I've just seen there, your commode. Last time I was here, the nurse said to you, what about using your commode and you didn't seem very keen?
>
> **Michelle (86)**: No, no, no.
>
> **Interviewer:** Unless I'm wrong?
>
> **Michelle (86)**: No, I didn't. I thought, 'Ooooh – disgusting', but by crikey, I did say, oh two, three weeks back, erm to one of the nurses, I said tell [Nurse] Ivy I'm pleased with that commode. I said I wouldn't be without it now.

Although Michelle could conceal it from view, commodes can invade space, as was acknowledged the discussion in chapter 5 of 'A bum thing', in which Brenda's commode was prominent in her bedroom, resulting in Nurse-Nieca using it as a seat during their intervention. The commode is a stigmatising artefact (described by Michelle as 'disgusting'), and thus it is not something people will accept lightly. In general, healthy bodies do not defecate in the lounge and introducing defecation into living areas of the home may be met with resistance. The lounge may also function as the 'home-clinic', but for it to also become 'toilet' may be a step too far for patients who have not come to terms with changes and declining health. Commodes in the home may challenge individuals' dignity, as they are difficult to conceal or gentrify.

Nurses' ownership of space

To undertake their duties, although nurses negotiate the use of space within patients' homes, they also use a variety of other spaces, which includes their cars to drive around the geographical locations in which they work and their office. No two people can occupy the same space at the same time (Urry, 1996) and 'individuals do not move about in social space in a random way' (Bourdieu (1979: 110). Thus, by considering how space is managed and how people make use of space, it is possible to demonstrate how 'environments of dignity' can be constructed.

Whilst the home is identified as the patient's domain, when inside the home, the nurse has ways and means of marking her territory, which may be a conscious or subconscious act. As each patient's house becomes the workplace, community nurses essentially have multiple places of work, and they must transport the equipment they need to undertake each intervention. In effect, they offer a ‘mobile-clinic’, which adapts to each individual environment in order to create the ‘home-clinic’, in which patients and nurses need to recreate dignified caring spaces which meet professional and patient requirements, needs and desires.

Although home spaces were usually under the direction and control of patients, one area which remained fully the domain of nurses were their cars. These were effectively their mobile offices and store cupboards. From looking inside many nurse’s cars, it is difficult to understand how community nurses were once able to perform their duties on bicycles, the most plausible explanation being that contemporary community nursing roles differ vastly from that of their predecessors. Over the years, the role of the community nurse has changed, as they are now performing more tasks that, previously, would have been outside their scope of practice. Accordingly, the tools and equipment they require to undertake their job are now more numerous and consume more space.

> **Nurse-Nieca**: I think…I mean, we’re not GPs but, but we’re doing jobs that they used to do and because_ that’s because there’s a shortage of GPs as well, so it’s_ we’re getting pushed into that arena.

Nieca recognised that nurses were now assuming responsibilities that formerly lay with GPs.

> **Nurse-Nieca**: Nurses didn’t prescribe, erm, so I’ve done the prescribing [course], so we’re not just looking after people now, we’re now having consultations. We’re now looking at signs and symptoms, diagnosing, and then treating. That didn’t happen 15 years ago, it was unheard-of. Erm…we didn’t look after complex needs in the community. We’ve got a lot of people, people’ve now got a lot more choice and if you were poorly years ago you went into hospital and it was dealt with in hospital, people are saying, ‘actually, I don’t want to go into hospital, I want to be cared for at home now’. Whether that be for end-of-life care, neurological care, chronic disease management erm, so we’ve had to go with the times and skill ourselves up in those areas to be able to give that care at home.

As care has been steadily moved out of the hospital and into the home, over the years the scope of community nursing practice has changed. The tasks that community nurses now undertake has broadened, to include prescribing certain medications (for those who are appropriately trained) and other tasks previously reserved for doctors. Medical equipment continues to develop and certain apparatus that was only available in hospitals is now available to patients within their own homes, such as syringe drivers. Nieca explained, fifteen years ago, ‘when I started, we didn’t even own a syringe driver’. It is now routine for community nurses to set up and maintain syringe drivers when working with patients receiving palliative care in their home. Due to the widening function of community care, nurses’ cars now need to be able to transport a range of clinical equipment, often resulting in car interiors that were always consumed by the tools of their trade.

In my study, I noted that the interiors of nurses’ cars were a strong reflection of their professional identity, revealing far less of the ‘private self’. Infrequently, some cars had a hint of the nurse’s private self – rare examples included an air freshener, the occasional child-seat, or a pair of high-heeled shoes strewn on the floor (which were the antithesis of the flat, ‘sensible’ shoes they wore when on duty). Car boots were routinely filled with plastic bags or boxes of dressings and various other nursing equipment.

Some nurses had even modified aspects of their car’s interiors to accommodate their work. Nurse-Anya proudly flaunted her boot to me, explaining that her husband had designed an internal ‘bunk bed’ so that she could use the lower berth for her nursing equipment and the upper berth could be retained for ‘family things’. I did not like to diminish her enthusiasm, but I could see nursing equipment overflowing onto the upper ‘bunk’. Many nurses drove small or medium-sized cars, and their boots were continually very close to full capacity with all the nursing resources they transported from house-to-house. Nurse-Sheila had a note permanently fixed to her steering wheel. The note read, ‘EXPENSES!!!’ I asked her about this, and she laughed, explaining that her idea was every time she entered her car, she would see this, and it would remind her to click the application on her mobile allowing her to log her mileage. She laughed because she said the note did not always work and she was now ‘blind’ to this as well.

Cars were important because they were a space that belonged to the nurse when most of her working day was spent in spaces that belonged to others. Thus, the nurse's car is a 'safe space'. It is important that cars can be used in this manner, as driving between visits often provided sufficient time to reflect and regain composure before the next visit. For Nurse-Denise, her car provided her with a sanctuary, a space in which she could debrief and mentally prepare herself for her next patient.

> **Nurse-Denise**: I feel, we do tend, I tend to debrief a lot in my car about things, when I'm not with the patient_ […] When you go in your car […] I mean driving. I mean everybody must think I'm crackers cos I have conversations about 'em [patients] in my car…and you go over it and then the next one, and then you get out your car and everything's okay and then you come out and then you do it again in the car.

Denise's explanation suggested that the 'nurse' performance ceased when she entered the 'backstage area' of her car. Thus, cars are a place of quiet (or, in Denise's example, not so quiet) reflection, a space in which nurses can be 'themselves' without having to perform to their audience. They may use the car to rehearse their next 'performance', particularly if it involves breaking bad news to people, or if there are certain problems or difficulties that they know they need to address in a future visit.

Driving between appointments demonstrates an overlap between time and space. Each time a nurse is in motion in her car, it takes a certain amount of time to move between two fixed points across a multiplicity of spaces within the geographic locality. Every day nurses plan their visits so that they drive the route that takes the shortest period of time. Rather than selecting routes that are the shortest mileage, they utilise their local knowledge of the area to focus on the fastest routes rather than the routes that cover the smallest space. On one occasion, Nurse-Nieca was driving us to a visit, but our travel was disrupted when we were halted at a level-crossing. Once the train had gone through and the barrier had not risen, after waiting a few more minutes, Nieca said, 'The barrier's broken again'. She did a three-point turn and diverted us onto an alternative route (and was hastily followed by other drivers). She drew on her previous memories of the barrier breaking to identify a substitute route that would save time waiting for the barrier to be repaired, which would take a substantially longer amount of time, thus ensuring an economy of space/ time.

Car parking was continually a contentious issue for nurses. Outside the office, parking was at a premium and thus, at busy times, it was commonplace for cars to be parked four behind each other, thus blocking access. ‘Who’s got the red Fiat?’ ‘Who’s is the black Toyota?’ were common cries in the office, when nurses had to locate the person restricting their own departures from the car park. Time was also at a premium, so when car owners could not be located promptly, tensions rose and people became agitated, as nurses challenged colleagues over their parking.

Although the office carpark was an inherently stressful and uncontrollable space, the office was a space in which the nurses assumed greater ownership. Corporate staff rarely visited them, so nurses could use the space how they wished, free from the corporate gaze: fire doors remained propped open in warm weather and signing in and out of the building was sporadic at times. The irony struck me that fire safety policies were regularly transgressed by many nurses when inside the offices, but policies of refusing to wear shoe covers in patient’s homes (which was described in ‘When “private” becomes “public” in the home’) was a policy most nurses maintained. It appeared acceptable and pragmatic to breach health and safety in the office, but not in patients’ homes.

The nurses were located in an open-plan office, with individual meeting rooms off the main space, including one room that was designated as a dining room, in which many nurses chose to eat their lunch, alongside the administrative staff who were based on the lower floor. The office had no designated seating; it was arranged for hot-desking. However, in line with many open-plan, hot-desking spaces, people generally remained seated at the same desk, or at least broadly in the same area. One cluster of tables was where the senior nurses sat, and, mirroring them at the opposite side, was where the junior nurses placed themselves. On the other side of the room was the space for the healthcare assistants, and workstations used by staff who only came in sporadically. This was where I chose to position myself, being mindful of office politics in the process.

The nursing office was a transitory space for the junior nurses and healthcare assistants who simply used it to eat their lunch, undertake paperwork and administrative duties, and mingle with each other to gain advice and support. These staff members never spent substantial amounts of time in the office. It was the senior nurses who spent significantly more time based at a desk. Office space was thus ultimately linked with hierarchy and rank:

> **Nurse-Denise**: I don't know whether I'm suited for a [band] six because…I'm not really a manager, I'm a hands-on and I'm a do-er and I still can't get my head round where we stay in the office and do things, cos I like to go out and visit my patients [pause] […] I like to go visit my patients cos how do you know how the wound's doing or the reassessment if you don't go and visit them? Else we're going like some GPs where we're doing consultations on the telephone and you need to go and look at your patient, cos 'Betty' might have been all right a month ago, she's struggling now, so then you refer on; and she's not eating properly so you refer to the dietician. You can't do that sat in front of your computer doing your work.

During my fieldwork, Nurse-Denise left the locality team to start her district nurse training, which involved a work placement in a different team, alongside academic studies at University. When she queried whether she was suited to a 'band 6', she was referring to the 'Agenda for Change' pay scale that she would be placed on when she was a qualified district nurse.

Although spending time in the office was linked with hierarchy (the higher up the hierarchy, the more office-bound a nurse became), the space itself was not always reflective of the elevated status of this position. Towards the end of my fieldwork, the office became infested with fleas. Somewhat ironically, the fleas were not biting staff lower in the hierarchy; they appeared only to affect the senior nurses' office space. As a result, they concluded the fleas were located in this area. During the infestation, junior nurses (and myself) actively avoided entering this area and we all remained unaffected. Two of the senior nurses had been bitten particularly badly. One of them had numerous bites on her lower arm, which remained exposed as the organisation has a health and safety policy of 'bare below the elbow' for all clinical staff. Thus, they were on display to her colleagues, as well as to any patients she visited. I was informed that in their previous office they regularly had fleas, but this was the first time it had occurred in this office and they had been there for around a year. If it is important for nurses to create an ‘environment of dignity’ when they perform care in the home, it must surely be important that the nurses’ offices are dignified environments. Nurses regarded fleas as an ‘occupational hazard’, due to some of the homes they visited. However, despite pest control being notified, the nurses had to work with the infestation for several weeks before the office was fumigated, raising questions over whether the nurses’ dignity remained intact in this scenario.

Although there are many areas which generally remain under the control of nurses, when community nurses enter patients’ homes to deliver care, they are no longer in control of the space. ‘Space is an aspect of time, and time is experience of space’ (Van Manen, 2014: 306): hence, in the home, experiences of dignity are interwoven with issues of time and space. Issues of temporality will therefore form the focus of discussion in the next section.

Temporality and the ‘poo diary’

Time is a crucial factor in understanding dignity for older adults, particularly as many ‘housebound’ patients may be time-rich, which may, at times, conflict with their nurses who are time-poor. The time-poverty of nurses is embedded in a social and cultural context in which there is an increased demand for care, compounded with difficulties in recruiting and retaining staff in district nursing. This, in effect, means there are fewer nurses undertaking more work. Hence, there is an argument that dignity is temporally bound and that time is necessary to create a ‘dignity encounter’.

This bureaucracy of time can be understood by considering how past, present and future exist temporally in relationship to each other. The UK, along with many other societies, is ordered and constructed around mechanical time from the Gregorian calendar, which separates time into units of days, weeks, months, years, decades and so forth, along with clock time, in which each individual day is divided into hours, minutes and seconds. Urry (1996) indicates that the first characteristic of modern civilisation was temporal ordering through the introduction of the clock. Clock-time can be a critical influencer over the delivering of nursing care, as, for example, community nurses were required to administer all their daily insulin injections before 10am in the morning, and, for those patients requiring a second dosage, this could only begin after 3pm.

Temporal relationships with dignity were apparent from an observation with Beth, aged 83, who I visited once when Nurse-Ella was going to administer an enema. Beth had instigated her own system of documenting bowel movements through the creation of a ‘poo diary’, which she shared with Ella, explaining ‘I write down when I’ve had a poo’. This diary enabled Beth to maintain a record of her bowel movements, thus enabling a comparison over time, allowing her to share and reflect on her excremental habits.

When one’s body is healthy, it is not normalised behaviour to maintain a ‘poo diary’, although many younger women record dates of menstruation, sharing this with clinicians when fertility or pregnancy issues require this disclosure. Recording times of bowel movements may be an important aspect of marking dignity in an ill body, as it may illustrate important changes to the body over time. The management of the ‘poo diary’ enabled Beth to have some control over the otherwise uncontrollable. As Beth and Ella discussed its contents, I wondered if Beth experienced any disruption to her dignity through the act of recording her toileting behaviours and then discussing it with the nurse, but Ella showed an interest in the records, and their conversation appeared normalised with no signs of a disruption to dignity.

As the two women discussed the contents of Beth’s ‘poo diary’, the aroma of bacon filled the room. On our arrival, we were greeted by two carers and one carer confirmed she was frying bacon for Beth’s breakfast. Social behaviours (including mealtimes) are guided by mechanical time; nurses and patients are temporal subjects, they have an orientation to time and are disciplined by the clock (Urry, 1996). As the carers were preparing food, this time had been allocated as time ‘to eat’. However, the nurse had arrived to undertake the enema, so she had simultaneously allocated this as the time to ‘defecate’. Therefore, if we assume that consuming and excreting food require different spaces in time, the carers’ time and the nurse’s time were incompatible with each other. However, what about Beth's time? What was her natural time and what did she want? Beth did not live in a total institution. She lived in her own home, yet she encountered and experienced institutionalisation by being subject to the timings imposed on her by her carers and the nurse.

The smell of bacon frying, along with Ella and Beth discussing the enema made me reflect on the lunchtime conversations in the staff room, in which nurses consumed food whilst discussing excretion (as discussed in Chapter 5: 'Dignity in Caring for the Body'). Beth informed Nurse-Ella she did not want her enema today because the carers had already ensured she was washed and dressed. She made no mention of the bacon being fried in the kitchen but indicated it was because she was 'clean' that she did not want to be soiled by the act of an enema. Ella accepted this and said she would reschedule the enema with another nurse the next day.

Twigg (2000) recognises that toileting may be done at set times in institutional lives, when carers have toileting tasks scheduled in their work. However, for many people who remain in their own homes, there is usually more flexibility around the times they attend to their toileting needs, which is based on their bodily needs, as opposed to the schedule and competing demands of staff. Carers may be employed to support people to live in their own homes and, in these instances, toileting may become clock-bound and timetabled to coincide with carers' visits. However, Beth's 'poo diary' exemplified how toileting had assumed an institutional component for her that required monitoring and review.

On our return to the office, I began typing up my notes from the observation. Ella approached me and asked if she could see what I was writing. For the duration of my fieldwork, this was the only occasion that anyone asked to view my writing. Ella had recently undertaken some Masters-level training, and she had shown a great interest in what it was like to do a PhD. At that moment, I needed to make a decision and I quickly assessed that to retain trust and transparency, it was important to allow Ella to view my notes. Ella had permitted me entry into her world of work, and so I needed to reciprocate. I moved my computer screen towards her, somewhat nervously making visible my fieldnotes about Beth declining her enema. Ella read my words and then said, ‘Well we can’t always do a poo when we’re told we need to, so why’s it different for this patient? She should be able to have an enema when she wants, not when we tell her she should have one.’ When the body needs to defecate, this cannot be scheduled through mechanical time by the order of the clock, but Ella’s comment presents an archetypal example of power and temporality, in which nurses control the basic bodily functions of their patients. Ella then continued, ‘It’s not about the quantity of visits, it’s about the quality. Write it down, that’s important.’ I obeyed her instructions as it would have been rude not to comply. I felt my instinct to allow Ella to view my notes was validated by her responses, which gave her the opportunity to reflect on my observations and draw her own learning from them.

Ella’s views of ‘quantity versus quality’ will be revisited in the next section, ‘The patient patient’, as this standpoint is not her view alone. Importantly, Ella also noted that people cannot excrete on demand; therefore, it should be no different for this patient and essentially an enema caused people to ‘do a poo when we’re told we need to’. On that day, Beth was scheduled to have an enema, but she did not want one, so Ella recognised the nursing timetable needed to adapt to the bodily desires of the patient. Twigg (2000) recognises the body has its own timings, meaning there are times we need to feed and other times we need to excrete, and these needs are not confined by clock time and thus cannot be scheduled. Beth’s lack of desire for an enema conflicted with the clock time of the nursing visit. An enema was rescheduled, but I wondered whether, ironically, Beth’s body timings had matched the re-scheduled time for the enema the following day.

The social construction of time clearly assists in the organisation of social behaviour – for Beth, routines were based on social expectations of anticipated behaviours at certain times of the day which was reinforced by the routines of her professional carers. Adam (1990) regards clock and calendar time as something that can be viewed either as an inevitable fact of life or as a social creation that is maintained through daily actions and social order. Clock time regulates behaviours, consigning certain acts to specific times of the day, ordering human life. Times to wake up and go to bed or times to go to work and then return home most easily fall within schedules of clock-time. However, other aspects of daily living, such as bodily functions, are more difficult to arrange around clock time.

Human beings do not simply live in time, but they have awareness of time passing (Giddens, 1981, 1984, 1991), and this differentiates humans from other species of the animal kingdom. ‘Space and time are basic categories of human existence. Yet we rarely debate their meanings; we tend to take them for granted, and give them common-sense or self-evident attributions’ (Harvey, 1989: 201), despite both space and time situating social relations (Lévi-Strauss, 1972). As has been shown from fieldwork examples, the importance of both space and time are apparent when exploring the delivery of dignified nursing care in the home. If either space or time is inadequate, or if social actors understand and interpret these differently, constructing a ‘dignity encounter’ will be problematic. In considering ‘temporality and ‘the poo diary’, it has been demonstrated how temporal aspects of care retain significance for the construction of dignity. Moving on from this, the next section will explore nurses’ views on the possible introduction of ‘timed visits’[9] and why patients having patience is important when generating a ‘dignity encounter’.

The patient patient and ‘timed visits’

> **Nurse-Sapphire**: We haven’t got enough time in the day to give to our patients and that is what it boils down to.

Having patience is important in the delivery of dignified care. Patience from the nurse allows patients time and space to reveal their troubles and enables nurses to gain a better understanding of the person’s holistic needs. Patience from the patient is needed as there are times nurses may run behind schedule if they have had a problematic or unanticipated issue to deal with. Having patience is important because dignity is not something that can necessarily be achieved quickly.

> **Nurse-Daisy**: I think time is massive like for showing dignity.

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[9] Informing patients of a specific two-hour time slot in which the nurse would attend.

Daisy used the verb to ‘show’, implying dignity is something that is visible, displayed or performed, rather than being something internally felt or experienced. Daisy worked on the wards for seven years before joining community nursing three years previously, and, thus, like many of the other nurses, she was able to contrast her nursing experiences in the two settings. She conceptualised time differently in these two locations:

> **Nurse-Daisy**: In the community there’s more time I think, than on the wards […] I will stay with that patient as long as I need to, because I know I can hand it over to someone, or I can do it later or… so I feel in the community it is more… able, you are more able to care better… with time.

Clock time remains constant across community and hospital locations, but Daisy acknowledged that experiences of the passage of time vary across these two settings. She described time differently in total institutions and in the home, and, as Daisy explained, ‘better care’ can be offered through the medium of ‘time’. So, if ‘better care’ is also dignity-enhancing care, time is required to achieve this. ‘Slow caring’ has been recognised by Lohne *et al.* (2017) as essential in providing dignified care.

However, on many occasions, nurses indicated that their work was becoming about ‘quantity and not quality’ (as also recognised in the previous section when discussing Nurse-Ella), and this is obviously strongly influenced by time factors, if quantity is the main motivator. Nurse Denise described her view of nursing and how over time there has been a shift in focus towards monetary concerns and budgets:

> **Nurse-Denise**: Cos it’s not the nursing that I joined…when I started all those years ago as an auxiliary. It’s not the nursing. I do feel sometimes…not so much the care…I think other factors…are stopping the care being delivered…that should be delivered. I think a lot is on budgets. Money. Resources. And that’s not what nursing’s about […] That other part of nursing that drew me to nursing. The caring and looking after. Some of that, I think, has gone out the way cos you’ve got to do this dressing you’ve got that time to do it, you’ve got that time and sometimes it’s not the quality, it’s the quantity we do. And we’ve got to get back to the quality […] It’s that quick in, quick out, quick in, quick out and that’s not quality. That’s quantity.

Denise’s view emphasises that delivering good care should focus on quality, rather than quantity; in the current climate of austerity and an increasingly ageing population, nurses are now working under a model in which care has become about managing numbers of patients, rather than focusing on the quality of the work they undertake. Many of the longer-serving nurses were able to compare contemporary nursing to nursing at an earlier time, and these concerns regularly featured in their conversations between themselves, in their interviews and in individual conversations with me. However, the nurses who had fewer years in the nursing profession did not identify this as a concern.

In her discussion of care work in Swedish nurseries, Davies (1994) coined the phrase ‘process time’. She argued that care requires process time, which is characterised by a lack of knowledge about how long a certain activity will take, making these activities difficult to schedule. She gave the example of careworkers feeding an older person who takes ‘the amount of time they need to take’ (Davies, 1994: 279). Davies (1994) recognises that, although caring activities can be structured by clock time (as is the case in total institutions), ‘this calls into question the issue of quality’ (Davies, 1994: 280). Quality relates to the fluidity of time whereby caring activities simply take as long as they take, and this may also include an element of time spent waiting. This can be a significant component of delivering quality care, although Urry (1996: 389) recognises a decline in what he describes as the ‘waiting culture’, as people are more inclined towards a faster pace of life.

Twigg (2000) recognises that, as many care recipients do not directly pay for their care, their moral claim on carers’ time is weakened. Similarly, patients receiving free community nursing care under the NHS are also aware that their nurses are busy and therefore try not to delay them. During the observational stage of this study, many patient-participants were acutely aware of time and did not want to delay the nurse in any way. As a result, they would undertake their own advance preparations prior to any care work beginning. For example, before every visit, Warren’s partner always ensured his dressings were laid out prior to the nurse’s arrival in order to ‘save time’. This was not to save *their* time, but to save the nurses’ time, as both Warren and his partner regularly expressed empathy towards the number of patients the nurse needed to see each day. Warren always assisted the nurses as much as possible in doing his bilateral leg dressings. His partner laid out all the dressings and Warren would unzip his outer bandage and rip pieces of microporous tape to hand to the nurse as she needed it, which he indicated quickened the process.

Community staff nurses received their allocations of visits on a weekly basis, which was further sub-divided into daily tasks. Each week, the senior nurses held a meeting in which they evaluated how much time would be necessary for each task, before allocating visits to staff members in their teams. Time was assessed and allocated in terms of time required to perform their clinical tasks (process time). No time was specifically allocated to ‘do dignity’. Likewise, although there was time to do a leg dressing, it was never specifically the time to ‘do dignity’, relegating this to a desirable by-product of care.

When undertaking allocations, to maintain equitability across staff nurses, the senior nurses would ‘weight’ the visits. The senior nurses explained, it was not appropriate to compare administering an insulin injection (which could take as little as a few minutes) to a bilateral leg dressing in which legs in water-retention could require substantial physical effort from the nurse, which, of course, required more time. The nurses described bilateral leg dressings as ‘heavy visits’, which corresponded with their description of ‘weighted visits’, in which time was measured by weight (‘heavy visit’ = slow, ‘light visit’ = fast). Delivering care to Warren was considered to be a ‘heavy visit’, so nurses were aware they would need to allow more time to undertake his bilateral leg dressings.

‘Weighting’ visits like this does not acknowledge that, regardless of the clinical intervention, patients are individuals. The previous chapter, ‘Dignity in caring for the body’, explained how reductionist terminology continues to be used in the nursing profession, whereby patients become known as their illness. Similarly, in a reductionist manner, all ‘bilateral legs’ were weighted the same, and all ‘insulins’ were weighted identically, which failed to account for individual variations between the people with a similar health condition. Some people may move more quickly than others; some may prefer to talk more than others; and some may disclose additional issues that the nurse need to respond to. Subsequently, to deliver dignified care, the amount of time patients require will vary and cannot be measured (‘weighted’) simply in accordance with their identified health intervention. All ‘bilateral legs’ are not equal.

Nurses spoke of working at a ‘fast-pace’ and undertaking ‘a high number of visits’. Thus, members of the nursing team focused on accomplishing the number of tasks they had been allocated each day. The number of visits nurses undertook remained controversial, as equity and fairness of workloads were a constant challenge.

> **Nurse-Anya**: I’m telling you I haven’t got capacity to do it. It’s not fair… when I can see that people are sat there on two visits and we’re sat there on eighteen visits. How is that a fair representation?

Other nurses may only have undertaken two visits, but these were the ‘heavy’ visits which involved tasks that were perceived to consume more time. Thus, the number of visits was never a measure of the time involved in the care, neither did it evaluate the quality of the interaction, nor did it offer any evidence of whether dignity was constructed during the visit.

During fieldwork, it became apparent that measuring time and the management of time was a major source of discontent with the nursing team. The only occasion I was asked to leave the office was when one of the managers arrived to brief the team about planned changes to the service that involved the introduction of ‘timed visits’. The manager said she knew it was a contentious issue and therefore felt it was better discussed without my presence. I willingly left the office, returning only the next day to ensure that I did not disrupt them. Despite my absence, and without any questioning from me, the nurses readily told me about the content of the meeting and they freely expressed their concerns about the changes. The proposal was for all appointments to become ‘timed visits’, which meant that each patient was to be informed (in advance) of a specific two-hour period in which the nurse would visit, as opposed to this being a reference to the duration of the call. The whole concept of ‘timed visits’ was contentious with the nurses and generated friction across the team’s hierarchy throughout the latter half of my fieldwork, especially as this was viewed as an initiative that ‘management’ was imposing on them.

> **Nurse-Denise**: The hierarchy [hand gestures above her head] do not understand the delivery of care that we give.

I was informed that ‘timed visits’ were being introduced by the commissioners as a new Key Performance Indicator (KPI) and the nurses were very reluctant to implement this change. They foresaw many potential problems with visits being timed: for example, if a patient was in a crisis and their visit took longer than planned, subsequent visits would be affected, potentially making nurses late, and thus the KPI would be breached unless they were potentially to leave patients in vulnerable situations. One of the nurses explained:

> **Nurse-Rina**: British Gas won’t even give a time slot of two hours!

The rigidity of ‘timed visits’ would place further temporal demands on nurses. However, as the commissioners had introduced this KPI, it was not optional. The nurses told me that ‘management’ had told the team that the commissioners were introducing this because ‘it is what patients want’ because it ‘allows them to plan to rest of their day’. By contrast, the nurses felt that this was not a valid argument: firstly because patients had not directly expressed this view to them; and secondly, because if a patient was under their care, they should be ‘housebound’ and it should not matter what time their nurse attended (hardly a dignified reaction as surely ‘housebound’ patients are also entitled to plan their day).

The nurses based their critique on practice-based experience, but the underlying assumption of ‘timed visits’ is also in conflict with the perspective that process-time is essential in quality care work. ‘Timed visits’ do not recognise what process time values, which is that the act of ‘caring’ cannot be allocated units of time, as each individual’s care takes as long as it takes. Constructing dignity takes as long as it takes – and this may vary from individual to individual. In addition, the feelings of caring do not stop once the ‘timed visit’ has ceased. Furthermore, this time becomes unboundaried and impacts on the nurses even when off-duty.

> **Nurse-Denise**: When you're leaving a vulnerable patient, you take that home with ya as well. And you do worry. I tend to worry.

The ability for nurses to manage the temporal aspects of patients' dignity remains a challenge, because, as has been previously noted, nurses are 'time-poor', whilst many of their patients are 'time-rich'. In the next section, the issue of care economies raises the question of how the time of nurses is inherently bound with funding and how this continues to pose problems for dignified community nursing care with older adults.

Care economies: Time means money, money means time; time and money means dignity

The context for the delivery of community nursing care is a situation of increased demand for care, compounded with difficulties in recruiting and retaining staff in district nursing. In practice, this means that there are fewer nurses undertaking more work, which contributes to the argument that time is a crucial factor in understanding dignity. Nurses and patients are involved in each other's biographies, even if minimally or momentarily, but these interactions can have a long-lasting influence over their experiences of dignity.

Care economies are based on transactions in which nurses are paid for the time they spend at work, not the amount of work they undertake within these hours. Thus, if a community staff nurse undertakes six visits in a day, she will receive the same remuneration as her colleague who has eighteen appointments. Many nurses explained how they 'took work home' by updating clinical records during the evening. In modern industrial societies, time is conceptualised as a commodity or resource; as Fabian (1983: ix) explains, 'time may give form to relations of power and inequality under the conditions of capitalist industrial production'. It is time that remains the focus of capital-labour disputes (Giddens, 1979), and, as it has been shown that time is required to deliver care with dignity, by extension, it is dignity that is at risk in these disputes, as dignity will be compromised if there is not sufficient time.

Although nursing is a caring industry, it is still an industry related to production – the reduction of illness and the maintenance of healthy bodies. The aforementioned introduction of ‘timed visits’ was one method of ensuring nurses worked to a pre-determined schedule, in which their workload would be established in line with patient numbers and organisational needs, rather than individual patient needs.

Although participants (nurses and patients) stated that, over time, healing was the goal of nursing interventions, the nurse’s time remained limited. As a result, maintenance of the health condition may be a more likely route rather than achieving an outcome of healing, as explained by Nurse-Sheila.

> **Nurse-Sheila**: We are so busy and a Doppler[10] takes like an hour to do, and sometimes… we just sort of push it to the side, and we think, ‘oh we are busy’. Like for example, if somebody rings in sick, the Doppler can wait till next week.

Sheila’s comment illustrates Walshe *et al.*’s (2012) finding that, although ‘caring in the moment’ is important, this has implications for future care, as current care needs become prioritised more highly than advanced care planning. As Sheila explains, if time is short, certain tasks are postponed. When Dopplers are delayed, this saves time in the short term which can be transferred to other (more immediately pressing) tasks. However, delaying Dopplers also means a delay in maximising the effective treatment of the patient, resulting in the patient remaining on the nurse’s caseload for longer, and therefore any time saved in the short-term is in fact borrowed from the future. In this context, time is a currency that can be loaned or borrowed. Delaying Dopplers, however, may be a false economy, as patients not only remain on caseloads longer, but they remain in ill-health for longer, and this can lead to other physical co-morbidities and mental health issues (such as depression) and indeed has the potential for patient complaints to increase if they are dissatisfied that they are not receiving timely assessments and interventions.

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[10] A Doppler is used as part of a comprehensive assessment for patients showing signs of venous disease, which if confirmed, would allow the safe application of compression bandaging as part of their management of care. It involves monitoring the blood flow through the veins and arteries and the whole assessment can last for an hour, or possibly even longer, particularly if the patient has not prepared themselves in advance by lying down for approximately 15-20 minutes prior to the nurse’s arrival.

On occasions when interventions, such as Dopplers or incontinence assessments (as described in ‘Anya’s “passion”’), are put to one side in order to achieve the goal of seeing the specified number of patients each day, the care becomes about ‘quantity and not quality’, (described by Nurse Ella in the ‘Poo diary’ and Nurse-Denise in ‘The patient patient’). In these scenarios, dignity may not be mindfully enacted by the nurse, as her focus is on achieving the number of visits, rather than the quality of the intervention (which would involve the conscious construction of a dignified encounter).

> **Nurse-Ivy**: Some days it’s great… you know you might have a very successful day and be able to do what you want for that particular patient, but other days it’s like time factor […] _ you’ve always got time in your mind, thinking, ‘my gosh I’ve got to do this and I’ve got to do that, I’ve got to get this, and do this person, and do that person…’

Ivy’s words suggest that, for her, a successful day involves simply having enough time. Care in this manner becomes akin to a production-line, as Ivy’s expression ‘do this person, and do that person’ objectifies the person as a task that must be achieved, rather than emphasising the relationship with a person with agency. If the quality of visits is prioritised over quantity, intersubjective conditions have the potential to create environments in which dignity may follow.

When I interviewed nurse-Daisy, she identified time factors as being an element of patients not being treated with dignity.

> **Nurse-Daisy**: I don’t like to think it happens, but I know it does, I know nurses do just go in-and-out, they don’t always ask how they are and… I hope not_ that it doesn’t happen often, but you see it everywhere, like on the wards as well, you just_ it’s just quick, quickly you know… do what they need to do quickly and rush off but… you know, these patients are vulnerable and I think they need to be cared for with dignity.

Daisy related a fast pace (‘quick’ and ‘quickly and rush’) to patients failing to receive dignified care in total institutions. By engaging in nursing tasks quickly, time is maximised and more patients can be ‘seen’. However, the quality of intervention may be lower, and although nursing tasks may be completed quickly, this is perhaps at the expense of other issues, such as dignity. Thus, a slower-pace of work could result in dignity-enhancing care. Despite their temporal coexistence, nurses may be pushed for time in a way that older adults are not and thus, as previously noted, there is paradoxically a potential mismatch in the expectations of the time-rich patient and time-poor nurse.

Giddens (1979) explains that it is labour-time and the creation of the clearly defined ‘working day’ that makes possible the transmutation of labour-power into a commodity. In modern societies, time is a scarce resource, and the commodification and control of time is an essential aspect of industrialised societies. Charles *et al.*, (2014: 26) recognise that, specifically within district nursing, ‘demand is rising faster than funding’, so that there is a potential for nurses to be exploited by their employers as their inherently caring nature means they may be more likely to take work home with them or to undertake longer, unpaid hours to ensure their patients receive sufficient care. Budgetary resources are not infinite. As a consequence, although nurses continue to trade their skills for monetary gains, employers are demanding increasingly more from the nursing workforce within each working day – more visits, more complex interventions and assuming more responsibilities that formerly lay with the GP or other professionals. Adam (1995: 26) recognises time as ‘the medium through which labour is translated into an abstract exchange value: it is fundamental to the exchange between work and money’. Essentially, time means money, and money means time. Time and money can mean dignity.

Nurses enter a transactional relationship with their employer in which they trade their time, knowledge and skills (through the giving of ‘care’) for a monetary value. Time, therefore, means money. If more nurses are employed, more time will be purchased and thus ‘heavy’ workloads could be reduced. Having additional time would allow nurses to focus on what nurse-participants deemed to be important – ‘quality and not quantity’, contributing to a dignified encounter. Thus, time not only means money, but money also means dignity, and, thus, without significant monetary investment in the health service, breaches of dignity may occur, as the focus remains on time-restricted interventions, rather than the quality of care within a dignified encounter. This is not to simply reduce dignity to a purchasable commodity in industrial societies, as this is only one dimension of a hugely complex phenomenon, in which individual social actors also have responsibilities in the creation and management of ‘environments of dignity’ through their intersubjective relationships during their ‘performances’ with each other (explored in Chapter 4: Dignity in Caring Relationships).

Summary

This chapter has explored how dignity can be constructed in the home, as opposed to creating ‘dignity encounters’ in hospitals. Boundaries of what have traditionally been private or public spaces are becoming blurred as the introduction of informal care into the home changes the location of the care from being a private/ domestic space to that of public/ domestic space (Milligan, 2000). Spatial concerns are integral to social activities; yet Giddens (1979) recognises that most forms of social theory fail to account for the temporality of social conduct and also its spatial attributes. This chapter contributes to this knowledge by providing insight into how space and temporality can influence the construction of dignity in the home.

District nurses conduct their business within the home, and this involves moving and interacting across both time and space. People live in a diverse range of social conditions, and community nurses adapt to undertake their work in a variety of environments. Although there are opportunities to create an ‘environment of dignity’, when people become unwell, health issues dominate their world and clinical artefacts may begin to consume, or dominate over, personal possessions in the home. Therefore, asserting agency through management of the home may become more difficult, making an ‘environment of dignity’ more difficult to achieve.

The home is a private space, hidden from outsiders’ gaze, but community nurses gain entry to this world: ‘to receive care within the home is thus to negotiate boundaries of privacy and intimacy’ (Conradson, 2003: 452). When nurses visit the home, public and private intersect, and the home is under the ‘clinical gaze’. There are tensions when the house has the dual purpose of both ‘home’ and ‘workplace’. This contrasts with the dominant discourse relating to the home, which is based on assumptions that it is spatially distinct from the workplace (Seymour, 2007). This duality means there are times when nurses must negotiate through complex workplace/ home dilemmas with their patients.

This study has demonstrated how three crucial factors influence patient dignity in community nursing by considering dignity in caring relationships (chapter 4), dignity in caring for the body (chapter 5) and dignity in the home (chapter 6). The following, and final, chapter will offer some further discussion about how these elements contribute to answering the research questions posed by this project, as well as recognising the limitations of the thesis, providing recommendations and reaching an overall conclusion.

Chapter 7: Discussion and conclusion

Aim and research questions revisited

In this concluding chapter, it is helpful to return to the overall aim of the research which was to consider staff and older adult patient experiences of dignity in community nursing care practices. This was addressed by considering the following questions:

1. What does dignity mean to nurses and patients?
2. How do older adults experience dignity in their homes?
3. Are dignity and human rights important to older adults?
4. How might staff deliver dignified care and are there any challenges to this?
5. What factors are needed to promote and influence dignity?

As demonstrated by the data, dignity is multifaceted, and a range of concepts, values and beliefs all contribute to the social construction of dignity. Although a simple definition of dignity is appealing, it would not fully encompass the complexities inherent in the meanings of the word (Häyry, 2004). Thus, this thesis did not attempt to offer a simplistic definition, but, instead, it presented features of people’s lived experiences of dignity that are worthy of further contemplation for nurses in practice as well as further academic reflection and analysis.

Evaluation of methods

Dignity is a highly complex phenomenon that cannot be understood effectively through a reductionist or quantitative approach; thus, this study adopted a qualitative methodology. Ethnography was selected as it is helpful in describing complexities and challenges, rather than attempting to quantify or measure. This methodology enabled participants to build trusting relationships with the researcher, maximising opportunities for them to become open and honest in their narratives, thereby contributing to the trustworthiness of the study.

Two methods of data collection were used: observations (of interactions between community nurses and their patients) and individual semi-structured interviews (with patients and nurses), which allowed participants the opportunity to reflect more deeply on their values and attitudes. Using these two methods enhanced the depth, breadth and richness of the findings, also allowing observed behaviours to be considered further and clarified through participants' interviews. The behaviours and attitudes of staff and patients were presented authentically. However, behaviours change when people are observed, so my own presence within the observations undoubtedly influenced interactions. In the descriptive accounts of observations, I located myself firmly in the ethnography, allowing the reader to evaluate the influence or impact I had on the situation.

Using ethnography as the methodology for this study was effective as its iterative and inductive nature allowed phenomena to reveal themselves through sustained engagement within a community nursing culture. To explore the narratives of nurses and older adults' experiences of dignity, ethnography allowed the production of a richly written account of fieldwork encounters, making this approach invaluable.

Research Question 1: What does dignity mean to nurses and patients?

The literature review demonstrated that, whilst some consider dignity a 'useless concept' (Macklin, 2003), others still regard it as powerful (Michael, 2014), and although it is difficult to define (Tranvåg *et al.*, 2016) and it resists measurement (Fenton and Mitchell, 2002), dignity remains a crucial element of NHS service delivery (DH, 2015a) and nursing practice (NMC, 2015). Dignity, therefore, whilst undeniably complex, remains an important aspect of care practices and the caring professions.

Dignity is constructed

Dignity does not exist absolutely, but it is socially (de)constructed when community nurses and their patients engage with each other. Dignity is experienced subjectively, and thus it is an individualised reaction to stimuli or behaviours, which are influenced by many factors, including feelings, social pressure, social convention, expectations, and understanding. The presence, or lack of, dignity occurs when two or more people come into contact through community nursing relationships. At times, dignity is taken for granted as patients and nurses co-create a ‘dignity encounter’, seemingly with little thought, effort, or formal negotiations, but it is secure relationships and tacit knowledge that enable dignity to manifest itself in these scenarios. When something occurs to disrupt or reduce dignity, it becomes recognisable by its absence, which echoes Arendt’s (1958) paradox of human rights, in which rights are only recognisable when they are non-existent. Opportunities arise for people to reinforce or increase dignity (such as by nurses fully empowering people to make their own decisions). However, opportunities to positively enhance dignity are less well evidenced, because bad experiences are stronger than good ones (Baumeister *et al.*, 2001). As a result, negative experiences remain at the forefront of explorations into dignity in care.

The dignity hierarchy

Certain nursing tasks (often those exposing parts of the intimate body) have the potential to reinforce (or reduce) dignity more than others. Thus, in future, it may be possible to rank clinical tasks in terms of their propensity to reinforce or, conversely, undermine patients’ dignity. The allocation of tasks that maximise dignity is often inversely proportional to the nurse’s position in the professional hierarchy. ‘Dirty’ jobs and tasks that retain and conceal malodour (such as continence work) are traditionally delegated to those low in the professional hierarchy. Yet from patient-participant responses, these are the tasks which, if successfully managed, can have the greatest impact on maintaining and reinforcing patients’ dignity.

Older adults perceive malodour as a marker of a lack of dignity

Bodily odours are normal, and ill bodies often smell. For many older adults, the potential for their own bodies to be malodourous was identified as a significant risk to dignity. Social expectations reinforce and stigmatise bodily malodour, which acquires specific importance as people age, since this can also be indicative of an ageing or ill body. As Twigg (2000) recognised, odorous ‘dirty work’ is delegated to those lowest in the professional hierarchy, and thus it sends out messages that this work remains outside the scope of the registered nurse’s care. When patients directly asked nurses if their bodies had odour, even when smell was present, it was usual for nurses to deny or minimise any smell (which was witnessed in observations and confirmed in nurse interviews). This strategy of denial ensured patients avoided any shame or embarrassment and allowed dignity to remain intact. Although there were times when participants' bodies smelt, when nurses denied the presence of smell, this reinforced the patient's dignity. By contrast, on the occasion I observed bodily malodour being acknowledged by a nurse, the patient's display of embarrassment indicated that the acknowledgement of smell had led to an evident disruption of her dignity.

Research Question 2: How do older adults experience dignity in their homes?

Respecting the social order of the home by following 'house-rules'

Every household has its own social order, which is constructed via inhabitants adopting and following 'house-rules', that is, a set of mainly unspoken rules which even guests are expected to follow. If nurses break one of these rules (for example, by failing to remove their shoes – Chapter 6), this can threaten and undermine her patient's dignity. At home, the patient is Queen or King of their province (the home). As a result, there are expectations for nurses entering this domain that they will adapt and conform to the 'house-rules'. In community nurses' encounters with patients, any contravention of the 'house-rules' may prohibit or even prevent the construction of dignity, as without displaying respect for the home, nurses risk breaching their patients' dignity. For older adults who are no longer able to leave their own home ('housebound patients'), the home becomes 'their world' (Nurse-Denise, Chapter 6), and any threats to their world (by not following 'house-rules') can cause dignity disruptions.

Empowerment and agency contribute to dignity in the home

Dignity is experienced and constructed differently in the home to hospitals. Older adults experience greater empowerment in the home environment. As a result, they are more likely to assert their individual agency to careworkers, which in turn reinforces their dignity. Professional and institutional expectations underlie how patients receiving care in hospitals may be more accepting of being in the ‘sick role’ (Parsons, 1951/91), as they adapt their behaviours in response to the predictability of the hospital setting. However, at home patients are less accepting of disruptions to their daily living routines and environment, so their adoption of the ‘sick role’ exists alongside other personas they adopt within the home (such as ‘mother’, ‘wife’, ‘cook’, ‘cleaner’ etc). Signs of illness cannot be easily concealed in the home, which can at times lead to patients’ refusals, such as Betty’s refusal of a commode (Chapter 6) or Lizzie’s refusal to use incontinence aids as advised (Chapter 5). Although these refusals are illustrative of what the nurses described as ‘non-compliant’ patients, they are also indicative of patients prioritising their own dignity considerations above clinical priorities. Hence their own agency contributed to reinforcing their dignity.

Dignity is the avoidance of shame and the (ill) body can betray inherent dignity (*Menschenwürde*)

When people become embarrassed, feelings of shame ensue. Nordenfelt (2004, 2009) linked his concept of the dignity of identity to ideas of humiliation, yet he also recognised the inherent dignity of all humans – *Menschenwürde*. When shame, embarrassment or humiliation occur, dignity is reduced. Embarrassment and shame often result from the (ill) body behaving in a manner that is beyond the usually socially acceptable limits – bodily leakages are a prime example. Leaky bodies are abject and viewed as a source of shame. Possessing a leaky body may cause a disruption to a person’s *Menschenwürde*. This dignity disruption may not be always be displayed outwardly but may be experienced internally by older adults. Throughout their careers, community nurses become highly experienced and adept at working with many leaky bodies, so that they may become desensitised to the potential threat these scenarios pose to patients’ dignity. The leaky ill body is normal for the nurse, but may not be normal for the patient. Hence it is easier for the nurse to fail to recognise that each individual patient may be experiencing a disruption to their *Menschenwürde* if the patient’s public displays do not visibly reflect any discomfort or embarrassment through their verbal or body language and other observable cues.

Environments of dignity and the ‘home-clinic’

An ‘environment of dignity’ can be created when nurses ensure the home remains within the control and direction of patients. The home can quickly become medicalised when patients receive care in their homes, and although some older adults accept the medicalisation of their home space, this can lead to a dignity disruption if it reflects a reality that is inconsistent with the person’s view of themselves. Thus, the introduction of clinical equipment into the home must be managed carefully and sensitively to ensure an ‘environment of dignity’ remains.

When nurses enter the home to deliver nursing care, the purpose of the space adapts to accommodate the ‘home-clinic’. Certain spaces in the home are more likely to be used in this manner, as nursing tasks are often performed in communal living areas. However, if the task involves intimate areas of the body, the privacy afforded by bedrooms is often employed as the ‘home-clinic’. Thus, there are certain areas of the home that are more likely than others to become environments of dignity. Ultimately, patient choice should dictate which area of the home will become an ‘environment of dignity’.

The paradox of dignity when the home is a source of risk and place of healing

Sometimes there is a dignity paradox, as some patients receive nursing care in their home, when their home itself was the initial cause for them needing to have nursing interventions. For example, older adults (such as Amber) may fall in their home and then receive nursing care in the same space where the accident occurred. Therefore, there are contradictions in the use of space, which may be regarded simultaneously as a source of risk and a site of healing. Space, therefore, may hold complex memories for people, and this may disrupt their dignity as thoughts of both harm and healing are associated with the home.

Research Question 3: Are dignity and human rights important to older adults?

Dignity is important to older adults, but human rights are not

Findings illustrated that dignity was very important to older adults – it was the oldest of the older adults who most strongly argued the importance of dignity. Participants indicated that aspects of age discrimination were specific threats to their dignity. Although the study did not specifically seek to explore experiences of death and dying, some older adult participants indicated that dying with dignity was especially important to them.

Human rights legislation was introduced to provide citizens with legal protection from state violation of their dignity, so that dignity and human rights are interrelated. Whereas dignity is abstract, human rights are tangible, as they are legislated and enforceable via the ECHR and the Human Rights Act 1998. All participants (nurses and patients) were asked how human rights were relevant to them. For older adults who were interviewed, the concept of human rights was imagined as a global phenomenon, remaining externalised from their own lives. They did not recognise that human rights offered them any safeguards. So, although legislative protection is in place at the macro-level, older adults may remain unaware of these safeguards in relation to their individual micro-context. Instead, patient-participants linked human rights to people living in other areas of the world (more specifically, regions of the global south). Thus, although human rights apply to everyone receiving intervention from the State, including community nursing patients, patient-participants did not recognise any impact human rights had on their lives, indicating this was part of their ontological security that was taken for granted.

Research Question 4: How might staff deliver dignified care and are there any challenges to this?

The ‘dignity encounter’

As Jacobson (2009: 1538) explained, ‘any human interaction can be a dignity encounter’. Therefore, when any nurse and patient come into contact there is the potential for a ‘dignity encounter’ to ensue. Dignity can be constructed by creating effective working relationships between nurses and patients. A ‘dignity encounter’ can be generated when both parties relate to each other on a similar level and enact shared standards and beliefs about what it means to treat someone with dignity. When patients and nurses share understandings of acceptable behaviours and standards, a ‘dignity encounter’ can be created more readily than if they hold different views. When patients or nurses enact behaviours that the other person regards as undesirable, a climate is created in which dignity is more readily reduced and possibilities to construct a ‘dignity encounter’ become problematic.

Dignity is fragile and can be easily shattered through speech

The way language is employed through spoken words can illuminate the fragility of dignity, because there are times when ill-thought words or misconstrued speech quickly destroy what was previously a ‘dignity encounter’. In this way, dignity can be easily shattered in nursing relationships. This is exemplified by scenarios in which speech identifies the presence of malodour – it is not the smell *per se* that diminishes dignity, but it is the verbal recognition of odour that disrupts the ‘dignity encounter’. In this example, dignity can remain intact if the taboo remains unspoken.

Emotional labour and dignity – nurses may need to ‘resist repulsion’

As social actors, patients and nurses engage in performances defined by these labels. Nurses recognise their two different identities of ‘personal self’ and ‘professional self’. The continual presentation of the ‘professional self’ to patients involves significant emotional labour, especially when nurses suppress their own (personal) responses to certain patient behaviours. For example, nurses do not accept sexual harassment (even though they say they ‘expect’ it), which is a violation of their dignity, but in response to sexualised behaviours, they engage in emotional labour to ensure their responses remain from the ‘professional self’.

Nurses are not alone in undertaking emotional labour, as older adults also undertake emotional labour through their performances of ‘patient’. During clinical interactions, ownership over the patient’s body may be temporarily transferred to the nurse; and as she undertakes bodywork, patients may engage in emotional labour to ensure they perform ‘correctly’ in their (passive) role. Patient and nurse performances involve emotional labour but contribute to dignity; thus, maintaining dignity can, at times, be exhausting.

Maintaining dignity may be at odds with medical knowledge of clinical effectiveness

There may be conflicts between medical knowledge of the effective treatment of the body-object and how the body-subject experiences dignity, as these may not be mutually dependent. Nurses work from evidence-based practice in terms of clinical effectiveness. However, some patients prefer to manage their own health needs in their own way (such as Lizzie managing continence how she wanted, which reinforced her dignity – Chapter 6). This can be a challenge or a threat to dignity.

Choice and consent

Fundamentally, without consent, care practices are abusive; thus, choice and consent are a baseline prerequisite for the possibility of care being delivered with dignity.

Research Question 5: What factors are needed to promote and influence dignity?

Respect and self-respect

Dignity is reinforced when social actors show respect towards others and, for older adults, having a sense of self-respect was identified as a key marker of dignity. How respect is displayed varies from individual to individual, but it involves issues mentioned previously, such as gaining consent, following ‘house-rules’ and ensuring (or denying) the absence of bodily smells.

Time is a variable that influences dignity

Time influences dignity. Time is necessary for dignity to unfold, as older adults express that they feel more dignified when nurses pace themselves more slowly, taking time to communicate. Thus, nurses’ performances may reduce dignity if they hurry when time is short. Despite temporal coexistence, older adults under community nursing care remain time-rich, whilst their nurses are time-poor. Therefore, a mismatch of expectations in this regard may contribute to violations of dignity if nurses believe they can deliver dignified care quickly.

Time is a mediator of dignity for two reasons. First, dignity can be disrupted if a private body part if exposed for a longer length of time than is necessary to perform the clinical intervention – this is specifically pertinent when an intimate body part is exposed. Secondly, temporality is experienced differently as time becomes slower when someone perceives dignity as absent (as explained in ‘a bum thing’ – Chapter 5).

Changing societal attitudes over time (exemplified by the presentation of nurses in the media through films such as *Carry on Nurse*) have also led to contradictions and differences in opinions (between older adult patients and younger nurses) over what are acceptable behaviours and attitudes. As a result there are greater possibilities for infringements on dignity, and as time passes, dignity expectations will continue to change as societal and cultural expectations evolve.

Enacting standards of mutually acceptable behaviours reinforce dignity

When social actors in community nursing scenarios enact standards of mutually acceptable behaviours, embarrassment is averted, and a ‘dignity encounter’ can ensue. It is this enactment of acceptable behaviours and attitudes that enables them to relate to each other in a manner that can be described as dignified.

Social actors are subject to social expectations, but they have individualised understandings of the world, and this gives them ontological security. However, if something disrupts this security, dignity may diminish. Differing ontological perspectives of the body invade interactions between nurses and patients. As described in Chapter 5, ‘A bum thing’, Brenda’s somatic experiences of nursing illustrated how Cartesian beliefs still prevailed (both from nurses and patients). Brenda and her nurse apparently shared dualist interpretations of the body which ensured that any somatic breach of dignity (as a result of lengthy exposure of Brenda’s bottom) remained detached from Brenda’s dignity of the mind, enabling Brenda’s overall dignity to remain intact. If relationships enact standards of mutually acceptable behaviours dignity can remain intact; however, if actors have grounded their relationships in differing ontologies, there is greater potential for dignity to be breached.

Nurses may experience breaches in dignity

An unanticipated finding was that all nurses indicated at least one occasion on which their dignity was violated by patients. Although human rights legislation offers protection for the dignity of subjects of the state (such as older adults under the care of district nurses), these legal protections do not extend to agents of the state. Thus, community nurses do not have any human rights protections within their professional roles. Despite campaigns of zero tolerance towards abuse of NHS staff (BBC, 1999), a report from Unison (Cowper, 2018) indicated that in 2016–17 assaults on NHS-provider staff had risen by 9.7% from the previous year, with 56,435 physical assaults on NHS staff reported in this period. Most incidents occurred in mental health inpatient treatment units and acute emergency care. However, this report only explored physical assaults of NHS staff, without considering the routine dignity violations or breaches of dignity experienced by healthcare professionals on a regular basis. These may not involve physical assaults but may comprise dignity reducing interactions (such as some of the examples described in Chapter 4, for example, Don’s sexualisation of his nurses*)*.

(Lack of) Dignity evokes emotional responses

Dignity is elusive. It is dynamic and remains fluid. Similarly, how one person understands dignity in their own personal context may not be applicable to another. Dignity cannot be touched or measured. Instead, it manifests itself as an emotional response or feeling experienced by people. Dignity often remains unacknowledged until it is reduced or removed. It is when dignity is absent that it is more likely to be recognised through a negative emotional reaction. This is a finding which is in keeping with Arendt’s (1958) paradox, in which human rights are only claimed when they are absent.

Limitations

This study offered a consideration of dignity in community nursing from the perspective of nurses and older adult patients in a city in northern England. However, there are limitations to the study that require acknowledgement.

The study purposefully excluded the experiences of people living in residential care homes, those aged under 60 and non-English speakers. Therefore, the voices of these community nursing consumers have not been considered. Older adults are not a homogenous group, and thus future research into these populations that were excluded from this study could offer greater insight into perspectives of a wider range of older adults.

Another potential limitation is that fieldwork occurred within a community nursing team in which all staff members were female. This ensured there was no opportunity to recruit any male nurse-participants. Nursing is a gendered profession, dominated by women, but due to this study’s gender-sample of nurses, the voices of male nurses remained unheard.

Access to patient-participants was gained via the community nurses themselves, and thus the sample selected for inclusion was not directly under my own control. Whilst the voices of nurses remain strong, there are times in this ethnography when there are some silences from older adults themselves, which I believe to be a consequence of the study’s design. The design of the study meant that although I spent many hours with community nurses, direct contact with their patients was less frequent and more short-lived, as my ethical approval only entitled me to access the older adults when attending to observe an appointment with the nurse, or for one pre-arranged interview. This severely limited my contact with older adults to ascertain their views.

Recommendations

This study identified a range of matters that are worthy of further consideration and reflection. Recommendations have been made for future research, including suggestions of how to develop important issues identified by this study. As nursing care is delivered in a broad socio-political context in which policymakers assume responsibility for the strategic direction of dignity in care, recommendations have been noted to aid future policy directives. Despite these structural influences over nursing practice, at an individual level, nurses can work in ways that enhance their patient’s dignity and these have been noted in the recommendations for practice, which also incorporates a consideration of how findings from this study can be applied to enhance safeguarding practice. Further recommendations relate to education and training, both for pre-registration student nurses, and also the continuous professional development and continuing education of registered nurses and other staff practice-based staff.

Research recommendations

The first recommendation is a somewhat generic request for further exploration into the experiences of older adults, who remain a population under-represented in empirical research, including research from health and the social sciences. The relative invisibility of older adults participating in research requires addressing through the academic community recognising the important contribution their voices can bring to our understanding, not just of healthcare, but of other social issues that affect society more generally. More specifically, within this study, ageism was identified as a threat to dignity, and, thus, further consideration of the threats posed by ageism could contribute to reducing the discrimination experienced by this group.

Another recommendation is that nursing care within the home, or even more broadly, the geographies of dignity, remain worthy of further study. The experiences of hospital patients and people living in care homes remain more widely studied than the experiences of patients receiving care in their homes, and for this reason, further knowledge about the complexities of care in this environment would be beneficial. Receiving care in one's own home makes people potentially more vulnerable to abuse, as the work is undertaken 'behind closed doors', often by lone-workers, free from the gaze of other professionals, increasing the likelihood of unwitnessed abuse in care, or unwitnessed delivery of poor care. In particular, people that lack capacity to consent to their care, may be more vulnerable to dignity violations as they are less likely to be able to advocate for themselves, and thus, researching the experiences of these people would assist in the growing evidence base around safeguarding practice.

Although this study aimed to explore the dignity of older adults under the care of community nurses, an unanticipated finding was that older adult patients may be disrupting the dignity of their nurses. This is as an important finding, and further research on this matter could be used to benefit nurses and other healthcare professionals, where their narratives of dignity in the workplace are not widely explored in contemporary research. If further research specifically addressed staff dignity, further knowledge could be used to address essential dignity issues for nurses in practice, which may result in staff that feel valued and more effective, and reduce the likelihood of nurses leaving the profession, thus assisting with retention.

Recommendations for policymakers

Ensuring dignity in practice raises cultural and structural considerations that must be addressed by policymakers, who must begin to address broader social and cultural issues that influence patient dignity. Policymakers have a direct influence over important factors that contribute to patients having dignified experiences of healthcare. This includes not just the legislation under which health staff work, but also includes policy directives such as establishing staffing levels, developing training standards for nurses and producing guidance that enhances dignity.

Existing policy focuses on the responsibility of nurses to treat their patients with dignity, but, policy directives have not acknowledged the reciprocity of dignity that has been highlighted in this thesis. For nurses to deliver care with dignity, they need to experience their own dignity within their relationships with others – including their patients and their families, colleagues, managers and employers. Just as patients receiving care in the home are more susceptible to dignity violations than those receiving care under the clinical gaze of a ward, community nurses usually perform their duties as lone-workers and this increases their own vulnerability to dignity violations. As lone-workers they often have no colleagues to guide or support them in these scenarios. Policy should ensure that both individual nurses and their healthcare employers are empowered to ensure patients are aware that dignity is a reciprocal arrangement, and, they too, are expected to treat their nurse with dignity and respect.

Although policymakers espouse the rhetoric of the importance of dignity in care, the findings in this study indicate that current social policies based on austerity may not fully support a dignified approach. Policymakers should acknowledge that for healthcare to be dignified, a holistic approach is necessary, in which clinical tasks are not prioritised over ensuring a quality experience of care. Nurse-participants emphasised ‘quality and not quantity’ was most important to deliver care with dignity, and indeed, time-rich patients appreciate slower approaches to care, in which they are not viewed as a task, but are recognised as a whole person. Nurses are under increasing pressure to undertake high volumes of work, but this must not compromise quality aspects of their work. This requires recognition in policy directives so that healthcare employers ensure sufficient staffing levels are in place to ensure time is available to ensure the quality of care. Similarly, a key finding in this thesis was that, for older adults, receiving dignified nursing care requires time – dignity is something that cannot be hurried. The time that older adults imply is necessary for a ‘dignity encounter’ is often more time than nurses have been allocated to undertake the specific clinical task. Thus, genuine movement away from task-centred care to person-centred care requires an acknowledgement that ‘all leg dressings are not equal’ and that, although nurses may be undertaking the same task with multiple patients, certain individuals may require more time than others to ensure a ‘dignity encounter’. Until this is acknowledged in health policy, nurses will continue to work in challenging circumstances in which, on the one hand, they are expected to ensure patients' dignity, but in which, on the other hand, they are not allocated the time that patients indicate is necessary for them to experience a 'dignity encounter'.

Recommendations for practice and safeguarding implications

Practitioners operate within legislative and policy frameworks, that constrain and influence their practice. Whilst acknowledging these boundaries of care, at an individual level, there are some actions nurses can take to ensure their care is delivered with dignity to safeguard their patients.

It is recommended that nurses take a proactive approach to construct 'dignity encounters' with their patients. The power of kindness cannot be overstated as individual nurses can construct dignity through showing kindness to those they care for. Every contact with a patient has the potential to be a 'dignity encounter', yet conversely, also has the potential to destabilise or breach someone's dignity. Abuse and neglect can thrive in the space in which dignity in not present and therefore, through the construction of a 'dignity encounter', nurses can ensure their patients remain safeguarded. The creation of the 'dignity encounter' can also be assisted when individual nurses ensure their patients have access to relevant information before seeking consent to a treatment, as well as undertaking clinical tasks in line with patients' wishes, which may require modification or adaptation from standard practice. Older adults value their relationships with their nurses, and, thus, although individual patients are only one of many patients a nurse encounters during the day, the nurse must remain mindful that this may be the only contact her patient has for the day (or a week, or even longer). This provides a vital opportunity to reduce social isolation, to reinforce patients' self-esteem and indeed generate a 'dignity encounter'. Nurses are able to create effective working relationships with patients by adapting their own behaviours in accordance with cues from patients, and it is through these relationships that dignity can also be enhanced.

The study also noted the importance of creating ‘environments of dignity’ when care is delivered in the home. It is recommended that when nursing care is delivered in the home, this space cannot be utilised in the same manner as the space within a hospital or outpatient clinic. Ownership of the home remains firmly with patients, and community nurses must undertake their work as guests within the home, ensuring the patient remains in control of their environment. When clinical equipment, such as commodes, are identified to be helpful aids, nurses must remain mindful that patients may be reluctant to accept these artefacts as they may not be ready or willing to adjust to their changing biographies as a result of illness. This can lead to refusals, but, nurses must recognise that in future, patients may become more accepting of the artefacts and their changing care needs. Being able to advise patients on how to gentrify clinical artefacts may also assist in maintaining an environment of dignity.

As a result of this study there are not only recommendations for individual practitioners, but this has potential implications for safeguarding practice. Dignified healthcare is free from abuse or neglect, and therefore, if nurses successfully deliver care with dignity through creating a ‘dignity encounter’ and constructing a dignified environment in the home, it is less likely that patients will be encompassed within safeguarding services. The preventative safeguarding agenda, is often usurped by reactive approaches in which safeguarding is necessitated following allegations of abuse or neglect, highlighting Arendt’s (1958) views that human rights are only noted in their absence. As a contribution to the preventative safeguarding agenda, this study highlighted how nurses can ensure their patients remain outside the scope of safeguarding if they deliver care with dignity. Therefore, if practitioners are supported to deliver dignified care, less people may experience abuse at the hands of healthcare staff and there may follow a reduction in safeguarding referrals as a result of poor or abusive nursing care.

Recommendations for education and training

Nurse training is embedded in the medical model in which healing and clinical effectiveness are valued above other outcomes. As this study has shown, many older adults are less concerned with these medicalised approaches to care, but are more concerned with having dignity outcomes met, which are achieved through the relational aspects of care, as opposed to the medical model of clinical effectiveness. Therefore, a medicalised approach to care (favoured by nurses) may be at odds with older adults' desires for relational care. Dignity outcomes are more readily achievable for older adults when they are able to direct and modify their nurse's approaches to care – examples within this study have included slackening compression bandages and adapting the use of continence pads. Therefore, it is recommended that nurse training programmes begin to introduce theories and models that indicates clinical effectiveness is not necessarily a good measure of dignity outcomes, even though this evidence may conflict with the medical model.

Although the reciprocity of dignity should feature in patient/ nurse relationships, this thesis explored how nurses' dignity is, at times, violated by patients. This thesis identified frequent examples of patients treating nurses as sexualised objects, as all nurse-participants were able to identify examples of this, and how these breached their dignity. Although all of the nurse-participants were able to recall at least one such example, they unanimously agreed that they had never received any training on how to manage unwanted sexual attention from patients. Training on how to manage these circumstances remain absent from current training programmes, leaving pre- and post-registration nurses to manage these scenarios individually, without any formal instruction in approaches to use in this context. As this issue seems to be a unifying experience within the nursing profession, it is time that nurse training acknowledged and addressed this issue, rather than simply ignore it.

Many nurse-participants acknowledged that throughout the course of their career they had received some training on 'dignity and respect'. However, it is acknowledged that this training cannot teach the essential tacit knowledge that is learnt through the life-course in terms of being able to adapt to each individual patient and their standards. Creation of the 'dignity encounter' can be assisted by nurses adapting their relationship with each individual patient, but some nurse-participants expressed anxieties because the relational aspects of care were based on their own tacit personal knowledge, they felt unsure whether their reactions were the most appropriate method. This may be particularly pertinent for community nurses, who work in isolation from others, as they do not have the opportunity to regularly observe how their colleagues perform relational aspects of care. Although this cannot be readily resolved, it is recommended training offers more opportunities for reflection and discussion of tacit approaches to dignity, which may increase the skills and confidence of the workforce in this regard. In addition, mentoring and opportunities for shadowing may assist community nurses to witness and observe how their peers operate in the home environment.

One further recommendation is required for education and training regarding the relational aspects of care, which relates to authenticity. There are times that nurses undertake difficult conversations with their patients and families, most specifically when patients are nearing end of life, where treatments may be withdrawn or amended to refocus care towards creating a pain-free and dignified death. Despite nurses' experiences leading difficult conversations such as these, it is noteworthy that this study identified how nurses had difficulty engaging in authentic conversations with their patients regarding their body odours. Instead, nurses denied the presence of odour to create an (inauthentic) 'dignity encounter' - examples described earlier in this thesis include Nurse-Sapphire's denials of Antonia's necrotic leg odour and Nurse-Rina's denials of Michelle's bodily smells. Patients identified their own malodorous bodies as a threat to their dignity, but when they commented on the odour to nurses, the most common strategy was for nurses to deny the presence of malodour. Although nurse training and education may incorporate breaking bad news to people, this does not extend to explore how nurses can respond to scenarios such as these, where to minimise embarrassment and to reinforce dignity, nurses find it easier to simply deny smell, rather than acknowledge this might be an issue that is troubling their patient, and explore ways that this anxiety can be reduced or addressed. Therefore, through considering scenarios they may encounter in practice, nurse training could explore how a more authentic approach, which may involve difficult conversations, may enhance the dignified care of patients.

Concluding remarks

This thesis offers a contribution to contemporary understandings of dignity in the care of older adults receiving community nursing in their own homes. It enables a deeper contribution towards understanding the lived experiences of older adults and moves away from bioethical views of dignity to provide a sociological perspective of dignity in healthcare by exploring micro-dignities, micro-powers and micro-disruptions to dignity. As the research was conducted by undertaking fieldwork in a community district nursing team, it offers a rare evaluation of dignity in nursing outside the hospital environment, in the home.

Nurses and patients construct dignity in their relationships and interactions with each other. Within community nursing encounters, dignity can be enhanced or, indeed, undermined. Dignity is, though, entirely subjective. Individuals experience dignity differently, and individuals display dignity to others in many different ways. It is when individual nurses and patients jointly enact mutually acceptable behaviours that dignity can be supported and maintained. This is operationalised through tacit knowledge, remaining neither spoken nor formally negotiated. It is the enactment of shared values, behaviours or standards that enable dignity to be experienced. When the beliefs of patients and nurses vary in terms of how dignity manifests itself, there is a mismatch in expectations, and this provides an important condition for a dignity violation to occur.

In an age of austerity, it might be argued that we are entering into a post-dignity society. Although government rhetoric espouses the importance of dignity, NICE guidelines recognise dignity as a quality indicator (NICE, 2012), implying this is a desirable extra rather than a baseline level of care. In contrast, for the older adults who participated in this study, dignity was not a desirable extra – it remained central to their encounters with nurses. The presence of dignity for the older adults in this study was dependent on their relationship with nurses, on the manner in which these professionals engaged with their bodies, and on the way space and time impacted on their nursing care within the home. If these aspects are managed effectively, dignity can thrive in daily encounters between nurses and patients.

Through this exploration into the mundane, day-to-day aspects of relationships in practice and dignity in action, the study has highlighted that dignity continues to remain a fundamental concern for community nurses and older adults in the UK.

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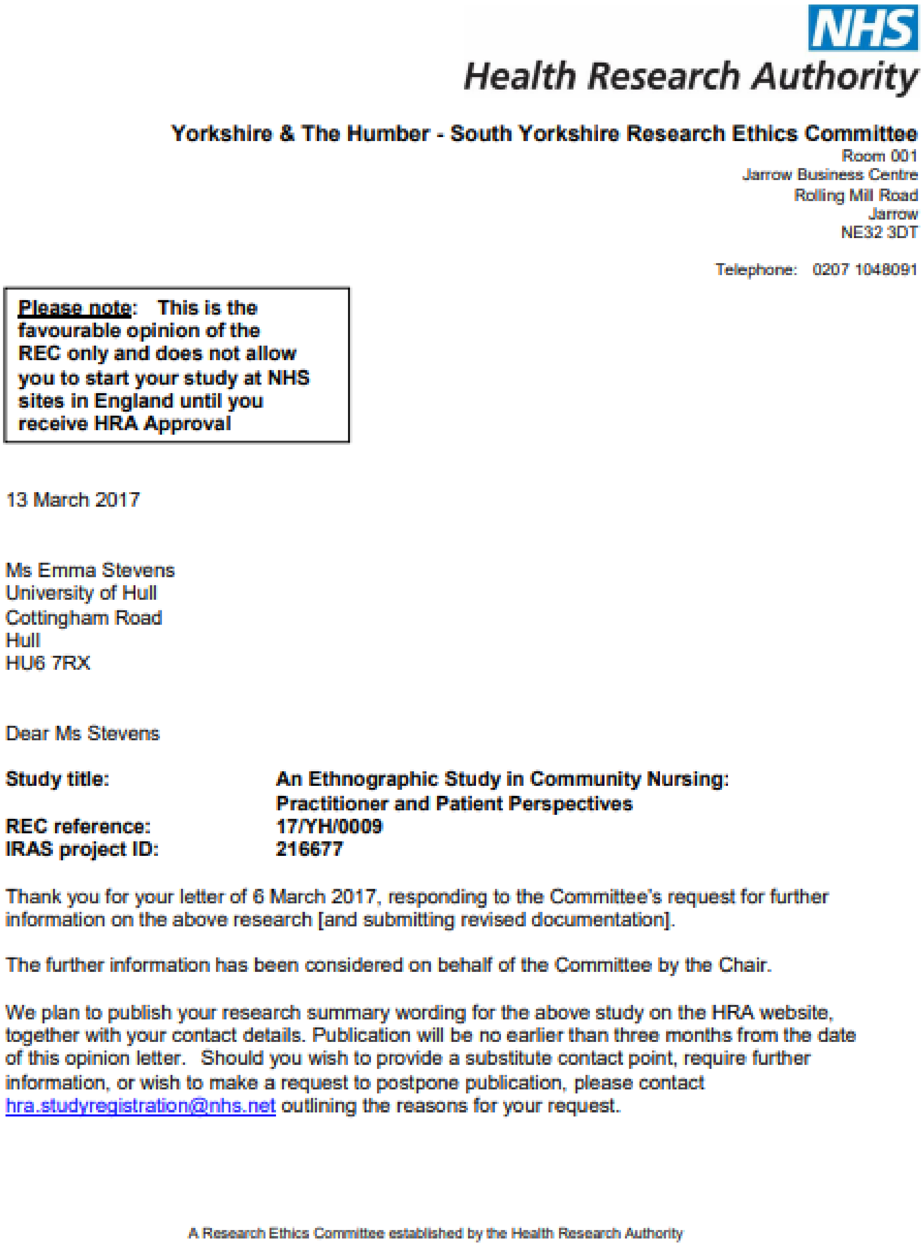
Appendix A: Ethical Approvals

A1: NHS REC Ethics Approval Confirmation



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Telephone: 0207 1048091

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

13 March 2017

Ms Emma Stevens
University of Hull
Cottingham Road
Hull
HU6 7RX

Dear Ms Stevens

Study title:	**An Ethnographic Study in Community Nursing: Practitioner and Patient Perspectives**
REC reference:	**17/YH/0009**
IRAS project ID:	**216677**

Thank you for your letter of 6 March 2017, responding to the Committee's request for further information on the above research [and submitting revised documentation].

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

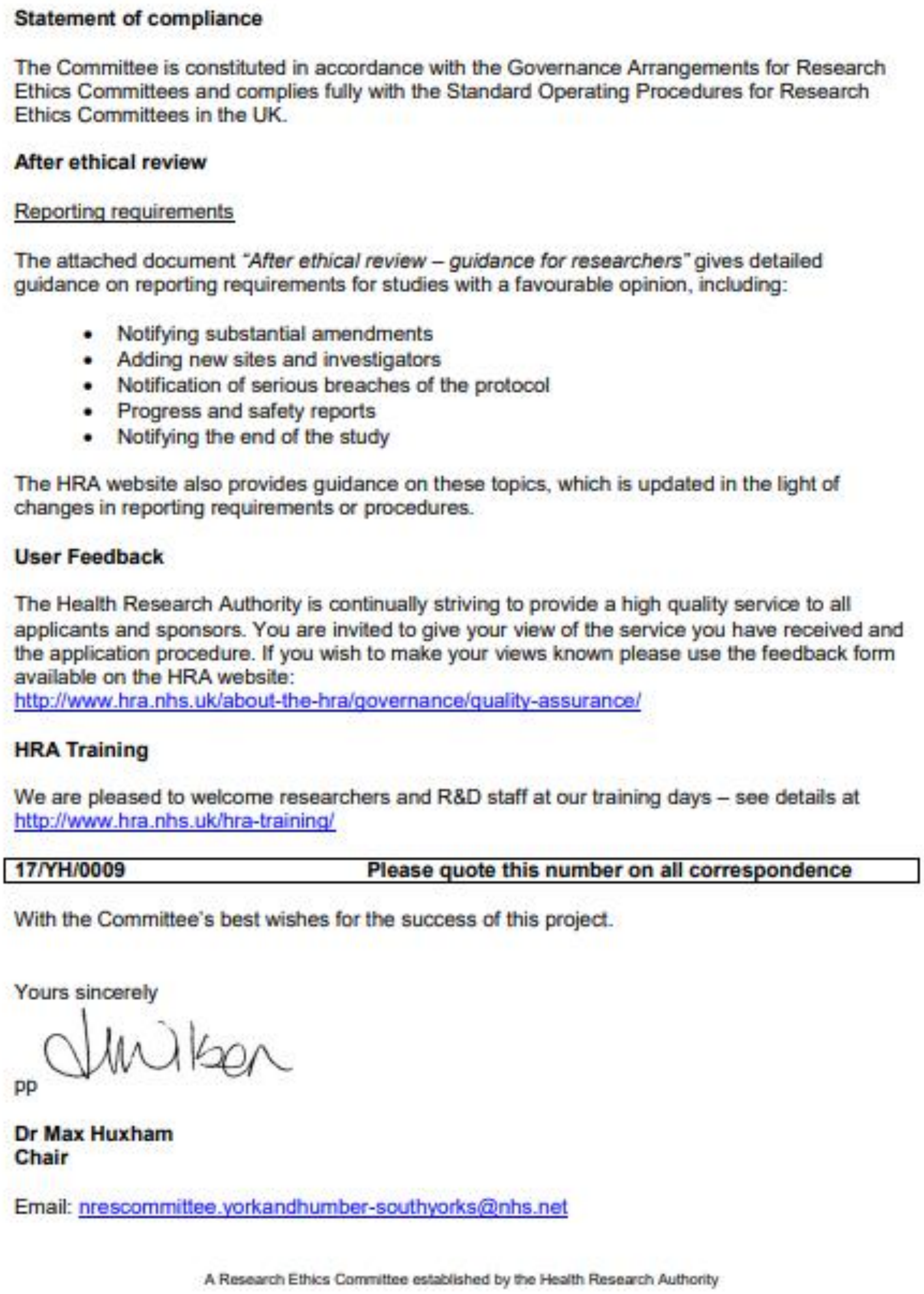
NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		07 September 2016
Interview schedules or topic guides for participants [Interview Schedules: Staff and Patients]	1	02 November 2016
IRAS Application Form [IRAS_Form_06032017]		06 March 2017
IRAS Checklist XML [Checklist_06032017]		06 March 2017
Other [CV - LW - 2nd supervisor]		02 November 2016
Other [Consent form 2A; patient observation]	1	21 November 2016
Other [Consent form 2B: Patient Interview]	1	21 November 2016
Other [Form 3: Consent and Confidentiality: Supporters]	1	21 November 2016
Other [Flowchart B: Patient Consent to Interview]	1	02 November 2016
Other [Response to unfavourable opinion letter]	1	21 November 2016
Other [Risk Assessment]	1	02 November 2016
Other [Data Management Plan]	1	09 June 2016
Other [Patient PIL]	2	26 February 2017
Other [Letter of Thanks]	1	21 November 2016
Other [Letter of Introduction (Patients)]	1	26 February 2017
Other [Letter of Introduction (Staff)]	1	26 February 2017
Other [Observation Template]	1	26 February 2017
Other [Letter to South Yorks REC]	1	26 February 2017
Participant consent form [Form 1: Staff Consent Form]	1	21 November 2016
Participant information sheet (PIS) [Staff Participant Information Leaflet]	2	26 February 2017
Research protocol or project proposal [Protocol]	1	21 November 2016
Summary CV for Chief Investigator (CI) [CV: ES]		02 November 2016
Summary CV for supervisor (student research) [CV - LP]		01 November 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flowchart A: Patient Consent to Observation]	1	02 November 2016



Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/YH/0009 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

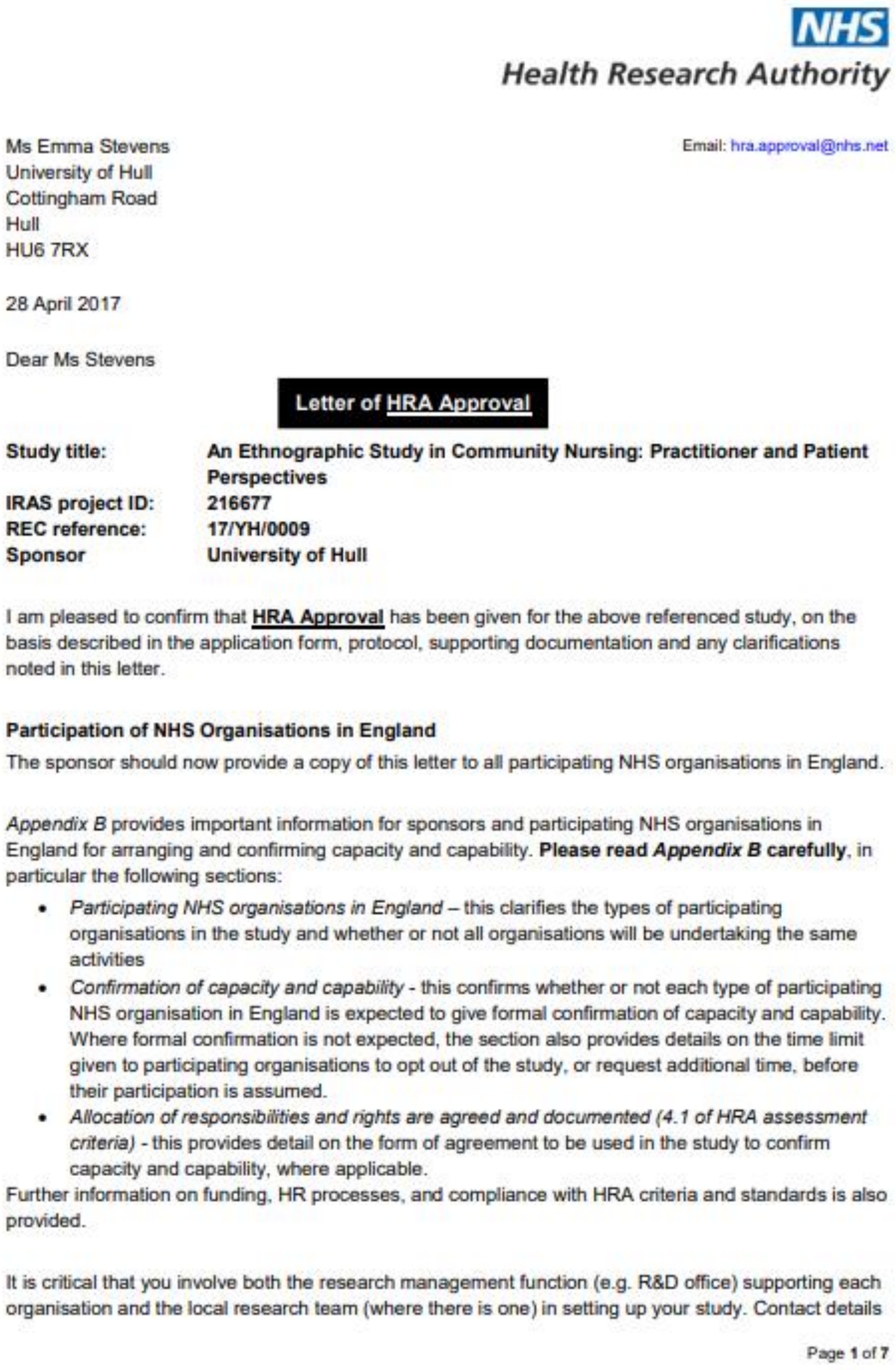
Yours sincerely

pp

Dr Max Huxham
Chair

Email: nrescommittee.yorkandhumber-southyorks@nhs.net

A2: HRA Ethical Approval Confirmation



NHS
Health Research Authority

Ms Emma Stevens
University of Hull
Cottingham Road
Hull
HU6 7RX

Email: hra.approval@nhs.net

28 April 2017

Dear Ms Stevens

Letter of HRA Approval

Study title:	**An Ethnographic Study in Community Nursing: Practitioner and Patient Perspectives**
IRAS project ID:	**216677**
REC reference:	**17/YH/0009**
Sponsor	**University of Hull**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **216677**. Please quote this on all correspondence.

Yours sincerely

Michael Higgs
Assessor
Email: hra.approval@nhs.net

Copy to: *Mr Andrew Taylor, University of Hull [Sponsor contact]*
Mrs Sue Pender, City Health Care Partnership CIC [Lead NHS R&D]

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Ms Emma Stevens
Email: e.stevens@2015.hull.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	Non-substantial amendments were made to participant information following REC review, in order to align with standards for HRA Approval.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A Statement of Activities and Schedule of Events have been provided for use with participating NHS organisations in England.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study

Section	HRA Assessment Criteria	Compliant with Standards	Comments
4.3	Financial arrangements assessed	Yes	No application for external funding has been made.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	The study received a favourable ethical opinion from the Yorkshire & The Humber - South Yorkshire Research Ethics Committee on 13 March 2017.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is a single type of participating NHS organisation, i.e. all sites are full research sites, at which research activities as described in the protocol and IRAS form will be conducted.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research**.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A Local Collaborator should be in place at each participating NHS organisation in England and a suitable individual has been identified for the sole participating site.

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

University researchers would be expected to obtain from participating NHS organisations a Letter of Access based on standard DBS checks and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix B: PPIL/SPIL

Appendix B1: PPIL

Letter of Introduction to Patients 04/05/17: Version 1.1

UNIVERSITY OF Hull

Faculty of Arts, Culture and Education

University of Hull,
Cottingham Road,
Hull HU6 7RX

July 2017

Dear Sir or Madam,

My name is Emma. I am a student at Hull University and a qualified social worker. I am studying for a Doctorate by doing a social study of community nursing and patient relationships. This looks at how patients and community nurses get on together, and how community nursing teams work with their patients. At the end of the study I will write up my findings. I hope that this will help health and social care teams learn more about how community nursing can make people’s lives better.

I am writing to ask if you will take part in my study. If you agree I will come out with your nurse on a number of visits and observe what happens. Your dignity and privacy is also very important. If your nurse is doing something private or personal I shall not stay. Confidentiality is assured and I will not have access to your health records.

If you agree, I will attend visits with your nurse for up to 12 weeks. You can ask me to leave or stop visiting at any time. As part of my study I also hope to interview you about your experiences of being looked after by community nurses. I would like to record our conversation so I can write it up later.

The study has been approved by both the University of Hull and an NHS ethics committee.

I have attached a leaflet with more detailed information about my study. Please get in touch if you have any questions or would like more information. If you feel able to help, please tell your community nurse when they visit.

Yours sincerely,

Emma Stevens

PhD student in Sociology & Social Anthropology

Email: E.Stevens@2015.hull.ac.uk
Tel: 07818211744

UNIVERSITY OF Hull

Participant Information Leaflet (Patients)

04/05/17: Version 2.2

Study Title: An Ethnographic Study in Community Nursing: Practitioner and Patient Perspectives

Name of Researcher: Emma Stevens

What is the purpose of the study?

This is a student research project for the award of PhD. The study aims to understand more about the care practices of the community nursing team when working with patients aged over 60. This will be achieved by observing community nursing practice and interviewing up to 24 people (12 staff and 12 patients) about their experiences. This will provide an insight into ‘the way things are done in community nursing’.

Why have I been chosen?

A researcher is observing a staff member that delivers your care. You have been chosen because you:

- Are aged over 60
- Are under the care of the community nursing team
- Do not live in residential care
- Understand English

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, the researcher will ask you to sign a consent form. You can withdraw at any time without giving a reason and this will not affect your care and treatment in any way. If you decide to withdraw, I shall use the data I have collected up to this point, but shall not collect any further information, nor make any further contact with you.

What will happen if I do take part?

- If you consent, the researcher shall attend a pre-arranged appointment with your nurse and ask you to sign a consent form.
- The researcher will observe future appointments you have with your nurse (up to a maximum of 12 weeks).
- Towards the end of this period, the researcher will ask if you would like to be interviewed about your experiences of community nursing.
- If you agree, the researcher will interview you for approximately one hour about your experiences of community nursing care. The interview will be held at a prearranged date, time and location that suits you.
- Before deciding whether to take part, if you have any questions or want any more details, please contact the researcher, Emma Stevens – tel: 07818211744.

What is being recorded?

The researcher shall record notes based on what she has observed. These notes do not contain any medical information or personal identifiable information and they are anonymised, so that no-one can be identified from them. You can see the observation template attached to this leaflet, which describes the content of the observations between you and your community nurse.

An audio recorder will be used to record the interview. This will be transcribed and anonymity will be ensured – so, for example, if you refer to your nurse by name, their name shall be removed from the transcript. Medical records and care plans are not being examined.

What are the possible disadvantages and risks of taking part?

A disadvantage is that you will have another person present at your appointments. If you agree to being interviewed about your experiences of community nursing care, you may discuss distressing or sensitive issues. If you become upset, we can stop the interview and you can be signposted to sources of support should you wish.

What are the possible benefits of taking part?

There are no direct benefits to taking part. However, you will be part of a research project that aims to contribute to the wider understanding of people's experiences of community nursing services and this may benefit others in the future.

What if there is a safeguarding issue?

Sometimes researchers may witness unsafe practice or someone may disclose harm or abuse. The researcher is a registered social worker and is bound by a professional code and therefore she will need to take action if she saw or was told about dangerous or unsafe behaviours that may place people at risk, which involves following local safeguarding policies and procedures.

Complaints

If you have concerns about any aspect of the study, please initially speak to the researcher, Emma Stevens. Alternatively you could speak to the project supervisor at the University of Hull: Dr Liz Price, Tel: 01482 463362, e.price@hull.ac.uk. Alternatively, you can raise a formal complaint via:

Customer Care Advisor, City Healthcare Partnership CIC, 5 Beacon Way, Hull, HU3 4AE Tel: 01482 347627. Email: chcp.customercare@nhs.net

Jeanette Strachan – University of Hull Registrar (complaints) Tel: 01482 465136. Email: registrar@hull.ac.uk

Harm

In the event that something does go wrong and you feel that you have been harmed by the study there are no special compensation arrangements. If this harm is due to the researcher's negligence then you may have grounds for a legal action for compensation against the University of Hull, but you may have to pay for your legal costs. Professional complaints procedures are also open to you.

Will my taking part in the study be kept confidential?

All information that is collected about you during the research will remain confidential, unless a safeguarding concern meant that confidentiality would need to be breached. Observational data will be recorded as anonymised notes and interview data will be recorded electronically and then transcribed. Data will be stored on a password-protected computer and lockable filing cabinet at the University. All material will anonymised, so that people are not identifiable by anyone other than the researcher. The researcher and her academic supervisors will have access to the data. We have a duty to you as a research participant and nothing that could reveal your identity will be disclosed outside of the research site. Anonymised data (including direct quotations) will be used for this study, possibly other future research, conference presentations and publications.

What will happen to the results of the research study?

The results of the research will initially be written up into a PhD thesis. The results may later be published or presented at conferences to disseminate the learning that you have helped acquire. You will not be identified in any publications and you can request a copy of the results at the end of the project. You can also keep up to date with the project by

looking at the website:
https: //emmalouisestevenswordpresscom.wordpress.com/

Who is organising and funding the research?
As a student study, the research is organised by the student (researcher) under the direct supervision of the University of Hull. It is funded through a University of Hull PhD Scholarship.

Will I be paid?
No. This is voluntary and there are no payments.

Do you have ethical approval?
Yes. Approval has been received from the University of Hull Faculty of Arts and Social Sciences 23/06/16 and Yorkshire and the Humber – South Yorkshire Research Ethics Committee 13/3/17 Ref: 17/YH/0009. IRAS ID: 21677. It has also been approved by the City Healthcare Partnership CIC Research and Development Committee.

If you have any questions about the study, please feel free to get in touch at any time now or during the study: Email: E.Stevens@2015.hull.ac.uk Further information on the research project
(including information leaflets and consent forms) can be found under 'research projects' at:
https: //emmalouisestevenswordpresscom.wordpress.com/

Appendix B2: SPIL

Letter of Introduction to Staff 04/05/17: Version 1.1

Faculty of Arts, Culture and Education
University of Hull,
Cottingham Road,
Hull HU6 7RX

July 2017

Dear Staff Member,

My name is Emma. I am a student at Hull University and a qualified social worker. I am studying for a Doctorate by doing a social study of community nursing and patient relationships. This looks at how patients and community nurses get on together and how community nursing teams work with their patients. At the end of the study I will write up my findings and I hope that this will help health and social care teams learn more about how community nursing can make people’s lives better.

I am writing to ask if you would like to be involved in my study. If you agree, I would like you to invite some of your patients (aged over 60) if they would also be willing to be involved. I have some leaflets that you can give them with more information. If you and you patient agrees, I would like to come out on a number of visits and observe the way things happen. Your patient’s dignity and privacy is also very important and I shall leave if you are delivering intimate care or if it would be insensitive for me to stay. Confidentiality is assured and I will not have access to any health records.

You and your patients can decide how many visits you will allow me to observe, but I am doing fieldwork for 12 weeks, so it will not be longer than this. You or your patient can ask me to leave or stop visiting at any time. As part of my study I also hope to interview you about your experiences of working in the community nursing team. I would like to record the interview so that I can write it up later.

The study has been approved by both the University of Hull and an NHS ethics committee.

I have attached a leaflet with more detailed information about my study. Please get in touch if you have any questions or would like more information. If you feel able to help, please make contact with me.

Yours sincerely,

Emma Stevens

PhD student in Sociology & Social Anthropology
Email: E.Stevens@2015.hull.ac.uk
Tel: 07818211744

Participant Information Leaflet (Staff)

04/05/17: Version 2.2

Study Title: An Ethnographic Study in Community Nursing: Practitioner and Patient Perspectives

Name of Researcher: Emma Stevens

What is the purpose of the study?

This is a student research project for the award of PhD. The study aims to understand more about the care practices of the community nursing team when working with patients aged over 60. This will be achieved by observing community nursing practice and interviewing up to 24 people (12 staff and 12 patients) about their experiences to provide an insight into 'the way things are done in community nursing'.

Why have I been chosen?

Your team has been chosen as a good place in which to study this. The study explores staff and patients (aged over 60) experiences and perspectives of community nursing care practices. The research will last 14 weeks and the researcher would like to observe up to 12 staff members delivering care to patients aged over 60 and then interview them about their experiences.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be asked to sign a consent form. You can withdraw at any time without giving a reason and this will not affect your employment rights in any way. If you have any questions before making your decision, you can contact the researcher on: 07818211744.

What will happen if I do take part?

Patient Observations: The researcher will be located within the team for 14 weeks and you can decide the length of time you are willing to be involved - you could invite her to attend only one appointment, or you may decide to work with her for a period of a few weeks. If you agree to participate, initially you will need to give your patients the participant information leaflet (you will be supplied with these) and then allow them a period of time (no less than 24 hours) to consider. On your next appointment, please ask your patient if they have read and understood the leaflet and if they will allow the researcher to attend the next appointment. If they agree, the researcher shall attend the next visit and seek consent (or refusal) from them for future participation. If the patient has any questions about the study, the researcher will answer these. This may potentially slow you down, but she will remain mindful that you have numerous appointments to keep. The researcher is there to observe what you do but she cannot assist with any clinical tasks and you or your patient can ask her to leave at any time.

Interviews: Twelve staff members will also be invited to be interviewed about their experiences of delivering community nursing care. The interview is likely to be about an hour and will be arranged at a time and place to suit you. You are not expected to make any extra journeys, nor to spend any extra time at work in order to participate.

What is being recorded?

The researcher shall record fieldnotes based on what she has observed – an observation template has been attached so you can see what is being recorded. These are not clinical notes and they do not contain any medical information or personal identifiable information. They will be written anonymously so that no-one can be identified from them.

An audio recorder will be used to record interview data, which will then be transcribed and anonymity will be ensured – so, for example, if you accidentally refer to a patient by name, their name shall be removed from the transcript.

Medical records and care plans are not being examined.

What are the possible disadvantages and risks of taking part?

A disadvantage is that you will need to give your patients the information leaflet and later gain verbal consent for the researcher to observe you, which may slow you down. You will also have the researcher attend your visits and she may want to ask you questions or discuss events with you, but she will not obstruct your work. If sensitive issues arise during our interview you will be signposted to sources of support.

What are the possible benefits of taking part?

There are no direct benefits to you taking part. However, you will gain experience of being involved in a research project and you may find it helpful and enjoyable to talk about your work. The study hopes to contribute to the wider understanding of care practices in community nursing so it may benefit others in the future.

What if there is a safeguarding issue?

Sometimes researchers may witness unsafe practice. The researcher is a registered social worker and is bound by a professional code and therefore she would need to take action if she witnessed or was told about dangerous or unsafe behaviours that may place people at risk. This involves following local safeguarding policies and procedures.

Complaints

If you have any concern about any aspect of the study, please initially speak to Emma Stevens. Alternatively, you could speak to the project supervisor at the University of Hull: Dr Liz Price, Tel: 01482 463362, e.price@hull.ac.uk. Alternatively, you can raise a formal complaint via:

Customer Care Advisor, City Healthcare Partnership CIC, 5 Beacon
Way, Hull, HU3 4AE Tel: 01482 347627. Email:
chcp.customercare@nhs.net

Jeanette Strachan – University Registrar (complaints)
Tel: 01482 465136. Email: registrar@hull.ac.uk

Harm

In the event that something does go wrong and you feel that you have been harmed by the study there are no special compensation arrangements. If this harm is due to the researcher's negligence then you may have grounds for a legal action for compensation against the University of Hull, but you may have to pay for your legal costs. Professional complaints procedures are also be open to you.

Will my taking part in the study be kept confidential?

All information that is collected about you during the research will be kept strictly confidential. Observational data will be recorded as fieldnotes and interview data will be recorded electronically and then transcribed. Data shall be stored on a password-protected computer and lockable filing cabinet at the University of Hull. All material will be anonymised, so that people are not identifiable by anyone other than the researcher. The researcher and her academic supervisors will have access to the data. We have a duty to you as a research participant and nothing that could reveal your identity will be disclosed outside of the research site. Anonymised data (including direct quotations) will be used for this study, possibly other future research, conference presentations and publications.

What will happen to the results of the research study?

The results of the research will initially be written up into a PhD thesis. The results may later be published or presented at conferences to disseminate the learning that you have helped acquire. You will not be identified in any publications and you can request a copy of the results at the end of the project. You can also keep up to date with the project by looking at the website: https: //emmalouisestevenswordpresscom.wordpress.com/

Who is organising and funding the research?

As a student study, the research is organised by the student (researcher) under the direct supervision of the University of Hull. It is funded through a University of Hull PhD Scholarship.

Will I be paid?

No. This is voluntary and there are no payments.

Do you have ethical approval?

Yes. Approval has been received from the University of Hull Faculty of Arts and Social Sciences 23/06/16 and Yorkshire and the Humber – South Yorkshire Research Ethics Committee 13/3/17 Ref: 17/YH/0009. IRAS ID: 21677. It has also been approved by the City Healthcare Partnership CIC Research and Development Committee.

If you have any questions about the study, please feel free to get in touch at any time now or during the study: Email: E.Stevens@2015.hull.ac.uk. Further information on the research project (including information leaflets and consent forms) can be found under ‘research projects’ at: https: //emmalouisestevenswordpresscom.wordpress.com/

Appendix C: Consent Forms

Appendix C1: Staff Consent

Version 1.2: 04/05/17 IRAS Project ID: 21677

UNIVERSITY OF Hull

OFFICE USE ONLY
Unique Participant Ref:

Project title: An Ethnographic Study of Community Nursing: Practitioner and Patient Perspectives.

Name of researcher: Emma Stevens Please initial boxes to consent.

	I confirm that I have read and understand the staff information sheet V2.2 for the above study.
	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I understand the benefits and risks of participating.
	I understand that the information collected about me may be used to support other research, conference presentations and publications in the future and it may be stored anonymously for re-use.
	I consent to the researcher observing, without undue interference and judgement, aspects of my work, including patient appointments (subject to their prior consent), meetings and training in which I participate. I consent to this for the duration of the project.
	I agree to distribute participant information leaflets to appropriate patients and then at a subsequent appointment, seek their verbal consent to be observed.
	I agree to be interviewed by the researcher at a time and day to be agreed in advance.
	I agree to the use of electronic recording equipment for the purpose of the accurate recording of interview data.
	I agree to the use and publication of anonymised direct quotations.
	I understand that everything that I say will be confidential unless I say something which might harm me or someone else. Should this arise, local safeguarding policies will be followed to ensure people are kept safe.
	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without it affecting my legal or employment rights. If I decide to withdraw, I understand you shall use the data you have collected up to this point, but you shall not collect any further information, nor make any further contact with me.

Name of Participant ..……………………………………………………….………………
Signature: ………………………………………………….....Date: ……………………..
Name of person taking consent ……………………………………….………………..
Signature: …………………………………………………… Date: …………..…………

When completed, one copy given to participant, one copy retained by researcher.

Appendix C2: Patient Consent to Observation

Version 1.2: 04/05/17 IRAS Project ID: 21677

UNIVERSITY OF Hull

OFFICE USE ONLY
Unique Participant Ref:

Project title: An Ethnographic Study of Community Nursing: Practitioner and Patient Perspectives.

Name of researcher: Emma Stevens Please initial boxes to consent.

	I confirm that I have read and understand the patient information sheet V2.2 for the above study.
	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I understand the benefits and risks of participating.
	I understand that the information collected about me may be used to support other research, conference presentations and publications in the future and it may be stored anonymously for re-use.
	I consent to the researcher observing, without undue interference and judgement, aspects of care delivered by the community nursing team, but I can ask her to leave at any time.
	I agree the researcher can invite me to be interviewed at a later date (no longer than 12 weeks time) and if I agree, we will arrange a date and time in advance.
	I agree to the use and publication of anonymised direct quotations.
	I understand that everything that I say will be confidential unless I say something which might harm me or someone else. Should this arise, local safeguarding policies will be followed to ensure people are safe.
	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without it affecting my medical care or legal rights. If I decide to withdraw, I understand you shall use the data you have collected up to this point, but you shall not collect any further information, nor make any further contact with me.
	I agree to take part in the above study

Name of Participant ..……………………………………………………….………………
Signature: ……………………………………………….....Date: ……….……………..
Name of person taking consent ………………………………………..………………..
Signature: …………………………………………………. Date: …………..…..……….

When completed, one copy given to participant, one copy retained by researcher, copy on patient record.

Appendix C3: Supporter Consent/ Confidentiality Form

Version 1.2: 04/05/17 IRAS Project ID: 21677

UNIVERSITY OF Hull

OFFICE USE ONLY
Unique Participant Ref:

Project title: An Ethnographic Study of Community Nursing: Practitioner and Patient Perspectives.

Name of researcher: Emma Stevens Please initial boxes to consent.

	I confirm that I have read and understand the patient information sheet V2.2 for the above study.
	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I understand the benefits and risks of participating.
	I agree to being observed by the researcher when she undertakes visits with a member of the community nursing team and I may offer support to my friend/ family member when they are interviewed by the researcher.
	I understand that observational and interview data may be used to support other research, conference presentations and publications in the future and it may be stored anonymously for re-use.
	I agree to the use of electronic recording equipment for the purpose of the accurate recording of interview data.
	I agree to the use and publication of anonymised direct quotations.
	I understand that everything that I say will be confidential unless I say something which might harm me or someone else. Should this arise, local safeguarding policies will be followed to ensure people are kept safe.
	I agree to retain the participant’s confidentiality and I shall not discuss the contents of the interview with any other person, other than the participant.
	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
	I agree to take part in the above study.

Name of Supporter ..…………………………………………………….………………….
Signature: ………………………………………………….....Date: ……..……………….
Name of person taking consent ……………………………………….………………..
Signature: ………………………………………………… Date: ……………………….

When completed, one copy given to participant, one copy retained by researcher.

Appendix C4: Patient Consent to Interview

Version 1.2: 04/05/17 IRAS Project ID: 21677

UNIVERSITY OF Hull

OFFICE USE ONLY
Unique Participant Ref:

Project title: An Ethnographic Study of Community Nursing: Practitioner and Patient Perspectives.

Name of researcher: Emma Stevens Please initial boxes to consent.

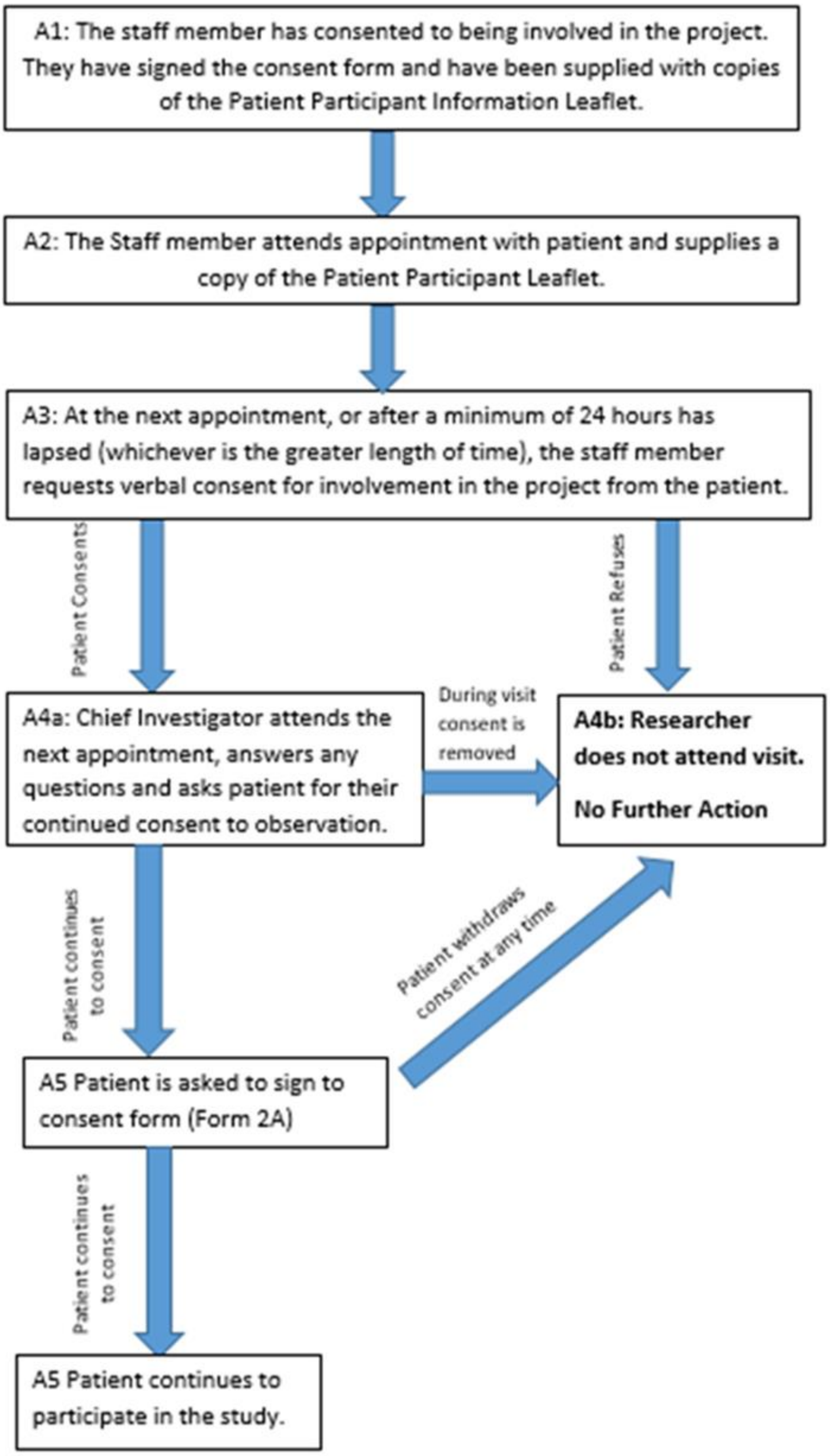
	I confirm that I have read and understand the patient information sheet V2.2 for the above study.
	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I understand the benefits and risks of participating.
	I understand that the information collected about me may be used to support other research, conference presentations and publications in the future and it may be stored anonymously for re-use.
	I agree to be interviewed by the researcher.
	I agree to the use of electronic recording equipment for the purpose of the accurate recording of interview data.
	I agree to the use and publication of anonymised direct quotations.
	I understand that everything that I say will be confidential unless I say something which might harm me or someone else. Should this arise, local safeguarding policies will be followed to ensure people are kept safe.
	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without it affecting my medical care or legal rights. If I decide to withdraw, I understand you shall use the data you have collected up to this point, but you shall not collect any further information, nor make any further contact with me.
	I agree to take part in the above study.

Name of Participant ..…………………………………………………….………………
Signature: …………………………………………………....Date: …………………….……..
Name of person taking consent ……………………………………….………………..
Signature: ………………………………………………… Date: ……………………….

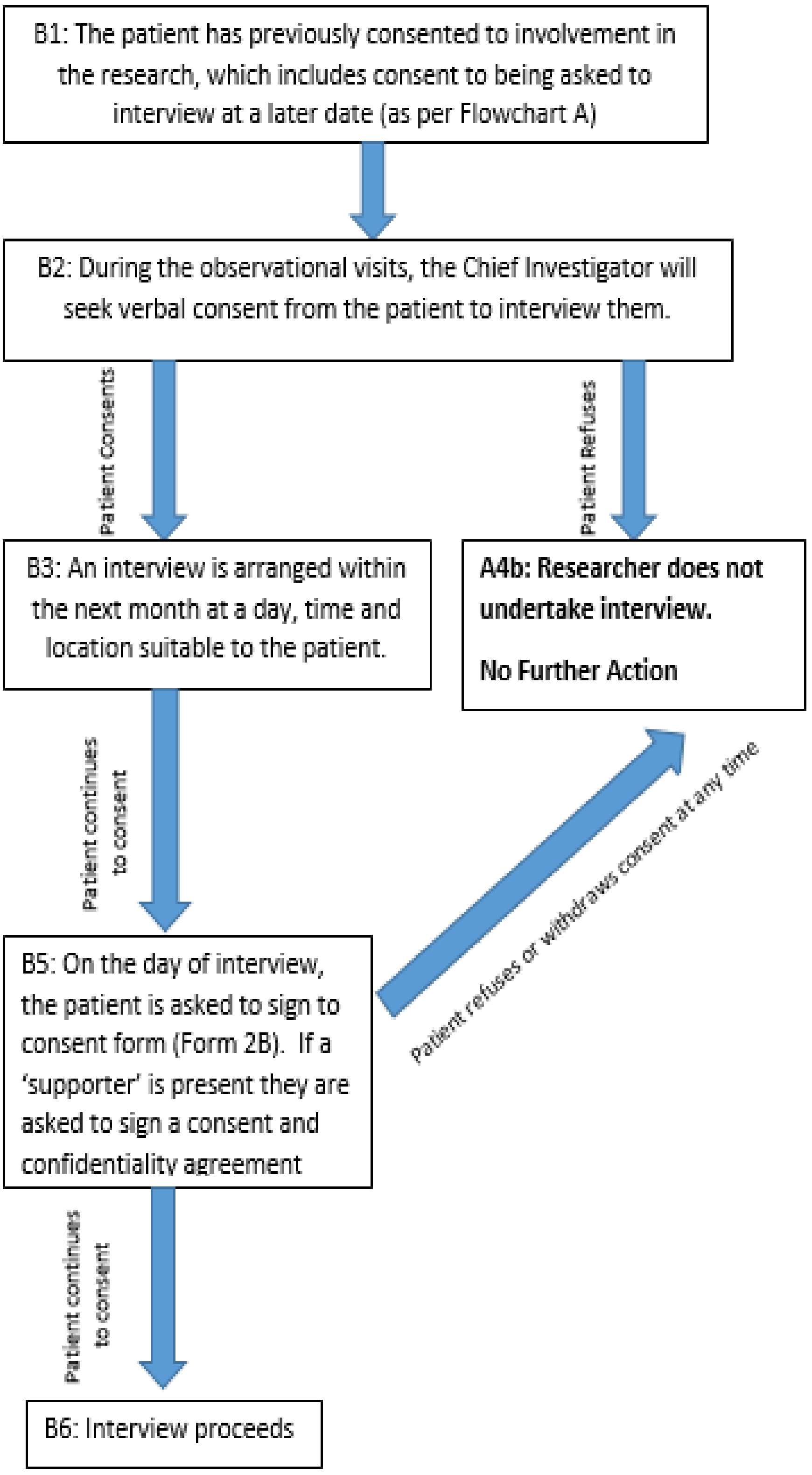
When completed, one copy given to participant, one copy retained by researcher, copy on patient record.

Appendix D: Consent Flowcharts

Flowchart A: Consent to observation



Flowchart B: Consent to interview



B1: The patient has previously consented to involvement in the research, which includes consent to being asked to interview at a later date (as per Flowchart A)

B2: During the observational visits, the Chief Investigator will seek verbal consent from the patient to interview them.

B3: An interview is arranged within the next month at a day, time and location suitable to the patient.

A4b: Researcher does not undertake interview.

No Further Action

B5: On the day of interview, the patient is asked to sign to consent form (Form 2B). If a 'supporter' is present they are asked to sign a consent and confidentiality agreement

B6: Interview proceeds

Appendix E: Interview Schedules

	STAFF	PATIENTS
1	What does good care look like to you? • Thinking about the good care that you have described, how does the care from the community nursing team fit this description? • What are the most important things to consider when giving good care to patients?	What does good care look like to you? • Thinking about the good care that you have described, how does the care from the community nursing team fit this description? • What are the most important things the nurses should consider when giving good care to you?
2	Tell me about a time you gave the best possible care to an older adult. • What was good about the care? • What enabled you to deliver this care? • Were there any problems/ challenges in delivering this care?	Tell me about a time you received the best possible care. • What was good about the care? • What enabled you to receive this care? • Were there any problems/ challenges in receiving this care?
3	Have care practices changed in nursing – do you have any examples?	Have care practices changed in nursing – do you have any examples of how care from the nurses has changed?
4	Dignity is said to be important in healthcare. What does dignity mean to you?	Dignity is said to be important in healthcare. What does dignity mean to you?
5	Do you think nurses can affect patients' dignity – how?	Do you think nurses can affect patients' dignity – how?
6	Do you think patients can affect nurses' dignity – how?	Do you think patients can affect nurses' dignity – how?
7	What are the consequences of having dignity (or not having dignity)?	What are the consequences of having dignity (or not having dignity)?
8	Have you been in any situations when you think your patient's dignity could have been lost? • What caused it to happen? • What effect did you, or other staff have on the situation?	Have you been in any situations with the nurses when you think your dignity was lost? • What caused it to happen?

	• Could you have done anything differently to help promote the patient’s dignity? Have you been in any situations with your patients when you think your dignity has been lost? • What caused it to happen? • What effect did you, or other people have on the situation? • Could you have done anything differently?	• What effect did you, or other people present have on the situation? • Would you now have done anything differently? Have you been in any situations when you think your nurse has lost her dignity? • What caused it to happen? • What effect did you, or other people have on the situation? • Could you have done anything differently?
9	What helps to promote your dignity? What helps to promote your patients' dignity?	What helps to promote your dignity? What helps to promote your nurses’ dignity?
10	Could anything more be done to promote dignity?	Could anything more be done to promote dignity?
11	Are there any factors about delivering care in the home that has an influence on dignity?	Are there any factors about receiving care in your home that has an influence on dignity?
12	How does dignity manifest in end of life care?	
13	Do you know of any laws, policies or anything else that supports dignity? How do these influence practice?	Do you know of any laws, policies or anything else that support dignity? How do these influence what the nurses do?
14	What do human rights mean to you?	What do human rights mean to you?
15	What do you think about the NHS? And that you now actually work for a social enterprise?	What do you think about the NHS?
16	Whilst I’ve been out observing you, I wonder if anything has happened in your work that relates to dignity?	Whilst I’ve been observing you, has anything happened that you think relates to dignity?
17	Is there anything else you would like to say about dignity?	Is there anything else you would like to say about dignity?
18	Finally, I have a few demographic questions: • Age?	Finally, I have a few demographic questions: • Age?

	• Ethnicity? • Length of time you have been a nurse? • Length of time doing this job? • Length of time working in the community?	• Ethnicity? • Length of time you have been under community nursing care?
19	Is there anything I’ve not asked, that you think I should have asked?	Is there anything I’ve not asked, that you think I should have asked?
20	Is there anything you would like to ask me?	Is there anything you would like to ask me?