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Compassionate Dementia Care: The Conceptualisations of Acute Hospital Nurses

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Compassionate Dementia Care: The Conceptualisations of Acute Hospital Nurses

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Declaration

Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.

I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

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The late Tom Kitwood has been the greatest inspiration in my work with people who are affected by dementia. I am grateful to him for the insight learned many years ago and never forgotten that ‘the self is shattered in dementia, the other is needed to hold the fragments together’. This rests with me as defining what compassionate dementia care is and where true suffering lies.

Chris Roberts has taught me more than anyone else ever could about the lived experience of dementia. He has shown me that people, like him, who are affected by dementia should never be defined in terms of ‘suffering’, they are still a person and should be seen as such, yet suffer they do, so do their families and those around them, and not all sit comfortably with the somewhat ubiquitous phrase ‘living well’. The emphasis must be ‘living with’.

Living with dementia includes the fear of the fragmentation of the sense of self which permeates every aspect of life. It is further jeopardised when that person comes into hospital. At such times suffering can become intense yet go unrecognised or, be denied. Over the last five years I have frequently asked myself, if compassion by itself cannot take away suffering, why then is it important for those who suffer and why does it deserve doctoral research attention?

In attempting to find answers to that and meaning in my endeavours I am grateful to my supervision team, Dr Sion Williams, Dr Jo Rycroft-Malone and Dr Carys Jones who have helped to shape my thinking and direction of travel.

I am grateful to all the nurse participants involved in this study who freely gave of their time to gather and open themselves to the Appreciative Inquiry process. I think that the findings which emerge are an honest reflection of their experience, thoughts and views. Some of those were not the same as held by me but I have faith in the redemptive properties of democratic social research and I acknowledge the overwhelming desire of these nurses to do good often under trying circumstances.

I am grateful to Dr Els Steeman of the Universiteit Ziekenhuis Gent, Belgium and, Cathy McHale of Tallaght University Hospital, Dublin. Both are fighting the good fight and I have found our conversations inspirational. Many of their notes on the progress of this thesis have been influential and ultimately have found their way into the spirit of the text.

Finally, the compassionate dementia care as set out in this thesis can never be a wholly practical endeavour. It is both spiritual and metaphysical and it involves giving something of oneself in service of the other. I am reminded of the quote from John Donne that emerged in one of the workshops, misquoted though it was, it, for me, encompasses the heart of this thesis;

'A candle lights others and consumes itself, yet is it far better to light the candle than to curse the darkness'

Dedication

To Annemieke and the boys, thanks for the time and space.

Abstract

Aims Compassion in general terms is regarded as one being sufficiently aware of the suffering of another that one is moved to alleviate that suffering. As a concept it is well rehearsed in the nursing literature but in the context of dementia care in the acute care setting that literature is lacking. This study aims to address that and sets out how acute hospital nurses conceptualise compassionate care for people affected by dementia.

Methods The methodological approach aimed for democratic research with Appreciative Inquiry as the specific method to facilitate the inclusion of nurse participants. Empirically the participants worked through a four stage model which had sufficient generative capacity to stimulate a normative discourse. Data derived from that discourse was subjected to a layered thematic analysis supported by Positioning theory and Functional Linguistics.

Results there were three conceptual findings. First, the practice of acute hospital nurses could be circumscribed by four relational themes within which the initial encounters between the nurses and people with dementia emerged as highly influential. Second, acute nurse's articulated a broad range of positions about people affected by dementia and, thirdly those positions facilitated identification of properties inherent to individual and collective concepts of compassionate dementia care. There were two methodological findings. First, Appreciative Inquiry functioned as an effective research methodology. Second, that Appreciative Inquiry had sufficient generative capacity to stimulate a normative discourse which acted to change previously held negative attitudes and beliefs about people affected by dementia.

In achieving these key findings an initial literature led and highly reflexive heuristic model was refined and strengthened to articulate six spaces of practice where compassionate dementia care could be positioned.

Conclusions a collective conceptualisation of compassionate dementia care distinct from compassionate nursing care was identified. The distinction was related to the importance of personhood and the vulnerability of people with dementia to curate and express their own sense of self.

Personal Reflection

My nursing career has been significantly influenced by two serious service failures involving the in-patient care of people with dementia both of which have had an effect on my personal and professional beliefs and values and both of which have highlighted the absence of compassion from dementia care.

In 2002 I was a Clinical Nurse Specialist for early dementia in Manchester. I had been asked to devote sessional time to support a nurse development programme for an older persons mental health ward. During a group supervision session for registered nurses on Rowan ward allegations of abuse of patients with dementia were made. Those initial allegations encompassed physical abuse that included hitting, slapping, stamping, thumb twisting and denial of food and; psychological abuse that included intimidatory language and playing on known anxieties and fears of patients.

I was the facilitator of that session and immediately escalated those allegations to the responsible director. Following actions to ensure an immediate safe environment, Rowan ward was subject to external investigation by the Commission for Health Improvement and Greater Manchester Police. The ward was closed and patients moved to another unit. Amidst a storm of media attention and hostility from families the Mental Health Trust concerned underwent a significant loss of legitimacy as a responsible service provider.

By 2013 I was Consultant Nurse for dementia working across North Wales with a specific remit to promote and improve the quality of dementia care in acute and community hospitals. I was recalled by the Associate Chief of Staff (Nursing) for the mental health division to advise the senior management team following a whistleblower's accusations of physical and psychological abuse of patients with dementia on Tawel-Fan ward. The ensuing process mirrored that which had taken place for Rowan ward; the ward was closed, patients moved to another unit, external investigations (including police) occurred, there was hostility from families, intense media attention and again de-legitimation for the local health board concerned.

These two events are separated by a decade but are identical in their presentation. The Rowan ward abuse led to National attention, recommendations from the

Commission for Health Improvement and the standard calls that this should never be allowed to happen again, and yet Tawel Fan shows quite clearly that it did happen again. One could be forgiven for thinking that two events separated by more than ten years could not indicate more systemic failings in the National Health Service (NHS) however, numerous similar serious failures occurred during that time interval.

Each of those failures involved the abuse of vulnerable people dependent upon the care of those who carried out the abuse. Throughout each failure there was clear evidence that those delivering care had lost, or in some cases never possessed, compassion for those receiving care. Those staff engaging in what is now described as wilful neglect deliberately chose to ignore the suffering of others or, again only in some cases, took a perverse delight from it. Each failure was subject to safeguarding, to investigation, to remedial action, to media attention and each led to the dissemination of recommendations (across health and social care) to ensure that it would never happen again; and again, each time, it happened again.

Following the inquiry into failures in care at Mid-Staffordshire NHS Trust (Francis, 2013) there was intense soul searching within the NHS regarding the absence of compassion from care and, an overwhelming cacophony of voices condemning such service failings. Within this has been the now traditional call that 'this must never happen again' and yet it did happen again. On fourteen occasions since Mid-Staffs there has been the need for inquiry into the failings in care provided generally and in thirteen of those inquiries it is the care of vulnerable older people, many of whom have dementia, which is called into question.

Such failures offend my sense of what is right not only in relation to the professional practice of Nursing but in respect of relating to fellow human beings. Rowan ward caused me to question what may have been naïve assumptions about the caring professions whilst Tawel Fan brought out feelings of frustration, about the passivity of others that has to a large extent shaped this research project. My view has come to generally mirror that of (Butler & Drakeford 2005) who state that;

"Scandals do not just happen. They are made. They are constructed out of such everyday tragedies as the small carelessnesses and institutional brutality of the long stay hospital" (p2).

The large long stay hospitals and county asylums are consigned to history and it has been noted that the modern day flagships, the District General Hospitals, established to meet the health care needs of the 1960's are now becoming incapable of meeting 21st century demands (Dalton 2014).

It is my view that we as a society make deliberate choices about how we construct social institutions and that with the passing of time, institutions (such as the acute hospital) appear to evolve organically becoming so complex that reconstruction seems almost an impossible proposition. Underpinning that is the evolution of cultures aimed at serving the interests of the individuals who make up that social organisation rather than those it is intended to serve.

I have come to believe that change is anathema to this culture and the dominant mantra is that 'the way we did things yesterday is the way we will do things tomorrow'. I am affronted by that in the same way that I find the 'small carelessnesses' of nurses more chilling (and more challenging to eradicate) than the claim of 'institutional brutality'. Where a nurse chooses not to meet the needs of patients in her care, in the presence of their suffering and in the absence of fear of breaking the nurses code, then I find that an astonishingly arrogant act. However as a social constructionist I also believe that, given sufficient will, change is possible, and, as a humanist, that even the arrogant are redeemable. Finding a way to liberate that will is at the heart of this research work which with a belief, always in the background, that redemption is to be found in the generative capacity of democratic participatory research.

Conventions

For the purposes of writing style I have used throughout this thesis the feminine to refer to the nurse and the masculine to refer to the person with dementia. I have used the term 'nurse participant' to refer to those individuals who took part in the research regardless of whether they were a registered nurse, a health care support worker or, a dementia support worker.

Chapter One

Introduction to the Thesis

1.0 Introduction

This thesis is about compassion in the context of acute care nurses who practice with people affected by dementia. In particular it is about the everyday experiences of those nurses and how their beliefs and behaviours have been shaped. Importantly it is also about how those nurses conceptualise compassionate dementia care and, it questions whether that can be distinguished from a much broader concept of compassionate nursing care. As the thesis progresses and these two questions are answered what is also set out is how important to those conceptualisations is an analysis of the nurse's beliefs and behaviours about dementia and those affected by it. What emerges is a new model for understanding the forces which shape those aspects of nursing practice and which shines a light as to why two nurses may hold very different views yet both claim to deliver compassionate care to people affected by dementia.

The thesis utilises a scaffolding approach towards the understanding of compassion. In doing so the reader is engaged with an exposition of the broader understanding of the concept and its many guises. The Aristotelian view of pity is drawn upon as both the starting point and the benchmark to which the thesis returns to at times where either comparisons are made or sense checking is indicated. This foundation allows the reader to progress beyond the general understanding of compassion and to establish a relationship with the concept of compassionate nursing care that is necessary for relating to the findings of the empirical work. Appreciative Inquiry was the methodology. This method took a democratic stance towards research and the approach drew in participants as co-researchers which in doing so drew out their narratives upon which everything else was constructed. In due course the thesis sets out, from the perspective of acute care nurses, a collective conceptualisation of compassionate dementia care that is distinct to that of compassionate nursing care.

In many respects this thesis also represents the narrative of compassion itself. It tells a story of a time when compassion was absent from the care of institutionalised vulnerable people and, of more recent times and circumstances in which such

absences have occurred again. It relates the tale of compassion being equally absent from nursing theory and of how it rose from obscurity to become positioned as the single most important aspect of nursing. Finally the later chapters of its narrative reveal the vulnerability of compassion and the challenges it must face as twenty-first century nursing becomes increasingly complex, technical and demanding.

1.1 Why Look at Compassion in the Context of Acute Hospitals and Dementia?

Chapter Six will show that the concept of compassion has maintained a presence throughout the development of nursing theory. Whilst at times that presence has been recognised through the use more populist terms of the day that acted as proxies it has nevertheless been there and has risen to become regarded as the core attribute of nursing. Despite this some nurses may find that compassion is a highly demanding standard to achieve even though it may be glimpsed in the smallest of acts, whilst others may consider it dangerous, always threatening to emotionally overwhelm those who practice in a world of vicarious suffering. As a consequence the core of nursing possesses a fragility and, under a certain set of circumstances, compassion may be lost by an individual nurse or, become absent from an organisations culture of care.

This thesis recognises that and underpinning the whole is a fundamental concern that people with dementia, who find themselves in acute hospital care, occupy a vulnerable space within which they may not experience compassionate care and ultimately may not always be protected from avoidable harm. It will be shown that over the past fifty years (from the first expose of abusive practices and inadequate (Robb, 1967) care to today) there have been, in the NHS, forty-six high profile serious service failures that involve abuse of those being cared for by those who provide care. Rooted within most of those failures has been the absence of compassion. Each of those failures has been responded to in a manner that has become traditional – an Independent inquiry was held, its findings reported, the facts made the subject of media and political condemnation, recommendations drafted and disseminated across the NHS. The process was intensive, lengthy, expensive and scholarly yet it does not appear to have mitigated the risks of further failures occurring at about the same rate as before each event.

Serious failings in care span the lifetime of the NHS, are frequently reported and intensely examined all of which has led to consistent patterns being found (Commission for Health Improvement 2004). Whilst the emphasis has been placed on cases of abusive practices and poor care, the Francis inquiry (Francis, 2013) most notably addressed the absence of compassion within the care culture. This absence would appear to sit behind those 'small carelessnesses' and, given the right set of circumstances can lead to, or be an aspect of, the physical and psychological abuse of vulnerable people (Butler & Drakeford 2005). Most recently the delivery of care without compassion and respect is found in the care culture at one Welsh Health Board (Andrews and Butler, 2014) whilst the Ockenden report reveals how a closed, inward looking ward culture thrives on malignant social psychology which forces out compassion and opens the door to abuse (Ockenden, 2015), and both Ockenden II (Ockenden 2018) and a wider review of services in the same Health Board (Johnstone, 2018) show how ineffective organisational governance can nurture such poor practice.

The serious service failures in health care (Appendix I) primarily involved the care of elderly, mentally ill people during an admission to an acute hospital. In compiling that overview of failure the approach has been to focus on the past fifty years commencing with the publication of 'Sans Everything' (Robb, 1967) which led to a series of inquiries across seven acute hospitals. Robb (1967) compiled evidence to suggest that, within the hidden world of geriatric and mental hospital wards, frail older people were routinely experiencing care that was inadequate to meet their needs, dehumanising and frequently abusive. The accounts of six anonymised nurses were prominently featured and led to investigation by independent committees of Inquiry, the structure and function of which has come to represent the traditional model of response to serious service failure (Butler & Drakeford 2005). Whilst those allegations were almost exclusively dismissed by inquiries whose findings have more recently been called into question (Jones & Fowles 1984) they resonate across fifty years with those made, and substantiated, in Stafford (Francis 2013), Abertawe (Butler and Andrews, 2014) and Rhyll (Ockenden 2015).

The greater majority of allegations that have been subjected to inquiry have been upheld they encompass severe premeditated physical and psychological harm alongside wilful neglect and aspects of malignant social psychology. They contain attitudes of indifference, insensitivity and the previously cited '*small carelessnesses*'

(Butler & Drakeford 2005) that reflect the pervasive devaluing of the person in care. Fundamentally the theme that runs throughout all inquiry findings is the obvious or implied lack of compassion shown by NHS care staff towards vulnerable and elderly people with mental health problems. These inquiries into abuse encompass a fifty year period. During that time the number of inquiries has ebbed and flowed but the average is for at least one major abuse inquiry a year. Predominantly they have focussed on mental health settings, however that is changing. Of the fifteen inquiries since 2011 all but two, Winterbourne View and Tawel Fan, have been in relation to acute or district general hospitals. This reflects an increasing awareness of, and concerns about, the quality of care experienced by people with dementia in the acute setting.

Two thirds of all acute hospital beds across the United Kingdom are occupied by older people generally and, people with dementia (diagnosed or otherwise) represent a significant cohort of that population (Smith 2007). Conservative estimates suggest that at any one point in time the average hospital will have around 100 patients who, in addition to their physical health complaint, also have dementia (Royal College of Psychiatrists, 2005). Such an incidence may lead one to infer that the acute hospital either by choice or necessity would be a specialist organisation in the delivery of safe and effective dementia care. This, however, is not so and inadequacies have left people with dementia feeling abandoned and lost (Edvardsson et al. 2011); distressed, and ignored by nurses they perceive as hostile and uncommunicative (Cowdell, 2010)

People with dementia find themselves admitted for the same clinical reasons as older people generally. In descending order those reasons are; falls, hip fractures, urinary tract infections, chest infections and cerebrovascular incidents (Alzheimer's Society, 2012). Whilst there may be common pathways leading to admission there is nothing common about either the experience itself or outcomes for the individual. In particular, regardless of the physical condition, length of stay is longer for a person with dementia in comparison to an older person without dementia and the longer one stays in hospital the more harmful that experience becomes (Fogg et al. 2018). There is increased physical morbidity and mortality associated with a prolonged length of stay whilst for those who survive there is marked atrophy of independent living skills, worsening of cognitive impairment, higher than average risk of being prescribed an antipsychotic

and greater likelihood of moving to permanent residential or nursing home care on discharge (Fogg et al. 2018).

Bringing further malignancy to that experience are the less than desirable but dominant care cultures (Dewing and Dijk 2014). In part these cultures are related to beliefs about the way in which care should be delivered, and in part are rooted in attitudes towards dementia and those affected by it. Such attitudes tend towards the negative and are deeply grounded in beliefs that see the person as being anxious, vulnerable, unpredictable, lonely, and frightened (Brodaty, Draper and Low. 2003). Taking an informed stance from qualitative work (principally by Cowdell, 2010) one could suggest that nurses are perceiving the emotional state of the patient with dementia correctly but are either failing to appreciate the part they play in bringing such emotions about or; are practising within a passive space where poor practice is excused, rationalised or seen as just 'the way things are' (Jenkins, 2002).

Negative attitudes have negative consequences for all. In particular, perceiving the person as of low value leads to objectification of that person but equally leaves the nurse in a psychologically vulnerable position with the suggestion that if the patient is meaningless, then so too is the nursing role associated with that person and ultimately so too is the nurse (Norbergh et al. 2006). Where positive attitudes are present they are the foundation for person centred care and lead to nurse behaviour that enhances well-being and satisfaction on the part of the person with dementia (Norbergh et al, 2006). Paradoxically however positive attitudes appear to be reserved for only one part of the dementia population, those with perceived compliant behaviour (Norman 2006). Compliancy may make the delivery of care easier for the nurse (hence its desirability) but it can be at odds with principles of autonomy that underpin person centeredness. Where the behaviour is regarded as deviant, such as from the belief that the patient with dementia 'deliberately' chooses to present with behaviours that challenge (Brodaty, Draper and Low, 2003) then there is an association with negative attitudes (Norman, 2006). Given that the person with dementia may no longer comprehend the social role of being a patient or be able to abide by the associated rules they are almost invariably positioned as aberrant and therefore likely to experience negative nursing attitudes.

Beliefs about care delivery predominantly focus upon tasks to be achieved that prioritise the meeting of physical needs (Edvardsson, Sandman and Rasmussen, 2011) and lead directly to the objectification of patients and the subsequent rationalisation that minimum interaction is acceptable; both of which place well-being, that depends on social interaction, in jeopardy (Norbergh et al, 2006).

The development of negative attitudes towards dementia begins early in one's nursing career and is related to professional socialisation (Chan and Chan, 2009). Student nurses find their encounters with patients with dementia challenging (Baillie et al. 2012) and they often occur within impoverished care environments where there is negative role modelling and inadequate support from mentors who lack the appropriate skills, knowledge or attitude (Brown et al, 2008). Whilst some students will undergo a process of dissonance that will see them challenge such attitudes it may be fair to say that most will assimilate what they see and hear as much as what they are taught. Where they are exposed to discriminatory practices and poor care standards they will develop negative attitudes (Scerri and Scerri, 2013). As those same students graduate they find themselves inadequately prepared to deliver dementia care and, as they undergo rapid workplace socialisation (Sidenvall, 1999), they come to adopt a state of detached concern and reduced empathy (Cowdell, 2010). Whilst one could regard this to some degree as a protective mechanism to reduce the experience of vicarious suffering one may also readily see how, as the student becomes part of the next generation of negative role models and ineffective mentors, it not only has a corrosive effect upon compassion but maintains the status quo.

Alongside this view of nurses, as holders of negative attitudes, which suggests an active, albeit schema driven thought process, lies an alternative concept that nurses have an 'authentic inability to think' (Arendt, 1992, p288) and are in reality, thoughtless. This suggests that when faced by the suffering of another there is less of a desire to respond and alleviate that suffering and more of an unreflective adherence to an assurance driven culture characterised by organisational rules, policies and procedures (Roberts and Ion, 2015) and reflected the view of Andrews (2013) that much of what nurses spend their time doing is futile and has no real impact on outcomes for the patient.:

Whilst there is premeditated harm and wilful neglect, this is relatively rare. What predominates is the unconscious participation in acts of malignant social psychology within an assurance driven culture which suggests that nurses thoughtlessly doing things that make things worse cannot be likened to claims that nurses have themselves become malignant, even though the care that they find themselves delivering may be. Such a concept is rooted in the seminal work of Arendt (Arendt, 1965) which aimed to understand how the average German citizen could come to participate, condone, ignore or tolerate the morally inexcusable acts against Jewish people and others by the Nazi regime. Her conclusion included the now famous suggestion that:

'Evil is banal' (p417)

This suggested that inhumane behaviours may become formalised and almost subjected to the predictable dullness of a bureaucratic process. Such a premise influenced Roberts and Ion (2014) to question how, in relation to the events at Mid Staffs, nurses could so comprehensively fail in their fundamental duty to protect the patient from harm and unnecessary suffering. The answer, evidently, was quite easily as the NHS had chosen to create a contextual way of performing that relied on *'instrumental, technical or calculating rationality'* (Roberts and Ion, 2013, p771). This they described as being a way of performing that was rooted in identifying the most effective method of achieving an outcome. Fundamental to the method was the acquisition of specialist knowledge and skills and the whole was circumscribed by strict adherence to the rules, policies, guidelines and processes that would ensure efficiency. It is a way of performing that, outside of applying the specialist technical skill, removes the need for practitioners to think and eventually leads to the habituation of the practitioner. That, over time, practitioners become habituated to follow the rules without question or critique is undesirable (Arendt, 1965) and shows that nurses either lack discretion or, more realistically, the nurse lacks sufficient authority and personal effectiveness to challenge the pointless activities that the system asks of them (Andrews, 2013) It is probably through such practice that, without there being any widespread intention to treat vulnerable patients poorly, widespread poor care of vulnerable patients becomes possible, then accepted as just 'the way things are' and no longer challenged; at some point that tips over into serious service failure.

Taking all of the above into consideration one must conclude that the acute care environment is a rich source of research potential for the study of compassionate dementia care. It is a space where, every day, many nurses are engaged in relationships of variable quality with many people who in addition to physical health problems are affected by dementia. It is a space in which the absence of compassion creates vulnerability for those receiving care but also where its presence can levy a toll on those who deliver care.

1.2 Person Centred Care

This thesis has been influenced by the well-rehearsed concerns about the care of people with dementia in a variety of formal settings (as described in section 1.1). Found within each serious service failure, and the many day to day experiences of poor quality care, is a common thread described by Butler and Drakeford, (2005);

“Scandals do not just happen. They are made. They are constructed out of such everyday tragedies as the small carelessnesses and institutional brutality of the long stay hospital” (p2).

Whilst brutality may be rare it is the small carelessnesses which dominate and which reveal not only the absence of compassion but also its antecedents; awareness of the other, valuing the others humanity and, having sensitivity to his or her needs. Kitwood (1997a) captured this powerfully;

“As I entered, the door was wide open; all four ladies were sitting on their commodes, and the smell of faeces permeated the air. There were no curtains or partitions to screen the ladies from each other or anyone else walking past. My colleagues Sandra and Mary were feeding two of the ladies, and talking about the night out they had just spent together. Sandra was feeding Mrs. T. As soon as there appeared a little room in her mouth, more food was inserted. Her cheeks were bulging with food she hadn’t had a chance to swallow. Mrs. T started to gag; food began to spill from her mouth; then she coughed and sprayed Sandra with half chewed food. Sandra proceeded to clean herself up, while leaving Mrs. T with food debris all over her clothes and exposed thighs” (p. 45).

The unthinking and task focussed carelessness of 'feeding' and 'toileting' whilst simultaneously ignoring needs for privacy, dignity and comfort highlight the dehumanising culture which by the 1980's was seen as acceptable dementia care (Epp, 2003). Taken together they identify objectification as one aspect of this culture which Kitwood conceptualised as the 'standard paradigm' (Baldwin and Capstick, 2007) and steadily developed arguments against.

The standard paradigm is suggested as not only inherently flawed but also inherently harmful to individuals affected by dementia. Prominent amongst those harmful aspects is the medicalisation of dementia which focuses on the neurophysiological understanding of dementia (Kitwood, 1989). This focus outlines the positivistic heritage of the standard paradigm and the belief that all aspects of dementia stem exclusively from dysfunction of the brain and, that developing knowledge of the dysfunction would, through medical or pharmacological intervention, be the only way to benefit those affected (Kitwood, 1995). Important though this may be, when occurring in isolation it comes at the expense of the phenomenological view of the lived experience of dementia as a whole and, most importantly, the impact of neurological change within the social context.

The standard view has profoundly and seductively influenced care practices and their associated belief system leading to an emphasis on care being ordered around tasks which relegate people with dementia to the status of objects or children. Within this kind of dehumanising care culture (Kitwood, 1996) that legitimises practices of 'warehousing', control, restraint and restriction (Epp, 2003) the individual narrative becomes of little importance beyond documenting personal and family medical history yet, as Cayton, (2004) states;

'Each of us has a life story in which illness will certainly play a part, but illness will never be the whole story' (p6)

The life story is absent within the standard paradigm and we are left with only a clinical story within which deficit, disturbed behaviour and pathology are the central characters whilst the multifaceted person is lost (Page and Fletcher, 2006).

Kitwood led the discourse around the development of a corrective mechanism and gradually moved to offer person centred dementia care as the alternative paradigm (see, Baldwin and Capstick (2007) for a detailed account of this process over time). Within person centred care the emphasis shifts so that regardless of the severity of neurophysiological change the core of the person is acknowledged as remaining present. It is therefore the person who has primacy and attention should be as much placed on understanding who he is and finding ways to connect to him, as on understanding his neurophysiology with a view to medical treatment (Kitwood, 1997b). Encapsulated within that shift is a fundamental value base that sees a person with dementia as a unique individual attempting to make sense of his world and who has a right to be supported and enabled to be as independent as possible (Brooker, 2004).

Person centred dementia care acknowledges that dementia care is complex as each person is not only an intricate and multifaceted individual but also inhabits a space which represents a social, relational, emotional and contextual maelstrom. There is no seductive simplicity of the standard paradigm and, such is its breadth that establishing a single definition is difficult. Brooker (2004) addressed, identified and gave order to this complexity by outlining the four all-encompassing elements of person centred dementia care as being;

$$'PCC \text{ (person-centred care)} = V + I + P + S' \text{ (p216)}$$

V – Valuing people with dementia and those who care for them

That people with dementia are still people of the same human worth and value as another should not be open to question. However, one aspect of the standard paradigm is to undermine this belief and to reposition those affected as being in some way different to those who do not have dementia. Brooker (2004) states that this view is expressed through 'dementia-ism' (p217) which is widespread and which makes personhood a vulnerable status when the person is denied recognition and respect from others. The belief system behind person centred care is that all human beings are, without exception, of absolute value and worth.

From this comes an emphasis on how care workers need to value the whole life experience and use knowledge of that to connect to people with dementia or to understand unmet needs.

I – Treating people as Individuals

This knowledge of the whole life experience cannot be divorced from a knowledge of who each person with dementia is as a unique individual as opposed to a medical label or symptoms of disease. The care delivered to each person should therefore be individualised and again complexity becomes an issue and the seductive simplicity of the standard paradigm is often favoured as care can be reduced to physical tasks which may be completed without any knowledge of who the person is. However, this represents a pathway through illness which is imposed regardless of the suffering it causes rather than one which is aimed at meeting individual needs and promoting well-being, inclusion and engagement.

P – Looking at the world from the perspective of the person with dementia

Attempting to look at the world through the eyes of each individual person with dementia is a phenomenological imperative at the heart of person centred dementia care. Kitwood (1997b) articulated 'access routes' to gain some potential understanding. These include; accessing first person narratives, from which a number of common themes emerge to offer considerable insight (Page and Keady, 2010); active listening to what people with dementia say in a number of contexts, and making use of one's poetic imagination. For the latter of these the work of Killick (2017) capturing the 'extraordinary vividness of language' (p10) which connects the expressed words to the experienced emotion as the person strives to find meaning.

S – A positive social environment

Dementia care is inherently relational and the quality of relationships will depend upon the belief system. The much earlier and highly influential work of Buber (1923/2008) identified that people find meaning through relationships which can be defined in two opposing ways, I-it or I-Thou. The 'it' refers to a relationship that one has with the inanimate from which Kitwood (1997b) drew out the objectification of the person with dementia under the standard paradigm and

contrasted with the 'Thou' which defined relationships of positivity, respect and engagement.

Taken separately one can appreciate the justification for inclusion of the V, I, P, and S, but when understood in combination it is clear how the quality and experience of care would naturally improve and, how the practices brought about by the standard paradigm would no longer be seen as acceptable. Kitwood offered no censure to those care staff who worked within the standard paradigm preferring instead to believe that practice was poor because they had been trained in that way and not exposed to the alternative paradigm (Kitwood and Bredin, 1992). The care worker was effectively involved in a reality within which;

'thousands upon thousands of hours of dementia care work pass by in which the people involved generally do not understand what they are doing' (p270)

These care workers are practising in a way that determines the relative well or ill-being of people in their care. The causality of ill-being was rooted in the concept of a Malignant Social Psychology within which good, well intentioned people deliver care that undermines the very personhood of those affected. There is no intent, they 'do not understand what they are doing' (Kitwood and Bredin, 1992) and redemption is to be found in making relatively modest changes to practice which can bring about well-being. If one returns to the extended quote from Kitwood (1997a) (offered at the start of this section) it becomes possible to see how the ignorance or absence of the alternative value base leads directly to the malignant social psychology displayed by the staff involved and, to identify the modest changes that would improve the quality of care.

1.3 Further Influences

As stated earlier the NHS is no stranger to service failures that disproportionately impact upon vulnerable groups (most commonly the elderly, the mentally ill and those

with learning disability). If failure is consistently patterned then so too is the response of the NHS to it. The traditional model of inquiry is set out as a retrospective examination of events and circumstances with a key aim of preventing recurrence by facilitating learning from those events (Walshe, 2003). To achieve this aim all inquiries conclude with a detailed report and recommendations the implementation of which does not usually fall to the inquiry team but to the commissioning organisation. The frequency and repetitive nature of service failure suggests that strategies for implementation of recommendations and associated learning may well be inadequate. In the case of failures that identify a loss of compassion and respect for the individual patient, it may be further argued that traditional strategies are having little influence on those who deliver care. If nurses have never acquired compassion whilst others are at risk of losing it then it follows that discovering, nurturing and expressing it must be a worthwhile endeavour and alternative approaches may be necessary.

Understanding the approach to dissemination may be a crucial factor. The traditional approach encourages a style that may have become stereotypical: the independent expert holding the inquiry sets out the recommendations and hands them down to the inquiry commissioners who in turn hand them down to individuals and teams within and across the organisation/s. Having done so there is an expectation that change will now occur and the problem is solved. That traditional approach is knowledge transfer and what may be required is a change of direction towards an alternative democratic or participatory mechanism that may be better placed to change practice. Theoretically these approaches must be understood in terms of the differing influences they have however, the place for that critical understanding is perhaps at a distance from the main body of the thesis. Consequently, they are discussed in this introductory chapter and it is stated from the outset that the position this thesis takes is that knowledge transfer is inadequate for the task in hand, whereas a knowledge translation method (such as the Appreciative Inquiry approach) has much to offer in changing practitioner behaviour.

Knowledge Transfer

The NHS, both as a unified whole and as a collaborative of constituent units, is committed to the concept of quality outcomes for those who use healthcare services.

Achieving this relies to a large extent upon both the whole organisation and the individual units understanding of; what to do, how to do it and perhaps most importantly how to do it better. When an organisational unit develops a way of working that meets quality outcomes then it has achieved, from within its own internal resources, a high level of performance. However, over time as the standard behind that performance changes (as new technologies emerge, new challenges arise and new paradigms dominate) so the effectiveness of performance will erode. The implications of this become apparent when a general problem that may impact upon (if not imperil) the organisation is identified. In relation to this thesis that general problem may be a serious service failure in one NHS hospital, that causes all other hospitals to question if such a problem could occur to itself, if so when, or potentially, if it is already happening. Faced with this situation the organisation will behave in one of three ways (Lane & Lubatkin 1998).

Firstly it may adopt an inward looking culture that denies the deficiency in performance and rejects a need for change; secondly, it may try to draw on its own internal knowledge to address a change in performance and thirdly it may turn to external knowledge sources (for a unit within the NHS 'external' may refer to both another NHS unit or an organisation that sits outside the NHS structure). Adopting the first or second option will invariably lead to organisational failure the only difference being how quickly that failure occurs (Lane and Lubatkin, 1998). It therefore follows that effective organisations are those that can manage external knowledge to strengthen and build upon their own internal experience and expertise (Mowery et al. 1996). Those organisations that can achieve this are more likely to be innovative, efficient and effective (Levin et al. 2002) but this in part is dependent upon their level of absorptive capacity. Absorptive capacity is:

'... the ability to recognise the value of new external information, assimilate it and apply it to commercial ends' (Cohen & Levinthal 1990, p128).

Where one changes 'commercial ends' for 'clinical outcomes' then the concept becomes relevant to the NHS. Absorptive capacity is not only about the acquisition and assimilation of knowledge but also the ability to exploit it to achieve an organisation specific goal, which could well be to implement evidence into practice. The level of absorptive capacity of the organisation is dependent upon the absorptive capacity of each individual person within that organisation. Individual absorptive

capacity relates to the critical or technical knowledge that the person has, their awareness of where and with whom other knowledge is held, the relative bridging positions they hold between the unit and the external world (Cohen and Levinthal, 1990) and the positions they take in respect of sharing knowledge whether that be as donors or receivers (Husted & Michailova, 2002). The movement of knowledge across internal units of the same organisation or from other external organisations is knowledge transfer and involves:

'Individuals from within one organisation communicating on specific problems and procedures with individuals from another organisation' (Darr & Kurtzberg, 2000, p3)

There is an interconnected element to effectiveness as those organisations that utilise knowledge transfer have a much more expansive repository of knowledge and experience to draw upon (Argote et al. 2000). Interconnected organisations have a greater capacity to achieve both continuous quality improvement and crisis prevention as they are open to the premise that groups can learn from each other's experience (Argote et al, 2000), compare their performance by benchmarking (Szulanski, 1996) and avoid lengthy and costly processes of trial and error to establish best practice (Gruenfeld et al. 2000). The knowledge transfer approach should, on the face of it, represent a graceful and straightforward process for remediation. It is however, in reality often inherently 'sticky' (Szulanski, 1996, p3). Such stickiness interferes with the elegant flow of information making knowledge transfer not only unreliable and inconsistent (Davis and Howden-Chapman, 1996) but somewhat counter intuitively ineffective as the possession of potentially valuable information in one part of an organisation does not necessarily see it flow easily to others for implementation. Two issues seem to be particularly sticky, the first and arguably most important is that:

'Knowledge sharing depends on people.' (Husted & Michailova 2002, p61)

Knowledge transfer as a process is inherently relational and consequently is as effective or ineffective as the individuals on whom it relies. Where there is a need for knowledge people tend to turn to other people and particularly to those with whom they have strong ties, associations or shared characteristics. Strong ties underpinning the relationship characterise the closeness of that relationship, the frequency of interaction, the accessibility of others, the willingness to help and the degree of trust that exists between individuals (Levin et al, 2002). The strength of the tie however has

little, if any, relationship to the quality of knowledge that is being shared. So, a relationship built around strong ties can involve supporting an individual to learn how to perform, how to relate to customers (patients) how to make sense of ambiguity or how to solve problems but, in doing so may reinforce all the factors that lead to poor quality outcomes in care or sustain malignant social psychology.

The strength of the tie is weakened by distance whether this be the distance associated with perceived social status, equity of individuals or units, intellectual ability or geography itself. The weaker the tie that binds the relationship the greater the degree of hostility to knowledge sharing with other individuals, units or organisations. This hostility can take the form of resistance to both donate knowledge or to receive it and such is its frequency that most attempts at knowledge transfer are doomed to fail (Husted and Michailova, 2002). Those who reject knowledge that is being shared from an external source may simply have limited absorptive capacity or may have behaviour that reflects resistance motivations.

The second sticky factor is that it is difficult to know when knowledge transfer has occurred in an effective manner. There are lower orders of transfer that carry lower levels of effectiveness and include; the simple act of exchanging as evidenced through one unit communicating with another about a practice it has found to be helpful in improving performance (this is the donation only model as the recipient has only a passive role in the transfer); and the sharing of knowledge that requires a more active part to be played by the recipient. That active part involves the movement of external knowledge into existing repositories that include; individuals; roles and structures; standard operating procedures or policies; culture and; the physical environment (Argote et al, 2000). For both of these whilst there is evidence of movement there is no requirement that performance of the organisation changes and one could argue that the risk remains. Both of these issues in relation to stickiness are important and influence ones perception as to whether knowledge transfer is an effective mechanism in relation to health care. Systematic reviews lean towards the cautious in suggesting that this is the case, they identify common methodological weaknesses and at best the achievement of only short lived improvements in practice (Aylward et al. 2003, Cohen-Mansfield et al. 1997). Such reviews highlight the reality that knowledge transfer is essentially reductionist and not effective at truly influencing practitioner behaviour. The approach is described (Kontos and Poland, 2009) as too simplistic to

give meaning to the complexity of decision making that is made within complex social and cultural contexts.

Knowledge Translation

If one believes it is inadequate to view organisations as social structures that an external knowledge base (such as derived through a guideline) can simply be grafted onto then one needs to offer an alternative approach. The movement of knowledge into and around the organisation should perhaps be seen as a dynamic rather than passive process and one that places emphasis upon making that knowledge relevant and meaningful. For that to be possible the process needs to be participatory, inclusive or democratic and it is evident that knowledge transfer may not be the appropriate method for this. An alternative approach may be Knowledge Translation which has been defined as:

“A dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge” (Canadian Institutes of Health Research 2004).

From this one notes the emphasis that is placed on the dynamic and iterative aspects of the process that aim for new knowledge to be used in practice (Straus et al. 2009). Knowledge translation is an interactive process that places value on effective exchanges between researchers and practitioners who together create new knowledge. Whilst bringing users and creators of knowledge together is fundamental to successful outcomes it does change the nature of the process moving it away from the straightforward but passive offer of Knowledge transfer towards something that is more complex as other factors (patient and practitioner preferences/values, resources, policies, institutional culture, and norms) come into play (Sudsawad 2007). That is captured within the overarching model for knowledge translation Canadian Institutes for Health Research (CIHR), 2005) which adopts a background of a traditional research cycle to identify six points at which democratic research, through interaction, communication and partnership work, can occur (Sudsawad, 2007, CIHR, 2005). Those six points encompass the whole spectrum of knowledge development from designing research through to implementing its findings and suggestions for the direction for further research. Under such a model those who are charged to implement a new practice are well positioned to overcome many of the factors that

make knowledge transfer sticky rather than elegant. Direct participation in the process of knowledge generation challenges many of the attitudes that apply to individuals who are resistance to receiving external knowledge. Firstly, there can be no doubt about the quality, validity and reliability of the new knowledge or doubts about the source of the knowledge where the individual has been involved in its development and secondly, the process accommodates those who have a preference for developing their own ideas and knowledge. Additionally the process, if engaged with, may support those with erroneous beliefs about their own ability to develop knowledge sufficient to acquire a reliable skill set or change their practice.

1.4 What this Thesis Contributes

This thesis is justified in seeking to understand compassionate dementia care from the perspective of acute hospital nurses and to do so through a methodology that is democratic and influenced by knowledge translation. Accepting that justification allows one to suggest that this thesis makes a contribution to the knowledge base concerning nursing and compassion in a number of ways. Firstly, it sets out the way in which acute hospital nurses conceptualise compassionate dementia care and argues that this can stand as a different concept to that of a more general compassionate nursing care. This helps to begin addressing the void in the literature related specifically to the understanding of what compassionate dementia care may be.

Secondly, it identifies that differences between nurses, in respect of their attitudes, beliefs and behaviour in respect of dementia care, are associated with the initial encounters that occur between nurses and people affected by dementia. Thirdly, it offers exposition of a model to outline the journey that the nurse may choose to undertake to become a practitioner of truly compassionate dementia care. The model suggests that whilst there is a world of potential lying beyond compassionate nursing care not all are able, or willing, to see that. As a consequence people with dementia are denied an opportunity to encounter an 'I-Thou' relationship at one of the most significant times of their life (Bryden 2015). Finally, it finds that democratic and participatory research through the medium of the Appreciative Inquiry approach can support nurses to reflect on change and craft provocative propositions that have meaning to them and which may change their practice.

1.5 The Structure of the Thesis

The thesis is made up of twelve chapters each of which is designed to progress the reader through the story as a whole. In Chapter Two theoretical foundations are laid before the research methodology is set out in Chapter Three. Appreciative Inquiry as the chosen methodology is critically reviewed and its ability to address the research questions is argued and established. The concepts of appreciation (Vickers, 1964) and generativity (Gergen, 1982) are explored and suggested as being fundamental to the outcome of the empirical work.

In Chapter Four the research design is described and attention placed on the approach towards data analysis. A layered triad of analysis is proposed so as to capture the meanings and subtleties of the data. That triad comprised of thematic analysis, positioning analysis and linguistic analysis is described in detail.

In Chapter Five the scaffolding framework is set out and a scoping review is undertaken to identify the literature that pertains to each level of that framework. Introduced at this point is the work of Meleis (2012) which explores the development of nursing theory over time across a number of specific milestones. The thesis returns to these milestones throughout (in the same way as it does to the Aristotelian concept of pity) as a standard that adds rigour to the integrity of the process.

In Chapter Six the identified literature is subject to substantive review within the scaffolding framework. The general understanding of compassion is identified in the broadest of terms with the Aristotelian concept of mercy chosen to represent a meaningful starting point. The literature is then ordered in line with the Meleis milestones (Meleis, 2012) to draw out compassion's journey in the context of its application to and relationship with nursing care. Finally, Chapter Five finds that compassionate dementia care is essentially absent from the literature and uses what little there is to suggest hints that could signpost towards the pollination of a possible concept.

In Chapter Seven the literature is explored further through the lens of positioning. A third influence, the spiritual journey, is introduced to sit with the Aristotelian concept of mercy and the Meleis milestones as constructs which ebb and flow through the thesis. Overall chapter seven draws out new insights from the literature that allow a very early and irregular heuristic model of the journey towards compassionate dementia care to

be proposed. That model, incomplete in many ways, does introduce an important aspect of the positive core of the thesis in that it poses the view that in practising compassionate dementia care the nurse moves away from the role bound notion of 'what is it I do?' towards the more metaphysical 'what kind of person am I?'

By Chapter Eight a point is reached at which the research findings can be disclosed. This is delivered over two chapters. Chapter Eight sets out the finding that four relational themes circumscribe and influence the practice of acute care nurses as they work with people affected by dementia. A number of sub-themes are identified and presented. In Chapter Nine the presentation of research findings continues. Positions articulated by acute care nurses which reflect their beliefs about dementia and those affected are presented. Finally, the conceptual properties which reflect the collective view of compassionate dementia care are presented. These are ordered to show where this concept may be distinguished from the more general concept of compassionate nursing care.

In Chapter Ten there is a synthesis of the conceptual and methodological research findings. In doing so the relationship between the, relevant literature, relational themes, articulated positions and conceptual properties. From this synthesis a layer of further meaning is found in those findings. The chapter is then able to set out a fundamental theoretical proposal that, the early symbolic representations formed by the nurse after having encountered a person or persons with dementia define the quality of the initial encounter. That in turn influences what happens next for her in respect of career choices, resilience and practitioner behaviour. Additionally those encounters play a significant part in how the nurse conceptualises compassionate dementia care and this further shapes her practice as she continues to encounter people who have dementia. Chapter Ten concludes by returning to and refining the model proposed in chapter six in such a way that individual differences in conceptualising compassionate dementia care can be understood and accommodated.

In Chapter Eleven there is an appraisal of the contribution that Appreciative Inquiry as the research methodology makes to draw out narrative from which the conceptual findings emerge. Additionally Chapter Eleven explores the linguistic properties of

provocative propositions made by the participants and finds evidence to strengthen the previously presented conceptual properties.

In Chapter Twelve the study as a whole is summarised and there is discussion of the findings alongside consideration of where they take the story to and, what further plot lines may need to be developed in the future.

1.6 Summary of Chapter One

This chapter has stated that the focus of the thesis is upon the study of compassion and that its purpose is the pursuit of a conceptualisation of compassionate dementia care. Chasing that concept from the perspective of nurses working in district general hospitals has been justified in detail. That detail has outlined the times and circumstances where compassion has been absent from care, where culture has negatively influence new generations of nurses and, the points of extremis where this plunges into abuse. The chapter has emphasised that in recognising and addressing this issue the thesis, as a whole, has a contribution to make to the general understanding of compassions place in nursing and, specifically to dementia care.

The chapter has also described the challenges associated with changing this. Traditional responses to high profile serious service failures have adopted a knowledge transfer approach which in the face of nursing's low level of absorptive capacity has not been adequate to prevent further failures. It has been suggested that a different approach may be required and Chapter Two takes that forward by setting out the theoretical foundations for a critical theory of compassion.

Chapter Two

Theoretical Foundations

2.0 Introduction

This chapter will prepare the way for almost everything that follows particularly in respect of the emancipatory potential of nursing praxis. In due course the thesis will identify conceptualisations of compassionate dementia care suggesting that the more the nurse practitioner breaks free of the restrictions imposed by her role, the more she is liberated to fully engage with the relational aspects of dementia care and, positioned to meet both physical and meta—physical needs of those in her care. Demonstrating that is through the research design and methodology which are nothing less than a framework within which a public sphere is created and within which generative discourse is supported. This will be shown by Chapter Ten in the synthesis of the findings and will culminate in drawing out, and modelling, a critical theory of compassionate dementia care.

However, this chapter precedes all of that by offering a focussed analytical lens through which an underpinning triad of theoretical concepts; generativity, discourse and, the democratisation of social research, are considered and justified. In developing that analytical lens Critical Theory is briefly discussed from two contrasting positions (from within an otherwise broad and varied philosophical field) namely, the early Marxist inspired perspective of Horkheimer (1947, 1972) and, the later discourse dominated re-interpretation by Habermas (1970, 1974, 1984). To achieve the necessary consideration and justification, this chapter will set out key aspects and criteria of both early and later Critical Theory so as to form the framework that will be used to order the analysis.

2.1 The lens of Critical Theory

Critical Theory emerged in the early part of the twentieth century as a new way of thinking about the impact of and, alternative to capitalist ideology. Prior to that Marx (1847) had discussed how the capitalist power structure gained and held power

through exploitation and enslavement of the working class. The themes of structures of social power, enslavement and, liberation through social reform, or revolution, were subsequently regarded by Horkheimer (1947) as fundamental to Critical Theory. Horkheimer stated that theory is seen to be critical if it facilitates,

“Human emancipation from slavery”, acts as a “liberating ... influence”, and works “to create a world which satisfies the needs and powers” of human beings, (p246).

‘Slavery’ may seem like a strong, possibly inappropriate word in the context of this thesis however, concepts of liberation and breaking free of the restrictions imposed by social roles will come to have a fundamental influence over the shape of what emerges. For Horkheimer the enslavement of the working classes was a social problem created by the social structure of industrialised capitalism and, perpetuated as capitalist ideology became the accepted status quo (Geuss, 1981). Critical Theory was seen as having a normative dimension that Horkheimer (1972) believed was the means of offering a challenge to this dominant social structure and its accepted value base.

According to Horkheimer (1972) a critical theory must meet three criteria: it must be explanatory, practical, and normative, and, importantly, these must be simultaneous. It must explain the inadequacies of the current social reality (the status quo), identify the potential change agents, and provide both clear norms for criticism and achievable practical goals for social transformation.

Habermas (1970) challenged the philosophical basis of Critical Theory as defined by Horkheimer (1947). He suggested that in the form as offered it had failed to achieve its aim, there had been no social revolution and it had nothing left to offer to weaken the power structure of industrial capitalism. If anything in Horkheimer’s particular temporal and locational context of 1930’s Germany exploitation of the working classes had been superseded by National Socialism as a new ideology bringing with it a new form of enslavement (Outhwaite, 1988).

Habermas stated that Critical Theory possessed two core concepts. First, it needed to possess breadth and be directed at the totality of human society and, second as a reflection of breadth it should improve understanding of many aspects of society. The emphases needed to shift and focus upon more general aspects of emancipation

alongside self-reflection and discourse within the public sphere (Habermas, 1993). Discourse, as a public function, was regarded as vital to the democratic process, with representative government being seen to offer citizens the right to engage in normative discourse (Hauser, 1983) and to allow policy to be guided by the outcome (Benhabib, 1992).

The concept of the public sphere was suggested by Habermas (1993) as the 'space' where people could come together to freely discuss social issues as opposed to the individuals themselves. Within this discursive space, which need not be physical nor have rules for membership, the need for social change could be discussed, public opinion formed and judgements made (Habermas, 2006). Certain criteria would apply (Habermas, 1993) so that there would be;

1. Disregard of status – no power structure would dominate nor interfere with the public sphere in order that the public could meaningfully participate in the political process and challenge any ruling elite in respect of ideology and impact on society as a whole.
2. A common concern - the role of the public was regarded as being to question the status quo which would involve, through discourse, determining the meaning of social structures and normative values.
3. Inclusivity – citizens would confer in an unrestricted manner with the guarantee of freedom of assembly and the freedom to express and publish opinion (Habermas, 2006). To assure this there is a need for adequate opportunities for people to; speak, to challenge, acquire the skills of discourse and, be free from coercion or violence (Habermas, 1993).

From this brief review of Critical Theory it is possible to model an analytical framework as a lens through which the triad of theoretical concepts which underpin this thesis may be considered and justified. Essentially what will be questioned is the relationship that each of the triad has with first, the principles of Critical Theory, second the potential to generate discourse and, third the context of the public sphere as all three combine to support emancipation from the status quo.

2.2 Democratisation and Participation

This thesis is grounded in democratic and participatory research as the basis through which acute care nurses can come together and collectively and contextually conceptualise what compassionate dementia care might be. By Democratic research I mean in short research exploring a social organisation (in this case the acute care hospital) within which it is the individuals who make up that organisation (various grades from the nursing rota) who equally participate in the research (that is they explore as much as they are explored).

Whilst Chapter Three will critique the research methodology in detail it is important to state here that Appreciative Inquiry will be seen to offer those who are being researched the opportunity to be engaged with the research process and, for that participation to be seen as fundamental. Contextually for the research methodology the participation of nurses in the research process is helpful in that it improves knowledge about the social system under examination for all, it allows the participants to identify what needs to change in respect of practice and belief systems, and commit to bringing that about, and, it ensures that the change will be directly related to their work (Bjerknes and Bratteteig, 1995). The approach drew in participants as co-researchers which in doing so drew out their narratives as the qualitative data from which compassionate dementia care was theorised. This theoretical concept is therefore compliant with the demands from Horkheimer (1972) for it to be simultaneously, explanatory, practical and normative.

As the democratic methodology the purpose of Appreciative Inquiry is to bring people together to engage in discourse and this indicates that democratisation as an underpinning theoretical concept is most strongly associated with the concept of the public sphere. The public sphere in the context of Appreciative Inquiry is a discursive workshop framed by a systematic process for the group as a whole to work through as they deeply focus on a social subject. That subject under examination is the 'common concern' which the research participants want to come to understand better and, if indicated, may want to challenge in pursuit of an alternative. This thesis will demonstrate that the concern common to all participants relates to the care of people with dementia in the acute hospital where the status quo is shown in both the literature and clinical reality to be potentially harmful. Democratising the research process within

a participatory framework that promotes discourse and appreciation of the common concern demonstrates compliant with the three requirements set by Habermas (1993).

For the collective outcome (Appreciative Inquiry terms this the provocative propositions) there must be consensus and to achieve this all participants are regarded equally and all are included in the process. For individual conceptualisations that are discussed later each participant is exposed to the self-reflective aspects and this is where real change in practitioner behaviour occurs through generativity.

2.3 Generativity

Whatever the focus of a particular approach to Critical Theory, at the heart is the idea that things we take for granted can be viewed in different ways which is necessary for human emancipation from potentially oppressive social structures or cultural trends. This represents the merging together of Critical Theory and the concept of generativity, which will be discussed more in Chapter Three, but represents a fundamental underpinning theoretical concept for this thesis.

In brief, generativity as set out by (Gergen, 1968) is a potent force capable of stimulating normative discourse through which the assumptions of the status quo may be challenged to the point of “*transforming social reality*” (Gergen, 1978 p1346). By ‘transforming’ he meant overturning the prevailing social structure and we can see in this the Marxist call to revolution not by any uprising of the proletariat but rather by occupation and ownership of the public sphere.

That occupation is populated by the creation of new images, metaphors and representations which provide a function of framing the common concern (Schon, 1979) and are sufficiently compelling that they cause people to change how they think, feel and act (Bushe, 2013). Predominantly the new metaphorical images are to be found within narrative (Cooperrider and Srivastva, 1987) and hence generativity is about inclusivity as all have a story to tell and those narratives become explanatory helping to improve understanding about the inadequacies of the status quo.

Generative capacity rests within these new, attractive, narrative driven images which help people to see the world differently and over time as increasing numbers of people adopt the new values and behaviours a ‘new normative order arises’ (Bushe, 2013 p4)

and culture is changed. In the context of a group of nurse participants the process is the same but on a smaller scale which gives pace to the new normative order within the group and directly leads to the collective actions to overturn those things that were previously taken for granted.

2.4 Discourse

So, as stated above, generativity exists within a normative discourse that creates attractive new metaphors and images of what an alternative to the status quo might look like. Whilst this is accepted it is important to emphasise that discourse is not a one directional process. The strength of generative capacity is to provoke a normative dialogue through which arguments about the alternative meanings that change may bring, can be proposed, refuted, or defended (Gergen, 1978). This suggests a multi-directional discourse that may or may not lead to change as proponents of the status quo may also offer compelling images and metaphors to defend the way things are. Ideologically this counter argument could be termed propaganda which becomes more effective if the norms of the dominant power structure exert control over the public sphere principally by excluding specific social groups (Fraser, 1990).

However, where the public sphere is democratically constituted and is compliant with the principle of inclusivity then the quality of discourse in respect of its generative capacity rests on the relative strength of the common concern. In the setting of this thesis there is a concern about the absence of compassion from health care but the wider concern is to understand what the concept of compassion means in the context of a number of disciplines. Drawn out from this is the need to explain and understand compassion in the specific context of Nursing and to question if there is a further and distinct concept of compassionate dementia care. As that discourse is explored through the substantive literature review (Chapter Six) what emerges are other relevant common concerns. Prominent amongst these is the cognitive positioning of the nurse as she challenges her expression of compassion within the constraints of her role and moves from asking 'what do I do as a nurse?' through 'how do I do it?' to a much more meta-physical 'what kind of person do I want to be?' This discursive progression through questioning fundamentally challenges the status quo in acute

care nursing and particularly acute care nursing's belief systems about people with dementia which were outlined as overwhelmingly negative in Chapter One.

This cognitive shift within the group aligns to all the principles for Critical Theory as outlined above. The discourse has to be explanatory and in this case the nurse participants are drawn towards understanding dementia in the context of compassionate care. It is self-reflective as each participant is compelled to position themselves as part of a narrative and to question their own practice. In doing it is both normative and practical as the value base is questioned and the nurses takes action to assimilate new learning into her practice. Consequently this discourse possesses the potential to both mitigate for low levels of individual absorptive capacity and promote a change in practitioner behaviour.

2.5 Summary of Chapter Two

This chapter has demonstrated that the triad of underpinning theoretical concepts align to the requirements for Critical Theory. In creating a simple framework it has been shown that democratisation and participation, generativity and, discourse have the capacity to bring individuals into the research process from within which they can occupy the public sphere and begin creating a new reality. This represents a strong position to begin from as the thesis moves on to address the ontological and epistemological roots of the research design and methodology in Chapter Three.

Chapter Three

Research Methodology

3.0 Introduction

The scoping review and the substantive literature review that later follow as Chapters Five and Six respectively, will suggest that, against a background of conceptual uncertainty, there is a void regarding the nursing conceptualisation of compassionate dementia care. This chapter introduces the research architecture required to address that. It begins with an outline of my personal ontology which positions me as a researcher and sets out my particular world view. Included in this are the epistemological influences which implicitly lead me to the selection of methodology. The chapter then moves to explore Appreciative Inquiry as the research methodology employed to generate the data required to help fill the void. Appreciative Inquiry will be critically examined as both an approach to organisational change and, as a research methodology. In particular its generative capacity (which is positioned as nothing less than fundamental to meeting the aims of the subsequent research project) is assessed. Chapter Four then follows on to state in detail the design by which Appreciative Inquiry was brought to bear.

3.1 Ontology and Epistemology

Ontology concerns itself with the beliefs individuals have about the nature of social reality whilst, epistemology is concerned with the ways individuals gain knowledge to understand that reality. Ultimately both lead the social researcher to methodology, the selection of which aims to strengthen the individuals understanding of their ontological belief systems (Grix, 2002).

Two opposing ontologies are described in the literature (see, Goertz and Mahoney, 2012) which in broad terms, and with many guises, reflect the division between positivistic and post-positivistic science. A third realm sitting in the overlap between the two is described by Furlong and Marsh, (2010) as realism which shares properties

from the other ontologies and highlights that within the discourse there can be a degree of ebb and flow around otherwise fixed points.

Positivistic ontology holds the assumption that social phenomena exist independently of social actors and their knowledge of the world they inhabit. As such nothing is socially constructed and observations of phenomena can be made objectively and, without influencing that which is under observation. Epistemologically the positivist social researcher leans towards the empirical, the quantifiable and the traditional scientific process (Kuhn, 1970).

The opposing paradigm is the post-positivist interpretist tradition which, in rejecting that the social world can be independent of our knowledge of it, holds an assumption that all is socially or discursively constructed (Furlong and Marsh, 2010). Observations cannot therefore be objective as all understanding is rooted in finding the meaning behind what is said and what is done (Keller and Clarke, 2018). This thesis will in due course reflect this through the statement that 'whenever language is used there is always something else going on' (Halliday, 2004 p49) and the 'something' as captured within the concept of positioning theory (Harre, 2008) is the interconnect between language, thought and action which together construct reality. The interpretist social researcher inherently leans towards the qualitative, and qualitative ontology in respect of concepts is further rooted in semantics with the meaning of a particular concept of interest represented as attributes or characteristics of that concept (Goertz and Mahoney, 2012).

Later in this chapter the work of Vickers (1964) in relation to the concept of appreciation is cited as a fundamental influence on the development of my preferred research methodology. Within his discourse Vickers (1964) stated that social research is never neutral but fashioned by the unconscious processes that shape ones perception of reality and the value placed on it. In essence a researcher's interest and approach can never be disconnected from his individual, and implicit, ontological and epistemological position (Furlong and Marsh, 2010). It therefore follows that if this chapter is to be a critical exposition of the preferred methodology then a reflective aspect of that must be related to my personal ontology

I entered my nursing career working in a hospice. Here I was struck not by the disease processes but rather everything that was going on around each person in respect of

language and ritual. In particular what confused me was how such things differed within and without the hospice, how joy and celebration could be found in the experience of illnesses that others found so horrific and frightening that they could not be mentioned. Sontag (1978) opened my eyes to the world I was witnessing and the role, and power, of language and metaphor as society attempts to ease its fears by blaming those who become ill and ascribe something akin to a personality to a disease process.

These thoughts followed me into my mental health nursing career and in the early days of training in a large county asylum with its own culture, belief systems, prejudices and narrative. The people fascinated me whilst much of the practices I found questionable and in particular I found beliefs and behaviours towards people with dementia at odds with my beliefs and values. There was no respect, there was no regard for the life each person had led and care was ordered around tasks undertaken with little or no compassion. An inspirational and frustrated ward sister led me to the work of Kitwood (1997) relating to a person centred dementia care (which has been described in Chapter One) and to resonance with what Dewing (2008) later called a moral concern for others. By this point as a ward manager in dementia care I was questioning why we seemed to find this state of affairs acceptable and why we didn't change anything, why we spoke the way we did about fellow human beings who needed our care and why the attitude was one of 'that's just how it is'. So, I changed things. I ran my ward and trained my team on person centred principles and values and the world (within that ward changed). I learned a major lesson that has been shown by others (see particularly, Dean, Briggs and Lindesay (1993) work on Domus philosophy) in that if there is sufficient will to do so the world which we construct around dementia care could be deconstructed and rebuilt differently. This followed through into my academic development, my own research portfolio, my publishing history and as a senior nurse my ability to influence service development.

I have come to know that my ontological paradigm is interpretist, I constantly lean towards the qualitative and as such I accept the bias inherent in my world view. I acknowledge the criticism that what may come out of this research is my construction of other people's constructions of what they and their compatriots think (Geertz, 1973). However, that should not diminish its value and the individual voices of those people and their compatriots, my research participants, will be given considerable space in

this thesis. My ontology has been a consistent aspect of me (even when I didn't know what ontology meant) reflecting the view of Furlong and Marsh (2010) that my ontology is my skin, it is not a sweater it cannot be taken off and replaced. It can however be developed and strengthened so, on commencing this lengthy and challenging period of doctoral study my encountering of the seminal paper by Cooperrider and Srivastva (1987) setting out Appreciative Inquiry spoke as powerfully to me as had Sontag (1978) on language and Kitwood (1997) on humanising dementia care.

The selection of Appreciative Inquiry is therefore not a random choice it is a conscious decision because epistemologically it best fits my interpretist ontology. Cooperrider and Srivastva (1987) identify the principle of simultaneity and state that once the first question is asked change begins. The nature of that change brought about by social agents is that it does not exist independently of our understanding and interpretation of it. It follows that social researchers should be explorers not just technicians (Cooperrider and Srivastva, 1987) and there is much to explore within the worlds of nursing, compassion and dementia care. So much so that additional data analysis methods are required. Functional linguistics reflects the power of language to create social reality and this thesis will show that there are differing conceptualisations of compassionate care and that once the concept is voiced it exists and its characteristics open to exploration and interpretation. Positioning theory (Harre and van Langenhove, 2008) allows that voice however ephemeral or contradictory it may be, to be drawn out of the discourse and captured as an aspect of each research participant's agency.

3.2 Methodology

Appreciative Inquiry defined and justified

Appreciative Inquiry is an approach towards bringing about change within social organisations that involves the application of a specific phase model to engage and work with those affected by change as co-researchers and equal partners in the process. This democratisation of research offers the potential for nurses to develop novel conceptualisations that have meaning for them. Consequently democratic participatory research possesses the potential to both mitigate for low levels of individual absorptive capacity and promote a generative discourse sufficient that practitioner behaviour may change. Such a paradigm is only to be found in the post

positivistic world as the traditional positivistic system of inquiry would place the 'democratic' as having no relevance in comparison to the research credibility that 'control' would achieve.

So fundamental is the concept of democratisation to social and organisational change that Lewin, (1951) served notice on positivistic science as having only a minor role to play in understanding social organisations and almost none in facilitating social change. Embedding the researcher in the social setting, working with the group, acknowledging interdependence and collaborating to drive change through action were promoted as the only routes to generating new social theory (Lewin, 1951).

Appreciative Inquiry as an approach to research is viewed in many ways all of which build upon its initial definition. If reconnoitred through the lexicon of words and phrases that often emerge when it is discussed then Appreciative Inquiry is; a dynamic *transformational* mechanism (Richer et al. 2009; Bushe and Kassam 2005) that adopts a *relational constructionist* stance (Trajkovski et al, 2013) evidenced through a *discursive* process and anchored in an *appreciative or affirmative* way of thinking about change and those who *collaborate* to bring it about (Watkins and Cooperrider 2000). Appreciative Inquiry practitioners believe that all organisations are socially and narratively co-constructed as affirmative systems with the emphasis placed upon discovering what gives life to that system when it functions at its best. As such, Appreciative Inquiry maintains that in every organisation there is something that works and works well (Hammond, 1996) but more importantly that there is virtue to be found in discovering what that might be in order to learn from what is 'good, strong, already working and already being achieved' (Liebling et al. 2001, p163). Accordingly, Appreciative Inquiry is transformational, it is related to change and it takes a dynamic stance about how change is brought about; Appreciative Inquiry is democratic, it promotes collaboration between the researcher and those being researched as they assemble new social theory; Appreciative Inquiry is appreciative, it looks to learn from positive experience and narrative; Appreciative Inquiry is generative, it seeks to influence how others, as individuals or collectively as organisations, think about what they do, how they do it and why, and; Appreciative Inquiry believes that all social systems or organisations can be deconstructed and reconstructed if there is the will to do so.

Fundamentally Appreciative Inquiry offers a novel, but increasingly tested, approach that is concerned with both the pursuit of knowledge and with acting as a method for collective action, both of which require it to ask the kind of questions that are not raised along the whole of the continuum from positivistic science to the standardized problem solving model of Action Research (Cooperrider & Srivastva 1987).

Antecedents

Whilst Appreciative Inquiry belongs within the Action Research family it does not sit there wholly at ease. To understand the relationship one needs to briefly rehearse the fundamentals of action research and then review the considered action of Cooperrider and Srivastva (1987) to position Appreciative Inquiry as part of a “conceptual reconfiguration of action research” (p129). Set out by Lewin (1946) Action Research is an approach towards achieving change that places emphasis upon the democratisation of research within a problem solving model. Its emergence lies in the context of a dilemma faced by community leaders in the 1940’s segregated world of the USA. Those leaders possessed an eager and enthusiastic desire to improve integration (between minority groups and the wider society) but lacked any understanding of an effective process for change. The transformational potential of goodwill on offer from well-intentioned ordinary people was not lost on Lewin but crafted into an argument for participative social enquiry that could pursue collaboration, on equal terms, between the researcher and those being researched. That process, he concluded, was Action Research which he viewed as an approach with a triplicity of purpose allied to one enduring core principle (Lewin, 1951).

Firstly there was a purpose attached to the study of a particular social setting, group or system to identify and describe the inherent problems that require change. Secondly, some form of social action was taken to effect that change and thirdly; the whole process including the outcomes was evaluated. The core principle being that there was no purpose to the process unless those individuals who make up the setting, group or system were involved in the co-production of the research being undertaken; in short, the democratisation of the research process. Action Research therefore distanced itself from positivistic science whilst retaining scientific validity as a research

methodology whose process was rooted in the active participation of non-researchers. For Lewin process was focussed around a series of cycles with four distinct elements; planning; acting; observing and; reflecting (Lewin, 1946). It was through this cyclical process that Action Research gained prominence as primarily a dynamic problem solving methodology. However, a casualty of that was the intention for Action Research to be generative and, the belief that the quest for social innovation was as important as the pursuit of social action to underpin the process of change were lost. Thus, whilst Lewin positioned Action Research as the only valid method for generating social theory it ultimately fell victim to claims of a failure to do so:

‘... it is suggested that the primary barrier limiting the potential of action research has been its romance with action at the expense of theory’
(Cooperrider and Srivastava, 1987, p130).

The concern raised was that any approach oriented around problem identification is itself problematic in that without the problem it has no raison d’être. All too often as Action Research searched for the problem it created the perception that any organisation, its groups or systems, must inherently have a problem if not be the problem. On reflection this may not be the most appropriate starting point for democratic participation. Ultimately, as Lewin introduced Action Research to correct the deficiencies of positivistic science so Cooperrider and Srivastava (1987) introduced Appreciative Inquiry as an attempt to conceptualise the kind of corrective mechanism required following the failure of action research to realise its promise. Underpinning that corrective mechanism were the concepts of appreciation and generativity that Cooperrider and Srivastava (1987) brought together as being as influential as democratisation.

Appreciation

Vickers (1964) conceptualised appreciation as the process of relating to the elements of a social system where that system may be an individual, an institution or some other less formalised human group. In relating to it one is offered the capacity to gain a heightened understanding of that system and its meanings within the context of the particular world it inhabits. It is ultimately through knowing this ‘appreciative world’ that one can most effectively and deeply explore those things one wishes to change. According to Vickers (1964) appreciation is a complex, continuous cyclical process

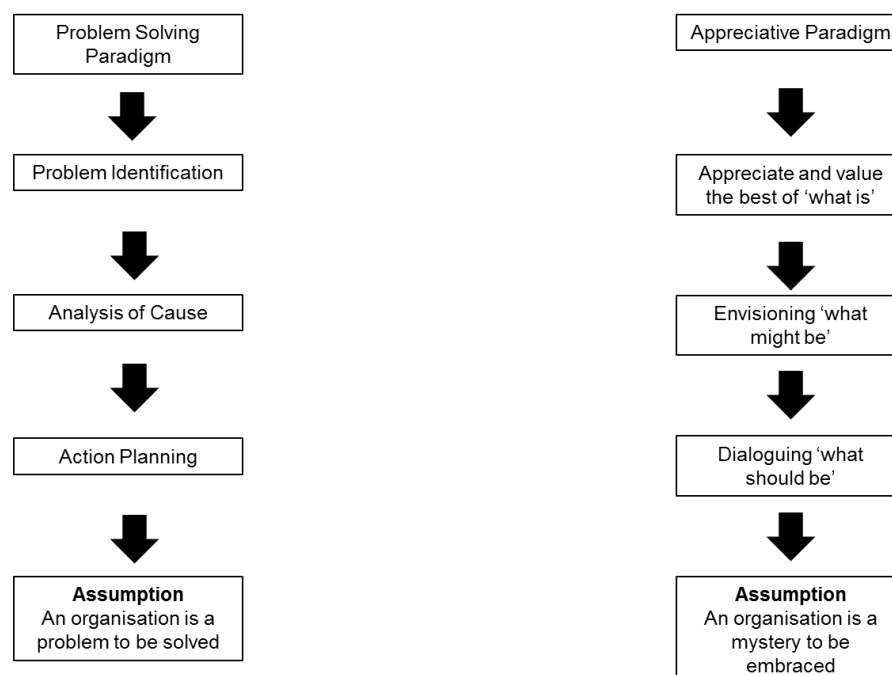
that encompasses three aspects; perception, judgment and action. As one works through the cycle, judgements are made about the perceived state of the system that is under examination, and actions to bring about change are proposed. These suggestions can never be neutral but always influenced by the unconscious processes that shape one's perception of reality and the value placed on it. As such, some may adopt a critical or deficit oriented stance as readily as others lean towards the positive. Whatever the unconscious predisposition, the cyclical model that underpins judgement formation is the same. Beyond the model lies the metaphysical world of appreciation which highlights the philosophical distance between a traditional problem solving approach, as adopted by Action Research, and Appreciative Inquiry's belief that social organisations contain 'life giving forces' to which individuals are drawn and inspired to take collective action (Thatchenkery, 2004). Inhabiting this world are concepts such as mystery and miracle that present as further reconfigurations of Action Research in that one can either regard a social organisation as a problem to be fixed or, as a mystery to be appreciated or, as a miracle for actually existing in the first place. It is ultimately through knowing this 'appreciative world' that one can most effectively and deeply explore those things one wishes to change. Vickers further argued that the process of appreciation is unconscious and that each individual instinctively leans towards a positive or deficit oriented stance (Vickers, 1964).

Inspired by this paradigm Cooperrider and Srivastava (1987) suggested that there were different ways of studying the same phenomenon and as the researcher elected to adopt one paradigm driven method over another then so that researcher had already started to directly influence the outcome. Such a belief underpinned their criticism of the standardized model of action research as fixed around a deficit oriented stance that concerned itself with seeing the world as made up of problems to be identified and fixed. That standardized model, they argued, had led to research fatigue through its repetitious use and caused action research to have lost its Lewinian vision to be adventurous, refreshing and revitalising (Lewin, 1951). The result for social researchers was dire:

'Instead of explorers we have become mechanics' (Cooperrider and Srivastava, 1987 p162)

To be liberated from that they introduced Appreciative Inquiry as a way of moving away from problem solving towards a more positive pursuit of discovering social innovation and set this out (Figure 1).

Figure 1 – Appreciative Inquiry - from Problem Solving to Positive Innovation



This movement to a large extent influenced the first (of four) principles that have guided the subsequent development of Appreciative Inquiry namely that:

'Research into the social (innovation) potential of organizational life should begin with appreciation' (Cooperrider and Srivastava, 1987 p160).

Rooted within this principle was the fundamental belief that every social system does, in reality and to some extent, have parts that actually function, work or perform well and it was these parts that research should focus upon. In setting this principle Cooperrider and Srivastava (1987) positioned social research as existing to identify these positive aspects, to strive to understand them and through that to discover the

organisations true potential. Whilst influenced by Vickers (1964) exposition of appreciation they clearly began to move this in a fundamentally new direction. Where Vickers argued that the process of appreciation was unconscious (Vickers, 1964) Cooperrider and Srivastava (1987) suggested that the choice was less unconscious or intuitive and that social researchers could, and did, make conscious choices in respect of methodology. Clearly in favouring the social researcher as 'explorer' rather than 'mechanic' Cooperrider and Srivastava (1987) reflected some alignment to Vickers (1964) view that the pursuit of social research was to achieve a heightened understanding of a social system alongside a deep exploration. However, whereas Vickers (1964) favoured the outcome of such exploration as the identification of those things that one wishes to change, Cooperrider and Srivastava (1987) rejected that as too close to the standardized Action Research model of problem solving.

Generativity

Within their criticism of action research, Cooperrider and Srivastva (1987) outlined that an undesirable state of generative incapacity had been achieved. This was, in their opinion, directly related to the emphasis placed on problem solving which had driven out the appreciation needed to acknowledge that:

'True science begins and ends in wonder' (p131).

For Cooperrider and Srivastva (1987) losing the wonder was inexcusable as generative capacity had to be at the very heart of social research outcomes. Gergen (1978) set out that such an approach should lead to the kind of discourse that can challenge prevailing assumptions to the point of "*transforming social reality*" (p1346). The capacity to do so was rooted in his earlier concept of 'generative potency' (Gergen, 1978) or the strength to provoke a normative dialogue through which arguments could be proposed, refuted, or defended about the alternative conceptual possibilities that change could bring. The findings presented later in this thesis will demonstrate that Appreciative Inquiry has sufficient generative capacity to reach beyond the deeply rooted and simplistically seductive dominance of the traditional dementia care paradigm. By doing so it can support some nurses to glimpse an alternative to the status quo. In considering this one is minded to establish the nature of generativity, the relationship it has with Appreciative Inquiry and outline any existing

evidence relating the two to dementia care. To begin, it is necessary to consider the traditional view of the function of theory and then to rehearse those arguments that are raised as a challenge to that view.

For positivistic science the crowning glory of achievement is reached when one emerges from a rigorous testing process with an understanding of the links between variables for whatever may constitute 'the whole' (Wasserman & Mcnamee 2010). One can continuously re-engage with that process to create increasingly accurate levels of understanding that can underpin increasingly accurate levels of prediction and control (Gergen, 1982). Positivism is therefore a philosophy of science that holds to only one understanding of valid knowledge (a truth) being that which is derived at through a logical or mathematical process that is built upon a series of testable explanations and predictions; from the perspective of positivistic science everything else is just speculation (Gergen, 1982). However, when this traditional view is applied to the understanding of social organisations, or to supporting effective social change, it is found wanting. As stated earlier, Lewin (1951) rejected positivistic science as having nothing but a minimal role to play, essentially little beyond offering descriptive quantitative data. An alternative view emerges when one steps back and questions the concept of understanding or at least considers that understanding is related to meaning. From this emerges an interpretive approach to inquiry from which springs Action Research and subsequently Appreciative Inquiry. Such a new approach is courageous as what is proposed is nothing less than a paradigm shift within which theory is no longer judged in terms of its predictive capacity but rather its generative capacity (Cooperrider and Srivastva, 1987).

For Gergen the 'generative capacity' of theory was rooted in his earlier concept of '*generative potency*' (Gergen, 1978, p1344) or the strength to provoke a normative dialogue through which arguments about the alternative meanings that change may bring could be proposed, refuted, or defended. The status of 'theory' was no longer to be conferred by asking 'does this proposed theory conform to the observable phenomena?' but rather by answering questions focussed around whether it presents provocative new possibilities for change or the extent to which it could stimulate this normative dialogue. If the theory in question were to win the day then it would produce a shift in the collective consciousness sufficient that there would be consensus about

the new social reality. Such a shift in collective consciousness would be a profoundly powerful action demonstrating success for the generative intention of theory to:

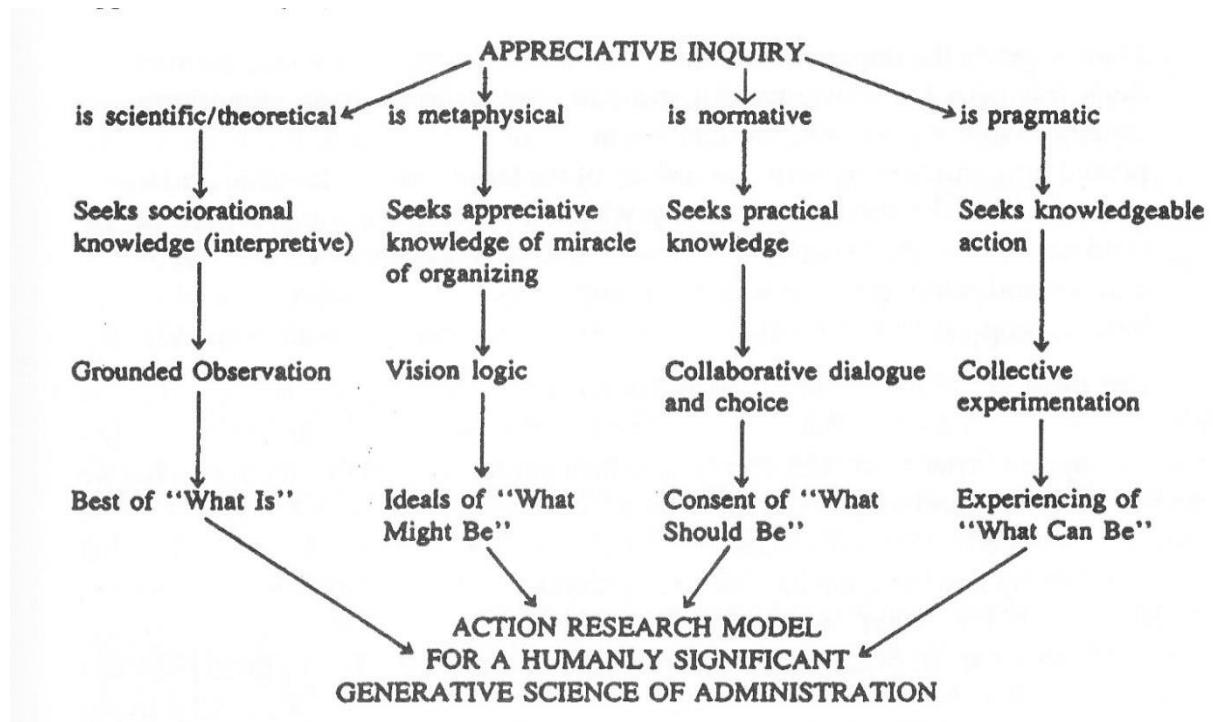
'Challenge the guiding assumptions of the culture, to raise fundamental questions regarding contemporary social life, to foster reconsideration of that which is 'taken for granted' (Gergen, 1982, p109).

The generative potential of Appreciative Inquiry therefore lay within a process that sought to liberate the imagination of participants and by doing so drew out innovative new ideas that could stimulate normative discourse. To fully realise this, potential attention would need to be placed on the quality and skills of the lead Appreciative Inquiry practitioner, a role that could often be played down in a body of literature that aimed to describe a participatory research process in which the Appreciative Inquiry practitioner should be regarded as just another participant. However, whilst the democratic stance is important so too is the effective use of the process and to facilitate generativity there must inherently be a lead person (Haringsma et al. 2011). That role, they argued, has two fundamental aspects, firstly the asking of generative questions that can shift participants out of their normal mind set and; secondly the reawakening of the participants' imaginative spirit. Bushe (1998) had previously explored the role and found its primary focus to be around shaping the discursive process from which new ideas and generative images (phrases, metaphors and narratives) would emerge. As the participants talk, the facilitator, reflecting the poetic principle, frames, shapes and embellishes the narratives into a language that the group can make use of to talk to each other in increasingly new ways.

Process

Whilst setting out Appreciative Inquiry as a corrective mechanism, Cooperrider and Srivastva (1987) went to some lengths to demonstrate that Appreciative Inquiry was not outside the broader scientific research community but rather lent itself to a model that, to some extent, shared aims with the scientific, the pragmatic, the metaphysical and the normative. They articulated this through their initial model (Figure 2) which as the first fundamental representation of Appreciative Inquiry captured how it sought to justify its place in that wider scientific community.

Figure 2 – The Initial Appreciative Inquiry Design (Cooperrider and Srivastva, 1987 p160)



In developing the initial Appreciative Inquiry model Cooperrider and Srivastva (1987) stated that they were guided by four principles all of which one might argue have stood the test of time and have influenced the further development of Appreciative Inquiry. These principles may be set out as;

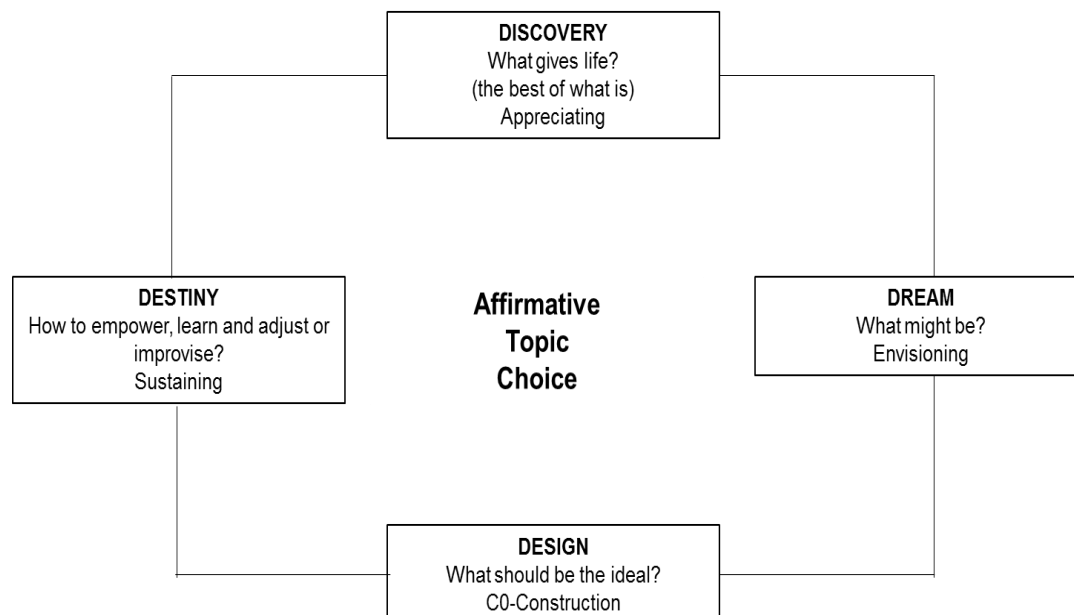
- 1: Research into the social (innovation) potential of organizational life should begin with appreciation. Essentially they advocated that in every social organisation there is always something that works well and it is that which should be the focus for socio-rational research.
- 2: Research into the social potential of organizational life should be applicable. Any theoretical knowledge that is generated should have relevance and meaning to all and be presented through everyday language and symbolism.
- 3: Research into the social potential of organizational life should be provocative. This positioned Appreciative Inquiry as both 'pragmatic and visionary' (Cooperrider and Srivastva, 1987 p161) and, provocative in that the abstract becomes normative as the

individuals who make up the social organization shape their world through their own imagination.

4: Research into the social potential of organizational life should be collaborative. The democratic nature of Appreciative Inquiry was to be evidenced through collaboration between the researcher and the members of the social organisation.

Cooperrider (1996) built upon the seminal 1987 paper by briefly introducing the 4-D approach for Appreciative Inquiry (Figure 3) that was later elaborated upon (Cooperrider and Whitney 2001). To some this could seem reductionist as the approach concerned itself only with the fourth level elements of the initial model. However it is perhaps more accurate to suggest that it was expansionist as it placed a very strong pragmatic emphasis upon the collaborative actions that a group must understand, and work through, in order to become generative and subsequently bring about change.

Figure 3 – The 4-D Approach



It has been emphasised that although not cyclical in nature the 4-D approach of Appreciative Inquiry is not linear as the emphasis is on continuous organisational development rather than a more traditional start and finish problem solving model

(Reed, 2007). The model does, however, allow one to operationalise a different way of thinking about change through a set of steps, stages, milestones or way points that can be used to monitor progress.

The Four Elements of the Appreciative Inquiry Cycle

Discovery:

Cooperrider, (2005) stated a profound position in very simple terms so that:

'At this point, inquiry begins' (p87)

As soon as the first appreciative question is asked, as soon as the first story is told the process of change has begun and there can be no going back. Attention was placed upon identifying who to ask and who to be invited to become story tellers as everything that follows would be built upon the experiences of those who comprised the social organisation when it was functioning at its most vital and alive and what it was about the organisation that made those experiences possible (Fitzgerald et al. 2001). Discovery was to involve the application of appreciative questions that could differentiate Appreciative Inquiry from both positivistic science and problem driven Action Research. Those affirmative questions would be set within an interview that aimed to elicit the positive capacity of the organisation (Havens et al. 2006). The quality of questions remains important as they must draw out from participants their creativity, imagination and vision (Cooperrider, Whitney and Stavros, 2005). To support this process and to maintain the democratic credentials of Appreciative Inquiry it is always the participants themselves who undertake the interviews (Bushe 2011).

Dreaming

This second phase shares interview material and participants adopt a constructive position as those narratives, representing 'moments of organisational life' (Cooperrider and Whitney 2001, p11), are used to build a database of positive imagery, metaphor and stories that are rooted in positive affect. As the database is collectively constructed participants review its total contents and make selections so that the best of the past is used to offer a glimpse of what the new or better world within that social organisation

could be (Fitzgerald et al. 2001, Cooperrider and Whitney, 2001). Common aspirations are elicited and, in some way, symbolised by the group (Bushe 2011) who, having established a positive core of material are asked to reflect upon what exponentially expanding this core might mean for the organisation (Havens et al. 2006). Such reflections become normative and from that the most compelling ideas are summarised and progress forward to the next phase within which participants are challenged to begin constructing:

‘What the world is calling us to become’ (Cooperrider and Whitney, 2001, p12).

Design

Having dreamt what might be participants begin grounding this in reality by designing appreciative systems that may support the co constructed dreams and crafting these as concrete and committed proposals for the new organisational state (Bushe, 2011). These proposals, termed provocative propositions’ align to the third of the original guiding principles as participants who make up the social system are now starting to shape their organisation through nothing more than their own imagination. Provocative propositions are bold, affirmative statements that express the collective vision in the present, rather than future, tense (Fitzgerald, Murrell and Newman, 2001) and encourage participants to review the structures and processes that need to be in place to secure that vision (Havens, Wood and Leeman, 2006).

Destiny (Delivery)

The final part of the process is realising the collective vision and implementing change. Working together participants ground provocative propositions into action plans that lead to project groups emerging to undertake the required actions (Fitzgerald, Murrell and Newman, 2001). There is an inherent tension associated with this phase as project groups traditionally fall back upon the need for outcomes that can be measurable as objectives to be met through targets. Such aspects, and indeed the addition of the alternative title ‘delivery’, are reflective of the standardized action research problem focussed model and anathema to Appreciative Inquiry and yet if

they do not occur there is a possibility for post design energy to dissipate over time. An improvisational model that suggests a way forward has been advocated by Bushe (2011). This model sees participants making personal commitments to undertake those actions they believe will support change. Organisational leaders reinforce that there is no formal action plan and that participants have authority to act within the remit of the provocative propositions.

Over the course of time the 4-D model for Appreciative Inquiry has become underpinned by a new set of five principles aimed at acting as a further means of communicating the approach (Cooperrider and Whitney 2001).

1: The Constructionist Principle

Through the discursive process explanations or theories emerge to explain aspects of a social organisation and if they possess generative capacity then they have the potential to shape perceptions, thinking and preferences. It is these kinds of social theories that influence the collective vision for a desirable future state and consequently the action needed to promote change is cued. Cooperrider and Whitney (2001) suggested that constructionism existed as essentially a normative force built around spoken language and discourses of all kinds. They stated that relationships between individuals within social systems were the locus of knowledge as expressed through language and what underpinned that process was imagination which represented the most potent of all social constructional tools. This was elaborated upon as Cooperrider and Whitney (2001) made clear that the 4-D model was all about constructing a new future for the social organisation as the emphasis would move away from understanding the past towards anticipating and articulating a future state.

2: The Simultaneity Principle

Inquiry and change are not separate events but rather they occur simultaneously; so, consequently inquiry is intervention (Cooperrider, Whitney and Stavros, 2005) and as one starts to inquire into something then one starts to change it as the very seeds of change are to be found in the discourse that Appreciative Inquiry holds to be fundamental (Bushe and Kassam, 2005). That discourse leads to reflection and in turn that leads to new ways of thinking and acting (Reed, 2007). Stating this principle

revealed some of the distance between Appreciative Inquiry and the standardized problem solving model of Action Research. For Appreciative Inquiry change starts as inquiry starts whereas for Action Research change occurs at the end of a process.

3: The Poetic Principle

The first two principles set out the belief that from the initial question asked in an Appreciative Inquiry interview there is no going back and change has already started. Questions are therefore important to Appreciative Inquiry as they open up participants to the transformational power of language and evoke feelings, meanings and understandings that may become potent symbols or icons within the stories that are shared (Bushe and Kassam, 2005). The social system was likened to an open book in which the story of that organisation was constantly being co-authored and its future direction shaped only by the imagination of participants (Cooperrider, Whitney and Stavros, 2005).

4: The Anticipatory Principle

The power and value of imagination was again placed centre stage as social systems were claimed to always project ahead of themselves, looking towards an 'horizon of expectation' that drew the future into the present (Cooperrider, Whitney and Stavros, 2005). All social organisations are therefore essentially illusory and only exist because there is a collective will for them to do so. Anticipating the future state by asking what they will become and what they will achieve serves to maintain the existence of the organisation (Cooperrider, Whitney and Stavros, 2005) as it is images of the future that will drive current behaviour (Cooperrider and Whitney, 2001). All parts of the 4-D model are rooted in this belief as all discourse is focussed upon how things can be and participants are constantly led to move from thinking about the past to dreaming about the desirable future state and committing in the present to bringing this about.

5: The Positive Principle

To seek and work with the positive has not been at the core of organisational change and one can readily see how the standardized problem solving model of Action Research takes the opposite stance with its focus upon the negative aspects of organisational life. This is anathema to Appreciative Inquiry as if one has an unconscious negative predisposition (Vickers, 1965) then one will either view the

future as bleak or hopeless and believe that there is no point in aspiring towards change (Reed, 2007) or will come to see the world as a problem (Cooperrider and Srivastva, 1987). In continuing to establish distance between the two methods, Cooperrider and Whitney (2001), advocated that Appreciative Inquiry was a much healthier approach to simply stop trying to fix the world. The emphasis shifted to the pursuit of the considerable positive energy needed to bring about change that was to be found in the collective hope, inspiration and joy of collaborating (Cooperrider, Whitney and Stavros, 2005) as the process gains momentum and creativity accelerates opening up new ideas (Bushe and Kassam, 2005).

3.3.2 Analytical Methodology I - Positioning Theory

Positioning theory analyses the discursive content of personal stories (in this case derived through the Appreciative Inquiry approach) to make each participants actions understandable in the context of the language they use to position themselves or to describe the positions that they take (Harré et al. 2009). The discursive nature of positioning theory has much to offer the analysis of organisational change but one is cautioned against an oversimplification of analysis (Zelle 2009). With that in mind it is important to explore the theoretical aspects of positioning before setting out its application as an analytical tool. Positioning theory perceives the individual as being held captive, willingly or otherwise, within the very restrictive conventions of the social roles that one has adopted or been assigned. Positioning is not about freeing one from those roles but rather about how the individual makes sense of them and deals with the inherent potential for tension and conflict that restriction brings (Harré & van Langenhove 1999). It therefore follows that one cannot undertake an exposition of positioning without first giving some attention to the concept of role and of role theory.

Role

Role theorists propose that social roles are fundamental to the attainment of a stable social structure within which all members are permitted to live together and to interact with each other. From a functionalist perspective roles dictate what one is permitted

to do as well as what one actually does, so each role has embedded within it a set of socially and culturally determined (and mediated) rules, rights, duties, patterns of thinking, perspectives and values which have a deterministic influence upon the social interaction that is being enacted (Linton, 1936). The relationship between rights and duties as a simple and elegant aspect of the social structure was set out by Harre, (2015); duties, he argued, are always oriented towards the other who has a vulnerability and are assigned to one who can overcome that vulnerability whilst rights are what one exercises as a result of ones vulnerability with the expectation that the other will fulfil his responsibility towards one. This expectation is possible because of the process of socialisation and the explanation that all actors have common expectations for social roles because all have been tutored in that way since birth. So, one behaves predictably within a context because one has learnt the contextual rules. Consequently in adopting the role of nurse one has to not only act in the prescribed and regulated way but also one has to tailor ones professional behaviour to the specific context within which one nurses.

Social interactionist theorists placed emphasis upon the contributions made by individual actors as they played out their roles and made sense of the limitations that were placed upon them (Turner, 1979, 1978, 1974). Therefore all social interaction was seen as the enactment of the many and varied socially defined categories or roles which one inhabits and which give one a sense of social identity. Through that identity one has legitimacy to encounter the social world and to become part of social groups, the membership of which gives an individual not only a social identity but also their personal identity (Mead, 1934). Overall, role theorists suggested that in the overwhelming majority of cases human behaviour was patterned, that humans across cultures were generally similar in the behaviours they exhibited and once we knew the person's identity and context his behavioural responses were generally predictable. If one felt disadvantaged in ones assigned social group or dissatisfied with one's social identity then in order to change ones social behaviour one must first changes ones role or group but where an exit is not possible (such as in the case of race, gender or disability) then conflict would emerge and one must changes ones beliefs or attitudes about ones role.

The whole is a very tidy and attractive way of viewing how people achieve consensus, agree to form society and enable it, in all its complexity, to function. Roles therefore bring a degree of predictability to the social interaction provided that one acts within the limits and expectations of one's role. However, society is messy and not all conform to the consensus (Biddle 1979). This has led to criticism that roles are too deterministic and role theory not flexible enough to allow for consideration of individually determined action or interpretation of the rule set (Turner, 1968) or even to have a space for the rejection of rights and duties that have been assigned (Harre, 2015).

Positioning

Like roles, positions are associated with sets of rights and duties that place boundaries around social acts (Harre et al. 2009). However positions are often described as ephemeral which places them as a contrast to roles whose rules may be fixed in place over whole parts of one's lifespan and are therefore bound up with social obligations and occupations (Benson 2003). Positions are more dynamic being situation specific and a defeasible set of rights and duties that are subject to a normative discourse within which the set may be disputed and re-negotiated allowing their focus to shift within the space of the interaction itself. Positioning theory is concerned with what happens in that space, in that moment and in that relationships between language, thought and action (Harre, 2008), in how one reasons and in particular with the meanings that emerge (Harré & van Langenhove 1999). Those meanings relate to oneself, ones identity and ones place in the social world and emerge as one acts to position oneself throughout the dialogue. Living as it does in the 'dynamic flux of social life' (Benson, 2003 p205) positioning reflects the belief that all persons are immersed in an ocean of language and constantly involved in intimate interactions with others as together they construct thinking at the social, public or communal level (Vygotsky 1978). Positioning theory is captured in the interconnectedness between the three dimensions of the positioning triangle which comprises of the position, the illocutionary force and the storyline.

The Position

Positions are collections of rights and duties expressed through thoughts, actions and speech which relate to what is socially possible and socially acceptable (Harré & van Langenhove, 1999). Positions may be activated at different levels of social intercourse (the intrapersonal, interpersonal and intergroup) and one may occupy more than one position at a time in the same social interaction. Such a concept itself positions interaction particularly at the micro or individual level as a dynamic, fast changing world of mutually interacting, influencing and potentially inconsistent identities which offers an insight into the complexity of society that rigid, inflexible roles cannot compete with. Positions also reveal the mechanisms by which the individual or the group constructs meaning thereby enabling one to identify pressures, inconsistencies and make some sense of this otherwise complex social world (O'Connor, 2007). Some actors may 'position' themselves within their socially assigned 'roles' whilst others make want to challenge and seek out those things which are negotiable. Harre and Moghaddam (2003) state that positions are also beliefs about rights and duties and so as one believes them to be defeasible they become part of a process within which ones identity is subject to constant reconstruction and in turn both the negotiation and construction work become a meaningful part of the narrative.

The Story Line

Story lines involve positions that relate in some definite way to the actors engaged in the social interaction. Every such interaction involves at least one story line which is boundaried by locally accepted rights and responsibilities to the extent that it is taken for granted (Harre, 2005). For positioning theory it is 'how' and 'why' people tell their stories which is of interest. There is overlap with Appreciative Inquiry as the 'Discovery' phase involves participants telling their story (Cooperrider and Srivastva 1987). In this thesis those story lines and narratives are related to the nurse telling her peers about a time she felt proud of the care she delivered to a person affected by dementia.

The Illocutionary Force

The illocutionary force of a speech utterance relates to a very specific linguistic device associated with the meaning of what has been said; it does not concern itself with what is achieved by saying it but rather what is conveyed in saying it (Austin, 1975). The

meaningful act is performed in the moment of the utterance so long as the performer has made it clear to the audience that the act has been performed. The illocutionary act sits in a relationship with two other linguistic devices; the locutionary act and the perlocutionary act. So whereas the illocutionary act relates to the meaning being conveyed, the locutionary is simply the act of the utterance itself whilst the perlocutionary is what happens as a result of understanding the implied meaning. Whilst locutionary and illocutionary acts are performed by the speaker the perlocutionary only occurs when the audience deems it so (Scarantino 2018).

3.4 Analytical Methodology II - Functional Linguistics

The functional linguistic approach (Halliday 2006) sees language as possessing two specific functions,

1. To consider how people use language.
2. To consider how language is itself structured for use.

In considering the first of these functions (in the context of linguistic analysis) language as text is assessed as to whether it conforms to the requirements for being text or, if would be non-text which cannot effectively be analysed. Text is defined as:

'Any passage, spoken or written that does form a unified whole' (Eggs 2004, p24).

Forming the unified whole is determined by the degree of texture the piece has, where texture is seen as being an interaction between properties of coherence and cohesion (Halliday and Hasan 1976).

Coherence is seen as being the relationship between that which is written or said and the social and cultural context of its occurrence, whilst cohesion relate to its internal properties and how they bind together. The interaction between the two represents a piece which uses language in a meaningful way within a situational and cultural context. Coherence is determined by asking the following questions of the text,

1. Is there 'situational coherence' (can all parts of this piece of language logically occur together?).
2. Is there 'field coherence' (does it retain a single frame of reference or jump from one to another?).
3. Is there 'mode coherence' (is there consistency in style?).
4. Is there 'tenor coherence' (is there clarity around the role being played by the speaker?)

Cohesion may be determined by asking if, the interpretation of one element in the piece is dependent upon another and if there is or are semantic ties between different parts of the piece in different places.

That first function of language is therefore clearly related to structure. The second relates to the nature of the content and what links both of these functions is the intention of people to communicate meaning to each other (Eggins 2007). As a consequence she suggests that the basic functions of language can be reframed as,

1. What sorts of meanings do we use language to make?
2. How is language organised to make meanings?

This thesis is particularly concerned with the second of these functions and theoretically underpinning that is the position offered by Halliday (2004) that:

'Whenever we use language there is always something else going on' (p29).

By that he meant that language is structured to simultaneously make three kinds of meaning; the ideational, interpersonal and textual. The ideational relates to those things that are represented by what is said. The interpersonal to the ways in which participants in discourse act, and the textual which creates a sense of relevance to the situational context of the utterance (Halliday, 2004). Texts as a whole may be considered as elements of social events which have the potential to effect change and to shape identity (Fairclough 2003). In the context of this thesis the social events in which the text arises are the appreciative inquiry workshops. The generative capacity of appreciative inquiry offers the potential for changing practitioner behaviour, in part, by changing practitioner identity and moving the discourse away from 'what does a

nurse do' towards 'what kind of person should the nurse be'? The analysis around that relates largely to meaning-making and understanding these processes through the applied use of language.

Establishing meaning moves functional linguistic analysis into the sphere of pragmatics where the focus is upon language in relation to those who use it (Mey, 2001) and in particular the way the speaker performs with emphasis shifting away from analysing the structure of language towards the use of language (Chomsky, 1965). Meaning making in each of the illocutionary spaces is determined by the producer or recipients place within the social organisation, their interests, values, intentions, aspirations and motivations. Involved with this, and adding to the complexity of the interplay, are decisions on the part of the producer around what to make explicit or leave as implied, thereby compelling the receiver to make assumptions about what was meant.

As identified by Levinson (1983) what a speaker means by the language used may not be related to the normal use of that language and there is potential for discrepancy between 'speaker-meaning' (that which is literal) and 'sentence-meaning' (that which is conveyed). On the part of the receiver is the requirement to make judgements as to the sincerity and veracity of the speaker and how congruent the text is with the social context of its production (Fairclough 2003). Positioned thematically the link between assumptions and judgements becomes transparent and resonates with the world view of appreciative inquiry as the three assumptive themes are,

1. Existential – about what exists.
2. Propositional – about what is.
3. Value – about what is good and desirable, what could be.

A further consideration was introduced by (Grice 1957) who distinguished between 'natural meaning' (similar to the locutionary force of the text or its explicit meaning) and 'non-natural meaning' which was much more illocutionary. As such the text may be framed as natural but intended as non-natural in order to convey that the receiver needs to do or think something which is itself achieved by the recipient recognising that this intention is present within the text. To support the answering of these questions a taxonomy of illocutionary acts was offered by Searle, (1975),

1. Assertives – speech acts that commit a speaker to the truth of a proposition.
2. Directives – speech acts that cause the recipient to act.
3. Commissives – speech acts which commit the speaker to a future action.
4. Expressives – speech acts that express the speaker's attitude or emotion towards the proposition.
5. Declarations – speech acts that change reality.

For a deeper level of analysis there is a need to build upon the relationship between the locutionary, illocutionary and perlocutionary forces that have been cited above. In particular as one seeks to understand how this group of nurses collectively create a conceptualisation there needs to be further analysis of the illocutionary aspects of provocative propositions as this thesis has hypothesised that this is where the concept will be found.

3.5 Summary of Chapter Three

This chapter has extensively set out Appreciative Inquiry and justified its selection as the research methodology. It has been shown that whilst Appreciative Inquiry has its roots in the Action Research family it has broken away from that and established a pedigree of its own. It is a methodology whose approach is democratic which is fundamental to the active involvement of the nurse participants and aimed at facilitating them to confront their own practitioner behaviour.

The chapter has introduced the theoretical architecture which will be relied upon later to support a bespoke triadic model of data analysis. Positioning theory is set out with a focus on the importance of making distinctions between socially ordained roles and individual positions. Accessing those positions will be important for the data analysis and this review of positioning theory has identified that it is from within the discursive aspects of narratives and workshop sessions that the data will emerge.

The functional linguistic approach has been introduced which suggests that analysis will explore what is really being said in those narratives and discourses. As stated by Halliday (2004) every time language is used 'there is always something else going on' (p29) and it is as much in the illocutionary meanings where this research will discover the conceptualisation and conceptual properties of compassionate dementia care. The next chapter moves all this along by showing how the theoretical will be worked

through as a research design to effectively release the potential of all aspects of the methodology.

Chapter Four

Research Design

4.0 Introduction

Having set out in Chapter Three the research methodology this chapter develops that further by considering the design of the study as a whole. In doing so it will state again the research questions that the study design was aiming to answer. It will outline the approach by which the nurse participants were recruited and the issues associated with that. It will show how data was collected and, in more detail how that data was analysed through a bespoke model. The reliability of the data will be discussed and assured. The chapter will also provide a guarantee of ethical probity and will transparently address the study's overall reliability, validity, generalisability and limitations. The aim is that by the end of this chapter there can be assurance that a correct approach has been taken to collect and analyse the research data. This assurance is fundamental as it is that data and its analysis which will underpin the findings that are set out later in Chapters Eight and Nine.

4.1 Ethical Considerations

Approval

Full ethical approval to undertake this research was sought and gained from the Bangor University Healthcare and Medical Sciences Academic Ethics Committee (HCMSAEC) and the NHS Research & Development (NHS R&D) panel for Betsi Cadwaladr University Health Board. HCMSAEC approval was applied for on the 23rd September 2015 and obtained on the 11th December 2015 (Appendix IV). NHS R&D approval was sought using the Integrated Research Application System (IRAS) for which the project number was 203492. The project was created on the 29th February 2016 and approved on 30th August 2016 (Appendix V). The final summary of study completion was reported and accepted on the 30th December 2018. A request for ethical approval of amendment to the PhD study protocol was made on the 28th September 2016. The amendment was to, recruit a fourth cohort of participants in addition to the three cohorts that had previously been approved. This fourth group

completed the same interview and 4-D workshop schedule as the three other groups. The difference was that these participants were drawn from a wider context and were regarded by the Health Board involved as having expertise in dementia care. Data collected from this group was not used to add to or influence the collective conceptualisation of the nurse participants but rather as an aid for the reflexive approach for discursive comparison principally within the supervisory process. That permitted a higher level of reflexivity which supported the heuristic development of the first model and will be referred to later in this thesis. The amendment was approved by the HCMSAEC on the 24th October 2016.

Consent

Nursing staff who took part in this research did so of their own free will and all had the right to decline to consent or, to withdraw their consent at any point during the study. The consent form is attached as Appendix II. Consent was informed and each potential participant had access to a study information sheet. That information sheet is offered as Appendix III. To ensure that consent was not only informed but was also freely obtained two other specific factors were considered and introduced as safeguards. These related to participant sensitivity and involved an acknowledgement of the concept of undue burden leading to mechanisms to minimise the potential for coercion. Given the importance of these two safeguards they are addressed in turn as sub-elements of the consent process.

Burden

This study aimed to involve acute hospital nursing staff whose practice was within clinical areas that brought them into frequent contact with patients who, in addition to their physical health problem, were also affected by dementia. Those areas included wards within the Medical Division such as Care of the Elderly, and the Surgical Division such as non-elective trauma and orthopaedic wards. It was acknowledged from the outset that nurses in those areas frequently worked under significant pressures. Such pressures related to the general volume of patients and the acuity of need. Frequently the admission of increasing numbers of people with dementia added additional pressure as nurses felt less confident in engaging and, inadequately trained to deliver

safe and effective dementia care. Furthermore there were the well-rehearsed difficulties in recruiting adequate numbers of staff and the challenges in balancing clinical and organisational demands. It was stated in the submissions for ethical approval, in the participant information sheet and verbally reinforced during the recruitment and consenting process that participation in this study should not add to that burden. The specific issues of coercion are addressed below.

Coercion

I cannot pretend that as a Consultant Nurse I do not hold a senior nursing position within the Health Board or, that I am known to many of the staff who work in the clinical areas from which the nurse participants involved in the research practiced. Those staff were assured that my role in this context was that of researcher and not as Consultant Nurse or senior clinician. Potential nurse participants were asked to put aside any relationship they had with me in either of those roles. That was not always easy particularly as the research itself was so closely related to my clinical role and at times there was a distinct, and unintentional, blurring of boundaries between researcher and senior nurse. In addition to this the outcomes of this research could well have been seen as informing the development of dementia strategy within the Health Board. To address this there was a very clear written statement about my role as a researcher inserted into the promotional material used to recruit participants and, there was a short verbal statement offered at the start of each interview. That statement was included in the audio-recording but, for brevity, has not been added to each transcript.

Protection of Anonymity

Interviews were audio recorded and 4-D workshops video-recorded. Those recordings could identify who each participant was and hence were kept in a secure location and used only for the purposes of data analysis. When recordings were transcribed this was also only for the purpose of data analysis and all transcripts were anonymised. Participants were allocated a code based on the location of the site of practice and of the ordering of their recruitment, so, DGH01/participant01, DGH02/participant01. A master log of participant codes and identities was held as a password protected electronic file on an encrypted computer at Bangor University. Nurse participants were

required to maintain the confidentiality of any personal information disclosed within the Appreciative Inquiry 4-D workshops. Any subsequent publication or presentation will only refer to participant codes and no nurse participant will otherwise be identified.

Prevention of Harm

It was not anticipated that participation in this research study would place participants at the risk of harm or loss. However, it was acknowledged that whilst Appreciative Inquiry focuses upon the positive, the nature of the discourse could lead some participants to become emotionally distressed. The mechanism of response was to be supportive intervention by either the research, the co-facilitator/camera-operator and, potentially by other nurse participants involved in the 4-D workshops.

4.2 Participant Management

Recruitment

Due to the nature of democratic or participatory research the sample group was essentially self-selecting and in the context of this research the associated potential bias was fully acknowledged from the start. The target group of nurses were those who were uncertain about dementia care and their feelings, perceptions or practice and curious enough to explore these within a research framework. The greatest risk within the study design was the ability of clinical areas to release staff to participate in the workshops and interviews. With this in mind the recruitment strategy was firstly to secure support from the Executive Director of Nurse with a view to promoting the potential value of the study outcomes within the Medical and Surgical Divisions. From that came a cascade process leading to a supported recruitment through which area managers for the three acute hospital sites supported and released staff who felt they could contribute and, importantly, who stated that they wished to be involved. This management support ensured a degree of commitment towards participation. The study was promoted across the previously identified areas with an open call for interested staff to consider participation. All applicants were assessed for relevance against the inclusion criteria and the researcher, in consultation with the principal academic supervisor decided who to invite and who to reject.

The Inclusion Criteria

1. Working within a clinical area that frequently delivered care to people affected by dementia.
2. Employed within the nursing workforce as a Registered Nurse, Dementia Support Worker or Health Care Support Worker by the Betsi Cadwaladr University Health Board.
3. Committed to devoting the time required to fully participate in both interviews and workshops.
4. Assured of managerial support to participate.
5. Consenting to be audio taped and video recorded as part of the data collection process.
6. Willing to work within an Appreciative Inquiry methodology.
7. Willing and able to work effectively within an Appreciative Inquiry 4-D workshop.

Sample

Each Appreciative Inquiry 4-D workshop was composed of approximately six nurses, drawn from across the Divisions of Medicine and Surgery, who were practicing within one of the three District General Hospitals in North Wales. The sample (Table 1) reflected the grading ratios found in clinical areas and the participants were registered nurses (Bands 5 through to 8), dementia support workers (Band 3) and health care support workers (Bands 3 and 4). From within this there was a sufficient breadth of experience that was captured in the individual interviews. The total consented sample size was twenty-five.

Table 1 – The Research Sample

Site	Number of participants at bands						Total
	3	4	5	6	7	8	
DGH 1	4	1	3	-	2	2	12
DGH 2	1	-	1	1	2	1	6
DGH 3	3	-	2	-	1	1	7
Totals	8	1	6	1	5	4	25

Of the twenty five nurse participants recruited one participant did not ultimately make any contribution nor respond to queries as to whether consent was being withdrawn. One participant withdrew after recording their interview as a period of sickness precluded her from involvement in any of the workshops. This left a total of twenty-three nurse participants who completed the study.

4.3 Application of the Appreciative Inquiry Methodology

Process

Twenty three nurse participants were involved in a series of Appreciative Inquiry interviews and 4-D workshops. The 4-D cycle of Appreciative Inquiry is normally delivered over one extended workshop with a duration of between two days and a week. Due to ward staffing issues (which precluded the release of nursing staff for extended periods) this was not possible and, following discussion with the principal supervisor, a pragmatic approach utilising the principles of Appreciative Inquiry within a very tightly focussed and time limited approach was adopted. Each Appreciative Inquiry 4-D workshop convened with a minimum duration of four hours and each participant was interviewed before they participated in that workshop. Interviews were tape recorded and transcribed whilst workshops were videotaped and transcribed. Initial interviews aimed to establish contextual information and an understanding of the positions, and underpinning beliefs, articulated by participants as to dementia, those affected by it and dementia care. The workshops were aimed at deriving the collective or consensus view as to the concept of compassionate dementia care.

Affirmative question setting

The Appreciative Inquiry approach involves asking affirmative questions of the group and this needed careful preparation as inquiry and change are not separate events, they occur simultaneously and as one starts to inquire into something one starts to change it through the discourse that Appreciative Inquiry holds to be fundamental. Taking this into consideration the quality of affirmative questions used in the initial interviews and workshops was crucial. Not only was this because of the principle of simultaneity but also because those question are needed to draw out from the

participants their creativity, imagination and vision. Consequently, prior to the interviews and workshops there was emphasis placed upon the crafting of these affirmative questions.

The affirmative topic choice (the key theme) around which the affirmative questions were crafted was compassion and for this study was elaborated further as the compassionate care of people with dementia admitted to the acute hospital. A consultation group with an external Appreciative Inquiry lead for a number of Welsh organisations, a cohort of Health Board staff who held the Appreciative Inquiry facilitator qualification, the principal supervisor and fellow doctoral students with an interest in the methodology was convened. That group advised on the requirements for an appropriate affirmative question for each part of the 4-D process. I then crafted those affirmative questions and the same questions were used for each 4-D workshop. The affirmative questions were,

Discovery Phase

‘Think of a time when the compassionate care given to a patient on your ward made you feel proud of the quality of care’.

Dream Phase

‘It is two years into the future. People from outside this Health Board are asking to visit your ward due to the high standard of care and, to see what compassionate dementia care looks like – what does your service look like? What is happening in the future that is not happening now? What does this compassionate dementia care look like?’

Design Phase

‘Using what we found in Discovery and imagined in Dream, can you now design the service that will deliver compassionate dementia care?’

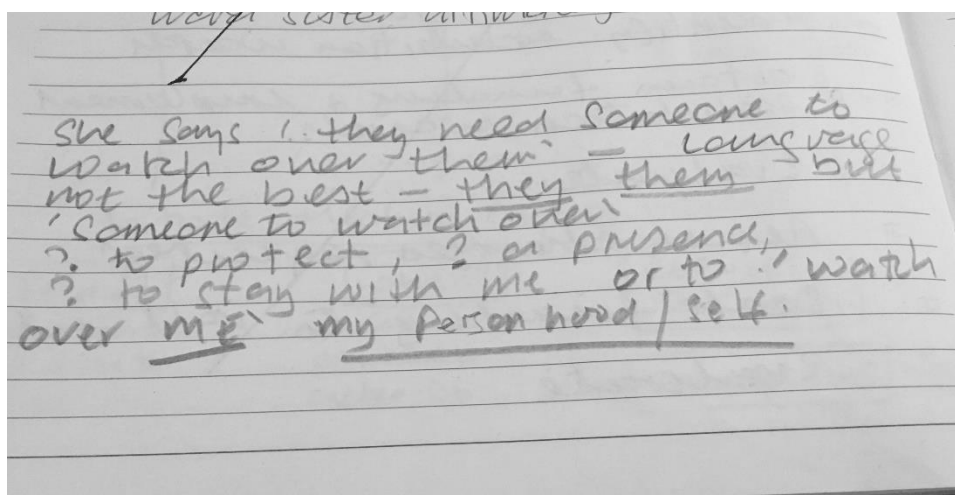
Delivery Phase

‘Create three provocative propositions whose challenges, if met, will help your ward to deliver compassionate dementia care’.

4.4 Data Collection and Security

Data was collected through recording each interview (audio) and each workshop (video). The recordings were transcribed. The output from the workshops (predominantly flip-chart papers) was regarded as narrative and retained to capture the emerging contributions made by each 4-D workshop. A small catalogue of field notes were made. These comprised of contemporaneous hand written notes made before, during and after both interviews and workshops. They were limited in number and essentially highlight aide-memoirs or comments made by the nurse participants that could be regarded as potential insightful moments, good practice or titles for themes (a representative example is offered as Image 1). All data was entered into a software system for managing qualitative data¹ and the programme containing the collected data was held securely in an encrypted programme file on a University computer that was accessible via 'desktop anywhere'. A copy of the data was held as a full back-up on an encrypted external hard drive that was kept in a locked cupboard.

Image 1 – Representative Field Note Extract 'Early signs of important themes'



4.5 Data Analysis

This section addresses the approach taken towards the analysis of the collected data. That analysis is positioned as having fundamental importance to the remainder of the

¹ QDA-miner Lite software (free edition) downloaded from Provalis Inc on 01/05/2017

thesis as the study outcomes are dependent upon correctly understanding and using the collected narrative data. It will be demonstrated that this has been done in a rigorous, methodical and trustworthy way and as such the quality of the subsequent findings can be assured. Providing that assurance lends legitimacy to two important aspects of the thesis. Firstly, that the ways in which acute nurses conceptualise compassionate dementia care and its associated properties has been determined. Secondly, that the academic architecture supporting the contextual framework to understand how the nurses arrives at this/these conceptualisations has been appropriately constructed. In providing the required assurance the concept of confirmability is addressed.

Confirmability

The triadic model of analysis was a bespoke model for the analysis of qualitative data which brought together three separate approaches one of which, positioning theory, was being used in a novel and innovative way. There was a need for the trustworthiness of that approach to be established and for it to be recognizable to other researchers as a legitimate approach (Nowell et al. 2017). Confirmability aims to establish that my interpretations and ultimately the findings offered by this thesis have been clearly derived from the data. To assure this the process by which outcomes have been reached must be demonstrated and confirmability can only be established when three requirements are met (Nowell et al. 2017). These are set out by Koch (1994) as; credibility, transferability, and dependability which if assured allows others to understand how and why analytical judgements were made.

1. Credibility

The requirement is that when another researcher reviews my analytical approach and the way it was undertaken then it can be recognized as being appropriate in terms of the data collection and data interpretation (Guba and Lincoln, 1989). To support this two techniques as recommended by Lincoln and Guba (1985) were introduced in addition to formal academic supervision, subjective reflexive discourse and informal peer supervision. The first was the establishment of an International external reference group which included PhD researchers from Belgium, Republic of Ireland, Wales and

England. That group was asked to act as critical friends and provided with appropriate sections of the analysis to discuss and comment upon. The second technique was rooted in the democratic research process and involved the nurse participants reviewing and analyzing their provocative propositions. At the close of each 4-D workshop the three propositions were discussed in terms of how they might be reframed (as an illocutionary technique) to relate directly to an underlying, but unstated, conceptualization of compassionate dementia care.

2. Transferability

Transferability refers to the extent to which the process could be generalised to involve other sites (Nowell et al, 2017). Contextually it is about how transferable that approach may be to analysing the narrative data of other acute care nurses at other sites. In part the methodology lent itself to this as three geographically distanced sites were included in the study and the same approach was applied to data analysis. It has been suggested (Lincoln and Guba, 1985) that the researcher is responsible for providing 'thick' descriptions, so that those who seek to transfer the findings to their own site can judge transferability. That concept of 'thick' description raises the level of detail beyond the superficial to a height of description from which a fellow researcher can be given knowledge, have it explained, shown how it has been applied sufficient that they can subsequently take it apart, analyse it and put it back together again (Bloom et al. 1936)

3. Dependability

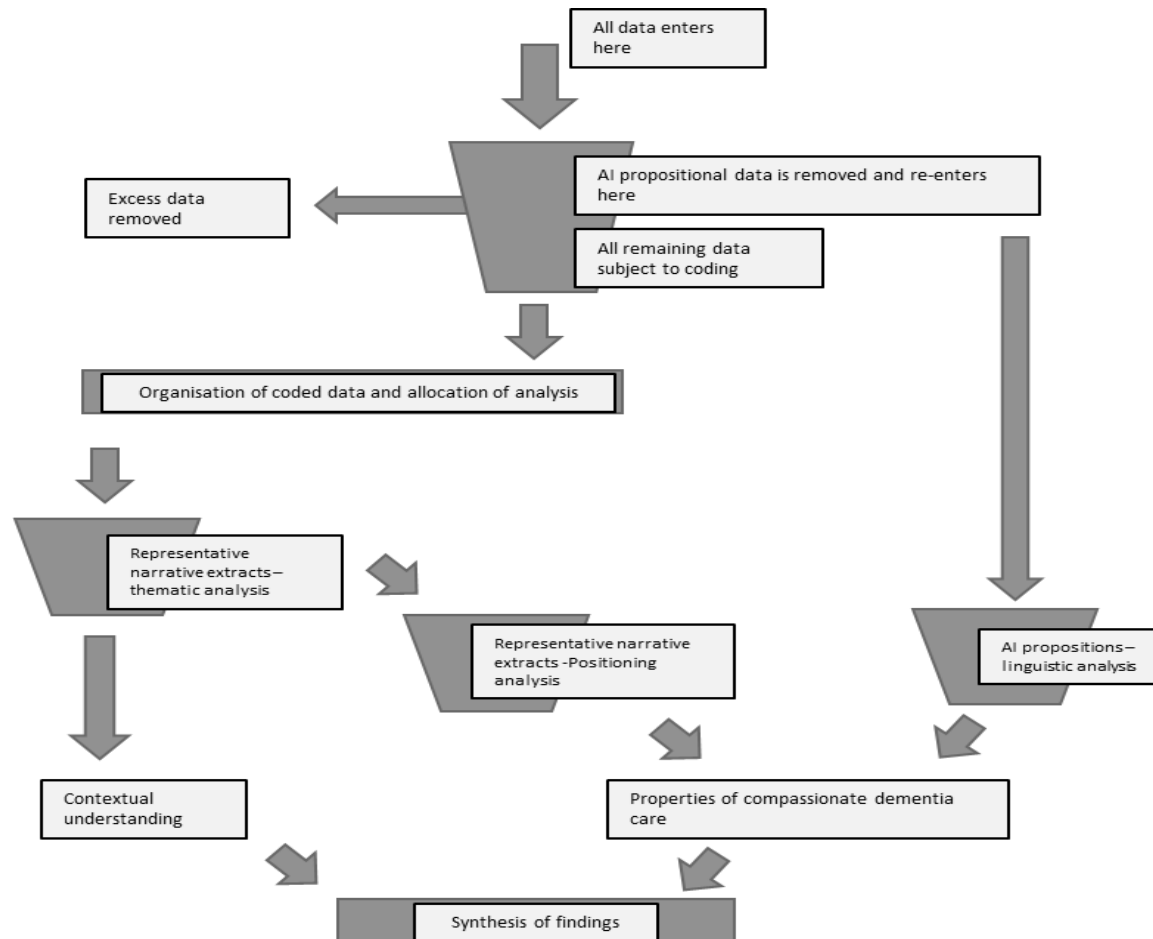
This thesis has aimed for a transparent exposition of the analytical process particularly as some aspects of the bespoke model were novel in respect of the analysis of qualitative data. When there is transparency the reader is better able to examine the research process and better able to judge the dependability of the research (Nowell et al, 2017). To achieve dependability, I have aimed to ensure the described research process is logical, traceable, and clearly documented.

4.6 The Analytical Approach

This thesis adopted a multi-layered approach towards data analysis. The aim of that approach was firstly to reach a point at which collective conceptual findings could be identified. That aim involved reaching a point at which the properties of compassionate dementia care could be set out from the perspective of nurses working across three acute hospital sites. Additionally, the aim involved understanding some of the broader context for these nurses which would allow me to subsequently hypothesise about factors which may have influenced their beliefs and practice of dementia care. A secondary aim came from a methodological perspective. In particular a suitable analysis of the generative capacity contained within Appreciative Inquiry and whether it was sufficient to impact upon certain nurse practitioners views of dementia care (see Chapter Eleven). Ultimately the purpose of the data analysis was to impose order on the data, to systematically examine it and to achieve a reliable set of evidence based findings that could themselves be connected in a process of synthesis and discussion. The multi-layered approach (Figure 4) is presented below.

The approach placed emphasis upon three types of data analysis. Firstly the thematic analysis which was seen as the vital first step towards legitimacy as it imposed order on the data set which had been collected (Nowell et al. 2017). This allowed the data to be identified, analysed, organised, described and reported. It offered a solid base from which secondary analyses would follow. Secondly there was analysis using positioning theory (Harre et al. 2009). This involved analysis of a smaller set of data which was the narrative extracts that the thematic analysis had identified as being representative of the whole. Thirdly there was analysis through functional linguistics (Halliday 2006) which aimed at identifying the true meaning of speech acts captured as research text. It involved the data included in the positioning analysis (as one aspect of the positioning triangle is the illocutionary act) as well as a separate linguistic analysis of the propositions arrived at through the appreciative inquiry workshops.

Figure 4 – The Multi-Layered Analytical Approach



Positioning and linguistic analysis were used further to explore the generative capacity within the Appreciative Inquiry methodology. Whilst the analytical process followed in the order as set out in Figure 4, the positioning analysis involved an element of functional linguistics and therefore to reduce unnecessary repetition the three aspects of the analytical approach are presented in this order,

1. Thematic analysis.
2. Linguistic analysis
3. Positioning analysis

4.6a Thematic Analysis

The thematic analysis in this thesis was undertaken using an approach set out by Nowell et al. (2017) that aimed to raise the quality of analysis through systemisation, traceability and verification of the process undertaken. In pursuit of that a six phase model with guidance on how the researcher can assure trustworthiness during each phase is offered (Nowell et al, 2017) and the process that was followed is summarised as;

1. Familiarize yourself with the data.
2. Generate initial codes.
3. Search for themes.
4. Review themes.
5. Define and name themes.
6. Produce the report.

The process of undertaking the thematic analysis which generated the themes and sub-themes included in this thesis (as well as the possible properties, and property clusters, that could define compassionate dementia care) is now set out.

1. Familiarity with the Data

The qualitative data was drawn from the collection of fifty-five transcripts with some additional field notes and flip chart materials produced in the appreciative inquiry workshops. Pre workshop interviews were audio recorded and workshops were video recorded so in addition to the transcribed narratives the spoken word could also be heard and nuances of behaviour and body language observed. All recordings and transcriptions are archived which is seen as helpful in providing an audit trail to support the trustworthiness of the data (Nowell et al, 2017). The prescribed action for the researcher is two-fold. Firstly to become immersed in the data, reading, re-reading and reading again. Secondly to be an honest broker of that data, bearing witness to its collection and having transparency in relation to pre-existing thoughts and beliefs about the direction the evidence leads to. So, for me this involved undertaking every interview and facilitating every workshop (with a fellow student acting as camera man and having little or no involvement in the facilitation). It involved me transcribing a

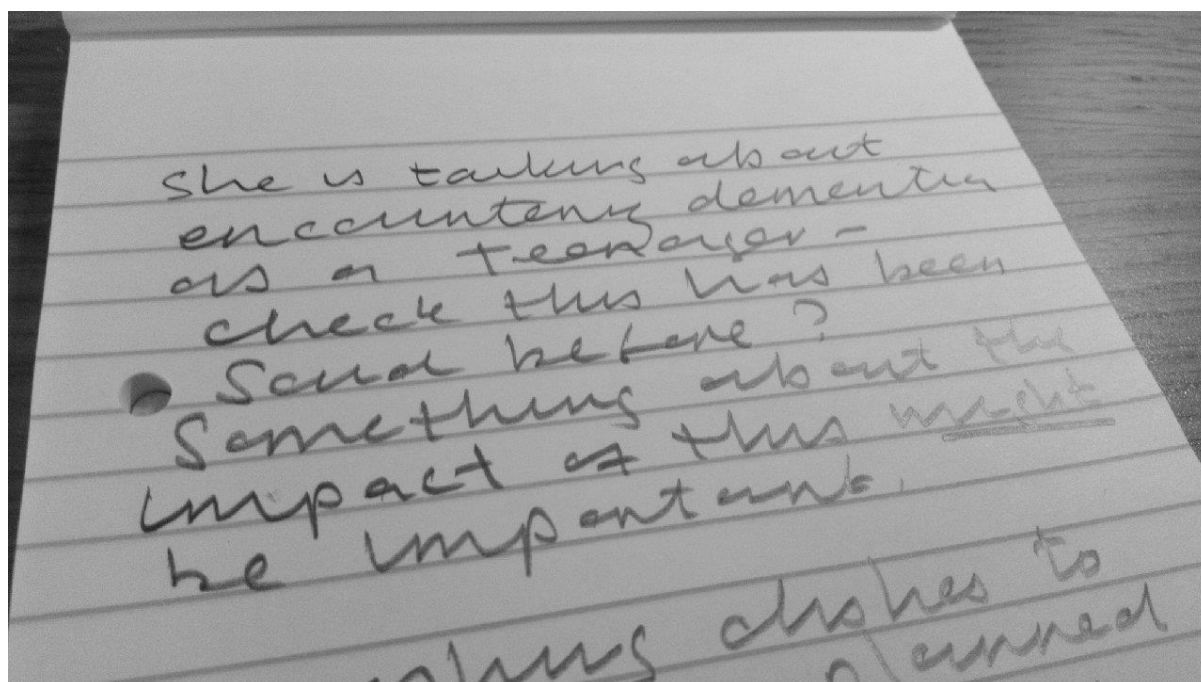
significant number of the 120,000 plus words of data and then reading, re-reading and reading again. It involved me making field notes of inspirational moments or of phrases that I wanted to retain and use in some way. Those notes which in honesty are not extensive, also captured points where what was being said, heard, read or observed echoed or possibly validated parts of the literature that had suggested the existence of an elusive concept of compassionate dementia care. Collecting all the transcribed data together in the software tool led me to undertake a further round of reading but with one eye on phase two of the process.

2. Generating Initial Codes

From having familiarity with the data I was able to begin forming an opinion as to what that data held which might be of interest. Certainly by the start of this process I had identified that whilst the transcripts could be categorised as sitting somewhere on a scale between relevant to irrelevant there were some very obvious statements, comments and, potential positions that would be influential. As I worked through each transcript again the analysis software allowed me to build the coding structure as I moved from paper to paper. In respect of the pre workshop interviews it soon became evident that my interviewing style had by the third or fourth interview started to crystallise around a pattern or rhythm of questioning. Underpinning that was the realisation that some commonalities existed and those commonalities could be drawn out further to become potential themes.

Exerting a reflexive force around that was four years reading of relevant literature and the influence of others. So, for example, when asking the nurses about personal experiences of dementia it was hard to put to one side the work of Travelbee (1969) who had drawn me to think in terms of a linear interactionist process within which the nurse encounters the patient and subsequently comes to see the person as their identity emerges. As I explored the transcripts it was evident that this is what many of the nurses were narrating and that a potent influence was to be found in the quality of those first encounters (Image 2) importantly the narratives appeared to be setting out what the difference in quality was and I note in my field notes that the difference ranged from the detached to the inspirational. The first set of initial codes were therefore in place to help describe the quality of four types of initial encounter.

Image 2 – Field note ‘Is the impact of encounter important?’



Following this was an exercise of viewing video recordings as nurses worked together within the 'discovery' phase of appreciative inquiry to relate positive narratives of dementia care. It was again evident that there were differences between the individuals who made up those groups. It was those differences in the way the nurses tended to describe the individual in their care that allowed the second set of initial codings to emerge.

The third set of initial coding's must have been influenced by the substantive literature review and in particular the accounts of nurses as to whether or not actively seeking to connect with the person affected by dementia was seen as important. Regardless of that influence the video material of the 'discovery' phase of the Appreciative Inquiry workshops was pertinent here and it was possible to identify distinct codes from within the narrative accounts. The fourth set of initial coding was shaped around a phrase used by one of the nurses. I noted as a field note (Image 1) at the time that what she had said in the flow of her narrative was profoundly important and the way she expressed it with some emotion behind the words suggested it was a view that she had been forming and reflecting upon from her own practice and personal experience. What was needed, she argued was 'someone to watch over me'. The different meanings within that phrase resonated with me and those meanings suggested themselves as codes.

Completion of this code generating exercise led to a second process of being immersed in the data and systematically progressing through each narrative making more notes in the software tool. From this two things happened. Firstly it allowed the earlier codes to be refined and more substantial possible themes to emerge. Secondly, it brought to life a quote I had slightly cynically written down almost a year earlier:

'The critical task in qualitative research is not to accumulate all the data you can but to 'can' (get rid of) most of the data you accumulate' (Wolcott, 1990, p35)

I was immersed in a sea of data and reliving the highs and lows of each interview and workshop as well as feeling again some of my emotions associated with the behaviour and language used by the nurses. At the risk of drowning in the data I found myself sifting the evidence, perhaps baling out the boat, and becoming as familiar with the empty narrative as with those which were powerful accounts delivered in a context of humility akin to 'this is what I do every day, it's not that special'. At this point the getting rid of data was more a mental than physical exercise with some clarity around which narratives might well be canned and which might become very important.

A point had been reached at which I believed it appropriate to start thinking in terms of conceptual properties that could be coded. This would allow for the general collection of features that a compassionate nurse may tend to possess to be identified and coded. Alongside this would be the utility of identifying the central exemplar which would act as the template for differentiating a concept of compassionate dementia care from that more general compassionate nursing care. This was a painstaking process and hard to divorce from the seduction of the illocutionary force. It was tempting to focus on specific words or phrases or interplays between nurses and question 'what did that nurse actually mean by that statement or the use of that word or phrase'. I found myself purposefully having to remind myself to focus on the locutionary and just take on face value that, for now, the word or phrase or narrative section simply meant what it meant. However having previously undertaken a substantive literature review and a repositioning of that literature I knew that throughout my period under investigation nursing theorists had frequently used proxy and populist words or phrases. I could see that happening again here in the spoken word but held back from over analysing. The only concession made was to allow codes

to be applied where the nurse's speech act had drawn attention to a property by describing its absence.

Week by week these initial codes were printed off and pinned up for consideration and reflection by myself and discussion with my supervision team so as to offer external challenges to the direction of travel. This was an important aspect of the high level reflexivity required as I was starting within the supervisory process to acquire an understanding of the potential held within the data

3. Searching for Themes

This phase involved establishing order over the collection of codes in an attempt to bring meaning to those things which when seen in isolation could appear to be meaningless. That had particular relevance during this phase in bringing together the potential properties of compassionate dementia care into collections or clusters and allocating the nurses into groups based around their initial encounters with people who have dementia. From this thematic networking there was a sense of order being imposed whilst creating a framework for later analysis. In this way the approach was inductive and driven by the data whilst my potential preconceptions (driven by the literature) were being reflexively acknowledged but resisted.

Alongside this there was the reconfiguration of primary codes into primary (working) themes. Despite this being a drawn out contemplative process there was ultimately little change between the initial possible primary codes and the subsequent primary themes. That the change was less than dramatic stems from the belief that they just seemed right in the context of how the nurses would arrive at conceptualising compassionate dementia care and what might be the antecedents of the properties that they regarded as important. The data was still suggesting that the quality of the initial encounter between that nurse and a person or persons affected by dementia was important in the context of what happened next. The quality of those encounters was firming up around four possible sub-themes all of which could be evidenced through narrative extracts. The earlier sub-codes had largely been abandoned although the meanings remained largely the same. As an example, 'Read the signs' which previously had described an approach which focussed upon the physical aspects of care was reassigned as 'categorise' or the act of labelling the person in a

homogenous way, viewing the experience of care through the eyes of the nurse not the person and holding physical signs and measures as having primacy.

There were six participants who did not initially achieve any coding related to their initial encounter. They were subject to a further round of very close reading in an attempt to identify anything that had been over looked. From that review I found that for two participants it was not clear which of the initial encounters they had experienced. One had been qualified for less than a year and one for more than twenty-five years. Both were working on a care of the elderly ward. Despite the limited experience of the former I was intending to code them both as 'brief' in that they had been working with people affected by dementia and initially it was as if that had made little impression. However in reading over their transcripts again it was clear that they were both very sensitive to people with dementia and whilst they had related no positive encounters it seemed that being coded negatively did not do them justice. I retained them because of this and because there was a quality to their narratives that would make a contribution to the later analyses. There were another three who described inspirational encounters that brought the participants into Nursing and into dementia care. However, whilst these encounters were inspirational they did not involve a person with dementia. I felt that provided reference were made to the source of inspiration in the later analysis it was appropriate to define this sub-code more generically. As such these two were added to the inspired group. Finally, there was one who on re-reading the transcript had alluded to being inspired, as such she too was assimilated into the inspirational group.

In addition to this exercise the potential properties of compassionate dementia care were also subjected to further attention. Firstly the transcripts relating to the fourth group of participants, those deemed by the organisation to be dementia experts or specialists, were opened to being coded. From that exercise four new potential sub-codes were identified. A re-reading of all the original transcripts was then undertaken to establish whether these four new codes could also be identified there or if they were products only of this specialist group of practitioners. Following this all twenty-three potential properties were brought together and dependent upon their semantic field (Jackson and Ze Amvela, 2007) and semantic closeness to each other (Small et al.

1988) were individually located under one of three clusters. Clusters were semantically driven devices (as they clustered together conceptual properties which shared a semantic relationship (Brinton 2000) that was meaningful rather than meaningless) and this allowed a definition based around the consensus from three online dictionaries² to be assigned to each cluster. Following this twenty-one of the potential properties that were amenable to the process of definition were also consensus defined by the online dictionary set. Two of the properties were not seen as suitable for this process as they were not conducive to being defined in this way but rather seemed to be self-evident.

4. Reviewing the Themes

It has been suggested that once the set of themes has been developed they can be further refined and questioned as to whether they form a credible or coherent pattern (Nowell et al, 2017). In part some of this had already occurred during phase three with the shaping of the possible sub-themes and the addition of new properties from the expert reference group. An important part of this review process was to look at which themes were inadequately supported by data or would probably not add to the later evidencing of the theme (due to the limited number or the quality of narrative and narrative sections) and, could therefore be legitimately removed. This removal process took me back into the original software data set and to examination of the distribution of codes. Firstly I looked at the potential sub-themes that sat beneath the four primary themes to see how much weight each carried. To begin with this involved a process of sifting through the coded items and grading each one with a system where green meant the narrative section would probably represent good evidence and red being inadequate quality of coding or too obvious a repetition. This acted to reduce down the coded sections and to better judge which codes would be viable. From this exercise 180 coded sections (62% of the total) were canned. Whilst this was a sizeable proportion it reflected the focus being applied without losing the generalisability of the surviving extracts.

² Oxford English Dictionary, Cambridge Free English Dictionary, Collins English Dictionary Online

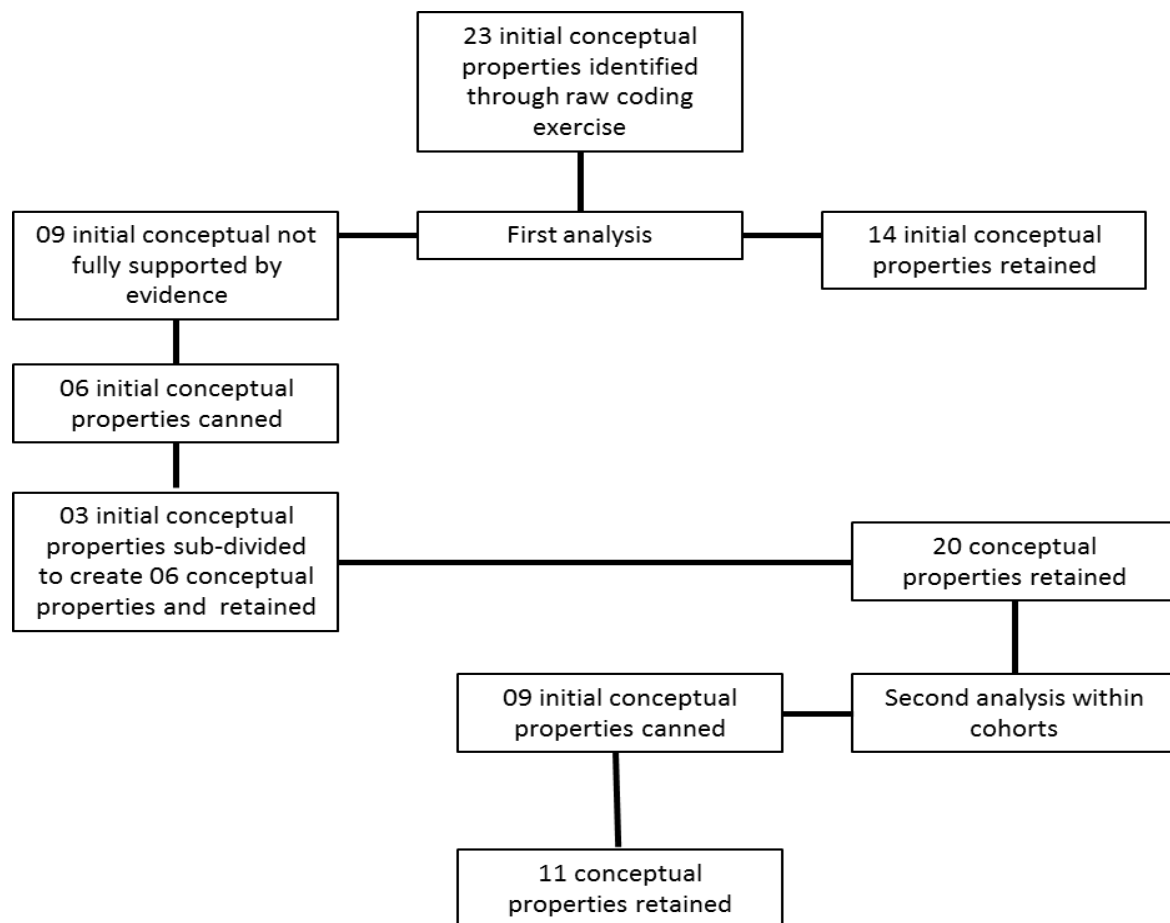
Following this each remaining potential theme and collection of sub-themes was separated out and reviewed to see how far each property was supported by an adequate weight of evidence. I looked at the potential conceptual properties for compassionate dementia care to review in a similar way how much weight each property possessed in respect of the distribution of codes. The analysis software generated a graph which showed that nine of the twenty-three properties were inadequately supported by the weight of data. Significantly these nine properties included all four codes which had been introduced only following review of the expert group transcript data. These four codes were canned. That left five others. Three of which I decided to sub divide and create six new codes which were added into the appropriate clusters. That left two codes/properties in need of review and given the lack of weight each possessed they too were canned. At this point the remaining properties were now analysed further in respect of their frequency as a percentage of all codes and as a percentage of all codes within their home cluster. This was to further determine the dominant properties that the participants were identifying as reflecting compassionate dementia care. Nine further properties were canned. The selection process for the conceptual properties is set out below (Figure 5)

The final remaining eleven properties were assigned heuristic categories (semantically influenced by (Williams & Keady 2012)) based on how strongly they emerged from the analysis. The categories were:

1. The spotlight property – the one central exemplar which emerges as dominant.
2. The centre stage properties – those that come secondary to the spotlight property.
3. The off-stage properties – those that have a presence but are more removed.

Based on this it could later be suggested that for a nurse to practice compassionate dementia care she would need to demonstrate the possession of the central exemplar and the centre stage properties rather than just the various off stage collection of properties. Finally, all the canned properties were placed in a state of quarantine so they were not lost from the overall discourse. A number of these properties re-emerge in Chapter Ten as part of the synthesis.

Figure 5 – Selecting the Conceptual Properties



Further Phases

It is stated that one of the most difficult decisions involved in thematic analysis is knowing when to stop (King, 2004). Although two further phases are set out by Nowell et al (2017), as phases five, 'defining and naming themes' and six, 'producing the report' I decided to end the thematic analysis at this point. Phase five was described as the process of determining what is interesting about the themes and why, with this being supported by a detailed analysis of the story being told and the contribution being made by the whole ordered data set. For me this naturally took the analysis further in the way that I had planned. I needed to look at the interactions between themes, the positioning within the selected narrative sections, the meanings behind the language being used and how these could all be drawn together to answer the primary questions posed by this thesis. Whilst a part of this would occur next in respect

of novel analysis of the data using both functional linguistics and positioning theory, I reasoned that phase five was essentially the rest of the thesis rather than one isolated section. Furthermore the writing up of the findings, the synthesis and subsequent discussion would quite naturally be phase six.

4.6b Functional Linguistic Analysis

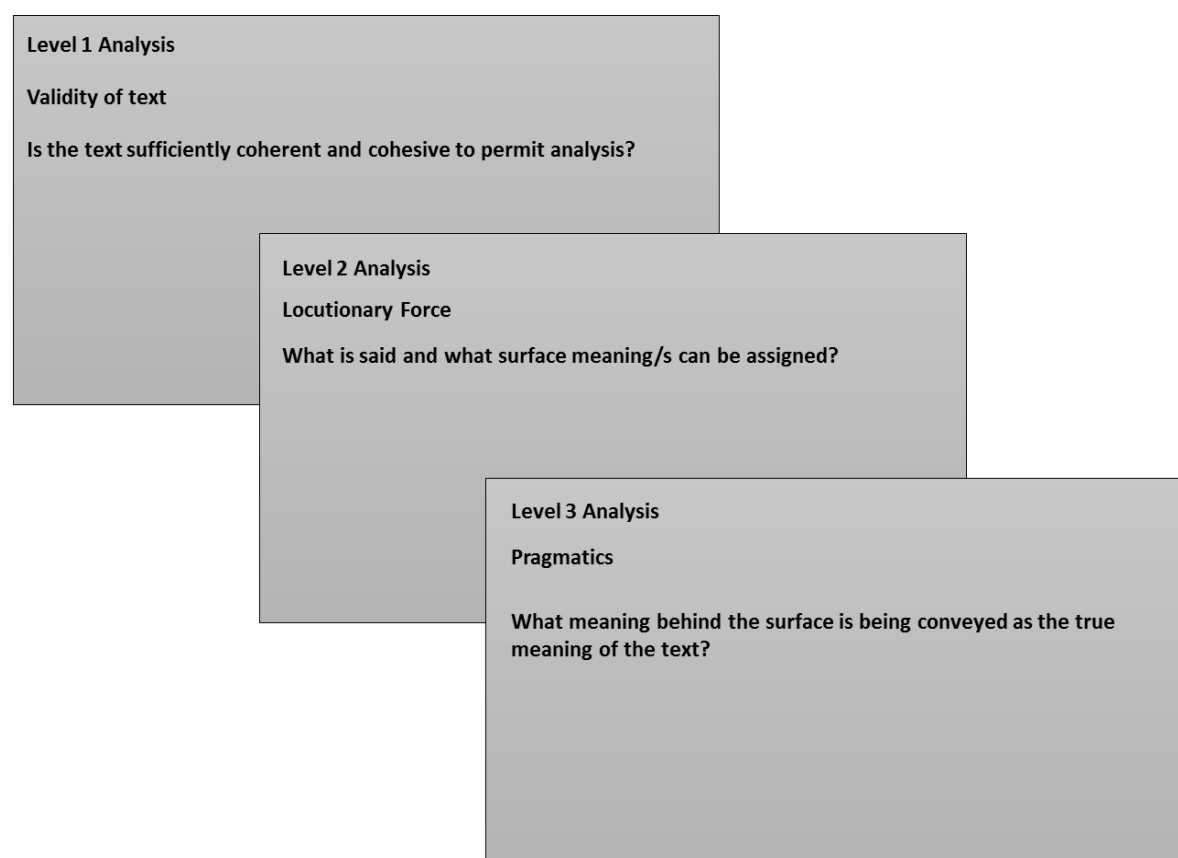
The nurses involved in this research were positioned as social agents who were engaged in the pursuit of a conceptualisation of compassionate dementia care. Their language captured as data for analysis within this thesis was their contribution to the discourse. They brought to the Appreciative Inquiry workshops their own representations of; dementia, those affected by it and the care that is required. The language they used and the differing perspectives they brought were the subjects of analysis which was aimed at supporting the identification of conceptual properties relating to compassionate dementia care.

Within the Appreciative Inquiry methodology the 4-D cycle was run in each of the three research sites. Whilst the first three elements; discovery, dream and design involved creating small sub-groups the final cycle, deliver, brought all participants at the site together as a cooperative collective³. From those collectives a series of provocative propositions emerged. These are set out in full in Chapter Eleven. A running hypothesis was related to these provocative propositions. That hypothesis stated that the meaning contained within the propositions would rehearse key aspects of the nurses' conceptualisation of compassionate dementia care.

To test this a bespoke three layered analytical model was applied (Figure 6). This model represented a process which utilised important theoretical aspects of functional linguistics.

³ Site DGH01 was the exception as due to the high number of participants there were two collectives established to identify provocative propositions.

Figure 6 - Layered Analytical Model for Linguistic Analysis



In analysing the content and meaning of those provocative propositions three linguistic forces were considered.

Layer 1 Validity of the Text

Each provocative proposition was analysed to provide assurance that they were indeed text. The documenting of the analytical process was expositional and whilst this is not the place to state those propositions it is important that the process be described. In determining whether the propositions constitute text for purposes of linguistic analysis the followings tests suggested as having relevance (Halliday, 2006) were applied,

1. Coherence

In linguistics coherence serves a valuable function of making a text semantically meaningful to the reader (De Beaugrande and Dressler, 1983). In order to achieve this a number of questions need to be posed;

- a) Is there 'situational coherence' (can all parts of this piece of language logically occur together?). The answer must be affirmative. The words used must have a logical arrangement and represent a unit of a lexico-grammar with a high order. If the proposition is written effectively as a single sentence then any semantic juxtapositioning is between words in that sentence rather than a more expansive set of sentences within a broader paragraph. Regardless of the length of the proposition it must follow a recognisable semiotic code (English) and have meaning to an English speaker. An example would be a proposition that states 'to show respect we will knock on the door before entering a patient's bedroom'. The arrangement is logical, grammatical and has meaning in that the concept of respect can be recognised as having a relationship to the act of knocking on a specific door.
- b) Is there 'field coherence' (does it retain a single frame of reference or jump from one to another?). In the example proposition there is a single frame of reference and no unnecessarily complicating material is added.
- c) Is there 'mode coherence' (is there consistency in style?) and is the text semantically meaningful? Again this must be affirmative. Regardless of the proposition being a short or lengthy piece of language the mode must be consistently expressed and consistently meaningful to the reader. In the context of research narrative the text must align to the reader's frame of reference such that it is rooted in the real world experience of both narrator and audience. The example proposition would meet these criteria.
- d) Is there 'tenor coherence' (is there clarity around the role being played by the speaker?) Again this must be affirmative. The propositions state a series of proposed actions which by themselves establish shared acts of commitment and responsibility on the part of group members. The use of 'we' is important in establishing who the speakers are or who the text is about whilst it also locates the act of knocking as a shared commitment. It adds further coherence by establishing that if 'we' commit to showing respect through the act of knocking on a door then 'we' can be located as sharing a cultural understanding behind a simple act.

2. Cohesion

Halliday (2004) suggested that this may be determined by asking if, the interpretation of one element in the piece is dependent upon another and, if there are semantic and grammatical ties between different parts of the piece in different places which give the text meaning to the reader. In respect of the propositions there needs to be a subject to each one that is tied to an action to be performed by the pronoun (we). 'We' acts as a meaningful referent, in context, as relating to this group of nurses who are now positioning themselves outside the research space and representing the ward team.

So, in proposing their intention 'to show respect we will knock on the door before entering a patient's bedroom' the nurse participants were in effect stating the collective will, the conviction of which was yet to be judged. Wherever or not that is reflective of the true meaning behind the words used is analysed later in the process. The proposition could also set up a second referent by placing references to 'it' in the discourse related to this proposition as being fixed and meaningful. To achieve this in the example proposition a second sentence is needed so the proposition could become, 'to show respect we will knock on the door before entering a patient's bedroom. *It is a small but symbolic act*'. In this context 'it' serves as referent for the act of knocking on a door to show respect and the addition strengthens the cohesive nature of the whole.

Layer 2 The Locutionary Force

The function of language was suggested by Eggins, (2004) as being related to two questions,

1. How is language organised to make meanings?
2. What sorts of meanings do we use language to make?

Layer one of analysis addressed the first of these and provided assurance that the provocative propositions possessed the required properties of coherence and cohesion. As such in moving to layer two there was a judgement that the 4-D workshop participants had used language in a way that permitted the second function of language to be considered. Consequently, the next level of linguistic analysis (utilised

by this thesis) considered the locutionary force possessed by the text. Locutionary, referred here to the utterance being made that constituted an act of speech which had a surface meaning (Austin 1975). One is cautioned that the surface meaning must be established even if it may not be the real or intended meaning behind the utterance (Eggins 2007). What lies beneath the surface is analysed at the next level.

The surface meaning is to be established by considering the way in which language has been used within the text and the relationship between the tone of language and the context within which the speech act was made. The tone itself must support, with or without context, the avoidance of ambiguity. So, for example, if the pronoun 'we' is used, to whom does it refer? In the context of the provocative propositions it must be those who have the authority to undertake the specified act. The tone should help the reader to establish what kind of statement is being offered and support distinctions to be made between different kinds of statements. For a number of 4-D propositions made by the nurse participants the tone was layered with an aspirational and informal style as the appreciative and democratic approach pulled participants away from the formal or the authoritative style of declaration. To establish the locutionary aspect, propositions as expressions of everyday speech need not have grammatical precision but the language must be understandable and the sentence has to possess a coherent structure. Provided these rules are followed aspects of the proposition can be clarified and the whole becomes understandable and thus at the end of a second level of linguistic analysis the surface meaning could be determined. All of the provocative propositions were treated in this way and a surface meaning fixed for each.

Layer 3 The Illocutionary Force

In general terms Appreciative Inquiry propositions suggest, as surface meanings, the possible real actions that people, as social agents, can commit themselves to undertaking in any social context (Bushe, 2010). However always around that locutionary expression is the illocutionary force which is exerted to discover the true meaning behind the words used. A hypothesis for this thesis suggests that contained within each provocative proposition would be a secondary level of meaning that would provide an insight into properties of compassionate dementia care. To pursue this a third level of linguistic analysis moved away from the locutionary aspects of the text to

consider the illocutionary properties or the real meaning/s sitting beneath the surface. That layer of analysis offers an opportunity to ask 'what does this group of nurses actually mean when they say that?' and, to also consider 'what it is they want me, as the listener, to think as they say it?', as well as, 'what is the relationship with action on the part of either the speaker or the listener?'

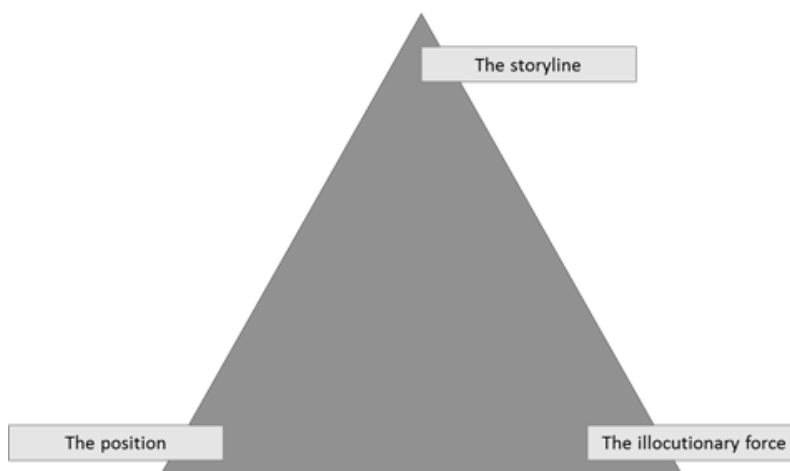
Most of the propositions that came out of the 4-D workshops sat within a fairly narrow commissive context. The nurse participants were in all cases committing to, at some undefined point in time, doing something. That was, however, too locutionary, too obviously the surface meaning. The illocutionary seeks to link the physicality of action to an underlying emotion and implicitly towards identity (Austin, 1975). Many of the subjects of the propositions could in some way be said to have defined aspects of the care being delivered and whilst Appreciative Inquiry emphasises the positive, the propositions were reflecting something that the nurse participants had become aware of which deviated from their sense of how things should be. Usually those subjects referred to something real and physical whilst in reality the desired change was about more than physical structures. As all care is provided by social organisations comprised of social agents and the most visible social agents in acute dementia care are nurses and patients then, the physical structure as metaphor may say something about the relationship between the two. It is this layer of meaning and, the alternative message which is being communicated that the illocutionary pursues.

In the context of this thesis and the research project and, without straying into the findings themselves, it has become clear that the nurse participants underwent a generative and reflective process which brought them to a space where they could voice something that may previously have gone unsaid. At the concluding point of the Appreciative Inquiry workshops there was a new commissive act. This meant that there was no need for the nurses to act in the way that the surface meaning implies (although to do so would have been highly symbolic) as, the nurses had already acted in conveying the change in their thinking which reflected the change in their practitioner identity. As they did so they entered a very different space that was no longer about what the nurse does but rather what kind of person she is. It is in that space where the concept of role became defeasible and the nurse participants instead adopted positions that were themselves amenable to a further layer of analysis.

4.6c Positioning Analysis

Positioning is captured in the interconnectedness between the three dimensions of the positioning triangle (Figure 7) which comprise of the position, the illocutionary force and the storyline (Harre et al. 2009).

Figure 7 – The Positioning Triangle



Having determined the probable themes and sub-themes this part of the analytical process sought to identify the positions being adopted by the nurses. In the context of this analysis positions had to be articulated and accessible. This was achieved through the pre workshop interviews and the subsequent appreciative inquiry workshops where the spoken word was captured in the moment by audio and video recordings and committed to print as a transcript.

Positions needed to be apparent and, as outlined earlier, much time was devoted to the process of reading, re-reading then reading again but with the academic discipline of this time looking for positions being taken or applied by the nurses and not being distracted by looking for potential codes or themes. In doing so a number of positions were identified from the data and refined through the one hundred and ten selected narrative sections. In analysing each in turn fifty-three applied positions were identified. Although some could be said to be vulnerable in respect of how much they were supported by the data one is reminded that this exercise is different to the thematic search for robust codes and sub-themes. If only one nurse articulated the

position then clearly it would not be the dominant position but it was noted and reported. It is accepted that this chapter is not the place to introduce findings from the research. However, for purposes of transparency and quality assurance of the analytical process, I have elected to break with this tradition. In order to clearly show the application of the positioning triangle as a novel analytical tool what is presented next is one worked through example of the analysis of a representative narrative extract which underpinned one of the identified themes.

Extract one

'Putting yourself in their position because I've been a terrible relative, it was someone I loved and I was there around the clock' (DGH01/participant10)

This narrative extract was offered by a registered nurse working in care of the elderly. By slightly extending the narrative to include the previous utterance, to which our selected participant herself added, a more rounded context was offered to support analysis:

So just giving that time I know some live away and don't visit their relatives but you're reassuring them and telling them how they feel... (DGH01/practitioner11)

... and putting yourself in their position because I've been a terrible relative, it was someone I loved and I was there around the clock. (DGH01/participant10)

Her storyline reflected a personal experience of loss which she referred to as her colleague provided her with an opening during the appreciative inquiry 4-D workshop. That experience of being on the other side of hospital care as a family member almost compelled her to bring to the discourse some important insights which helped inform and shape its direction. From a linguistic perspective both the brief and more rounded extracts possessed coherence and cohesion and, progressed successfully through the first layer of analysis. Perhaps not surprisingly all the extracts selected as representative evidence passed successfully through the first layer of analysis and as such this will not be referred to further in this section.

At the second layer the locutionary force produced a reliable surface meaning related to the actions of a nurse towards a family. There was a semantic tie between the use of the noun *relatives* and the adjective '*terrible*' in such a way that it appeared relatives were being described negatively. In particular the semantic tying between '*their position*' and '*a terrible relative*' gave voice to a possible position on families and carers. However, the true meaning being expressed was the direct opposite of the surface meaning. The speaker was directing the audience away from a negative position towards something more positive following her admission and use of the personal pronoun '*I've been a terrible relative*' and an explanation '*it was someone I loved*' which offered an alternative context. The active part of the sentence '*Putting yourself in their position*' is where the meaning and therefore the position lay. There was a combination here of reframing the view of family members away from being 'terrible' towards something more empathic which involved an acknowledgement of the carers situational context. In achieving this, this nurse meaningfully brought her own past experience into the present and the position was one of '*I use my experience*'

4.7 Analysis of Generative Capacity

If one is aiming to transform social reality then the generative capacity of democratic research is fundamental to the success or otherwise of that process. Generative capacity changes how people, think, feel, behave and, how they choose to express those things to others. This thesis asked the question whether Appreciative Inquiry has the generative capacity required to change practitioner behaviour in respect of dementia care. To determine that involved assessing the degree of change that nurse participants experienced as they went through the phases of the Appreciative Inquiry 4-D approach. In particular those nurse participants experiencing one particular type of impoverished relational encounter were the cohort of interest. Narratives derived through the discovery phase generally provided the views of individual nurses whilst provocative propositions, as the final act of the delivery phase, served to offer the view of a collective within which this specific cohort had membership.

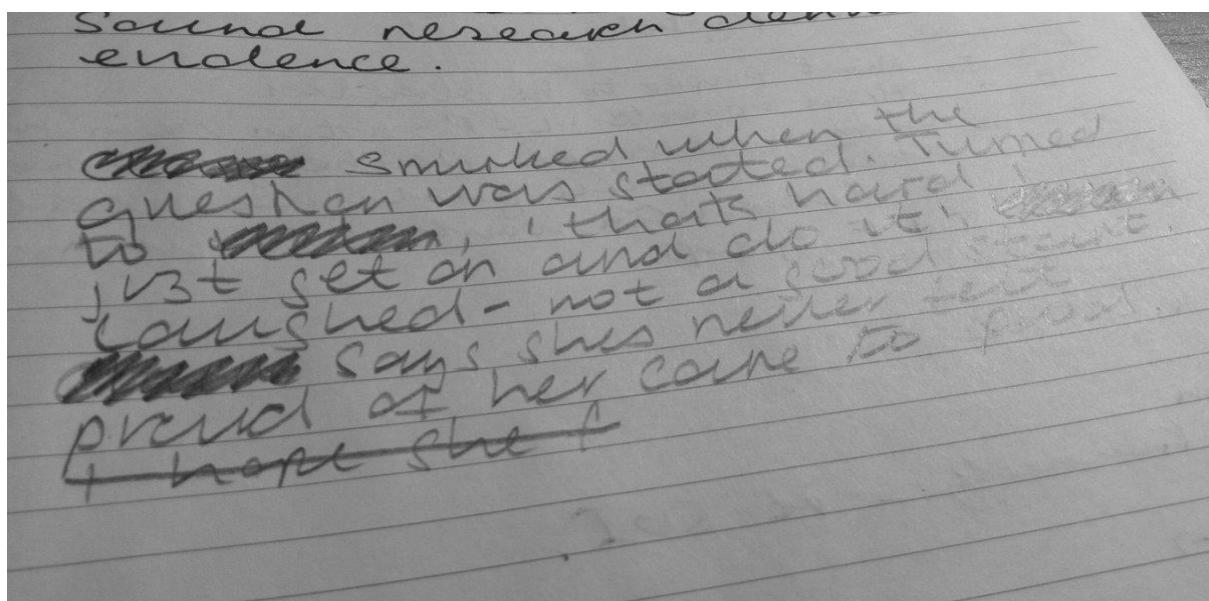
Normative discourse occupied the middle stages (dream and design) during which the nurse participants were encouraged to free their imagination and to then to ground their thoughts back into reality. It is during these two phases where the generative

capacity of Appreciative Inquiry should sit with the other two phases (discover and deliver) acting as bookends. There were a number of nurse participants who had experienced the relational encounter of interest. In keeping with the approach previously adopted all of those were analysed and one is offered here as a representative example of how the analysis was worked through. DGH01/participant10 was a female registered nurse working in a care of the elderly ward. Aged in her mid-30's she had been qualified for a little short of fifteen years and had worked with people affected by dementia throughout that whole time. In the context of this study she was part of a wider group of five nurses from the same ward.

Appreciative Inquiry 'Discover' Phase

DGH01/participant10 chose not to offer a personal narrative. A field note suggests that she did not feel able to identify a time when she had been proud of the compassionate care she had delivered to a person affected by dementia (Image 3). Despite not offering a personal narrative she participated in this phase of the workshop however, her actions were largely aimed at undermining the narrative of another participant. DGH01/participant09, a young dementia support worker attempted to offer a narrative about a man with complex needs from his physical health, his mental health (experiencing lifelong an obsessive compulsive disorder) and, his dementia.

Image 3 – Field Note Extract 'I'm Not Proud of my Care'



The video recording of the entire narration shows DGH01/participant10 expressing humour and encouraging others to do so from the outset. The first verbal intervention came as DGH01/participant09 described how the ritualistic behaviour of the man affected him from early in the day and made it slow for him to eat breakfast. DGH01/participant10 interrupted apparently to seek clarification and offered what on paper could be taken as an empathic response:

'Ah, bless him'. (DGH01/participant10 – line152)

On film what is captured is that this is not offered empathically but as a continuation of her humour and it can be seen and heard as patronising. As the discourse around the positive relationship between this man and DGH01/participant09 was developed DGH01/participant10 interrupted with the comment:

'Didn't he make cards? He made a hat once, we all sat and put it on and that was funny'. (DGH01/participant10 – line152)

Whilst DGH01/participant09 attempted to relate this to his identity (he made Easter cards for others as a meaningful expression of his religious beliefs) the comments from DGH01/participant10 were belittling of his activity and of the time spent by her colleague on them. Additionally she reinforced this view by trying to emphasise that clinical time was more valuable than this kind of use of time. Her phrasing was deliberate and aimed at establishing the professional difference between a registered nurse and a dementia support worker:

'I just don't have the opportunity to do that. When you're clinical we don't have that time. We don't do we?' (DGH01/participant10 – line152)

Latterly here her actions and use of the referent 'we' were to draw other registered nurses into an alliance with her. DGH01/participant09 was clearly undermined by DGH01/participant10 who, in just this first phase of the Appreciative Inquiry approach was displaying evidence that she held little value for the non-physical aspects of care and had little regard for the man who was the subject of the narrative.

Appreciative Inquiry 'Dream' Phase

For this phase the participants were told:

It is two years into your future. As a team you have won an award for providing the most compassionate care for people affected by dementia who also have acute medical needs, in the world. What does your look and feel like?

As the whole group of the five nurse participants formed a single group to talk through the dream phase an incremental change came over DGH01/participant10. Firstly, she engaged with this and was clearly possessed of a good imagination that put some attention on her. This perhaps allowed some defensiveness to fall away and active participation to emerge. As the session progressed there was a shift away from the more outlandish (on the surface) suggestions towards aspects which may have been suggesting unmet needs on the part of the nurse participants. The group discussed being a dementia specialist ward and the need to have mental health nurses working with them to better meet holistic needs. DGH01/participant10 then introduced the thought that they needed more education and related this to understanding what it might be like to have dementia. She became more animated talking about virtual reality training:

'I'd love to do that, they had it on radio 4 they put a mask on you they totally ... so it's exactly like having dementia and you see it that way' (DGH01/participant10 – line153 - 154)

'It's surreal but the understanding that you have afterwards is just ...' (DGH01/participant10 – line159).

As the session progressed she joined her reflections to her practice and made the connection with aspects of her own practice that had perhaps previously led her to ponder but not to reflect:

'I would love to be able to see it in their eyes. Do you remember when we had a very smart lady? We had her and her husband and she thought she was on a cruise ship and I'd look around and think I can see how she thinks it is. You know the little windows at the top and the bars coming down. I could see in her mind's eye' (DGH01/participant10 – line172 - 175).

Her thinking had now changed away from making fun of the dementia support worker for spending time trying to understand who the person behind the dementia was to

now understanding the importance of that action and to herself wanting to know what it might feel like to be that person and to understand his world:

'It's like you were saying 'where's my mum?' and they're 80 and you think gosh, how could ... it's unbelievable sometimes. It's hard for us to understand how they imagine where they are. Do you know what I mean?' (DGH01/participant10 – line182 - 184).

Quite quickly after this she introduced an emotional aspect:

'It must be terrifying' (DGH01/participant10 – line189).

Later the discourse turned to end of life care which could often be cold and clinical and DGH01/participant10 now brought to the discourse her own personal experience of bereavement and related it to her growing awareness of the needs of people affected by dementia particularly for closeness and human contact. She suggested double beds:

'So, the spouse or the partner can get in there with them give them a cuddle, or the daughter because I know I would want to do that with my mum or my dad, do you know what I mean?' (DGH01/participant10 – line243 - 245).

She then built upon her personal experience to describe how the physical layout of the ward could be redesigned to better meet the needs of not only the person affected by dementia but also his family.

Appreciative Inquiry 'Design' and 'Deliver' Phases

For this group of nurse participants these two phases naturally became one as they discussed the actions which they could carry forward into provocative propositions. DGH01/participant10 had been purposefully engaged with the dream phase and she carried this forward with her into these final parts of the workshop. She had brought forward important aspects of care related to being open to understanding the experience of the person affected by dementia and using her own personal experience

to find shared needs. These found their way into the provocative propositions made by the collective of which she became an important member.

DGH01/participant10 was affected by her involvement with this participatory style of research. Her opening positions were to patronise, belittle and blame whereas by the close of the workshop she was making valuable contributions. Those contributions initiated or strengthened the provocative propositions made by the DGH01/Collective 1 the importance of which are set out further in Chapter Eleven. Perhaps most telling of all in respect of how DGH01/participant10 was changed by the Appreciative Inquiry process was one of her locutionary acts which this thesis took inspiration from:

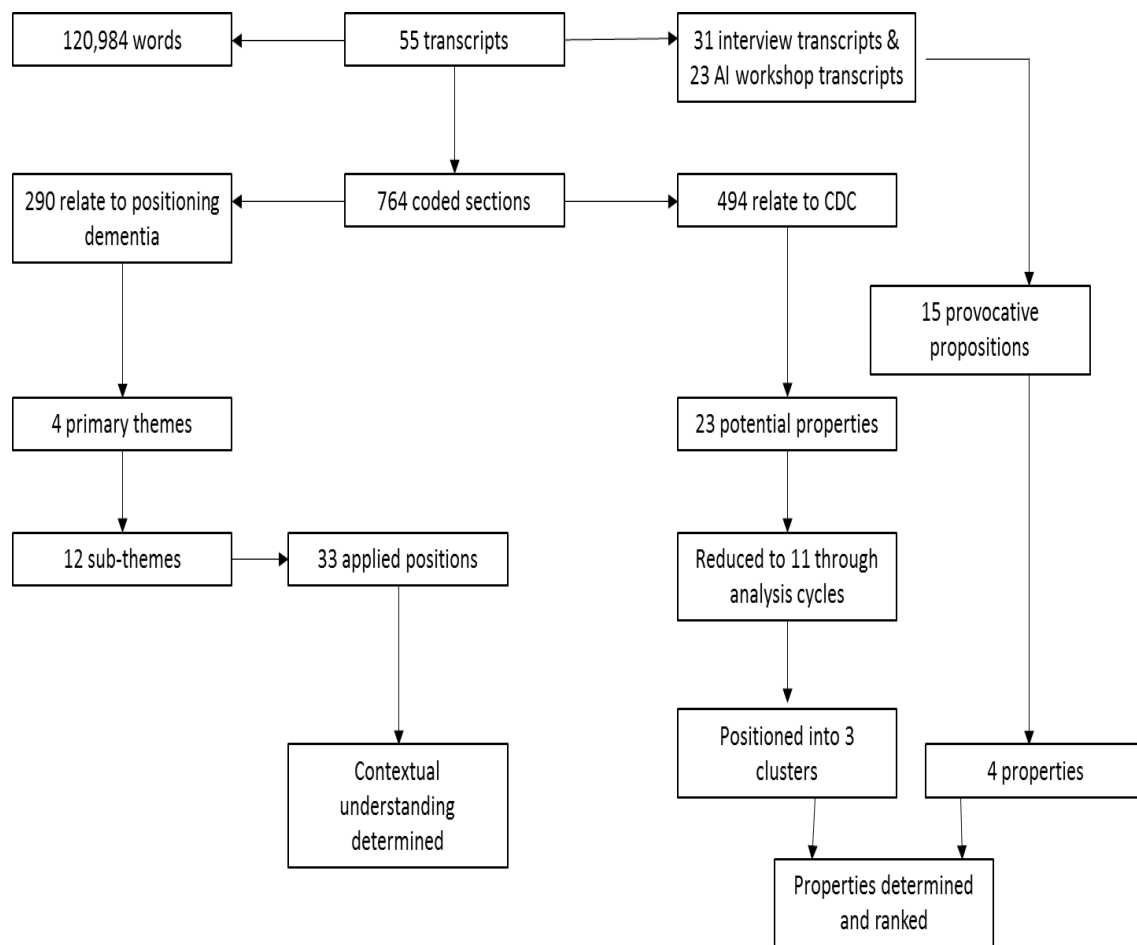
'They need someone to watch over them and need to know they're not alone'
(DGH01/participant10 – design phase, line 55)

Overall, in the case of this nurse participant, the criteria for generative capacity as stated by Gergen (1982) were met and the potential for a change in practitioner behaviour realised. The same analytical process was followed for the other nurse participants who had experienced the same relational encounter.

4.8 Chapter Summary

At the close of the data analysis process a sense of order had been imposed which now allowed findings to be set out. The themes were essentially fixed and regarded as having earned their place and helping to form a coherent pattern for later discussion. The codes representing potential conceptual properties of compassionate dementia care had been clustered, reduced in number and in three cases repackaged to reflect alternative meanings. Linguistic analysis of the provocative propositions had offered an alternative mechanism for property generation. Importantly, the dominant properties had emerged. Finally, in the context of this thesis the generative capacity of Appreciative Inquiry as a viable mechanism for democratic and participatory research had been established. The whole is set out (Figure 8).

Figure 8 – The Analytical Process in Whole



Chapter Five

The Scoping Review

5.0 Introduction

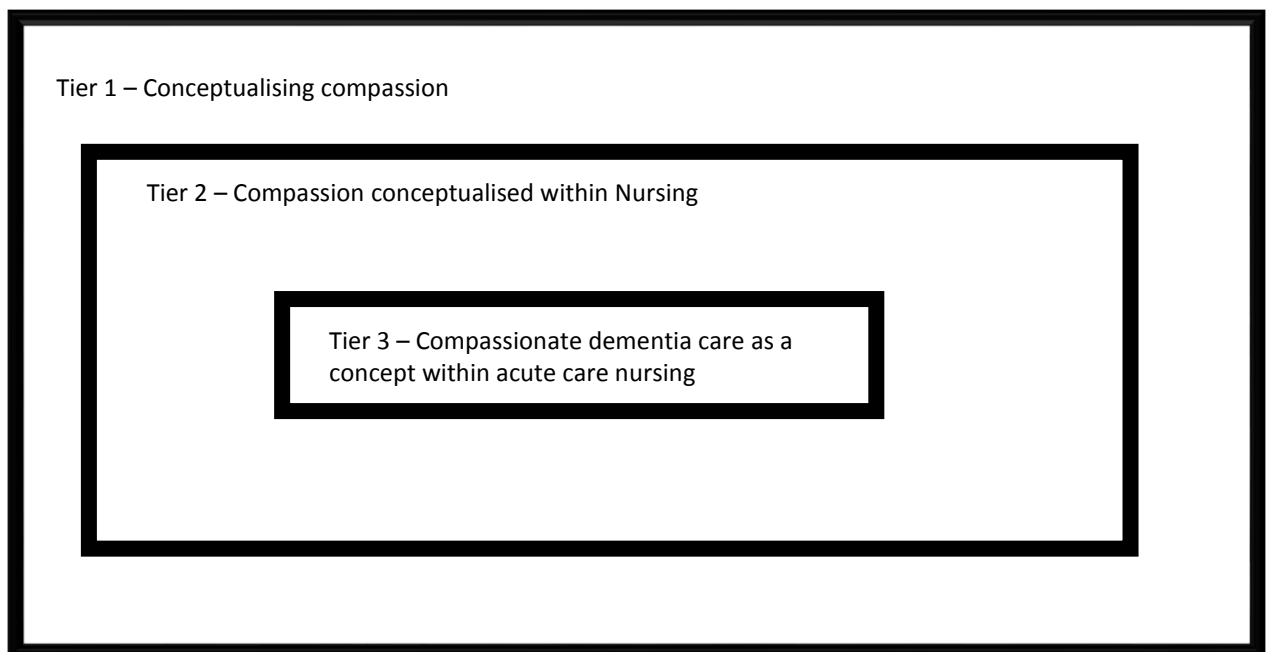
This chapter sets out the scoping review used to identify the evidence that subsequently comprises the substantive literature review. The whole exercise commenced here and then carried forward to completion in Chapters Six and Seven was frame worked by an academic scaffold of three tiers that allowed a logical direction towards understanding to be followed. The results of the exercise showed that in broad terms compassion has by no means been a neglected area of study and the scope of literature selected as representative of a larger body was inclusive and diverse. However, as one attempted to move into deeper realms of understanding, the literature to allow that became much sparser. In relation to understanding how acute care nurses conceptualise compassionate dementia care, the literature was essentially absent. As a consequence the thesis has entered new academic territory and opened up a novel view on what compassion means not only for a specific patient group but for a very specific group of nurses.

The work of Meleis (2012) is introduced as a fundamental part of this chapter. She outlined historical milestones in the development of nursing theory that serve to narrate a story of how nursing has undertaken a journey which in many ways is reflected in the heuristic model of compassionate dementia care that is set out in Chapter Seven. However, those milestones are introduced in this chapter, not only as a way of ordering the nursing literature, but as a means of showing how nursing's relationship with the concept of compassion was facilitated by nursing's liberation and empowerment to find its own research and theoretical identity. The Milestones (Meleis, 2012) did also permit an insightful ordering of the literature across a timeline of around thirty years. This allowed me to see where the literature sat in time and to compare that directly with nursing's interest at that same time period (as what gets published reflects nursing's contemporary interest).

5.1 Scaffolding

The review followed a scaffolding approach (Figure 9) that aimed to support the development of a deep understanding of compassion and its relationship to nursing care.

Figure 9 - The Scaffold Framework



The scaffold was constructed in three tiers; firstly it broadly addressed the question of what compassion is, its origins and the various theoretical, theological and philosophical approaches that claim to bring meaning to the subject. Having achieved this the focus of work within the first tier shifted to support understanding of the process, sequence or enacting of compassion. A second scaffold was then constructed to allow one to consider the concept and process of compassion within the field of Nursing. The final tier built on these foundations to support a deeper understanding of the concept of compassion and its relationship to the nursing care of people with dementia.

5.2 Scoping

The scaffolding framework was been constructed to hold an appropriate body of literature identified using a scoping review approach as set out by Arksey and O'Malley (2005) and later refined by Levac et al. (2010). This approach complemented the scaffold that has been put in place and was more relevant than a traditional systematic review. That relevance is reflected in the suggestion that scoping allows for the synthesis and analysis of a wide range of material derived through research alongside evidence from other approaches to provide conceptual clarity about a specific topic (Davis et al. 2009). For this dissertation there was a need to achieve conceptual clarity in respect of understanding what compassion is and how it is conceptualised within Nursing and achieving this would rest on synthesising material derived through empirical and non-empirical approaches. Additionally scoping allows the researcher to; address broad concepts (such as compassion) to a variable depth; map the key concepts that underpin research in this area (such as those that define compassion as a process); and crucially, identify research gaps in the existing literature that can give authenticity and purpose to the empirical work that follows (Arksey and O'Malley, 2005). Importantly for this dissertation a scoping review is also seen as useful when there are suspicions of too much literature being available (as characterised in search 1 below) or when (as characterised in search 3 below) one suspects there may be very little literature (Canadian Institutes of Health Research, 2015). For the appropriate conducting of a scoping review a four step framework has been proposed and comprises of:

1: Identifying the Research Question/s

Chapter One has set out that when serious service failure involving people with dementia occurs within the NHS the risk of reoccurrence is not adequately mitigated. It has been proposed (by this thesis) that the mechanism for dissemination of learning is flawed and there is a need to adopt a more participatory approach. Through that approach the most common theme of compassion (and its absence) can be explored and new understanding assimilated into practitioner behaviour. Such an argument raises issues that may be addressed in this scoping review through two broad types of question. Sackett et al, (2000) term these the background and foreground questions

where the background seeks an answer that is essentially general knowledge, and the foreground is more clinically relevant. The background question regards what compassion is and how it is generally conceptualised whilst the foreground asks, more specifically, what is known about the conceptualisation of compassion in the context of nursing care? The guidelines offered by the Centre for Reviews and Dissemination (Centre for reviews and dissemination 2008) have been used to inform the formulation of the foreground questions that would be addressed through this scoping review. The P.E.O (population, exposure, outcome) approach advocated by Bettany-Saltikov (2012) further supported this process and is set out below (Table 2):

Table 2 – The P.E.O Format			
Foreground question	Population and their characteristics	Exposure	Outcomes or themes
2	The nursing community	To the knowledge base related to compassion	Understanding how nursing conceptualises compassion
3	Acute hospital nurses working in clinical settings that deliver care to people affected by dementia.	To people affected by dementia who are admitted for physical care	understanding how this nursing group conceptualise compassionate care in relation to those with dementia

This led to the following three search questions being developed, all of which are highly congruent with the scaffolding framework;

1 – How is compassion conceptualised?

2 - What is known about acute care nurses conceptualisation of compassionate care?

3 - What is known about acute care nurses conceptualisation of compassionate dementia care?

It is suggested that this first step should go beyond just identifying the research question/s and that simultaneously there should be attention placed upon the specific purpose of the scoping review (Levac et al. 2010). In tying the two together at this early stage a clear rationale for undertaking the scoping is set out that will aid later steps in the process and give some indication as to when, or if, there needs to be remodelling of the scaffold, i.e. when one tier has achieved its purpose and a second can be constructed. In line with this advice the purpose of the scoping study is set out alongside each of the three research questions (Table 3):

Table 3 – Defining Research Questions		
Question type	Research question	Related purpose of this scoping review
Background	How is compassion conceptualised?	To summarise the extent, range and nature of research activity with a view to gaining a breadth of understanding about the core concept of compassion.
Foreground	What is known about acute care nurses conceptualisation of compassionate care?	To identify gaps in the current literature
Foreground	What is known about acute care nurses conceptualisation of compassionate dementia care?	

2: Identify Relevant Studies

Regardless of the overall approach, all literature searches are essentially bound by the same traditional processes that ensure rigor and, if necessary, permit replication. This step in the scoping review was divided into three phases (searches 1, 2 and 3) that mirrored the three questions. The standard search template suggests that electronic databases be approached initially. Five databases were utilised; JSTOR archives, Medline, CINAHL, PubMed and the Philosophers Index. Whilst it was anticipated to produce very limited results in respect of nursing care the Philosophers Index was chosen specifically because compassion as a subject is heavily influenced by philosophy and therefore a breadth of material could be sourced.

Search Method

As recommended by Sackett et al, (2000) the background and foreground questions were reframed as database search indexing terms. Search filters were imposed, so, papers would be in the English language, published as articles or books and within the date range 1967 to 2015. The search indexing terms used are set out in Appendix VI. The overall search results were viewed and papers rejected if regarded as not relevant. From this first pass selection a possible data set was identified and duplications between databases were removed. Papers were further rejected if they had been superseded by a newer paper that addressed the same material. Following that exercise the abstracts of remaining papers were screened and subject to rejection. At this point reference lists were examined and possible papers or books added to the literature that was selected for closer review. Papers were read online and books sourced. From that exercise further rejections were made and a final body of literature identified. Screening remained in place as the literature review was written and papers that ultimately were not adding to the discourse were removed. The primary literature search was undertaken on the 9th August 2015. A small number of papers were later iteratively identified and included in the phase of 'charting the data'.

Selection of Papers for Inclusion

For searches 1 through 3 the process was the same and permitted the selection of papers to be refined over at least four cycles of examination. The results of the selection process as applied to each search is presented narratively below and the overall results visually (Figure 10).

Search 1

From this exercise 1,038 possible papers were initially identified of which 893 were rejected as not relevant or duplicates. The remaining 145 papers were screened and 85 were further rejected. The iterative review of the reference lists added a further 30 possible pieces of literature to the total. The remaining 90 papers were read and 12 rejected as having been superseded or not offering as much as first thought. This left a total of 78 pieces of literature for final inclusion however, as the review was further refined through the writing process a further 56 papers were judged as not adding to the exposition and consequently set aside.

Search 2

From this exercise 2,033 possible papers were initially identified of which 1,896 were rejected as not relevant or duplicates. The remaining 137 papers were screened and 50 were further rejected. The iterative review of the reference lists added a further ten possible pieces of literature to the total. The remaining 97 papers were read and 43 rejected as having been superseded or not offering as much as first thought. This left a total of 54 pieces of literature for final inclusion. As the literature was periodically revisited during 2016, 2017 and 2018 a small number of papers were included after the scoping review was closed.

Search 3

From this exercise (Figure 10) 482 possible papers were initially identified of which 203 were rejected as not relevant or duplicates. The remaining 279 papers were screened and 258 were further rejected. The iterative review of the reference lists added no further literature to the total. The remaining 21 papers were read and 14

rejected as having been superseded or not offering as much as first thought. This left a total of seven pieces of literature for final inclusion. The outcome of the search process within a scoping review reveals that which was suspected before the process was commenced. Namely that for search 1 there would be the possibility of too much material to effectively synthesise (initial unfiltered searches produced in the region of 50 000+ possible hits) and in search 3 there would be very little if any relevant literature.

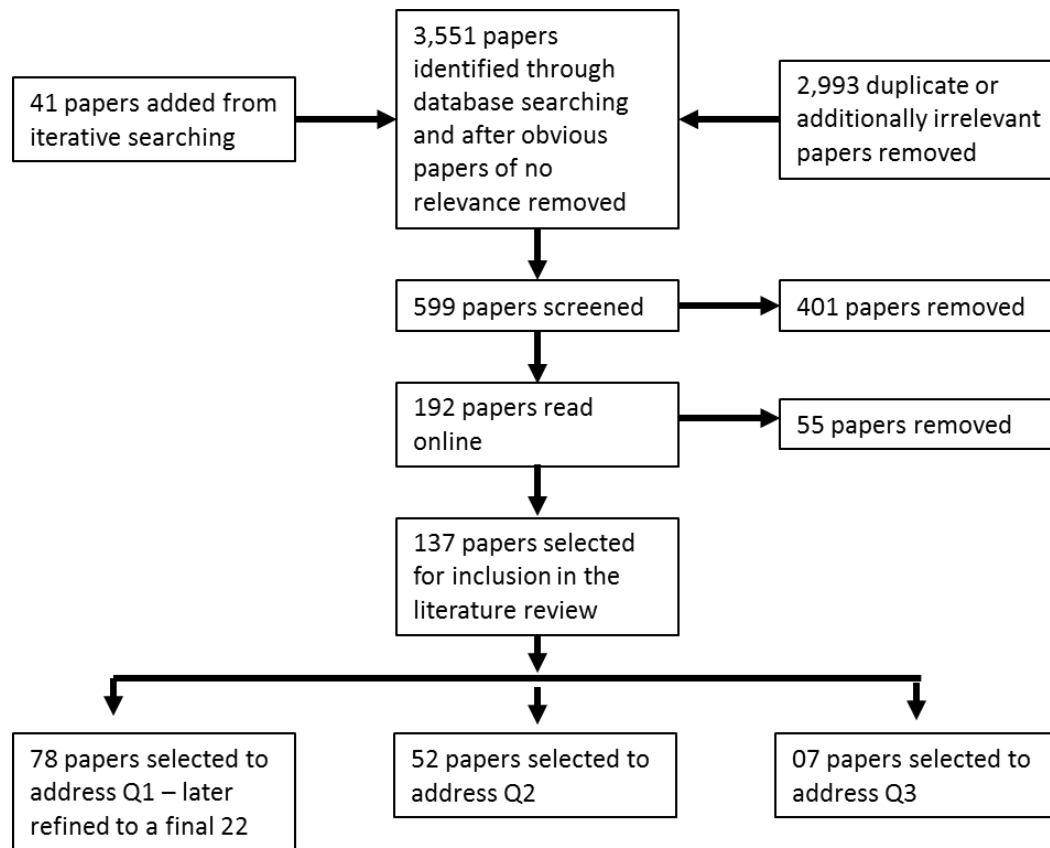
The range was also as suspected being wide and diverse. Papers span the historical, the empirical, the theological, the philosophical and the unscientifically subjective. What was evident in the literature selected to inform the review was that a proportion were dated (eventually some beyond the 1967 cut off) but these were still included, either because they were seminal and authoritative pieces of work that later papers referred to (or occasionally challenged) or, their content had stood the test of time and not been superseded by later sources.

Overall by undertaking the scoping review gaps in the literature base were revealed and the construction of research questions validated as appropriate. In particular such is the poverty of evidence in respect of acute nurses' conceptualisation of compassionate dementia care that it is essentially absent from the literature.

3: Chart the Data

Arksey and O'Malley (2005) stated that the next stage in the scoping review is that of charting the data. This involves extracting sufficient data from the selected literature to assure how that data will address the research questions. The data is presented thematically as key categories and dependent sub-categories as suggested by Daudt et al, (2013) and further influenced stylistically by Rutter et al, (2013). Additionally each paper was given an identity prefix and number coding to support a later stage of aligning each paper to milestones in the development of nursing theory. The prefix C related to a paper from search 1 (where C referred to compassion in general terms); N related to a search 2 paper (where N referred to compassionate nursing care) and, D to a search 3 paper (where D referred to compassionate dementia care). The data that was selected as the final literature to be used in the review May be found as Appendix VII. Each paper is discussed in greater detail in the substantive literature review that follows as Chapter Six.

Figure 10 – Overall Literature Search and Selection



4: Collate and Summarise the Results

Once presented graphically and temporally (Graph 1) it was evident that (with the exception of the historically seminal) papers from search 1 began to emerge from the late 1970's onwards, whereas for search 2 they emerged a decade later and for search 3 it was almost thirty years later. Search 1 papers were therefore relatively evenly distributed whilst search 2 papers incrementally appeared across the decades and search 3 sat within a short five year period at the far end of the graph. The search results presented thus reflected the contextual narrative within which the papers sat. Concepts build theories and it was indicated (Graph 1) that from the 1980's, and in respect of compassion, a conceptual journey had been underway in nursing; that the necessary steps towards a conceptualisation of compassion within nursing had been taken; and there had been increased pace since Mid-Staffs. However, it was evident that, as yet, there was no theory of compassionate dementia care that was to be found within the literature. It was uncertain if the topic itself had previously been subject to concept clarification or if it had been conceptualised in the round. Such a finding again validated the research questions that underpin this thesis.

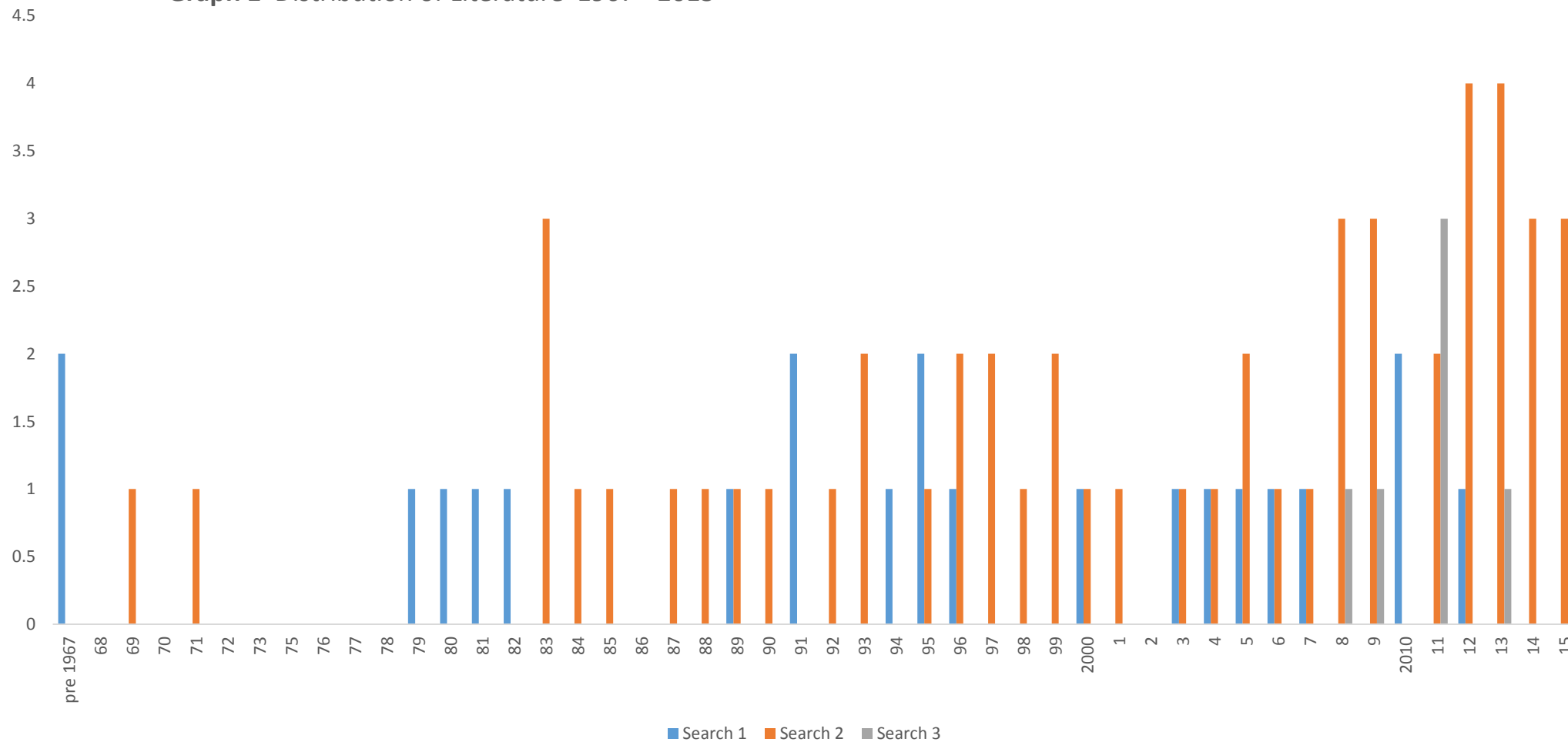
5.3 Mapping the Scoping Outcomes

The distribution of literature that was identified through searches 2 and 3 of the scoping review may be mapped further alongside the historical milestones for the development of nursing theory as set out by Meleis (2012) below (Table 4).

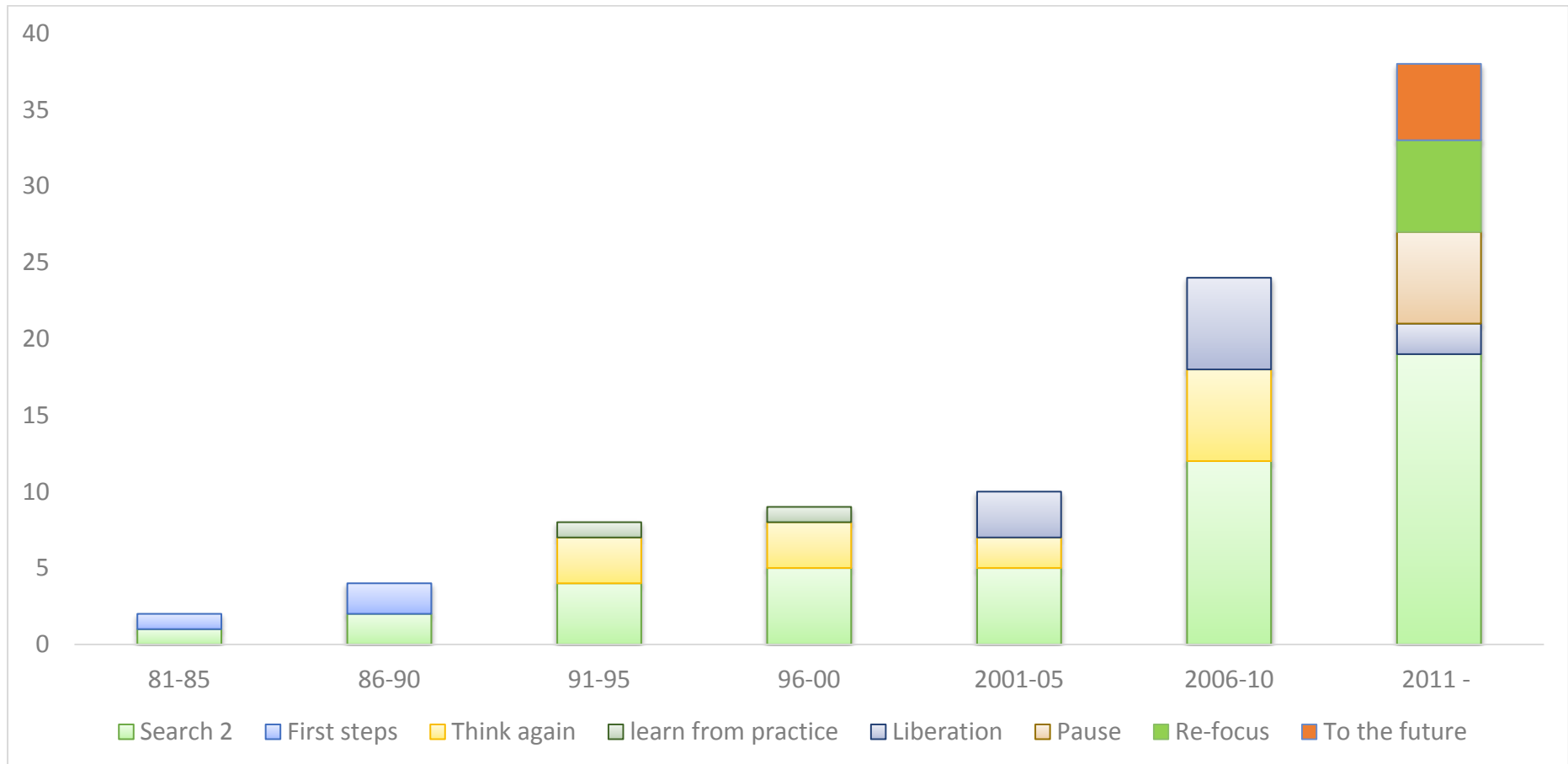
Table 4 – Historical Milestones in the Development of Nursing Theory	
Milestone	Theme
1981 – 85	Emergence of domain concepts
1986 – 1990	From meta-theory to concept development
1991 – 95	Development of mid-range theories
1996 – 2000	Evidence means research not theory
2001 – 2005	Epistemic diversity
2006 – 2010	Liberation of nursing theory
2011 -	Onwards into the future

That mapping, (Appendix VIII and Graphs 2 and 3) validated the search strategy and scoping review results in that the characteristics of the papers identified aligned to the characteristics of the milestones set out by Meleis (2012). Additionally the mapping exercise further shaped the narrative behind the literature that gave a logical and progressive flow to the literature review that follows as Chapter Six.

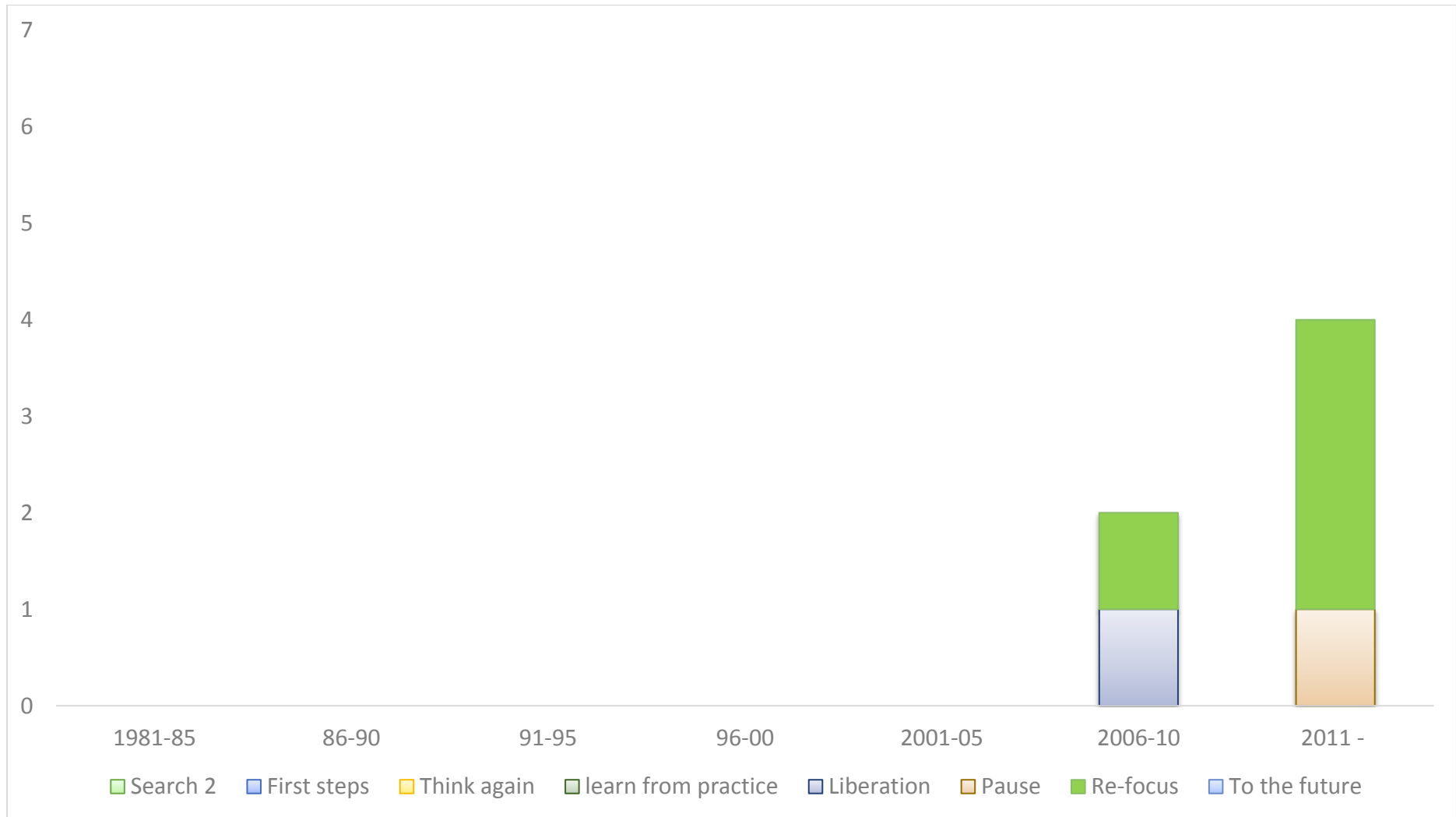
Graph 1 Distribution of Literature 1967 - 2015



Graph 2 – Search 2 Themed Distribution



Graph 3 – Search 3 Themed Distribution



5.4 Alignment to Nursing Theory - Analysis

This scoping review initially adopted a fifty year time period to identify literature that relates to the nursing conceptualisation of compassion since the publication of 'Sans Everything – a case to answer' (Robb, 1967). However, what became evident from this approach was that such literature began to appear later, predominantly from the 1980's. As such the further analysis of that literature was oriented around the almost forty year period involving the latter half of Meleis' milestones and it was acknowledged that Meleis (2012) placed no such limits on her discourse. Rather she offered a much broader historical analysis outlining nursing's theoretical heritage across both the eastern and western traditions and from the Crimea to the 1950's. The focus of those earlier periods had, however, been upon exploring and establishing how one nurses and how one is trained or educated to do so. As those periods progress towards the 1980's there was an organised attempt to understand not just the practice of nursing but also to capture its essence. From this emerged an appreciation of the need for nursing theory, an exploration of methods to shape such theorisation and ultimately the '*birth of nursing theory*' (Meleis, 2012, p68).

Perhaps it is of importance that by the point at which papers published during the 1980's was reached one can see two lines of inquiry (that of Meleis and that of the scoping review for this dissertation) achieving convergence. As nursing theorists began to understand the components of nursing practice so we can now see the emergence of literature related to compassion as a concept within nursing. A second convergence emerged from 2008 onwards as Meleis showed that nurse theorists became increasingly liberated from the positivistic approach. Not only were they encouraged to pursue alternative paradigms but to do so in a way that generated nursing theory that was relevant to specifically defined populations, such as those with chronic conditions associated with old age (Meleis, 2012). The small body of literature that addresses compassion and the nursing care of people with dementia is exclusively, perhaps unsurprisingly, to be found at these later milestones. Unsurprisingly because one could perhaps predict that attempting to explore compassion in this context does require a degree of creativity that positivistic science may not offer. However, whilst having been liberated to utilise qualitative mechanisms that would not have been widely accepted in health care sciences at an earlier time, and correspondingly the size of the literature devoted to the phenomenological

understanding of dementia being sizeable, the proportion of that literature exploring compassionate dementia care in the acute sector still remained limited.

In seeking to strengthen the connection between Meleis' milestones and the emergence of the search 2 and 3 literature from this scoping review it is possible to place the literature within seven reflexive themes that have been influenced by the language used by Meleis (2012). Those themes positioned alongside those of Meleis are set (Table 5) and subsequently discussed further:

Table 5 – Scoping Themes and Meleis Milestones		
Milestone	Meleis Theme	Scoping review theme
1981 – 85	Emergence of domain concepts	Taking first steps
1986 – 1990	From meta-theory to concept development	Thinking again about the concept of compassion
1991 – 95	Development of mid-range theories	Learning about compassion from nursing praxis
1996 – 2000	Evidence means research not theory	Liberation in thinking about compassion
2001 – 2005	Epistemic diversity	Pausing to reflect upon the journey undertaken
2006 – 2010	Liberation of nursing theory	Refocusing thinking about compassion
2011 -	Onwards into the future	Moving ahead towards a new future

Taking First Steps

Meleis (2012) set out that in the period 1981-85 those concepts at the core of nursing began to be identified from existing theory and refined through the development of new theory. This scoping review found that the literature from that period was sparse and spanned across the border with the second milestone period (1986-1990). Three papers were identified the first of which positioned compassion within the broader category of 'caring' whilst the two later papers brought it into the emerging discourse around care ethics.

Thinking Again about the Concept of Compassion

The fifteen selected papers related to this theme spanned the period 1991 to 2010 and sat across four of the Meleis milestones. The whole period was characterised by nursing's inability to make its mind up about where compassion sat. The earliest papers argued that compassion had been ill-defined and misplaced as a component of the broader concept of care. That it may have represented something much more important was glimpsed but in order to explore that nursing theory needed to move beyond the grip of positivistic science. By 2005 the opposite was being suggested and compassion was repositioned as part of other models rather than a stand-alone item. Papers into 2007 and through to 2009 suggested that this indecisiveness may have made compassion within nursing practice vulnerable and there were calls for a return to theological based theories of nursing that could best promote the practical expression of compassion. Through 2009 compassion was said to be lost from nursing (perhaps influenced by a context of early reporting from the Francis Inquiry) and by 2010 questions were raised as to why, as it cannot remove suffering, it needed to be seen as fundamental to nursing.

Learning about Compassion from Nursing Praxis

There are two papers identified through this theme and they sat across two of the Meleis milestones covering 1991 to 2000. Those milestones contained foci that were complementary in that they emphasised the importance of exploring nursing phenomena that emerged from practice and the need to identify best evidence that could be transferred to influence best practice. The first identified paper from 1993 offered a grounded theory approach to show that nurses had sensitivity towards the vulnerable and that by itself suggested compassion as an aspect of nursing care. Furthermore that sensitivity fuelled the compassionate motivation to alleviate the suffering being experienced. The second from 1997 took a narrative approach to suggest that compassion was embodied within nursing practice and expressed predominantly through the relationship between nurse and patient.

Liberation in Thinking about Compassion

Meleis (2012) suggested that through 2006 to 2010 nursing realised that in order to truly develop nursing theory it had to create distance between itself and the bio-medical model. That realisation acted as an empowerment for nurses to pursue theory through alternative paradigms and influences. During that period, and into the 2011 onwards milestone, this survey has included eight papers. Each paper adopted an approach that was qualitative and a variety of approaches, phenomenological inquiry, narrative, hermeneutics, and philosophical discourse were represented. The journey undertaken demonstrated that broadening the methodology allowed new ideas to emerge. So, one saw compassion being promoted as a force for healing that was subject to external and organisational constraints whilst there was less indecisiveness as it was firmly positioned as a core feature that had its own dimensions.

Pausing to Reflect upon the Journey Undertaken

By the final of the Meleis milestones, nursing had travelled some distance in respect of developing theory and by this point Meleis stated that nurses were now empowered and making a real difference and could continue to do so into the future (Meleis, 2012). She did not see any evidence or need for a period of reflection before nursing forged ahead into a different future. That future would be characterised by theory which would reflect the realities of an ageing population and the increasing numbers of those who would be affected by chronic illness. There were six papers identified by the scoping review that sat within the 2011 onwards milestone and that are at odds with Meleis on this. They collectively adopted a stance of pausing, taking stock and reflecting on the journey already travelled rather than launching into the future with compassion fixed as a core concept.

Refocusing Thinking about Compassion

Meleis ended her discourse on the historical development of nursing theory by briefly alluding to the future challenges that nursing would face and that theory will need to respond to (Meleis, 2012). In contrast to the previous theme where the literature was suggesting a desire to pause and reflect there was now more agreement with the

opportunity to refocus ones attention on what compassionate nursing might mean to specific patient groups. There were six papers that themed together highlighted this attention and brought it to bear upon the needs of older people, those using emergency departments and those in the acute hospital. To some extent the papers highlighted again a fragility associated with compassion and the importance of educating new entrants to nursing in its importance to practice.

Moving Ahead Towards a New Future

As stated above Meleis (2012) articulated that nursing theory must move into the future and that nursing was better placed to do so than it had been in the past. The scoping identified five papers that fell within the 2011 onwards time frame and also fitted into a theme. Three papers addressed the means by which the new generation of nurses could not only be supported to practice with compassion but could develop the skills to challenge poor practice in others. Taken together they hinted at a mitigation of the fragility that dissonance and negative socialisation bring to compassion. One paper set out an emancipatory theory of compassion that could support future research whilst the fifth reconceptualised compassion from the perspective of older people.

5.5 Compassionate Dementia Care –

The scoping review found that the nursing conceptualisation of compassionate dementia care was almost non-existent in the literature. There were only six papers selected and it could be considered that their relationship to compassionate dementia care was somewhat oblique. Whilst these papers were also themed there were so few that they could not be taken as a whole in the context of a short timeline. The first paper from 2008 set out a philosophical discourse stating that the label of dementia impacted upon compassion when the 'other' becomes regarded as the 'demented other' and one is less able to comprehend the suffering involved; the second paper that year scorned the first but essentially reinforced the points made. Whilst in no way setting out the conceptualisation of compassionate dementia care the contribution made was nevertheless important. Together they were responding to the freedom to

explore from an alternative paradigm and in doing so to refocus ones view of dementia care.

The remaining four papers could be said to build upon that although it would be wrong to infer any planned or coordinated action was involved. They suggested that in refocussing attention on compassion the distance between the other with dementia and the nurse could be reduced. That emphasis on the nurse drawing closer to the person with dementia in the context of a healing relationship could in itself be liberating and perhaps reflective of the 'new culture of dementia care' achieving more acceptance in a world still dominated by positivistic science.

5.6 Chapter Summary

This chapter has set out in full a scoping review that has identified a representative body of literature to be reconnoitred further in Chapter Six where the original search questions are explored and answered. The exercise has set the literature relating to searches 2 and 3 into an appropriate context by aligning it to the historical milestones for the development of nursing theory as offered by Meleis (2012). In ordering the literature around those milestones a narrative has emerged that has brought clarity and understanding to the way in which nursing has wrestled with the concept of compassion and how it has been somewhat slower at clarifying the concept of compassionate dementia care. Overall, the exercise has led to a validated literature set being identified in a systematic manner using an accepted approach that overall has shown that within the following substantive literature review there is a story to be told.

Chapter Six

Review of the Literature

6.0 Introduction

This chapter begins with actions that are accommodated within the first tier of the scaffolding framework. That is, it will set out the various components that assist one to construct a generally acceptable definition and understanding of compassion. Escalation to the second tier allows one to move away from this general descriptive stance and to consider how nursing conceptualises compassion. The literature review associated with this part of the scaffold has been organised around historical milestones for the development of nursing theory as identified by Meleis (2012). The literature that is drawn out of the scoping aligned to these milestones suggesting that what gets published reflects the research agenda of the day. That approach allowed the review to take a narrative approach within which the ebb and flow of discourse was captured whilst also using the milestones to give a structure to the review. The second tier of scaffolding concluded with the consensus that the place of compassion as a core component of nursing praxis had been established. The third tier essentially entered new territory and the narrative reconnoitred the landscape in an attempt to determine how, or even if, acute hospital nurses conceptualised compassionate dementia care.

6.1 The General Understanding of Compassion

In setting out the necessary rhetorical skills to engage an audience by provoking an emotional response, Aristotle offered what may be regarded as the first real systematic definition of compassion:

“.. a kind of pain excited by the sight of evil, deadly or painful, which befalls one who does not deserve it and which one might expect to come upon himself or one of his friends and when it seems near” (1384a)

Essentially one witnesses the actor dramatising some painful event and as a result feels something reflective of the others pain. One is aware of the actor being present

and one has sufficient understanding of the experience being portrayed to elicit an emotional response. Through this lens, awareness, feeling and the relationship between the two are positioned as vital to compassion and yet, however skilled the rhetorician may be it is relevant that his role is to play a part rather than to truly embody a lived experience. Rhetorical compassion is therefore sufficiently dynamic to be felt but not so dynamic that one must intervene. As such it has been criticised for lacking authenticity as one is still sufficiently detached to know the rhetoric is only a representation of reality (Carr 1996). An earlier critique suggested that it is possible to differentiate between 'authentic' compassion and something, such as rhetorical compassion which masquerades as such (Roberts 1989). Authentic compassion is a more dynamic experience but must be felt in the right way at the right time, where the 'right way' is inferred as being a realist application of the Aristotelian construals (Roberts, 1989). This set of rules endow compassion with elements of measurement, judgement and moral decision making, and state that in responding to the suffering of the other;

- 1: there is a judgement to be made as to when the threshold for acceptable levels of loss is breached and the other is seen to be at serious risk of harm or death.
- 2: the loss that is experienced is not the fault of the other so represents undeserved suffering.
- 3: the other is in some way like us and we too could suffer in the same way.

Alongside the definition drawn from Aristotle's 'Rhetoric' it is these construals which represent his philosophical legacy and in establishing the general understanding of compassion each are worthy of being explored further. However, before applying his rules Aristotle suggested that if one is to be aware of the suffering of others then one must first be aware of *the other*. Aristotle positioned this as emerging out of a fairly broad, innate, intuitive connectedness between all humans which he termed 'philia' or a natural friendship and that Nussbaum (2003) has described as being a 'fellow feeling' (p481). Whereas Aristotle regarded this as a connection between all humans Nussbaum (2000) has argued that fellow feeling is not universal and is strongest with one's own distinct social group. This echoes Wang (2005), who suggested that in order to become aware of others one must first develop a model of the world that identifies differences between social groups and also the more fundamental belief that before

one can appreciate the state of the other one must simply be aware of him (Blum 1980).

Rule 1

Assessment of Size of Suffering

The first of the Aristotelian construals requires that a measurement be made as to the degree of suffering that the other is experiencing. In order to do so one must not only be aware of the other but is now required to be aware that the other is suffering and must have some understanding as to the nature of suffering. As a human and holistic experience suffering, related to whatever cause, may have been defined as:

“A state of severe distress associated with events that threaten the intactness of the person” (Cassell 1982, p639)

Whilst it is a singular event borne by the individual it does not remain the individuals alone but invariably draws in others so that it may be recognised and elicit an emotional response (Malpas 2012). This concept of the mobility of suffering involves not just sensitivity towards the others existence but also empathy which allows one to imaginatively put oneself in another's position and adopt the perspective of the other (Shott 1979). Empathy drives the desire to act and alleviate the suffering that one sees in the other consequently where it is absent compassion is essentially unauthentic and passive (Dutton et al. 2006). By aligning to empathy the concept of compassion is liberated from Aristotelian rhetoric towards something more dynamic that all world religions would recognise. Christianity, Judaism and Islam all view compassion as a God given virtue that rests within oneself and so, the Christ of the bible is shown as modelling compassionate actions to others in dire straits; he forgives the sinner, heals the sick, restores sight to the blind and advocates for his followers to help those in need (Walton, 1997). The monotheistic religions root that active dimension within a sense of duty implying that passive observation, even passive empathy, is not enough.

However, whether one is feeling compassion or acting upon that feeling the first Aristotelian construal applies and there is a measurement to be made as to whether the suffering has sufficient size to warrant an emotional or behavioural response, essentially it must be judged to be serious rather than trivial. The requirement for a threshold of distress to be reached suggests that having awareness of the suffering of

the other, sufficient to compel one to act, is not unconditional but part of a rational decision making process. It raises questions as to from whose perspective the measurement is being made, that of the sufferer or the one experiencing the suffering. Measurement of suffering creates tension within the theological paradigm where there is largely a rejection of models that place constraints upon compassion. From a Christian perspective (although a similar principle could be argued for most world religions) adherent's actions are expected to be grounded in agape, which is spontaneous, unconditional, unmotivated and indifferent to the value of the other. Agape demands of the Christian that he acts as intuitively as the Good Samaritan, without judgement, without moralisation and without any constraint. It is a challenging principle that itself is subject to generative debate. In a revisionist paper defending the moralistic Victorian (and Christian) social reformers, Himmelfarb, (1991) argued that compassion towards the other is not meant to be a selfless act but rather aimed at promoting the common good. The inference is that the other is not one's equal, that some form of moral decision making is necessary and that social policy should not be divorced from morality.

Rule 2

Appraisal of Fault

So, the compassionate response may be based on a reasoned, thought through process that involves making a moral judgement of what one has observed. If having judged that the suffering of the other has sufficient 'size' for it to be seriously considered, then Aristotelian rules for compassion suggest that a further round of evaluation is required before one may be moved by the plight of the other. There is initially the question as to how deserved is the misfortune or the suffering that the other is experiencing and to what extent has he brought this about himself? Secondly, if the other is in some way responsible, is the suffering judged to be unjust? Nussbaum (2000) argued that one only feels compassion for others who are either blameless or, where the degree of suffering is disproportionate to the fault of the other, should these criteria not be met then the common response is to blame and reproach rather than have compassion. She continued to reflect Aristotle by claiming that unjustified suffering in the blameless other appeals to our sense of injustice. This is felt particularly strongly if the affected is otherwise regarded as a good person who finds

their fate in the hands of the gods and Aristotelian philosophy is rooted in beliefs about the behaviour of the gods with unjust suffering caused by either their neglect or their excessive punishment.

Overall, the Aristotelian view of compassion as summarised by Nussbaum (2000) is that there is as much a need for responsibility and blame as there is an acknowledgement that sometimes bad things just happen to good people through no fault of their own. The former rarely move us to empathy, the latter almost always do and the whole process is enshrined within a broader moral decision making process.

Rule 3

Similarity with the Other and the Belief that we too Could Suffer

The less the other is like us the weaker is the connectedness and the more unlikely it becomes that one will respond or as Atran and Norenzayan, (2004) stated:

'Compassion falls away steeply as the genetic distance increases between individuals' (p4).

In pursuing a rationale for this the evolutionary theory of compassion proposes a theory of mind to help explain one's ability to recognise the other by the degree of similarity to oneself, and to have insight into what he may be thinking or feeling about an experience (Byrne 1995). It is argued that to have insight into the mind of the other one must first have evolved insight into one's own. That allows one to make an assumption of the other using oneself as the reference point and the closer we are to the other the more accurate that assumption will be (one has the evolved capacity to change or update one's assumption if we discover the other does not think or feel in the same way). Such assumptions are projections of the way we feel or think about the circumstances of the other and the less like us the other is the less confidence we will have in those projections.

A broader empirical review of the evolution of compassion was set out by Goetz et al, (2010) who concluded that the strongest feeling is reserved for one's genetic relations and there is a descending order of similar relationships involving non-kin others. That scale defined those who are regarded as self-relevant by which they mean others who are important to one's own well-being, those who are close others (reproductive partners, friends, comrades etc.) and those who are in some way similar others

(Goetz, Keltner and Simon-Thomas, 2010, Oveis, et al, 2010). Similarity was seen as related to the recognition of features or attributes that one shares in common with others allowing one to place the other as having a part in one's life even though the relationship may be of a lower order (Oveis et al. 2010). Social processes have evolved to allow the initiation, maintenance and regulation of lower order non-kin relationships and the relationship between compassion and social connectedness has been explored. Such connectedness is evidenced through the strong emotional desire to belong to a supportive group within which one may derive certain benefits of membership namely, to be acknowledged, recognised and accepted (Oceja and Jiménez 2007). This connectedness is psychologically fragile particularly as the group grows in size and includes many non kin members. Religions, of whatever type, have found that in order to survive and prosper there is a need to harness the tolerance of non kin others and consequently doctrine is utilised as a valuable social function aimed at supporting cohesion and solidarity within the larger group (Durkheim 1912). As religious beliefs and practices became widespread they facilitated the development of large communities of genetically unrelated individuals the majority of which were unknown to each other but were still aware of through shared ritual, speech and even manner of dress.

In placing the third Aristotelian construal within a theological perspective it has been suggested that although God's compassion is without end, man needs to work within a more defined limitation, from this emerges the 'union of affections' and the 'true union' (Aquinas, Q.30 a.1). The former is empathic in that one sees the suffering of a close other who one regards as another self and feels his hurt as if it were his own. This is not universal but limited and determined by those who one regards as another self, whilst the true union is different and reflects more of a view that understanding the plight of others is not innate but is an ability shaped from one's own experience of suffering. It is again Aristotelian in that the compassionate person recognises his own vulnerability to experiencing the same kind of suffering as the other, because one has already done so. Aquinas was clear that this kind of compassion is not empathic but learned, one does not feel the pain of the other but remembers one's own pain and assigns that to the other (Aquinas, Q.30a.1.). This in part resonates with the views of Snow (1991) and Nussbaum (2000) that one must believe one is experiencing the same feeling as the other and would ask the question 'how would I feel in that

situation?’ For Aquinas that question would be too close to speculative empathy and, in order to reflect one’s learning from experience the question would rather become ‘how did I feel in that situation?’

6.2 Compassion Summarised

The systematic view of compassion as set out by Aristotle forms a significant part of the Aristotelian philosophical legacy and remains the primary influence on the contemporary understanding of the concept and its definition. Drawing on that legacy the definition includes firstly, the recognition, acknowledgement and awareness of the other and their suffering; secondly, the capacity to feel something for the other who is suffering and; thirdly, the desire to take action that may alleviate the suffering. With this in mind the definition of compassion that is taken into the second tier of the scaffold is encapsulated as:

“.. The feeling that arises in witnessing another’s suffering and that motivates a subsequent desire to help” (Goetz, Kiltner and Simon-Thomas, 2010 p2),

6.3 The Concept of Compassionate Nursing Care

As Nursing has striven to understand itself it has written a story which has been captured by Meleis (2012) and laid out metaphorically as journey which has passed a series of milestones along the way. What is narrated is a story of nursing trying to define the core features that give it a unique identity and waxing and waning through that is the part played by compassion. This examination of the literature will show that even when compassion appeared to be absent it was very much present often in the guise of proxies such as empathy or care. Each milestone passed has brought compassion a little more to the fore. The story has no final chapter, nursing is a constantly developing discipline, but in this thesis the whole thus far may be conveniently bookended by the interactionist perspective of Travelbee (1969).

That first involvement is to be found within the very early of Meleis’ milestones. The period 1966 to 1975 covers two milestones related to theory development and theory syntax during which nursing started to acknowledge that theory was significant for the

practice of nursing and that nurses were capable of theorizing (Meleis, 2012). During this period Travelbee (1971, 1969) defined nursing from an interactionist perspective as existing within the one to one relationship between the nurse and the patient and conceptualised that the fundamental basis of nursing was to support the other who is suffering to find meaning in that experience. Whilst compassion was never mentioned its core aspects are present in that the nurse is aware of the other; she sees the suffering of the other and she acts to alleviate that suffering by supporting the other to understand what is happening, to find meaning and to come to acceptance of the cause of suffering.

Milestone One 1981-1985

The Emergence of Domain Concepts

Amongst the milestones for nursing theory development was the focus upon metatheory and the subsequent emergence of domain concepts during the early to mid-1980's (Meleis 2012). That emergence was made possible by a new generation of nursing theorists re-visiting and re-examining the pioneering work of the 1960's and subsequently re-constructing a nursing metatheory (Meleis 2012). Directly from that came a broad consensus of agreement as to what nursing's 'phenomena of interest' were, the relations that exist between those phenomena and the domain concepts that would underpin the whole (Fawcett 1997). Those core domain concepts were seen to encompass the interplay between; the nurse; the patient; the situation in which they find themselves and; the purpose of their being together (Newman 1983, Chick and Meleis, 1986). At this level of theory development compassion was not being explicitly referred to but was implicit in that holding all these phenomena together was the concept of caring that sat within and influenced the core domains of nursing. Placing attention upon the concept of care represented, at that time, a change of direction as whilst the previous decade had seen much use of the term 'caring' in the nursing literature there had been limited interest in the concept itself (Gaut 1983, Morse et al. 1990). Consequently at this milestone of nursing theory development, where the attention was placed on restructuring and drawing together the metatheory, compassion was relegated to the role of sub-component of the more important concept

of caring and examples of the literature identified through the scoping review directly reflect this.

Griffin (1983) set out a philosophical analysis of caring in relation to nursing. Whilst at no point in that analysis was the term 'compassion' used she argued that within the multiple meanings of caring, two in particular stood out as important and both resonated with the Aristotelian definition of compassion and its associated construals. Firstly, caring involves showing an interest in others sufficient to show concern, to want to protect or take care of and, secondly, caring is about attachment to the other with whom one has an affinity to or a sympathetic identification with. Furthermore, she contended that the giver of care is aware of the predicament of the recipient of care and that such awareness is grounded in the nurses perception and judgement of the others needs at that particular time (Griffin 1983). That judgement links to an emotional response which in turn becomes a call to action to protect 'someone not unlike ourselves' (p294). Two aspects of caring were therefore identified with awareness of the other, with emotion, with judgement and with action, all of which tier one of the scaffold has set out as dynamic or authentic compassion.

Orem (1985) stated that nurses 'experience events and happenings that involve themselves and others' (p36) and as such caring as applied to nursing is relational in that care givers and cared for must be in contact with each other as they share an experience. Usually that experience is one in which the caregiver compensates for those things that the cared for cannot do. Compensatory actions, she argued, were deliberate attempts on the part of the individual nurse to bring about events that will benefit others and the effective nurse is claimed to be one who recognises when the other is in need of nursing even though she may not be able to articulate how she recognises that need (Orem 1985). As she laid out her theory of nursing this was the fundamental point that was reiterated; nurses act in a deliberate manner, they:

'Observe, reflect, reason and understand as persons who know nursing' (p25).

This act of 'knowing nursing' is a cognitive process because nurses must be able to think as well as perform. When they do perform they undertake a 'practical endeavour' (Orem, 1985 p26) or a deliberate act that brings about a practical result, however, those acts are restricted to those who have a legitimate need for nursing and, legitimacy in this theory of nursing relates to a deficit in meeting a known self-care

need. Whilst some traces of compassion are present, in the form of awareness of suffering (however oblique that may be) and taking action to alleviate it, it seems that emotion, as the bridge between these two, does not form part of the discourse. The nurse recognises a need and acts but she is not *moved* to act; she does not empathise and; she does not feel the pain of the other. In acknowledging the need, the nurse has measured its size and judged it to be regarded as legitimate for nursing attention as such there is a direct link with the first of the Aristotelian construals for compassion.

Milestone Two 1986-1990

From Meta-theory to Concept Development

The second milestone identified by Meleis was the movement away from identifying and setting out nursing's meta-theory towards the further development of core concepts with an analytical process that had become more focussed and more grounded in nursing praxis (Meleis 2012).

Roach (1987) stated that whilst caring is to be found outside of nursing, nursing itself is unique in that all of its core attributes are located within the concept of caring. Reflected within that belief was the earlier mantra of Leininger (1984):

"Caring is nursing and nursing is caring" (p83).

There is no distinction and implicitly no need to question it further. However it begs the question 'what is caring?' and in answer to that Roach (1987) suggested that there were five core aspects of nursing that defined what it is that a nurse does when she is engaged in caring. Those five aspects encompassed; compassion, competence, confidence, conscience and commitment. Compassion was therefore, perhaps for the first time, openly cited although Roach drew short of defining in her own way what it may be.

Ray (1988) carried the philosophical analysis of caring into this second period with the argument that the re-examination of caring had identified a number of constructs within which compassion was acknowledged but was by no means the most important. That

primacy belonged to the concept of oblation love evidenced through the nurturing of well-being of the other without the expectation of personal gain.

Fry (1989) considered from a feminist perspective the role of caring in relation to nursing ethics. She began by stating that nursing ethics has traditionally been seen as a subset of medical ethics which has been at the cost of failing to acknowledge the role of nurses and the value of nursing. As a consequence nursing ethics was paternalised, adopted the 'language of the father' (Fry, 1989 p89) and was ultimately diminished. She argued that caring should become the foundational value of any theory of nursing ethics and in doing so set out an exposition of the concept of caring. When articulated through the relationship between the nurse and the patient caring could be perceived as a commitment to achieving a positive outcome for the patient whilst caring actions, such as touch, mitigate for the objectification of the patient and promote human dignity. Caring was described further as a natural state of human existence; a way of relating to the world and others within it and; a natural sentiment of being human (Fry, 1989).

By the close of this decade it was still possible for 35 separate definitions of caring in the nursing literature to be identified but no consensus to be reached regarding not just its definition but also the components of care or the process of caring (Morse et al. 1990). Despite this confusion as to what it might be, it was certainly becoming more compassion like. There were direct parallels emerging with the Aristotelian concept of *philia* and the 'fellow feeling' set out by Nussbaum (2006) as well as the evolutionary theories of compassion. However as nurse theorists passed by the second of Meleis milestones compassion remained almost an anonymous force that was in no way having any status of importance bestowed upon it.

Milestone Three 1991-1995

Development of Mid-Range Theories

The third of Meleis' milestones relates to the many middle-range theories that were developed at this time (Meleis, 2012). This allowed nursing to start moving away from the broader scope of meta-theory and instead to focus upon specific phenomena in more detail. Again the nursing literature from this period reflect what was happening

in the theoretical world and again compassion whilst not absent remained relatively anonymous although by the close of this time period there were indications that its presence had been not only noticed but quietly championed. Morse et al. (1992) opened up a discourse around the concept of empathy and challenged its uncritical integration into nursing. Whilst, they argued, it had become regarded as vital to the nurse-patient relationship empathy was not fully understood and, in a nursing context, had never been fully explored. Where empathy had been looked at the methodological issues were such that nothing meaningful could be taken from research findings, those issues included poor replication of results between studies and a reliance upon measurement tools from other disciplines. In particular they argued that empathy existed as two distinct forms; firstly as a natural human trait and secondly as a quality which one may learn or a clinical skill in which one may be trained (Morse et al. 1992). Both of these resonate with the debate surrounding the Aristotelian legacy whether that be his original belief in 'philia' as the force which connects all humans or the view of Aquinas (Q.30a.1) that one learns to be empathic as, rather than being able to feel the pain of the other, one remembers one's own pain from a similar event.

Browne (1993) undertook a concept clarification for the phenomena of respect arguing that whilst the term was frequently used in nursing literature it had never been extensively defined from a nursing perspective. More importantly, she regarded it as an antecedent to caring which itself remained in need of further exploration and elaboration. In undertaking the clarification exercise Browne (1993) revealed the interdependent existence of fundamental aspects of nursing. As she talked about respect what one now hears are indirect references to compassion. So, respect is an expression of one's sensitivity and commitment to the other; it arises from an interest in the other; it acknowledges the presence of the other and it is demonstrated through empathy with the other. On these terms respect is the antecedent to compassion as awareness of the other is the antecedent to awareness of suffering in the other.

Lützén and Nordin (1993) undertook a similar exercise in relation to the concept of benevolence within nursing from which it was possible to draw out very strong compassion-like behaviours. Firstly they identified that benevolence encompassed both the wish to do good and the practice of doing good for the other, it is therefore oriented around an awareness that the other exists and possessed of both cognitive and dynamic aspects. Secondly, they placed emphasis upon the nurses' 'sensing of

the patients vulnerability' (p1108) by which they meant that even in the absence of direct information about the other the nurse is intuitively aware of and understands the situation that person finds themselves in. Thirdly, they built upon this heightened sensitivity of the other by rooting it in the nurses' ability to experience emotions that are different from her own, in short to have highly developed empathic qualities. Finally, they offered descriptions of how nurses respond to 'do good' for the other, how decisions are made and how nurses take moral responsibility for those decisions (Lützén and Nordin 1993). This whole exercise around benevolence resonates with the concept of compassion. There is awareness that the other exists; sensitivity to their suffering (vulnerability); and an emotional response from the nurse that allows her to feel what the other is feeling and moves her to respond.

Scott (1995) explored those things that are required if a nurse is to sufficiently understand the predicament of the other and effectively meet *his* needs rather than those *she* believes him to have. Early on in the paper 'compassion' was introduced and related to a perception that the nurse has of the other as a person of equal worth whose suffering could happen to anyone. More importantly what ran through her paper was an emphasis on the nurse's awareness of the other which at times must be intense so as to allow that nurse a glimpse into the others emotional experience. This intensity involves the use of imagination, that is so powerful it can bypass the nurses own sense of self, to try to understand the others perspective. It is a view of compassion that dwells considerably upon awareness of the other as a highly developed skill that places heavy demands on the nurse in respect of energy, imagination, time and emotion. Despite this it was argued that every nurse should be capable of such intensity when circumstances require it (Scott, 1995).

These discourses around empathy, respect, benevolence and awareness exemplified the activity occurring around this Meleis milestone as broad concepts were re-examined and appraised. Whilst there was still work to be done (as clearly no consensus had been reached regarding empathy) they stand as important to ones understanding of nursing's relationship with compassion as when each of the phenomena are explored, awareness of and sensitivity towards the other are found to be essential and nursing moved closer to acknowledging compassion as being central to the practice of nursing.

Milestone Four 1996 – 2000

Evidence Means Research not Theory

Meleis notes that this milestone was characterised by nursing having a much greater focus on research and research activity that could support the identification and introduction (to practice) of best evidence (Meleis, 2012). The milestone was suggested as having a number of properties; firstly that much of the research was positivistic and influenced by the biomedical model; secondly, whilst a critical dialogue opened up about the meaning of evidence, no broader eclectic criteria had been sufficiently explored; fourthly, some emphasis was placed on identifying the best method by which best evidence could be implemented; finally, there was an absence of any discourse as to how theory could support the development and implementation of evidence (Meleis, 2012).

Czerwiec (1996) reported on a narrative research project exploring perceptions about care held by families of those at the end of life receiving palliative nursing. Themes emerged to suggest that nursing actions (such as providing comfort, pain relief and attending to dignity and personal hygiene) and the nurses demeanour or attitude behind the action were highly regarded. A high frequency descriptor was 'compassionate' and was applied to both actions and attitudes. Overall, the study suggested that families of patients can identify the caring actions and attitudes that have meaning to them and that they chose to describe these as compassionate (Czerwiec 1996).

Halldorsdottir (1996) in setting out her theory of nursing assimilated findings from previous qualitative research studies oriented around the patients experience of encountering nurses. Two clear metaphors emerged to give structure to her theory; firstly *the bridge* and secondly *the wall*. Both are related to the quality of connectedness between the carer and the cared for as perceived by those on the receiving end of care. The bridge is founded upon compassion which patients perceive as the motivational force that compels the caring person to provide care. In reality the bridge is a metaphor for compassion as it relates to the connectedness between carer and cared for. The wall was also metaphorical and described the stance that prevented a connection being made. Nurses who built walls rather than bridges were seen as being indifferent, disconnected and uncaring (Halldorsdottir, 1996). A later paper,

(Tierney et al. 2017) introduced a range of factors to suggest how practitioner behaviour could be contextually shaped to drain or defend the flow of compassion in a healthcare setting. Halldorsdottir (1996) would argue that those whose compassion is drained are more likely to build walls whilst bridge builders are those whose compassion is buttressed by defender factors. Arguably more important than the factors themselves was the recognition that they can override professional benevolence with the result that practitioners have the capacity, (one might say vulnerability) to be connected or disconnected to those in their care (Tierney et al, 2017).

Sherwood (1997) identified that there needed to be greater research rigour around exploration of the core concept of caring than had been seen in the preceding two decades and that the research evidence that did exist was in need of synthesis. She undertook a meta-synthesis of qualitative research analyses of caring with two aims. Firstly, to support the development of new research methods that could serve to clarify the operational parameters of a new model of caring and; secondly, to then create instruments to test the proposed interventions within that model (Sherwood, 1997). From that came a view that compassion within nursing practice was part of a value system that believes in the recognition of each individual patient and that this recognition was rooted in allied concepts of interest, sensitivity, dignity and respect. Overall, in this analysis compassion does not come to the fore as a core concept of caring although it must be acknowledged that neither did it in any of the papers that were included.

Tuckett (1998) considered nursing from the stance of virtue ethics and placed emphasis not on 'what ought a nurse do?' but rather on 'who ought a nurse be?' (p220). She stated that compassion was a moral virtue whose value rested in setting an ethical context for nursing actions. The nurse who acted from compassion did so with the intent of doing good and that this sat within caring as the central core of nursing. Caring acts occurred after the nurse had recognised the other and their suffering and were aimed at alleviating that suffering. Caring was therefore equated with compassion and as an intensive form of benevolence (Tuckett, 1998).

Reynolds and Scott, (1999) undertook a review of empathy in relation to nursing that identified polarised reports of highly positive beliefs of its crucial nature when another

is suffering (Rogers, 1975) to the deconstructive expression that empathy is impossible in nursing (Morse et al 1992). It was suggested there was sufficient overlap between the findings from others to state that empathy was a crucial component of the caring relationship and that it was a way of communicating that the other, their suffering and their perception of their suffering were understood by the nurse. Additionally they opened up a discourse around those factors that interfered with this and prevented nurses doing those things that they should be doing.

Swanson (1999) overtly acknowledged the tension within nursing as it tried to achieve consensus as to the most appropriate method for exploring its own core phenomena. She undertook a comprehensive literary meta-analysis of caring that in part served to tie a large body of previous work together whilst at the same time highlighting that caring was still not adequately understood to allow evidence to inform practice. What emerged from that was the finding that five levels of caring capacities could be identified; those levels being;

1. Some people have the capacity to show caring attributes.
2. Specific beliefs and values underpin that capacity.
3. Conditions specific to the nurse, the patient and the organisation exist which may enhance or diminish the likelihood that caring will take place.
4. Caring actions may themselves be defined.
5. The implications of caring both negative and positive may be identified.

Moving upwards through those levels was dependent upon assumptions about the veracity of the previous level being accepted. As such the second level could not be reached if one were to doubt that some people have the capacity to care for and about others (Swanson, 1999). Additionally a significant finding from her review suggested that there was variance in ranking caring behaviours between those giving and those receiving care. A sample of 517 nurses pooled from nine studies compared to a sample of 385 patients pooled from eight studies showed no agreement as to what were important caring actions. Those identified by nurses were much more reflective of compassionate traits whereas those endorsed by patients focussed more on technical competence. The concern from that was that in respect of translating

research evidence into practice any attempt would be a potentially flawed process as the research base around caring was still incomplete (Swanson, 1999).

Dietze and Orb (2000) reflected upon the meaning that compassion has for nursing, positioned it as greater than a part of a broader caring concept, raised it beyond only an emotional connection and in doing so distanced it from empathy (which emerged as not authentic). Compassion, they argued, must be more than an emotion in that it is relational and dynamic; it articulates reverence for the other and demands that one acts altruistically whilst throughout the compassionate act is ultimately based upon a moral and rational decision making process (Dietze and Orb, 2000). Whilst it is strongly aligned to action those acts themselves are not where compassion resides, rather it is to be found in the way in which they are enacted; thus as Swanson (1999) stated 'not all nursing care equates with nurse caring' (p32) so not all caring acts equate with compassionate acts but those that do have their locus within the context of virtue ethics as set out above by Tuckett (1998). Having stated that out Dietze and Orb (2000) moved on to consider what compassionate nursing care may be. It is, they argued, a moral way of treating the other because they are more than just an individual and their needs exist within the context of a broader community. When the other suffers the nurse acts compassionately to alleviate that because we are all part of the shared humanity, thus nursing compassion is rooted back in Aristotelian *philia* and now directly related to the professional practice of nursing.

This Meleis milestone was marked by nursing theorists emphasising the need for research that could be translated into practice and the nursing literature allied to compassion did, to some extent, echo that. Where theorists placed emphasis upon nursing praxis and the shaping of evidence based practice the literature accentuated and explored the dynamic nature of compassion or compassion-like caring. What emerged from that was a discursive bridge and a shift away from what it was that the nurse was doing to how it was being done and why? Ultimately as this milestone was passed it was evident that compassion was becoming better understood but could not yet be reduced to a translatable best practice guide as the research base remained inadequate.

Milestone Five 2001 – 2005

Epistemic Diversity

During this milestone there was a focus upon diversity in thinking that influenced the development of nursing theory. That diversity encompassed not only theorists themselves through their culture, ethnicity, language, and geography, but also how those elements influenced the possession of beliefs and values that underpinned theory. Grounded theory emerged as a research methodology well suited to working with diversity particularly as attention also focussed upon diversity in health-illness situations and in particular within patient groups. Overall, the main properties of this milestone were; critique of the *status quo*; reconceptualization that was situated and contexted and; analyses that were acknowledging of diversity (Meleis, 2012). At the close of milestone three it had been noted that nursing had still not reached consensus about empathy and the focus of milestone four was not conducive to a further review so it is of interest that Kunyk and Olson (2001) open up milestone five with another concept clarification of empathy using literature from 1992 to 2000. They concluded that at the last major review (see Morse et al. 1992) nursing was challenged to identify the subjective and non-measurable components of empathy. Accepting that the challenge had been taken up led Kunyk and Olsen (2001) to state that there was much more diversity amongst the conceptualisations of empathy than had previously been reported. Despite this they concluded that the concept was not yet mature and a number of discrepancies still existed (Kunyk and Olsen, 2001). Despite this the paper remains important for the study of compassion within nursing as their analysis helped to draw out the point at which empathy diverged from compassion. They identified five conceptualisations of empathy (as a human trait; a professional state; a communication style; a form of caring and a special relationship) all of which could sit comfortably with conceptualisations of compassion drawn from the general literature. However, in empathy as a form of caring which implied a more dynamic quality only a minority of interest had been shown. This directly related to the findings of von Dietze and Orb (2000) that stated compassion transcended just the emotional and cognitive and it was the call to act that distinguished compassion in nursing from empathic nursing.

Boleyn-Fitzgerald (2003) continued the distinguishing of compassion from other concepts considered to be similar or the same. Drawing on a body of philosophical literature he identified two key aspects for consideration, firstly 'caring for' and secondly 'caring about'. The first aspect has been discussed earlier in this literature review (see von Dietze and Orb, 2000; Swanson, 1999; Tuckett, 1998) and rests within the deliberate benevolent actions of the nurse in meeting the needs of the other (Boleyn-Fitzgerald, 2003). For the other, as reported in the review by Swanson (1999), this is where the important aspects of caring lay and what they said was required was technical competence and confidence. Whilst 'caring for' was largely uncontroversial, Boleyn-Fitzgerald (2003) did critique the emotional nature inherent in 'caring about' arguing that the degree of engrossment with the other that is required was unsustainable in nursing (if not dangerous as it would create a vulnerability to 'burn-out'). In doing so he echoed the much earlier view of theorists such as Orem (1985) that nursing care is not emotionally driven. However, Boleyn-Fitzgerald (2003) acknowledged that this left something of a hole in understanding the documented relationship between good care being delivered by caring people and poor practice being mostly associated with those who did not really 'care about' their patients. Clearly, he suggested, some kind of emotional element must be involved in good practice. He then drew on Kuhse, (1997) to suggest that sympathy may be that element and then, cited Snow (2000) to suggest that sympathy means 'feeling for the other' whilst empathy means 'feeling with the other'.

Compassion, whilst clearly sharing with empathy the realm of 'feeling with the other', goes beyond it as the emotional element involved is only the trigger that moves the nurse to relieve the suffering of the patient. More importantly compassionate nursing has a sympathetic element that allows the nurse to also accept with equanimity the pain of the other without being overwhelmed by it (Boleyn-Fitzgerald, 2003). It represents, he argued, an ideal to face the suffering of the other with sympathetic understanding, benevolence and equanimity rather than an obligation for nurses as it would be unreasonable to expect continuous conformity or to condemn those who fall short of the ideal. However, it would not be unreasonable, he concluded, to regard trying to cultivate compassion as a professional nursing obligation.

Sadler (2004) offered some insight into the semantics of core concepts and argued that such concepts are contextually located and understandings often change over

time. Whilst the terms 'empathy' and 'caring' gained popularity in earlier decades they were probably all attempting to describe the same thing. As a result whilst 'compassion' had largely been absent from the literature in favour of these more populist terms the literature itself may have believed it to be more than present. As these concepts were clarified they were in reality not becoming more compassion-like but instead increasingly divorced from compassion and the term compassion was being used more to discuss those things that were clearly compassionate.

Jormsri et al. (2005) highlighted that nursing has always had a requirement for its practitioners to be competent and they subsequently identified three areas of competence, clinical, general and moral. Whilst patients highly value clinical competence (see Swanson (1999) above) moral competence is more about the patient being able to trust that the nurse will act in his best interests, perhaps reflecting the benevolence discussed above by Tucker (1998). Compassion was positioned as one of eight indicators of moral competence in nursing practice and seen as an aspect of daily nursing practice by which the nurse perceives the patients suffering; supports his feelings; and then perform nursing roles 'in a spirit of loving kindness' (Jormsri et al, 2005 p588) to alleviate that suffering.

Spichiger et al. (2005) challenged the call from some nursing theorists for quantification of the concept of care. They argued that positivistic science is inadequate for the understanding of caring praxis particularly where that practice is based around a cultural tradition or specific social group. The desire is understandable, if nursing care can be reduced to a defined set of context free, measurable variables then its introduction and application as evidence will more easily be translated into practice. The problem is however that intangibles like compassion cannot be defined in any meaningfully measureable way and they therefore proposed a methodological shift towards the phenomenological exploration of caring (Spichiger et al. 2005).

At the close of this milestone compassion had started to be divergent from empathy and its relationship to nursing. Pulling them apart was the recognition that unlike compassion, empathy possessed no dynamic qualities and if anything the degree of engrossment required to truly feel with the other (when applied to a nursing context) was potentially paralysing. The necessity for an emotional aspect of compassionate

nursing was acknowledged and sympathy positioned as the agent for this, the argument being that it could promote the equanimity needed to protect the nurse from being overwhelmed by empathic engrossment. Supporting the whole was the principle of benevolence in that the nurse would always aim to act in the best interest of the patient and the dynamic act of compassionate nursing evidences this by alleviating the suffering of the other.

Milestone Six 2006 – 2010

Nurses Empowered and the Liberation of Nursing Theory

At this milestone one was required to dwell upon the journey that nursing theory has taken as it increasingly moved away from the bio-medical model towards embracing new paradigms and methodologies that could better inform nursing practice. There is one eye upon future milestones as Meleis (2012) argued for the need to develop theory that could better reflect the specific needs of particular patient groups, such as those with chronic illness or the elderly.

Peters (2006) undertook a phenomenological review of compassion in the context of nurse educators to draw out those themes that nurse faculty members would expose themselves to as, they supported their students to build the elements of their individual praxis and effectively work with patients as they prepared to enter professional nursing. Emphasis was placed upon the fundamental importance of; connecting with the other who is in a state of suffering; understanding the experience of the other; recognising the needs of the other; opening oneself up to an emotional response; and, acting to make it better (Peters, 2006). Within the theme '*walking a mile in another's shoes*' the educators described levels of empathic response that were reflective of the engrossment which others (see in particular Boleyn-Fitzgerald, 2003 as discussed above) have raised concerns about as unsustainable for the practice of nursing. One may infer from this that the fit of literature around milestones is not exact and indeed the journey being undertaken is in no way linear. Whilst by the close of the previous milestone nursing was seemingly moving away from empathy towards benevolent sympathetic equanimity to characterise nursing compassion, there was patently still an ebb and flow and a revisiting of earlier concepts from within the literature.

Schantz (2007) suggested that 'compassion is nursing's most precious asset' (p48) but voiced concern that it was not being widely promoted in the context of everyday nursing practice. She undertook a concept clarification using an evolutionary perspective approach in an attempt to determine the meaning of compassion and its relevance for everyday nursing. She addressed earlier work (see principally Sadler (2004)) that drew compassion out from the shadows of its more populist substitutions, caring, empathy and sympathy and, further positioned it as a distinct concept again differentiated from others by its 'intrinsic motion-generated effect' (Schantz, 2007 p51) or put simply its dynamic quality. She suggested that this dynamic aspect must be important and stated that the enacting of compassion is no small undertaking but anything less would be unacceptable for the practice of professional nursing.

Hudacek (2008) undertook a phenomenological study of narrative descriptions of nursing practice. She identified seven dimensions of caring in nursing, one of which, compassion, was universally present in all narratives. Despite this it was relegated to being dimension number two whilst first place was taken by 'caring' that was described as being the very core of nursing and characterised by empathic caring through which the nurse could feel the individual's pain. Compassion followed this and its focus was upon taking action to alleviate the suffering of the other (Hudacek, 2008).

Sayers and de Vries (2008) completed a concept analysis of sensitivity in nursing and identified an association with compassion in that both are closely aligned to 'feeling'. They reported that 'being sensitive' as conceptualised by nurses had two features; firstly being aware of the needs of the other and; secondly acting to meet those needs. Both are reflective of authentic compassion in that there is an active response or motivated behaviour that builds on the awareness of the other and their situation.

Austgard (2008) carried out a hermeneutical inquiry, from a Scandinavian perspective, to determine the characteristics of care. She introduced one aspect of the whole that had not previously been addressed namely, that the nurse must not only be sensitive to the suffering of the other but must also understand the concept of suffering itself. Citing the Swedish philosopher Eriksson, she argued that suffering threatens the absolute dignity of the human being without which personhood is diminished. The nurses caring role is to go beyond showing respect to the body itself and treating it in the best possible way, towards adopting a holistic stance to protect body, soul and

spirit. This resonated with the view of Cassell (1982), discussed earlier, that suffering is:

“A state of severe distress associated with events that threaten the intactness of the person” p639).

Such a state is a singular, particular felt experience that another cannot share but can recognise and in some way understand whether that be through experience or empathy.

Bradshaw (2009) critically addressed the Government of the United Kingdom’s call to measure nursing care for compassion and in doing so further reviewed the concept as applied to nursing. She stated that compassion was no abstract theoretical idea but rather a dynamic, virtuous act that was given life through nursing praxis and expressed through action. Turning this into a target would not only be hard to measure as the concept is essentially unquantifiable. Any simplistic attempt to do so would focus upon the appearance of compassion and potentially cause nurses to become actors working to a scripted façade. This is more the rhetorical Aristotelian performance whilst authentic compassion through the early twentieth century was unashamedly regarded as the *raison d’être* of nursing (Bradshaw, 2009). However, by the start of the fifty year timescale (1967) that this dissertation concerns itself with its influence was on the wane and alternative, populist terms were being used.

Dunn, (2009) discussed the potential vulnerability of compassion fatigue for nurses who are routinely exposed to the vicarious suffering of others. She cited previous work (particularly, Joinson, 1992: Figley, 1995) to set out the risk factors for those nurses who are empathically engaged with their patients. In doing so she echoed the previous concerns of Boleyn-Fitzgerald (2003) concerning the engrossment that empathy demands and the unsustainable nature of this.

Van Der Cingel (2009) questioned why, if compassion cannot take away suffering, is it important for those who suffer that their nurses be compassionate? Early on she distinguished the construct of compassion from concepts such as sympathy and empathy although accepted that it was a strong emotion evoked by the suffering of another. Even though that emotion could be compelling, she argued that compassion was a deliberate process of decision making and that even when caught up in the

moment or being moved to respond, decisions could still be weighed and for nurses those decisions were clinical judgements.

Lundgren and Berg (2011) reported outcomes from a phenomenological study exploring the meanings of receiving care. Overwhelmingly the threat associated with needing care came to the fore with the loss of control over one's life and the powerlessness of dependency characterising the theme. Where the caregiver is a professional then invariably they will be a stranger and the patient must adjust to a situation that is rife with exposure and vulnerability. However, this was balanced by the more positive theme that there is hope to be found in those caregivers who acted in the best possible way (beneficence); who treated the patient individually; who alleviated suffering and; who supported that patient to achieve optimum recovery (Lundgren and Berg, 2011). Here there was no reported expectation in the patient that the nurse will be empathic and no call for her to share the pain or to have anything resembling an engrossing relationship. Rather the patient accepted the roulette of care and hoped for a practitioner who would display what are clearly compassionate behaviours.

As this milestone came to a close it was of note that compassion had become effectively divorced from empathy or sympathy and was now the more populist term; of the nine papers selected to represent the literature through this period eight directly used the term compassion.

Milestone Seven 2011 –

Onwards into the Future

Whilst the milestones from Meleis are arrested by the publishing date of her 5th edition (Meleis, 2012) she advocated that, of course, nursing theory cannot stand still but must move forever forward. There is a role for a new generation of theorists to play in setting out the future direction of nursing and to do so with increased confidence in a diverse range of research methodologies and practice based around the very particular needs of specific patient populations.

Cole-King and Gilbert (2011) opened up the milestone by directly addressing what compassion is in relation to health care and offered their definition as being:

‘... A sensitivity to the distress of self and others with a commitment to try to do something about it and prevent it’ (p30)

There is acknowledgement here of the potential impact that vicarious suffering can bring as well as a very clearly stated dynamic quality. That ‘doing something about it’ and the motivation behind it they believed raised compassion above caring which they subsequently repositioned as less specific (so, one can care for one’s car but only be compassionate towards a fellow human). Motivation, they argued, was the most fundamental aspect of compassion without it those other aspects lose much of their value and potentially become pointless (Cole-King and Gilbert 2011). They reconnected empathy to compassion but with less intensity than previous accounts and consequently with less vulnerability to becoming engrossed and overwhelmed. Empathy, they suggested, was about trying to understand the experience of the other and the possible emotions involved in that experience. In moving on from that they rejected the second Aristotelian construal and included ‘non-judgement’ as one of the aspects of compassion. The suffering of the other has been acknowledged and an attempt made to understand its nature and emotional context but there one stops; it is now accepted and validated but not judged and the compassionate person now acts to alleviate that suffering (Cole-King and Gilbert, 2011).

Sargent (2012) undertook a critical review of conceptual analyses of caring as presented in the nursing literature since 2000. The time had been reached, he argued, to consider anew the relationship between caring and nursing and to question if nursing were not being held back by being synonymous with caring alone. Caring, he contended, had been subjected to repeat conceptual analysis whilst there had been no critical discourse as to why it needed to be conceptualised at all. As part of this critique he itemised those things which had previously been regarded as the individual elements of caring, such as compassion, and credited them with achieving maturity and an ability to stand alone as critical components of nursing praxis. In challenging the accepted nursing doctrine that “Caring is nursing and nursing is caring” (Leininger 1984) he repositioned compassion as an independent and dominant domain concept that on its own merit deserved a place at the core of nursing.

Curtis et al. (2012) explored, through grounded theory, compassion from the perspective of student nurses at the point registering as nurses. The students suggested that compassion could be found in the small things that matter to the patient

alongside taking time to listen and try to understand the others experience. It is that genuine interest to know more about the other, developed from spending time meeting personal care needs that they considered to be the empathic element of compassion. The compassionate nurse is one who makes a moral choice to try to do those things and yet they feared that as a registered nurse the opportunity to do so would be less sustainable than for a supernumerary student. Compassion therefore has a vulnerability of its own particularly as registered nurses become separated from close contact with their patients. Within that vulnerability lay the potential for future disillusionment particularly if organisations placed more emphasis on outcome measures than upon professional values or, if the need to be assimilated into a team would constrain a nurses challenge of uncompassionate care should that be necessary (Curtis et al. 2012). Overall the findings outlined that compassion was seen as fundamental to professional nursing practice but it is a challenging ideal to live up to in reality and, in the context of workplace socialisation, it is vulnerable.

Straughair (2012) in exploring the implications for nursing of rising to the challenges that compassion brings showed that as a concept it was becoming ubiquitous and incorporated into contemporary policy, in principles of best practice, and in regulatory standards (Department of Health, 2010; Royal College of Nursing, 2010; Nursing and Midwifery Council, 2010). However whilst compassion was increasingly included in health care literature and strategy it was still somewhat vague as a concept and, whilst increasingly being recognised as a fundamental of nursing it was also increasingly fragile and vulnerable in the face of 21st century technological nursing. To promote compassion within nursing praxis nurses needed to; find appropriate role models who were already delivering compassionate care; have access to appropriate support to reduce the potential burn out that even a less engrossing model could bring and; develop leadership through which compassion could be championed within organisations (Straughair, 2012).

Fry et al. (2013) undertook qualitative research involving non participant observation of specialist emergency department nurses. What emerged from that further echoed the recognition that compassion was a fundamental core domain of nursing but the context of modern nursing itself led to its vulnerability and fragility. Their observations showed that compassion was enacted through the interpersonal connections each nurse makes with others, often these were founded upon relatively small acts of

positive body language, humour, touch or eye contact. They noted that these acts had a calming effect for patients but were contextually and negatively impacted upon when the nurses were experiencing challenging circumstances or when organisational pressures created tensions which held back the delivery of compassionate care. In this study it was not the technicalisation of senior nurses that impacted negatively on the interpersonal aspects of compassionate care, as the two can harmoniously co-exist, but rather it was organisational needs and competing demands that created barriers (Fry et al, 2013).

Curtis (2013) undertook a phenomenological exploration of nurse tutors concerns about how prepared student nurses were to deliver compassionate care. In doing so she outlined more fully those 21st century challenges to compassion that Straughair (2012) and Fry et al (2013) had introduced. She set out three themes as being; the delegation of care tasks to healthcare support workers; practice reality being greatly time constrained in comparison to university placement and; the ability, resource or capacity to meet needs for emotional support (Curtis, 2013). She concluded that one must question how realistic it may be to expect student nurses to aspire towards the ideal of compassionate care.

Horsburgh and Ross (2013) built upon the findings of Curtis (2013) particularly that there was a need for support but that such support may not be there. They explored newly qualified nurses' perceptions of compassionate care and found that the transition from student to registered nurse was a challenging time during which they struggled to deliver the compassionate care that they aspired towards. However despite those aspirations it seems clear from the transcripts offered that some had little understanding of what compassion was and their tendency was to identify it more through its absence. Those who attempted to conceptualise it suggested it was related to comfort, to reciprocity, to being genuine and to forming connections to others.

Georges (2013) carried the debate around the fragility of compassion further by introducing the concept of biopower and establishing the relationship between the two. Biopower she described as related to power over life including over the life of the other and, in part, locates this in the spaces such as hospitals where power over life may be exercised. She introduced to this discourse the concept of the 'unspeakable' (p6) as the everyday accepted erasure of personhood through unequal power relations that

ultimately lead to violence. One may set this in context by acknowledging that much of the abuse this dissertation has identified in Chapter One could be seen as having a relationship with biopower and the unspeakable. Georges (2013) further introduced an emancipatory theory of compassion for nursing which highlighted the protective role of compassion in mitigating the risk of biopower that may cause additional suffering.

Dunn and Rivas (2014) clarified that nurses felt under pressure to deliver compassionate care within the demanding and multifaceted modern world of health care and subsequently discussed the concept of compassionate energy to consider showing compassion in the moment. They suggested that it is such energy that drives the dynamic nature of compassionate nursing and allows positive outcomes to emerge for the other. They drew on evidence from their phenomenological study that was originally aimed at identifying the things that keep nurses in nursing to identify that; compassion has a degree of spontaneity about it that was expressed through allusions to action; nurses can establish a time and a space for their presence itself to be the compassionate force; within that space the nurse can connect with grace and even in the moment show love, kindness and dignity (Dunn and Rivas, 2014).

Dewar et al. (2014) discussed the meaning of compassion in relation to health care and sought to extend its influence. They accepted that the understanding of compassion was related to awareness of the suffering of the other but advocated that sensitivity towards vulnerability was also important. The argument made was that there are many small but significant interactions between nurses and patients not aimed at alleviating suffering but at meeting needs that left unmet could cause suffering or distress. Within this lies the simplicity of compassion as such sensitivity may be to the fundamentals of care (so, supporting the other to relieve hunger, thirst etc.) but also reflected is its complexity as one attempts to value, connect, engage and respond to the other in a way that has meaning for him (Dewar et al. 2014).

Bramley and Matiti (2014) explored compassion through the eyes of those on the receiving end of care. They found that patients echoed those things that had become relatively common in the nursing literature, in particular that compassion was rooted in action and those acts were associated with nurses giving their time and making efforts to understand the patient experience. They broadened the context of 21st

century health care to suggest that nurses learned caring in a more complicated, moral, emotional and organisational world that had itself been responsible for deficits in compassion.

Richardson et al. (2015) addressed how to prepare student nurses to deliver compassionate care in practice by establishing an undergraduate module specifically focussed upon compassion, caring and empathy. They argued that these core elements of nursing could be taught through a reflective medium that emphasised the connection between the nurses' actions and patient outcomes. By doing so they also connected action with compassion in the context of nursing and as such there is a further resonance with earlier literature.

Borgstrom and Walter (2015) continued the critique of contemporary health care by exploring discourses around choice and compassion at the end of life. In doing so they theorised compassion as dynamic, relational and rooted in a sense of social solidarity through which the other is brought within a kinship with the care worker. It is that kinship which in part mediates for the problems of 21st century health and social care which has created systems that contract out care to the lowest bidder. Whilst physical care is in the contract compassion, as defined through small acts of kindness, is not. However, that sense of kinship which develops between carer and cared for was claimed to see carers finding the time to spend with the cared for even when this was at a financial loss to the carer. Overall compassion is again associated with dynamic action and whilst there is fragility in the face of the modern world there is a sense of rescue to be found in the ancient Aristotelian concept of *philia*.

van Lieshout et al. (2015) outlined the person centred approach as another means of buttressing compassion against the challenges of 21st century health care. Similarities between person centeredness and compassion were suggested with both being relational caring activities involving mutual respect and aiming for understanding of the other. Their study showed through narrative analysis that compassion was valuable yet fragile and challenging to develop and retain in real-world practice. They argued that those who are championing compassion in nursing practice have dynamic moments of synchronicity when they and practitioners achieve mutual understanding. Outside of those moments there is vulnerability as relationships that are aimed at

being built on kindness and compassion may be negatively affected by broader external influences.

6.4 The Concept of Compassionate Nursing Care – Summarised

This literature review has revealed that whilst nursing theory could generally be aligned to fixed milestones its contemplations regarding compassion have ebbed and flowed across, around and amidst those milestones. Originally compassion as a semantic aspect within the nursing theory discourse appears to be a casualty of the development of early theory in the 1960's. Compassion is essentially not present but this review finds that those early theorists adopted two other populist terms, caring and empathy, as proxies for compassion and as such it has always had a place in the nursing literature during this time period. What is readily apparent is that there has been both a semantic and a positional shift as the literature under review has developed over time. Semantically compassion has regained populist status in that by the final milestones it is commonly used in the titles of relevant literature. Aligning to this is the finding that compassion has been repositioned as one of a number of elements of the more dominant core domain of caring to being respected as an independent and dominant domain concept frequently alluded to as the very core of nursing.

The literature has shown that compassion in the context of nursing has certain qualities that give a breadth to its conceptualisation. It is dangerous, demanding but also fragile and vulnerable; it is readily observable but essentially unmeasurable; it is a prophylactic mechanism to prevent biopower and the inevitable abuse associated with it, and; it is the most important aspect of nursing yet most powerfully evidenced through the smallest of nursing acts. Nursing compassion is comprised of a number of elements that may allow a working conceptualisation to be offered. It is principally characterised by dynamic action that is initiated by benevolence towards the other and sustained through sympathetic equanimity and driven by the positive energy that benevolence generates. The whole is oriented around a relational connectedness that reflects the Aristotelian concept of *philia*. In short the nurse acts to do good for the other because both she and he are part of a greater ontological whole. In doing good she is aware of the other and his suffering and whilst understanding this she is not so

engrossed that she becomes overwhelmed and paralysed by it so as to no longer be capable of the rational decision making that underpins the prescribed nursing care that aims to alleviate his suffering.

6.5 The Concept of Compassionate Dementia Care

Having established that compassion in the context of nursing can be conceptualised from the nursing literature the aim of the second scaffold was achieved and one could progress to the next level. The third scaffold was constructed around a paucity of literature, tentatively some pieces that relate to older people with chronic conditions were included and consequently that structure was at risk of being built, out of necessity, without a strong foundation. With that caveat in mind the seven papers identified by the scoping review were reviewed to explore if such a concept extension actually existed.

Naue and Kroll (2009) stated that the diagnosis of dementia makes a dramatic and negative statement about the individual who is labelled. It creates a new identity and that previously multi-faceted adult human being becomes simply the 'demented other'. This new identity is subject to an intermingling of medicalisation, sympathy and compassion and the person emerges as at the other end as someone who has lost his mind, his identity, his independence and consequently his status. There is, they argued, no going back from that; once the label is assigned it is for life. There is redemption to be found in nursing actions that are aimed at the preservation of personhood, identity and positive sense of self and, perhaps one could see virtue in this as a very specific element that could serve to define in part a nursing view of compassionate *dementia* care as a distinct concept.

Perry (2009) attempted to explore the means by which the nurse communicates to older people, with chronic conditions, that their suffering is acknowledged and that she is prepared to act to alleviate that. The first mechanism relates to giving attention to the ordinary everyday things that have meaning to the other and was seen to be important to the nursing definition of compassion as outlined above. The second, however, was new and themed as 'keeping the promise never to abandon' (Perry, 2009 p19). It highlighted the importance of presence and the act of staying with the other who experiences difficult or traumatic moments. One would argue that this is

different from acknowledging the suffering of the other or attempting to share their pain but is rather standing by the other as they are suffering and communicating that they are not alone. The paper drew out that this was particularly so when the other is facing death without doubt the most profound singular event to be borne by the individual (see Malpas, (2012) above) and shows the role of compassionate nursing in providing a sense of comfort .

van der Cingel (2011) explored compassion through the lens of the relationship between the nurse and the older person with chronic disease. She began by acknowledging that compassion was the most appropriate mechanism through which the humane aspects of nursing care could be delivered, then questioned whether it could also give a sense of meaning to those care acts. In answering that question she provided some original elements that were subsequently themed into seven dimensions one of whom 'presence' has been addressed above by Perry (2009) the others encompassed; attentiveness; listening; confronting; involvement; helping and; understanding. Attentiveness involves sending a signal to the other that the nurse is deliberately inviting him to make contact, (perhaps, if one uses the metaphorical language of Halldorsdottir (1996) to work together to build a bridge). That signal could be sent through eye contact, slowing ones pace or taking a chair to sit by the person, all deliberate acts on the part of the nurse. Following this the next theme 'listening' gives space for the others narrative to be relayed and the nurse's actions are to only speak when by doing so the other is encouraged to continue the narrative. van der Cingel (2011) suggested that the compassionate nurse has become the compassionate audience and that may be enough for the other or it may create 'room to breathe' (p677) which can subsequently be a space for mutual dialogue.

It is in that space that the suffering of the other can be acknowledged and the emotions around it explored. The third theme 'confronting' is to be found there and relates to the nurse confirming that the way the other is feeling is appropriate. The fourth theme 'involvement' in which a bond is established around the mutual recognition of the others suffering. The truly dynamic aspect occurs in theme five 'helping' which echoed the earlier literature in that it is attention to the small things and the little acts of kindness that has meaning for the other. The last theme, 'understanding' or at least the attempt by the nurse to show that she is trying to understand the experience of the other. The paper moved on to set out further findings. Firstly that suffering in the

context of chronic illness was not all about pain or difficulty in breathing but was to be found in a myriad of everyday troubles and physical restrictions that threaten the other's independence. Secondly was the importance of imagination for nurses to picture themselves in that person's body or world. Thirdly the belief that compassion must be felt and the nurse moved in order for it to be authentic. Fourthly that compassion must change the nurse's view of the 'difficult patient', he who has 'challenging behaviour' or with whom co-construction of the bridge is hard labour. Having insight into that persons experience softens the perception of his behaviour and makes it easier to understand (van der Cingel, 2011).

One could comment that within this exposition of the act of compassionate behaviour there were some aspects that could lend themselves to the discourse around dementia and compassion even though the paper did not refer to dementia at any point. Whilst one may question the positioning of the other with dementia as essentially passive whilst the nurse takes the more dynamic role this could be the experience in cases of advanced dementia. To balance this there is an enabling quality as the nurse seeks solutions to some of that myriad of physical (and in this case cognitive) restrictions. In cases of those apparently affected by severe impairment it is the nurse who will signal her intent to purposefully be with that person and within the listening space there is a possibility for personhood as expressed through the unspoken voice to be heard. Finally, there is a great need to reposition 'challenging behaviour' generally but specifically to distance it from the reductionist damage to the brain explanation.

Sabat et al. (2011) revisited the contribution made by Naue and Kroll (2009) to make the case that whilst one may have dementia one may still have a life and that life may still have meaning. They challenged the language used in that earlier paper and in particular the descriptive term 'demented person' by arguing that there was a considerable difference between being a person who has been diagnosed with dementia and being 'demented'. They raised points that reinforce some of the elements van der Cingel (2011) outlined (see above) stating that the person with dementia is a whole person that the nurse's role is, in part, to listen to that person and to support him to attain his desired lifestyle.

Bryon et al. (2012) undertook a grounded theory exploration of Flemish nurses experiences of caring for people with dementia who were hospitalised and at the end

of life. They described that the nurse is touched by the vulnerability of the other the first time they meet and that this increases as the relationship builds. They come to know the individual person sufficiently well to understand when he was sending signals that they interpreted as communicating a weariness for life and an expression of its meaninglessness. They stood by that person as such suffering was being endured and took pride in what Perry (2009) has called 'keeping the promise never to abandon'. Being touched by the other and aware of his signals led nurses to act to try anything to bring about dignified care even if this led to conflict with physicians, families and other nurses. Within that was the danger of engrossment and some nurses described being on the losing end so often that they lost their fighting spirit, became resigned to defeat and one could suggest that therein lies the danger of compassion.

Dewar and Nolan (2013) reported on an appreciative inquiry study to define compassionate relationship centred care for hospitalised older people. Findings were indicative of a less passive model than that proposed by van der Cingel (2011), with their first dimension entitled 'knowing who I am and what matters to me' which is articulated through three sub-themes which reflected again a possible discourse around compassionate dementia care; firstly 'making a connection'; secondly, 'knowing the little things that matter' and; thirdly, not assuming how people want to be cared for'. Other dimensions focussed upon understanding, engagement and working together all of which one could argue would find a place in the broader set of compassionate elements.

Finally, Eldh et al. (2016) report on a narrative study of what nurses in long term care valued about their work. What emerged was the satisfaction to be found the smaller acts of kindness rooted in sensitivity and knowledge of the other.

6.6 The Concept of Compassion Dementia Care – Summarised

There was very little in this literature to suggest that the nursing conceptualisation of compassion could be built upon to have a distinct subset of elements that applied exclusively to dementia care. There were, however, three indications that further focussed inquiry could follow to identify that subset. Firstly, the idea of presence, the standing with the other or alongside the other rather than in their shoes and the promise never to abandon the other who is suffering both have potential in the context

of dementia care. Secondly, the possibilities of the breathing space suggested by van der Cingel (2011) may also give a space within which the nurse can listen to the voice of the person with dementia and through that listening begin offering to support the individual's personhood and positive sense of self. Thirdly, there is the notion of signalling as a relational process between the nurse and the person with dementia. The nurse can act to signal her invitation to engage with the patient and he can signal to her his emotional state; the more time the nurse devotes to being with him the more enhanced her sensitivity becomes and the better the signalling becomes. That said, there were significant limitations in attempting to draw out of these seven pieces of literature anything that could be called a nursing conceptualisation of compassionate dementia care; that validates the research question that this dissertation is oriented around.

6.7 Summary of Chapter Six

This chapter has set out a comprehensive review of the literature identified through the earlier scoping review. It has been shown that compassion has been classically defined for centuries and that the study of compassion reaches across cultures, religions and academic disciplines. Compassion has naturally had a close relationship with nursing even though at times the strength of that relationship has ebbed and flowed and semantically the word itself has been in and out of fashion. The literature pertaining to compassionate nursing is possessed of a breadth and width that spans the world of nursing research as captured elegantly within the Meleis-milestones (Meleis, 2012). Whilst it is a dominant library of literature it holds no obvious sub-set devoted to compassionate dementia care. This aspect of the review has been anything but substantive. That is not from any academic inadequacy but from the surprising fact as a concept it is essentially absent.

This chapter ends with that acknowledgement and, from that comes the necessary drive to explore empirically what that concept may be from the perspective of acute care nurses. The next chapter stays with the literature and subjects it to a further level of analysis which draws out its inherent positions. That will act as a necessary and important bridge from the theoretical to the empirical, joining together the two halves

of this thesis and establishing a base from which to understand and find meaning in the findings that will be presented later.

Chapter Seven

A Reflexive and Generative Positioning of the Literature

7.0 Introduction

This chapter forms a bridge between different parts of the thesis. It spans the distance from, on one side, the descriptive aspects to the other which represents the more empirical and dynamic realm populated by the analysis, interpretation and presentation of data. This is important as the bridge here has acted as a device, not only to connect potentially isolated chapters, but also to begin the process of signposting the style of theorising that was necessarily applied to support the emergence of legitimate findings. Its content has in part been rehearsed in earlier chapters, related to methodology and the substantive literature review, and its construction is such that aspects of the two were brought together to further analyse the literature. However, enacting this was in no way a mere extension of the literature review but rather a deliberate attempt to further use Positioning Theory (Harre and van Langenhove, 2008) in an innovative manner with the aim of drawing out a deeper understanding. The theorising associated with that was as deliberately reflexive as the approach applied to the other analytical uses of positioning in this thesis. In doing so reflexivity (Skeggs 2002) became generative (Gergen 1978) and the subsequent normative discourse offered new insights. From this a number of broader influences and a model illustrating the journey that one must take to become a practitioner of compassionate dementia care emerged. That journey was seen to be cognitive, affective and inherently spiritual rather than physical. It represented a journey away from 'what do I do?' which was associated with role towards the more metaphysical question 'who am I?' which was aligned to positioning. This chapter will demonstrate that the process of moving from reviewing the literature to an early heuristic model was therefore a highly reflexive and generative aspect of supervision that underlined the importance of a close supervisory relationship.

Finally, this chapter's emphasis upon the nurse undertaking a journey towards authentic compassion (Carr 1996) makes an early and, useful contribution to the thesis as a whole in that it proposes that compassionate dementia care is probably not a fixed entity which is observable at some static point. Rather it is more likely to be

incrementally acquired by the nurse as a consequence of a diverse range of relational experiences. That incremental acquisition was the journey the model set out. Whatever the concept of compassionate dementia care is will be determined through the empirical work that follows in subsequent chapters.

7.1 Positioning the Literature

The literature related to nursing's relationship with compassion has been positioned (by this thesis) as narrative and when viewed across the chosen timeline (set by the Meleis milestones for nursing theory (Meleis, 2012) and the publication of *Sans Everything* (Robb, 1967)) there is a story to tell. The published work which comprises the chapters of that story also appear to fit well with the characteristics of each milestone suggesting that what gets published reflects the theoretical agenda of the day. Whilst the literature is a written narrative one is minded to reflect upon the utterances of speech, in conferences, corridors and classrooms, that have shaped the literature as well as the rights and duties of theorists, researchers, authors, publishers and readers as they act to establish positions or to facilitate the normative discourse which legitimises a renegotiation of what nursing is, what nurses do, how nurses do it and finally what the future possibilities may be. Whilst positions are inherently ephemeral that changes once they are committed to text and this could be seen as a limitation however, there is mitigation if one considers the literature as a whole possessing a storyline that is itself subject to the ebb and flow of discourse and semantic popularity. In this way the body of literature is likened to a conversation comprised of many differing voices and occurring over an indefinite period of time. The act of committing thoughts and beliefs to text would therefore be the locutionary act whilst the meaning beyond those written words that the author wishes to convey is the illocutionary act. In some ways this permits the text to possess an ephemeral nature as it comes to represent the thought or belief of that time and place within a conversation that moves on and other voices emerge or fade to continuously construct the social reality.

For most of this chosen time period compassion as the lead actor in this conversational narrative, sat on the outside of a group that was dominated by concepts like empathy before gaining a footing, rising to ascendancy, signposting the way to a future full of

possibility and then becoming victim to the relentless demands placed on 21st century health care. There is also a plot which unravels to reveal how published nursing literature is inspired, shaped and led by the dominant theoretical trends of the day. Over the course of the story one can see how the Meleis milestones are reflected in the compassion literature and equally importantly how that literature ultimately shifted away from the influence of role theory towards the less restrictive world of positioning.

In the way that an individual may simultaneously hold multiple positions so the literature appears to be somewhat contradictory so there can be an emphasis placed upon roles, and their inherent rights and duties, whilst at the same time a positioning stance may be adopted. Within the work of nurse theorists and researchers one can see how they appear to have taken the view that their own roles contained the right to challenge what had previously been taken for granted. As such they believed nursing's original phenomena of interest to be a defeasible set of rights and responsibilities and in turn that belief positioned nursing's core concepts as open to negotiation. Some went further and stated that the core of nursing was to be glimpsed in the interplay between the nurse; patient; situation; and the context which brought all together (Newman, 1983). This view of nursing as a dynamic social interaction was almost pure positioning although the concepts that emerged were still inflexible, and the nursing role was correspondingly still held captive within strict conventions. Those conventions are to be found in the initial phases of the model which emerge later in this chapter. In particular there is reference to the existence of a 'traditional' space which it was suggested is where the lay persons understanding of compassion resides. That understanding I suggest is naively or unknowingly associated with the Aristotelian rules that allow one to withhold compassion from the other who;

1. Is not deemed to have suffered sufficiently.
2. Has somehow brought that suffering on himself.
3. Is somehow not like us.

It is accepted that there are no absolutes and that it may be unfair to suggest all members of society not associated with the 'caring' professions have an impoverished or naïve view of compassion. In considering the illocutionary act behind naming the naïve space one needs to establish distance to show the higher expectations that society has, in this case, for the nurse. Sitting behind that act of naming is the implied

meaning that it is only from within the caring professions that one can be presented with sufficient opportunities to question and develop one's compassion for others which may involve breaking the Aristotelian rules as a matter of course. In play here are again both roles and positions; it is naively acceptable for there to be a lower expectation of compassionate behaviour for many social roles whilst others (the caring professions) are positionally associated with much higher expectations which in turn leads to compassionate behaviour becoming monitored, regulated and its absence subject to penalty.

It is during the first Meleis milestones (Meleis, 2012) when new domain concepts for nursing were emerging from new meta-theory that Griffin's philosophical analysis of caring (Griffin, 1983) aligned nursing closely to the Aristotelian construals which placed nursing care as a traditional role within a traditional space. She did create distance by disowning the layman's right to withhold his compassion from the other who is not like us and by insisting that the nurse was expected to respond to an emotional call to action to alleviate the suffering of the other without distinction. That compassion was not discussed in that analysis was not uncommon at this time as more attention was focussed around caring by nursing theorists who were re-examining the theoretical work of the 1960's and generating a new meta-theory base for nursing. Emerging from that was the duty to care which received most attention during this time period and whilst in Orem's model (Orem, 1985) care was identified as relational, so offering a further point towards positioning, the overwhelming view was still that nursing care was to be delivered from within the boundaries of the social role. For Orem this meant that if the other had a legitimate need for nursing care (stated as being a deficit in meeting a known self-care need) then the nurse was duty bound to meet that need. The rule reflected the inflexible relationship between rights and responsibilities as tightly bound to roles as set out above by Harre (2015) in that once the need is legitimated the other has a right to expect care whilst the nurse has a duty to provide that care. Placing care as the fundamental basis of nursing should have cemented the role as restricted by the boundaries of its core concepts and legitimised beyond question the mantra that 'caring is nursing and nursing is caring' (Leininger, 1984, p83). However the failure of nursing to reach consensus about what constituted 'care' as evidenced through thirty-five separate definitions identified through systematic review (Morse et al, 1990) suggests that the discourse was very

much alive. Within that discourse compassion had by the end of the 1980's gained the footing it had been looking for and nudged its way into the group to be cited by Roach (1987) as one of the five core elements of care.

The mantra offered by Leininger (1984) offers an opportunity to consider the literature as a developing conversation made up of locutionary, illocutionary and perlocutionary acts. In stating that 'caring is nursing and nursing is caring' she performed the locutionary act but one is minded to think more about the illocutionary, what did she mean by these words? The substantive literature review has identified that she implied caring to be the dominant domain concept with all other contenders firmly relegated to, at best, the status of sub-domain. It meant that nurses are positioned into a very restricted social role and it also meant that it was not open to debate. However, the conversation evolved over time and new voices emerged to suggest that such restrictions were defeasible. There were direct challenges to Leininger when Sargent (2012) repositioned compassion as the dominant domain concept and when Swanson (1999) threw doubt on the belief that all nurses have the capacity to care and stated that in something could be missing from the completion of nursing tasks or actions:

'Not all nursing care equates to nurse caring' (p32),

Through those challenges in a conversation spanning twenty nine years they each have blocked perlocutionary acts by deeming that the mantra is not correct and that other possibilities exist.

Whilst the positioning of compassion as a recognised element was a major step forward the next period of theory development, focussing upon mid-range theory, saw it positioned as very much the junior member of the group and whilst theorists were aware of it they seemingly couldn't quite remember its name. Developmental work followed around respect (Browne, 1993) benevolence (Lutzen and Nordin, 1993) and awareness (Scott, 1995) all of which led to the emergence of crucial factors that signposted towards compassion as perhaps being the central concept.

In the closing years of the twentieth century, as milestone four was reached, nurse researchers started to explore a new phenomenological storyline and to ask what those on the receiving end of care might consider compassion to look like. Whilst this emancipation from positivistic science allowed novel outcomes, including hearing the

voice of those receiving care, to emerge and give breadth to the understanding of compassionate nursing, it did not come without tension.

As nurse researchers embraced the qualitative so the literature also questioned this new direction and expressed concern about the quality of research (Swanson, 1999). Meleis (2012) referred to this as the critical dialogue about the meaning of evidence but one may also see it as part of an ongoing discourse as nursing, through its literature, teases at the knots of role restrictions and begins to regard previous restrictions around acceptable evidence as becoming indefensible. This was perhaps positioning with some justification as up to this point the voice of the other had largely been absent from compassion theory as a whole. The compassionate person was exclusively placed as the active player and their actions were of research interest whilst the more passive recipient was assigned a much less important social role. The literature went further and the emphasis favoured by Tuckett (1998) that one should question 'what ought a nurse to be?' rather than the traditional '*what ought a nurse to do?*' (p220) encapsulated the whole of this emerging discourse and established a new position rooted in virtue ethics. That position married the active component of compassion with the moral virtues possessed by the nurse and claimed that the compassionate person must inherently be a benevolent person. Focussing on the nurses virtuous nature rather than her observable behaviour in no way diminished her care as other than compassionate, rather the focus resonated with the Buddhist stance that the virtuous person always instinctively acts with compassion therefore all her actions must be compassionate.

This somewhat naïve positioning of the nurse as possessed with a compassionate wisdom was possibly a step too far and at odds with slightly earlier research. Czerwiec (1996) had shown that whilst the nurse's attitude or demeanour behind her actions was observable to her patient, those actions were not being universally described as compassionate. As such this opens up the possibility for the nurse to reflect upon her actions, question her moral virtues and, if found wanting, develop a more sensitive or compassionate approach. This is an important contribution as the heuristic model that emerges from this literature (and which is set out later in this chapter) articulates a journey taken by the nurse away from 'what do I do?' towards 'who am I?' however, that is an enormous step to take and what Czerwiec (1996) offered was an important reflective mid-point that asked 'how am I doing it?' In partially answering that question

Halldorsdottir (1996) positioned nurses as agents of relational construction building either bridges or walls. Those who constructed bridges undertook nursing actions whilst seeking to connect to the other were more virtuous or benevolent than the wall builders who delivered care in a cold, detached and clinical manner. Swanson (1999) supported this by introducing to the discourse a new position which set out the belief that individual nurses possess individual caring capacities, defined within five levels of capacity, and that not all nurses have the capacity to practice compassionately.

Meleis (2012) argued that whereas nursing theory around milestone four had started to challenge the nature of acceptable evidence the literature coming out from milestone five shook the foundations of the status quo and welcomed epistemic diversity, both of which, one may suggest, were further acts of positioning. Most significantly was the perception of the accepted semantic understanding of concepts being as defeasible as the nurse's role that is built upon those concepts. This led to the point at which compassion divorced itself from empathy and pursued an independent course rooted in the call to act. The dynamic around this point was set out strongly by Boleyn-Fitzgerald (2003) who took the position that nursing was comprised of two types of nurses. The first being those who *care for* the other which is based around a systematic, considered process glued together by sympathetic equanimity, so, the nurse feels something for the other but draws short of feeling with him. That way of feeling characterises the second type of nurse who *cares about* the other and associates herself more closely with his experience and suffering. The former is associated with empathy and the latter with compassion. The former creates a safe space for the nurse to practice when faced with vicarious suffering and will lead to good care whilst the second is more risky but will lead to much better holistic outcomes for the other. The first meets the requirement from the other that the nurse be competent whilst the second goes beyond that to meet the requirement for moral competence and for the compassionate nurse to not only be competent but also to practice 'in a spirit of loving kindness' (Jormsri et al, 2005, p588). One may be inclined to introduce a third group of nurse namely the one who 'cares neither for or about the other' who takes centre stage as an actor during all inquiries into serious service failure and whose practice echoes the reality that 'not all nursing care equates with nurse caring' (Swanson, 1999, p32).

Milestone six clearly reveals that the discourse continued and that compassion was now at the very core of the group of nursing concepts and positioned as a rising star. Its fall and rise was being explored (Bradshaw, 2009), its re-discovery as nursing's 'most precious asset' (Schantz, 2007, p48) celebrated and its absence bemoaned as leading to a roulette of care (Lundgren and Berg, 2011). By milestone seven as Meleis looked towards the future and the new generation of nursing theorists being handed the baton and responsibility to ensure that theory does not stand still (Meleis, 2012) so the discourse around compassion continued. Entering this discourse was the reality that sitting outside the group of core concepts was the challenging and threatening context of the real world. Compassion became positioned now not only as fundamental but increasingly as frail and fragile as organisations strive to meet targets, as outcome measures replace professional values, as compliance with process prevents emancipation and therapeutic risk taking, as registered nurses spend less time with patients and as newly qualified nurses undergo rapid socialisation and become assimilated into structures where the aspiration is for sympathetic equanimity and their understanding of compassion befuddled.

By the close of the literature captured for this thesis that discourse was actively being fought around two stances. Firstly given the fragility of compassion how realistic is it to expect student nurses to aspire towards such an ideal (Curtis, 2013) and secondly how to support compassion to survive. For the latter, two principle mechanisms were set out; the use of national strategy and professional governance to provide compassion with the clothes of authority and, the simplification of compassion to make it more understandable to practitioners and more likely to be a part of practice. In particular the proposition that compassion equates to sensitivity and as such exists in small acts of kindness, in delivering the fundamentals of care and in promoting dignity. A degree of semantic re-positioning was therefore underway and possibly a new proxy (sensitivity) emerging to ensure that in the face of external pressures the core of compassion survives.

7.2 Compassionate Dementia Care - the Heuristic Model

There were specific aspects of the literature that gave a shape to a potential heuristic model which utilises a breadth of literature to outline the spaces where compassionate

dementia care may sit. At this point the heuristic was appropriate as any model which emerged in advance of the empirical data being available could not be guaranteed to be flawless or even fully coherent however, at this point in the study it was probably satisfactory. The heuristic model (Figure 11) is a representation of an informed and intuitive guess as to what the final model could look like when it is to be offered at the close of this thesis.

The process of making such an informed and intuitive guess which I couch in terms of the heuristic is inherently subjective and to begin with is a singular experience. The heuristic begins as a thought process shaped by ones reading and then immersion in the fieldwork and propelled both emotionally and incrementally as a picture emerges from the data. Elliott et al. (2011) have questioned how one can be aware of oneself in the fieldwork process and how can subjective and reflexive data be communicated to others? For them the answer was found within an informal supervisory space within which the researcher's subjective thoughts could be explored and analysed (Elliott et al, 2011). In developing the heuristic model of compassionate dementia care this reflexive informal supervision was fundamental to the process as week by week evolving iterations were posted on the office wall and discussed in the round. How the model was constructed from where the building materials were gathered was open to challenge and alternative interpretation. What was underway over a number of months was a valuable process that has previously been identified by Skeggs (2002):

'Reflexivity is about collective practice, thrashed out in discussion, always trying to be responsible, accountable and ethical with an awareness of our positioning and partialities ...' (p368)

The specific aspects being thrashed out in discussion by myself, my supervisor and my colleagues were drawn from a base which itself, perhaps unknowingly, adopted a positioning stance towards what nursing was all about. The story offered had been one where the plot had ebbed and flowed between roles and positions but which overall (and again in a subjectively reflexive manner) led to a model that was the embodiment of the drama as a whole. That heuristic model aimed to describe the differences between the basic understanding of compassion, the concept of compassionate nursing care and, the space within which the concept of compassionate dementia care might sit. Alongside that were an identification of factors that could be important for defining the practice of compassionate dementia care.

First, whilst emotion has been treated with caution within the definition of compassionate nursing care it does become increasingly important if one moves forward towards a more challenging space. The literature review suggested that nursing had spent some time understanding concepts of empathy and compassion and disentangling them from each other, sufficient that by 2000 nursing authors were starting to redefine the relationship between the two. This had been a complicated divorce but it seems that compassion required not only a call to feel but also a call to action whilst empathy required only the need to feel for the other. Because of this and the fear of empathic engrossment then sympathy, and its ally equanimity, could become the safer proxies for empathy and as such something else that is more authentic must be involved in compassion.

Secondly, movement was fundamental to the enacting of compassion, without movement it any feeling would become of little relevance. Arriving at the space where compassionate dementia care may reside and consequently achieving higher degrees of compassion required the nurse to be mentally, philosophically and emotionally a dynamic actor. Movement may be captured in the metaphor of a journey and in many respects likened to a spiritual journey; some such as von Dietze & Orb, (2000) reflected this through their choice of language. So, compassion was the articulation of reverence for the other; it was buttressed by altruistic acts; involved solidarity and standing alongside our fellow sufferers. For others, such as Austgard, (2008), nursing had to go beyond showing respect to the physical body and caring for it in the best possible way by aiming to also protect soul and spirit.

Thirdly, as the journey progressed connectedness must be encouraged and the quality of the connection was as important as its pursuit. The metaphors of the bridge and the wall (Halldorsdottir, 1996) were influential and may offer points within the journey where decisions could be made about the direction and duration of travel; so, nurses who build bridges were more likely to travel further. Overall the heuristic framework progressed from the very traditional associations with role (what do I do?) into a reflective mid-way point (how do I do it?) and ultimately towards a much more challenging association with positioning (who am I?). This design was itself reflexively influenced by the discourse around virtue ethics and benevolence (see Tuckett, 1998) which moved the emphasis away from what ought a nurse do towards who ought a nurse be? It is these emphases and associations that represented the poles whilst the

spaces within the framework acted as bridges. Fourthly, the journey was one of emancipation. In the context of Meleis emancipation represented the freeing of nursing research from the constraints of the medical model and the empowerment of nurse researchers and theorists to apply other methodologies (Meleis, 2012). For the pursuit of compassionate dementia care emancipation was similar in that nurses were empowered to move away from the restrictions of roles that they can leave behind in the traditional space. It is emancipatory to legitimately think, feel and behave differently in respect of dementia and those affected by it. Part of that emancipation is the freedom to take the risk presented by engrossment and to enshrine that within the concept of service and the giving of oneself to the other.

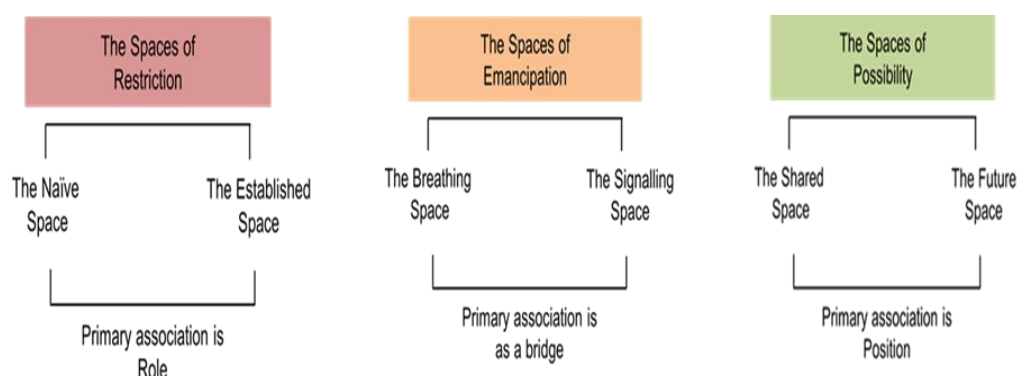
These are all challenging thoughts about the nature of nursing and the freedom that nurses have to be empowered in the strongly hierarchical structure of health care. The reflexive debate reflected this but also placed some emphasis upon the transformational needs of a health service facing a crisis of capacity versus demand which lent itself to arguments that nursing could become either highly restrictive (and ultimately personally and professionally unsatisfactory) or highly emancipatory (and highly satisfying). Almost anticipating this and in support of the more positive response to the challenge Meleis (2012) ended her milestones with the notion of moving forward into a future where a new generation of nurse theorists could confidently wield a diverse range of methodologies to influence nursing practice and orient it to the needs of specific patient populations. Whilst the literature was more restrained it may be of note that the majority of the limited literature related to compassion and dementia emerged at this point although it was overshadowed by the emphasis being placed on the vulnerability of compassion when faced by 21st century technology driven health care. However, within this discourse was the argument that those who strived to pursue compassion were to be rewarded with experience of dynamic moments of synchronicity when they and the other achieved mutual understanding (van Lieshout et al, 2005).

Having re-examined the literature through the lens of a positioning exercise three very tentative possibilities, from a paucity of literature, emerged to suggest that compassionate dementia care as a distinct entity from compassionate nursing care could be conceptualised. As a possible model of compassionate dementia care was sketched out those three factors assumed more significance and it is appropriate to

rehearse them again. Firstly, the idea of solidarity or presence as evidenced through the act of standing with, or alongside the other, and the promise never to abandon the other who is lost and suffering both have potential in the context of dementia care. Secondly, the possibilities of the breathing space suggested by van der Cingel (2011) may also give a space within which the nurse can safely move towards adopting a compassionate stance with an option of retreat if feeling overwhelmed by the engrossment involved. It may also be a space for the nurse to listen to the voice of the person with dementia and through that listening begin offering to support the individual's personhood and positive sense of self. Thirdly, there is the notion of signalling as a relational process between the nurse and the person with dementia; the nurse can act to signal her invitation to engage with the patient and he can signal to her his emotional state.

What emerged was a heuristic model that could be portrayed metaphorically as a journey the stages of which would be undertaken only to the point at which the nurse felt the journey was complete. For the purposes of this thesis that point would articulate how acute hospital nurses conceptualise compassionate dementia care even though it may represent an incomplete journey with spaces untraveled. All will start the journey with some degree of awareness of the other and a sensitivity towards suffering and all will feel something whether it be sympathetic equanimity, empathy or compassion. Being open to the risks of emotion draws the nurse towards new parts of the journey away from the restrictive confines of her role towards an emancipatory experience that borders on the spiritual. In choosing to travel further the journey brings her to a world of possibility, of mutual understanding and synchronicity in which she re-positions herself by asking the question 'who am I?' At this point the answer is likely to relate to solidarity and fellowship with the other who has dementia and will not so much be the concept of 'we lepers' or 'we poor' (that is set out later under the spiritual process) but 'we, humans' or 'we, people' or perhaps 'we, citizens'.

Figure 11 – The Early Heuristic Model



Movement across and into the spaces by each individual nurse is determined by how far they are cognitively and emotionally compelled to move and what the constraints are upon such movement. In considering a framework for movement, that also references showing reverence and being of service to the body, spirit and soul one is drawn to the spiritual process for experiencing God in the poor, as followed by the Vincentian religious order, which offers something to our understanding. In describing this process Wiesner, (1987) set out the following three stage process that can be mapped to this early model (Figure 12).

Under the Vincentian model the first compulsion towards movement, described as the first conversion, is when the religious sees ‘the poor in Christ and Christ in the poor’ (Wiesner, 1987 p214) this leads to a personal decision being made to purposefully work for the poor and the adherent enters upon the way of appreciation. This way is characterised by becoming aware of the poor, observing their suffering, hearing their cry and actively responding. It is similar to Vickerian appreciation (Vickers, 1964) and leads to the development of a dynamic compassion that most world religions favour it is however seen as just a beginning on the spiritual journey and although there is concern for the poor the greater emphasis is upon self-improvement. The poor therefore become objects of ones efforts they are:

‘Talked about but rarely talked to, we work for the poor but rarely with them’
(Wiesner, 1987 p216).

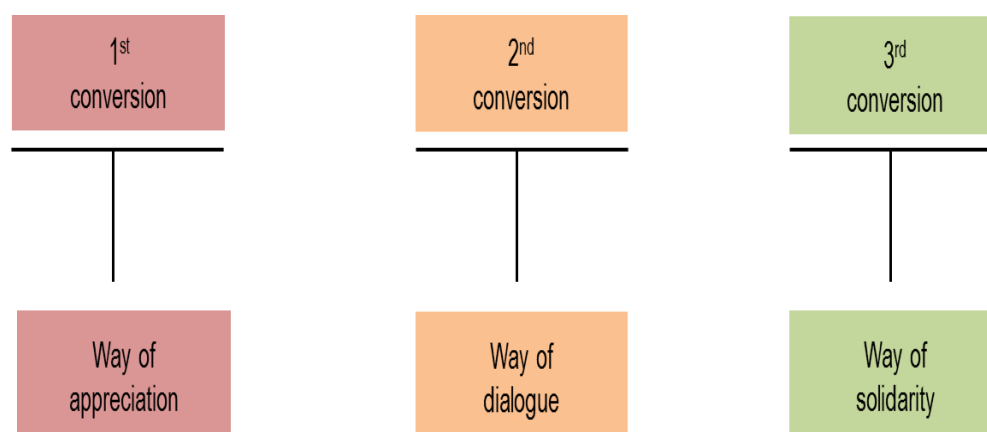
The second conversion occurs when one comes to the awareness that poverty is not only an individual problem but very much a structural one which brings with it injustice and oppression. There is anger within this second conversion but also a crisis as one

is challenged to extend ones compassion to those who may be acting unjustly. More importantly the true point of conversion lies in the realisation that not only does that structural problem exist but that one is part of it. At this point there are now additional emotions of frustration and guilt which can lead to either paralysis or excess activity both of which are effectively harmful. Survival is found through the way of dialogue which sees one developing personal relationships with the poor as barriers start to be broken down:

'Names are exchanged, friendships are formed' (Wiesner, 1987 p217).

The focus then shifts away from oneself and becomes more collegiate and actions are more on being with the poor rather than doing for the poor. This shift also involves crisis as the closer one moves towards being with the poor the more incomprehensible this is to one's peers and one is now open to being alienated, misunderstood, criticised and possibly persecuted (Wiesner, 1987). As a consequence one stands on the threshold of the third conversion.

Figure 12 – The Vincentian Spiritual Process



The third conversion represents a cognitive shift of seismic proportion. In the way of appreciation one places oneself above the poor but in order to progress one must be taken down from that lofty position so that in the way of dialogue it is the poor themselves who are placed on the pedestal, idealised, romanticised and regarded as wiser than we. This is untenable and as one comes to the truth that the poor are as flawed as everyone else a crisis of disappointment occurs. One comes to see the poor

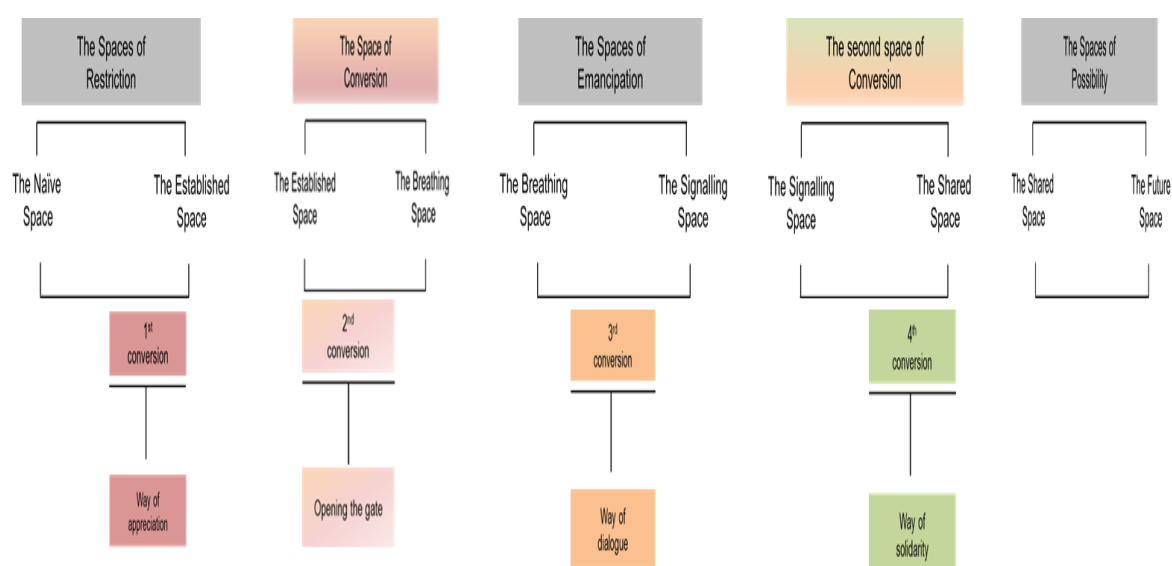
for what they are which is essentially the same as all other human beings, and then one enters the way of solidarity. Although one continues in the same work with the poor as before there are now no longer distinctions, and both parties now stand together, as a consequence the relationship and stance has fundamentally and permanently changed (Wiesner, 1987).

This Vincentian model has much to offer in respect of considering how the nurse may progress through one or more of the spaces and showing the direct relationship with compassion. Firstly it is necessary to change some of the core terms used, so in the heuristic model one is not looking at coming into contact with God through the experience of others, although one does not exclude that for some nurses this may be the motivational trigger that is involved, and naturally one is concerned with those affected by dementia rather than the 'poor'.

Conversions as Bridges

Movement through the secular heuristic model occurs through a series of generative experiences (Gergen, 1968) or incremental eye openers that have the capacity to challenge assumptions, raise the level of discourse and think anew about those things that may have been taken for granted. In this model it is such experiences that are referred to as conversions and which act to provide the bridging structures that are necessary if movement is to be facilitated. The conversion points as set out in the Vincentian model do not dovetail with the three spaces and therefore two additional spaces for conversion to occur are conceptualised alongside an additional but vital conversion that this thesis has termed 'opening the gate'. The whole once fully constructed (Figure 13) becomes a dynamic model within which the nurse may ebb and flow dependent upon whatever barriers to, or opportunities for, conversion are present.

Figure 13 – The Conversions



Adding a further layer to the development of this emerging model was the Interpersonal Model of Nursing (Travelbee, 1971) as briefly cited in both the scoping review and the substantive literature review and worthy of further elaboration here. Travelbee (1971) regarded nursing as a process of interaction between the patient and the nurse with the goal of assisting the patient to cope with the experience of illness and suffering and to find meaning in those experiences. The dominant nursing intervention was seen as the nurse's use of her sense of self with a focus upon identity, empathy, dialogue and rapport. It is a view of nursing that, at first sight, appears to fit comfortably with the perspective of compassionate nursing as set out earlier in this thesis, in that nursing is an interpersonal process occurring between a person in need of help and a person capable of giving that help. But it is potentially more profound than that and possesses sufficient width to go beyond this and find a place and appeal to the other with a chronic and enduring condition (such as dementia) in that illness is a human experience that one can understand, find meaning in and subsequently come to terms with.

Travelbee (1971) set out four distinct phases (Figure 14) to the development of the relationship between the nurse and 'her patient'. Whilst that possessive view has been rehearsed by some of the nurse participants involved in the research underpinning this thesis, it found no place in the heuristic model. The characteristics of the four phases are of valuing the other and there was resonance to be found here with the spiritual process.

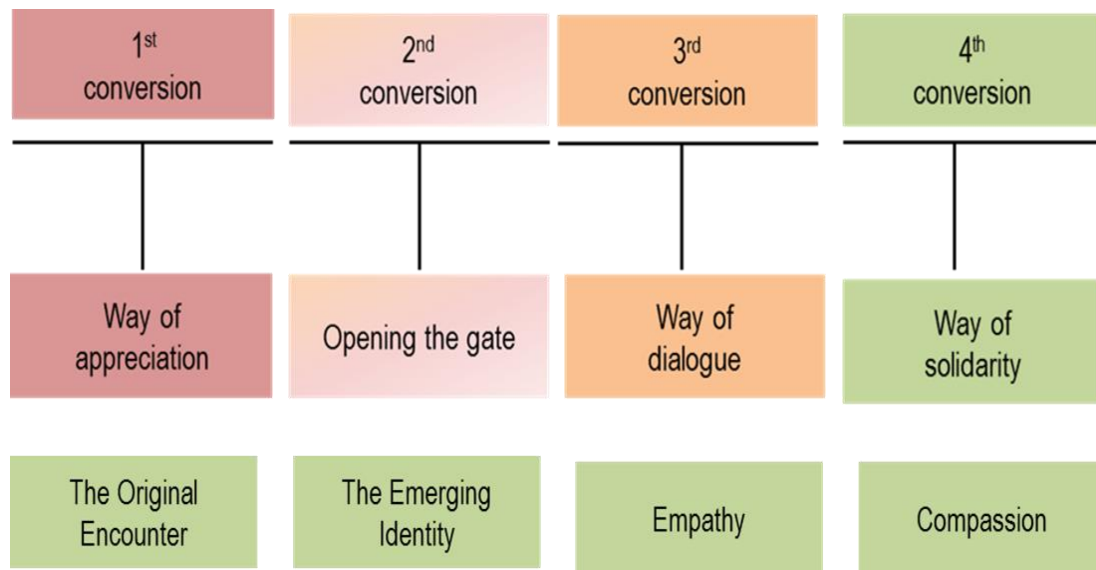
Figure 14 – Travelbee's Four Phases of Interaction



The original encounter is similar to the way of appreciation, as one becomes aware of the other and notes their suffering but, does not yet know the individual beyond the assigned social role or category. The way of dialogue aligns to the process of understanding the emerging identity of the other as a fellow individual whose suffering we may well be part of. We begin to feel for the plight of the other and may be moved to anger or guilt. Whilst it is an emotional phase the dominant feeling is of empathy but that limits what can happen in this phase to meet the needs of the other. The way of solidarity occurs when the nurse is motivated by some other feeling, Travelbee called this sympathy (Travelbee, 1971) but we now know from analysing the literature that this was frequently used a proxy for compassion. The phase of sympathy/compassion is characterised by the need to alleviate the suffering of the other which for Travelbee meant both helping the other to find meaning in and a way of coming to terms with their illness experience (Travelbee, 1969). Solidarity becomes part of compassion and as the nurse asks 'who am I?' the answer comes 'you are the same as him'. This has taken the nurse a long way from the categorisation of the original encounter and whilst she has not lost her identity as a nurse she has challenged the restrictions of her role. In finding the courage to ask 'what do I do?' she has considered the concept of role to be defeasible and begun to take a position. It is when she asks 'how do I do it?' that she questions her identity and stands on the brink of becoming compassionate in a way that has meaning for the other.

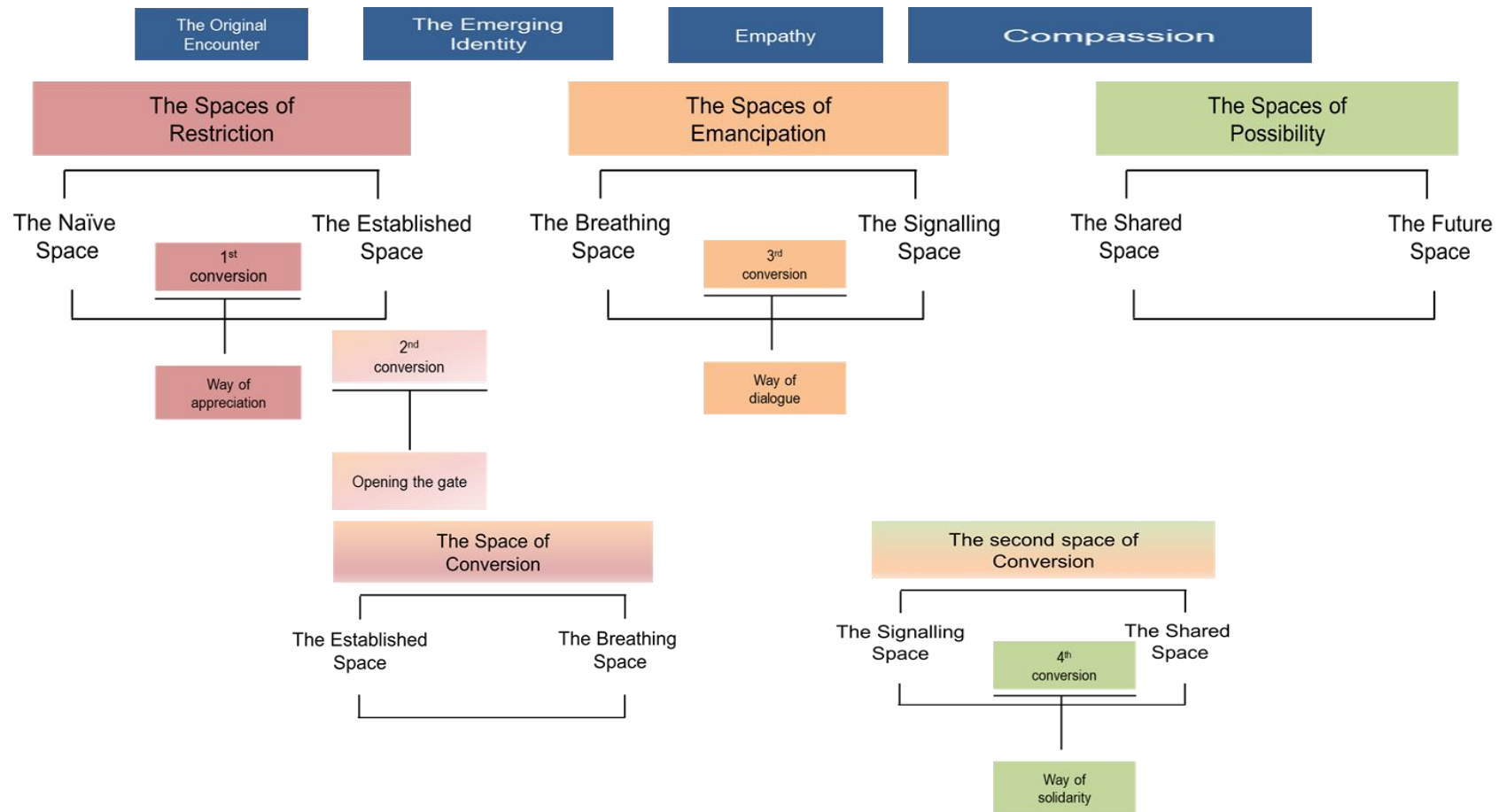
And so, the phases as set out by Travelbee (1969, 1971) seemed to achieve a fit with the spiritual process and both influenced the emerging heuristic, however, some minor rephrasing was required (Figure 15). In accepting that empathy was inadequate to provide the necessary dynamic properties and that sympathy was associated with equanimity the logical change was to make compassion the final destination and thus the nurses journey towards the 'man-to-man' relationship can be suggested as the following four stages which are superimposed on the spiritual process;

Figure 15 – The Four Phases Amended and Mapped to Conversions



This now allowed the fully formed heuristic model to be illustrated (Figure 16).

Figure 16 – The Dynamic Heuristic Model

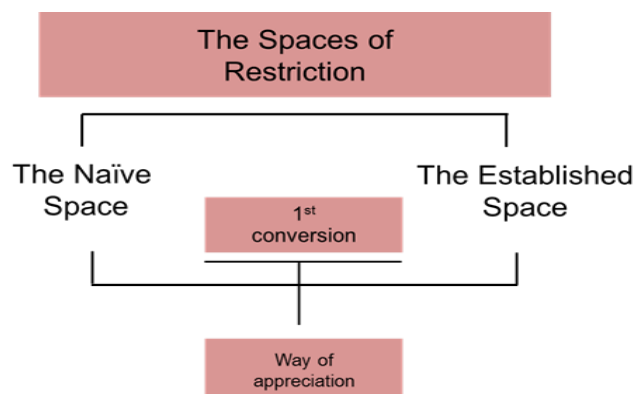


The model is best described by discussing each stage of the process in turn.

The Spaces of Restriction

All elements that have built the heuristic model have identified that a process of personal or spiritual development must begin somewhere and all identify the act of becoming aware of the other as the starting point. The spaces of restriction (Figure 17) reveal how an initial tipping point promotes entry into nurse education following which the individual is assigned a new social role that is bounded by expectations as to her behaviour towards others.

Figure 17 - The Spaces of Restriction



There is a direct link to compassion theory in that these are spaces and acts in which one not only becomes aware of the other but also develops a degree of sensitivity towards his suffering, recognising his unmet need and feeling compelled to act to alleviate those things. However in the Naïve space the view of compassion is a reflection of the Aristotelian construals:

- 1: *there is a judgement to be made as to when the threshold for acceptable levels of loss is breached and the other is seen to be at serious risk of harm or death.*
- 2: *the loss that is experienced is not the fault of the other so represents undeserved suffering.*
- 3: *the other is in some way like us and we too could suffer in the same way.*

When rephrased as negatives these represent the language of the layman who may believe it acceptable to withhold compassion where;

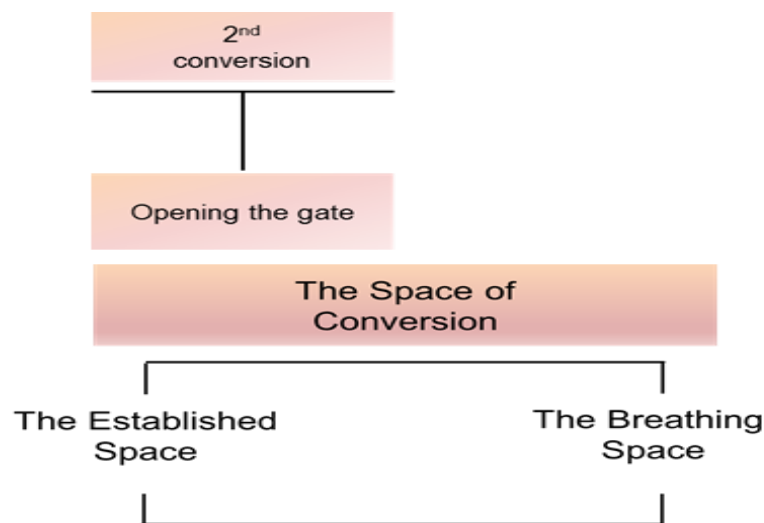
- 1: *the other has not suffered enough.*
- 2: *the other is in some way believed to be responsible for his suffering.*
- 3: *the other is not like us in respect of race, culture, geography, religion or some other quality.*

Movement from the naïve to the established space involves becoming more sophisticated in respect of the value one places on the other and the act of compassion itself. Underpinning that involves a number of smaller conversions which one might simply call choices or decisions; they would include, for example, the decision to embark upon nurse education and the associated choice around which branch of nursing to follow. Such decisions may be triggered by some kind of event that creates sufficient emotional energy to create a tipping point that propels one forward into a new space. The literature has allowed a concept of compassionate nursing care to emerge and this thesis has positioned that as sitting at the far end of the established space. A considerable distance is travelled to arrive here from the naïve space and it may well be as far as most acute nurses will be able, or prepared, to travel and it is suggested that many will not even perceive that this is but the start of the journey. As such some nurses will regard this as the point at which the appropriate standard of nursing care has been attained however in thinking that more is possible one is minded to recall the words of Wiesner (1987) describing the stance found at the way of appreciation:

‘The poor are the object of our efforts, we talk about them but rarely to them, we work for them but rarely with them’ (p216).

The Space of Conversion

Figure 18 - The Space of Conversion



Seeking to free herself from delivering care in the restricted spaces represents a severing of strong ties for the nurse who may have undergone a process of workplace socialisation potentially from within impoverished care environments where there is negative role modelling and inadequate support from mentors who lack the appropriate skills, knowledge or attitude (Brown et al, 2008). If that practice is also characterised by low levels of individual absorptive capacity within an inward looking care culture then it is increasingly unlikely that the nurse will feel any need to move beyond the established space. Even in areas that deliver care of a sufficiently good standard to be considered as at the peak of the established space (that is, delivering compassionate nursing care) there may be difficulty or unwillingness to see that even better care is possible. However, this thesis suggests that some nurses will believe that there is more that can be offered to the care of people with dementia and entering the space of conversion is seen as the first encounter with another way of practicing. The space of conversion is a neutral space, a no-man's land sitting between opposing traditions of care, which the nurse can inhabit without commitment or expectation. It is an emotional space as the tipping point for commitment has to come from a personal encounter that moves her to want to do more even if she does not know what that means.

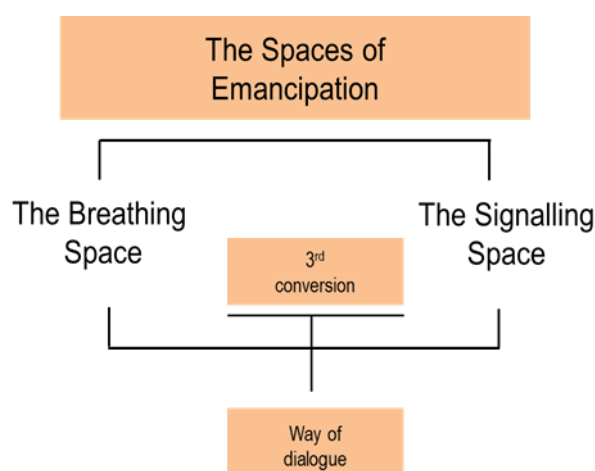
For some that will involve emotional turmoil but unless she moves through this space that turmoil will not end as it is only through continuing the journey that a peace of

mind is to be found. Under the spiritual model this turmoil is termed the 'dark night of the senses' (Garrigou-Lagrange, 1977) to describe a spiritual crisis as one breaks ones attachments to the physical world. In the secularised heuristic model the turmoil is equally associated with breaking attachments and especially the strong ties with a previous way of practicing that one may previously have thought acceptable. Resolution may be found through the seduction of cognitive dissonance but more effectively through making a personal commitment to explore the belief that more is possible. To achieve that the nurse must undergo the second conversion. This acts to move her to a safe space of initial inquiry and learning where she can start to reframe her views, attitudes and beliefs about people with dementia, whilst also developing a greater depth of phenomenological knowledge. That space will be filled with learning whether that be by the nurse undertaking a formal course of study or simply talking to people living with or affected by dementia. The second conversion is a dynamic, if metaphorical, act which this model has termed 'opening the gate' and once the gate is opened the nurse is ready to enter the breathing space.

As she has been through the crisis and accepted that the established space no longer offers the safety and security of belief that it once did this breathing space is a less turbulent place although the decision to 'open the gate' does present risks. Those risks are to herself as she is now on a journey into phenomenology which will potentially take her to a place in which she can not only care about the person with dementia but also truly and ultimately achieve a sense of solidarity. That leads her practice to knowingly incorporate empathy despite this being a purer form of emotional connection than compassionate nursing care has permitted, because of the dangers of engrossment that empathy brings (Boleyn-Fitzgerald, 2003). By 'opening the gate' the nurse has started to question her role and the restrictions imposed by rights and responsibilities, she is in effect starting to adopt a position about herself within the context of dementia care and her relationship with those affected.

The Spaces of Emancipation

Figure 19 - The Spaces of Emancipation



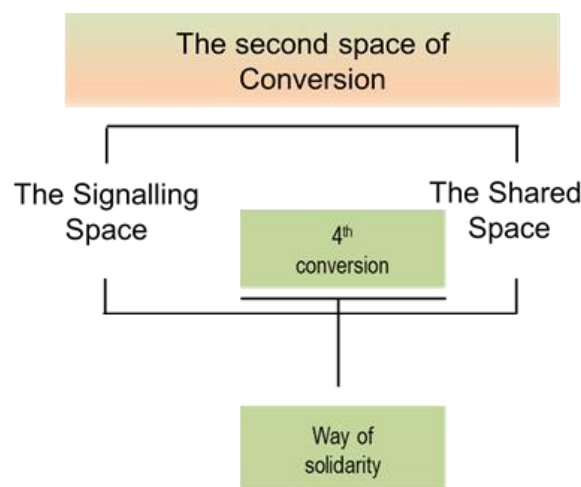
Movement into the spaces of emancipation see the nurse being liberated from nursing care that, as good as it may appear, does not truly meet the fundamental holistic needs of the person with dementia. The breathing space initially set out by van der Cingel (2011) as finding ‘room *to breathe*’ (p677) is the opportunity for the nurse to become audience and start listening to the voice of the person with dementia. However, in considering the relationship with the phase of the emerging identity (Travelbee, 1971) it is a point of reflection for the nurse to also consider her own emerging identity and to start hearing her own voice, which may carry the whisper of ‘we lepers’, which will may be sufficient to carry her safely through the way of dialogue to the way of solidarity and the spaces of possibility.

The third conversion arrives as the way of dialogue and the dawning realisation that much of the challenges found in dementia care nursing are not located within the person who has dementia but rather in the social system of health care and in the nurse herself as part of that system. The nurse is presented with a choice as to which direction to now take. The first choice is to move back to the established space to find comfort in ‘*thoughtlessness*’ (Arendt, 1992 p288) to practice in a way that complies with the assurance driven organisational culture and that sees her doing futile things that will have no holistic benefit to the other but which will not be criticised by colleagues or the organisation (Andrews, 2013). The second choice is to acknowledge that she may be part of the problem and commit to changing that. Fundamental to that is acting to show that the not only has she heard the voice of the other but is actively

listening and receptive. This signalling is a relational act which leads the nurse and the other to draw closer together. Given sufficient time the sending and receiving properties around the act of signalling improve in quality and draw the nurse into the final conversion.

The Second Space of Conversion

Figure 20 - The Second Space of Conversion



The relational act of signalling reflects a profound level of practice which on its own could be seen as moving the nurse towards more holistic practice than is possible in the spaces of restriction. Compassionate nursing care found back in the established space can help to alleviate physical suffering but it is only through human relationships that people can be supported to cope with emotional, psychological and spiritual suffering (Travelbee, 1971). These aspects are previously rehearsed by Cassell (1982) who identified suffering as:

“A state of severe distress associated with events that threaten the intactness of the person” (p639)

Which perhaps propels the other into those:

‘..... phases beyond anguish, namely, the malignant phase of despair, the feeling of ‘not caring’ and the terminal phase of apathetic indifference’ (Travelbee, 1966, p70).

Both it could be argued reflect the pain of people with dementia experiencing acute hospital care who (as set out in Chapter One) report feeling abandoned and lost (Edvardsson, Sandman and Rasmussen, 2011); distressed, and ignored by nurses they perceive as hostile and uncommunicative (Cowdell, 2010). Fundamentally, admission to hospital presents the person with dementia with the risk that the loss of the sense of self and self-identity is frighteningly possible. Signalling acts to both express and reduce that fear. Projecting the emotional state is an attempt by the person with dementia to begin building a bridge towards any other person who is receptive and ideally who is prepared to connect. The act of connecting is a benevolent act on the part of the nurse but it is also relational and opens up the possibility of standing in solidarity with the other. The substantive literature review hinted at this through the idea of presence, the standing with or alongside the other and the promise never to abandon the other who is highly at risk of losing himself. What is important here is the act of 'standing with' the other and how this aligns to the third conversion, the way of solidarity, and the broader concept of solidarity itself.

The need to stand alongside the person with dementia in an act of solidarity is highlighted by Bryden (2015) who describes her descent into dementia as an experience of exile not only from her former self but more broadly as an act imposed by society. Through her description she likens the stigma of dementia to the experience of the leper:

'I must live outside normal society, and be sent out toward the wilderness. There is no coming back'. (p95)

The realisation that there is no return is profound and distressing. She expresses a sense of grief and loss for her sense of self that has become distant, lost in a mist and moving further away from her. Walking in the '*slow lane of dementia*' (p95) she finds others who journey with her, uphold her and in the case of her husband offer to be beside her to the very end. Solidarity in the context of health care can be addressed from one of three perspectives. Firstly, solidarity as duty, in that within the civic society:

'all are responsible for all' (Pope John Paul II, 1987, section 38)

Thus solidarity is the obligation that society, as a whole, owes to its less fortunate members who may be in need. From this perspective each individual member of society does not need to know the circumstances of the other and as such solidarity

becomes an abstract in that needs are met from behind a '*veil of ignorance*' (Rawls, 1989 p123). It is an approach from which concepts like justice and fairness emerge to underpin a welfare state model that is itself sustained by the contributions that members make when able to do so or draw upon when necessity demands (Rawls 1989).

Secondly, solidarity is an intrinsic value possessed by the individual and enacted for the benefit of another person or group of people without any self-interest or expectation of reciprocity (ter Meulen 2015). Importantly one is not blind to the plight of the other, there is no veil of ignorance, the other is seen, their suffering is noted and one makes a conscious decision to offer support because one believes the other is worthy of protection. Worth is drawn from the intrinsic value of the other as a fellow person with whom one shares the status of person, the state of existence and potentially the same fate. Ter Meulen (2015) states that this humanitarian solidarity can be described as simply taking care of the other who can no longer take care of himself.

Thirdly is the sense of solidarity that is mutual, reciprocal and aligns itself to the concept of 'being with' (Nairn 2014, p80) the other. This is similar to organic solidarity as set out by Durkheim (1893) which considers the mutual obligations that members of society share alongside the regard they have for each other as fellow travellers striving to achieve a common purpose, such as a fair and just society. That mutuality is motivated through the recognition by two people that they have a shared identity and are both:

'allies fighting on different terrains towards common goals' (Samora, 1986, p54).

However, whilst 'being with' draws upon that it goes further and articulates a deeper commitment between these two people than is necessary and thus solidarity is positioned as a relational act defined by mutual support, acceptance and standing up for each other (Jaeggi, 2001). It is this third perspective around which the shared space, and the conversion through the way of solidarity, is constructed. In doing so the previously taken for granted and relatively fixed roles, of donor and recipient of compassion, are challenged as solidarity becomes acknowledged as much more a mutually interdependent relationship (van Oorschot, 1998). The bigger challenge is to acknowledge that the other, a person with dementia, has an active and reciprocal part

to play and that the nurse whilst giving something of herself to the relationship will also be enriched, in that she will find herself and be liberated.

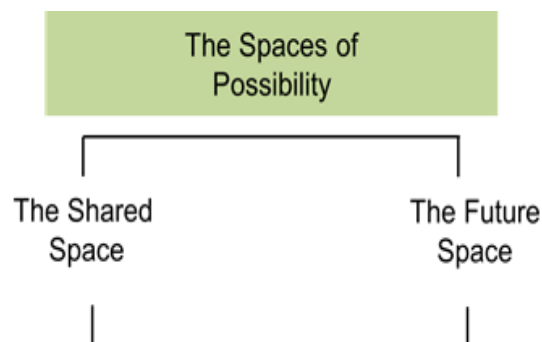
Engaging with the other is no longer a limiting or restrictive act which way back in the traditional space may cause the nurse to feel anxious or threatened if either party strays outside of their imposed social roles. The act of solidarity is transformational so, although one continues in the same work with the other as before there are now no longer the distinctions that roles impose:

'We stand together' (Wiesner, 1987 p217)

By doing so the relationship and stance has fundamentally and permanently changed. That change opens up a new space of possibility.

The Spaces of Possibility

Figure 21 - The Spaces of Possibility



The concept of a 'new culture of dementia care' introduced the belief that if the negative aspects of the 'old culture' could be removed then a world of possibility for those affected by dementia would emerge. It is a space in which a new relational paradigm should emerge, one in which there is inherent equality between not the nurse and her patient but two people working together towards a common goal. That goal is to preserve the self-hood of the person who is living with dementia. Aspiring to achieve that goal empowers both to pursue creativity and to be emancipated from more rigid and traditional approaches to dementia care.

7.3 Chapter Seven Summary

This chapter has re-examined the literature through the lens of positioning theory and revealed a new narrative about the place of compassion in the context of nursing practice and nursing theory. From that further analysis, a framework worked within a reflexive approach that has allowed subjectivity to be managed, a heuristic has emerged which shows a wider world lying beyond compassionate nursing care. That may act as a map for nurses who feel compelled to embark on the journey to a different place from which they can deliver dementia care in a way that they regard as compassionate. Within that model and despite a paucity of literature the elements of compassionate dementia care may be glimpsed. So, at this stage compassionate dementia care is suggested as a dynamic way of being that is rooted in empathy, connectedness and solidarity, sufficient to offer protection to not only the others body and soul but fundamentally their very sense of self. It is a challenging but potentially emancipatory way of practicing nursing as it involves freeing oneself from the constraints imposed by one's role and legitimises one to think, feel and behave differently.

Finally as this chapter closes, the direction of the thesis changes and what comes next is oriented around the empirical collection, analysis and presentation of research data. The first seven chapters have brought us to the point of suggesting that a phenomenon called compassionate dementia care may exist. What now remains to be seen is whether acute hospital nurses can conceive of such a possibility and if so how it varies from what has thus far been conceptualised by the thesis.

Chapter Eight

Findings – Part One:

The Relational Themes that Shape Nursing Practice in the Context of Dementia Care.

8.0 Introduction

Chapter One set out the research questions for this thesis as being,

1. How is compassionate dementia care conceptualised by acute hospital nurses?
2. Can compassion in the context of dementia care be distinguished from compassion in the context of nursing care?
3. What factors influence those nurses who are practitioners of compassionate dementia care?

In answering these questions three key conceptual findings have emerged from the data analysis. Those findings in broad terms are that,

1. Four relational themes circumscribe the practice of acute care nurses working with people who have dementia.
2. Positions that reflect beliefs about people who have dementia are articulated by acute care nurses.
3. Acute care nurses conceptualise compassionate dementia care through a series of properties that are amenable to clustering.

This chapter starts the process of reporting in full the findings by focussing on the first of these whilst Chapter Nine reports on findings two and three and, Chapter Ten provides a synthesis of all three conceptual findings (Chapter Eleven reports on methodological findings related to Appreciative Inquiry). Finding number one is fundamentally concerned with there being four central themes each of which is supported by a number of sub-themes. These are all relational and offer an insight into the ways in which the nurse participants through their practice encounter and interact with people affected by dementia. Representative narrative samples are utilised to

give an understanding of the nurse participant's testimonies, thoughts, beliefs and behaviour related to each of the sub-themes.

8.1 Finding 1 Four relational themes circumscribe the practice of acute care nurses working with people who have dementia.

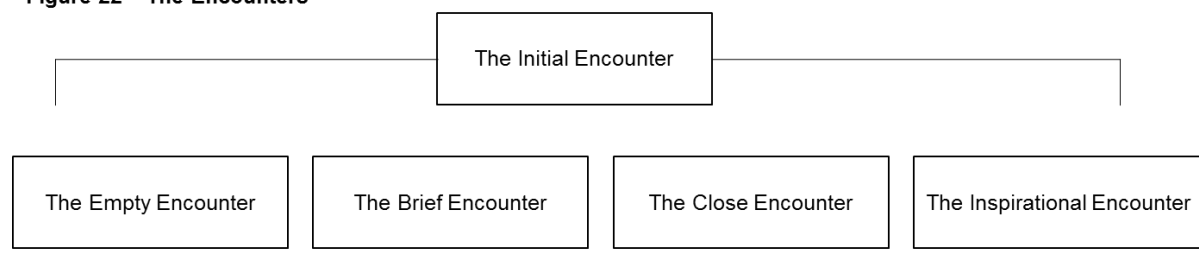
Four clear themes emerged from the thematic analysis of the transcript collection,

1. The initial encounter.
2. The emerging identity.
3. Reaching Out.
4. Someone to watch over me.

The Initial Encounter

A majority of the nurses (91%, n = 21) involved in this study spoke about personal experiences and encounters with people affected by dementia. Four specific sub-themes (Figure 22) were identified and served to differentiate the nurses between not only themselves but also the quality and impact of their initial encounters.

Figure 22 – The Encounters



The Empty Encounter

This described an encounter with a person or persons with dementia which might as well not have happened at all. It left behind either no meaningful trace or was the antecedent of negative beliefs or behaviours. 30.4% (n = 07) of the participants had an initial encounter of this kind and overall there were twenty three narrative sections which were coded. This accounted for twenty-nine percent of all coding within this theme. Fourteen narrative sections (61%) were selected as representative.

One participant, a health care support worker who had worked with people with dementia for almost ten years, is representative of this group, she stated that:

'It varies because if they are newly diagnosed then they are not so bad or needing help but there are a lot who say things like, I have forgotten my way and then get upset. With the very advanced dementia, they don't recognise family members and then you get patients that can't do things. If you bring food to them they don't realise it is for them and you have to feed them. You have to help them with their basic toilet needs. They can become agitated'. (DGH01/participant08)

The quoted participant encountered people affected by dementia after starting work in a care of the elderly ward where she had not chosen to be placed. A further representative voice came from a ward sister working in an orthopaedic ward:

'It's mentally exhausting especially if you've got quite a few dementia patients who are quite challenging on the ward' (DGH02/participant04)

Some degree of consensus formed around the following extract:

'Yes we have to be more clinical than caring sometimes' (DGH01/participant06)

The Brief Encounter

This described a further type of limited encounter but one which left the nurse with a trace, minimal though it was, of understanding. Three nurses (13%) had an encounter of this sort and a total of seventeen narrative sections were coded which represents 21.25% of all coded sections. Four narrative sections were selected as representative.

These came from all three nurses all of whom were registered nurses and two were in senior positions.

A representative narrative section came during an appreciative inquiry workshop from a ward sister working in care of the elderly with fifteen years' experience of dementia care:

'He would shout out a lot, he wasn't aggressive in a way that he would hit, he never did, but he was quite challenging, he was tall, he was a big guy and he would be quite intimidating to the staff and to the other patients. But he never hit out or anything like that but the opportunity to, the chances were there. And he would just walk and walk all day, looking for his wife and trying to get out. And things like that and we didn't really have the time to sit' (DGH01/participant11)

As she stopped talking a colleague of the narrating nurse immediately offered a hand of rescue through a 'that's not what we do' statement:

'Well we're not that kind of ward are we?' (DGH01/Group1 member)

That defence was further evidenced through this representative quote from a matron, with only one years' experience of dementia care in a career of more than twenty-five years:

Interviewer – 'So, are you acknowledging that the other person is there and is there an element of that about that you acknowledge the person, you acknowledge the pain, the suffering, the discomfort, the distress?'

'As a nurse it is easy to acknowledge all of those things because we can actually do something about that. It's the other bit as general nurses we are not sure how to deal with. Things like their confusion, things that are real to them, they are angry, they are upset, because we don't understand it as a general nurse (DGH01/participant03)

The Close Encounter

This sub-theme described encountering dementia through the experience of a family member or other close person. Ten narrative sections were coded under this sub-theme which represented 12.5% of the whole. Seven (30%) of the nurses had this

personal experience mostly with a grandparent. Eight narrative sections owned by six of the nurses were selected as sufficiently representative for inclusion:

'Yes my dad's dad had Alzheimer's. He had it for about four years, it was quite rapid and he completely changed. He was a hardworking man and he could do anything, he could build anything and then he just stopped. He was aggressive with his dementia and took it out on the ones that was closest to him, like my dad would go every day to see him and yet my dad's brother who would go once in a blue moon. Every time my dad went he would say "you haven't been here, your brother comes here more than you" and that would always upset my dad. When his brother went he said "oh I am so glad you are here". We would be there sometimes and we would think well you haven't been for months and that did upset my dad. I was only about sixteen, seventeen so I didn't have a great understanding and it's not that I found it funny but I did laugh at some of the things he said but now I realise why my dad was so upset to see his dad like this'. (DGH01/participant02)

The close encounter here was between the nurse and her father who is positioned as the distressed and unjustly treated carer in the narrative. The world of the carer may be more understandable and familiar to the nurse and as the next narrative extract shows aligning oneself to that worldview may be used purposefully by the nurse to reassure carers and families:

'I say to a relative my nana has got dementia and it gives them that reassurance that you know what you are talking about, that you understand it from their point of view. You are not just a person in uniform talking to them like you know better, you actually understand the feeling'. (DGH01/participant06)

The Inspirational Encounter

These encounters are significantly different to the other three sub-themes in that they have had a direct influence on either the nurses' decision to work with people who have dementia or to change their practice. Overall thirty (37.5%) of narrative sections were coded for relating to an inspirational encounter. Fifteen sections were selected as representative of the whole and twelve nurses contributed to this collection.

The encounters could be powerful and emotive events. One participant, a hospital matron described the first time she was required to deliver care to people with dementia on a hospital ward:

'You almost felt their pain. It's hard to explain because, what these people have been through in life that is what we need to see'. (DGH01/participant01)

Interviewer – 'This obviously has led you to want to move forward. Was there an assumption before that, before you worked with people with dementia that they were already being provided with the right quality of care? Maybe somewhere else the care was being provided. Is this something that you would have thought about?'

'No, that probably wouldn't be an area that I would have explored. You have the occasional patient with dementia, you would treat them with compassion but wouldn't know the level of service they required, you just do what you need to do for them. (DGH01/participant01)

Often these encounters occurred early on in the life of the person who would go on to become a nurse. A representative account is offered by a participant who as a teenager worked in the care home run by her mother:

'I could see even though the standard of care in that home was quite high, the people that may have some particular issues, that had dementia, it was easy for them to get pushed aside and for them not to be seen as a person as everyone else would be. You can see that in there is a person, they are in there but they weren't given the opportunity to say what they wanted to say or they were struggling to communicate or something like that. So I wanted to see if I could make a difference with that particular group of people'. DGH03/participant08

This participant had entered nurse education but failed to complete the course. Rather than give up on her ambition to 'make a difference' she had then sought out the post of dementia support worker in a care of the elderly ward. Her colleague offered a very similar experience. Working initially as a domestic on a hospital ward she spent time talking with one lady affected by dementia and grew to know her as a person. She began to see the lady's needs as frequently unmet and was frustrated at being unable to help:

'I would stop and talk to her when I was a domestic and as a domestic you are not allowed to have contact, I wasn't allowed to put her slippers on her, I wasn't allowed to do stuff for her and I really wanted to because she was a really nice lady and she inspired me. It changed my life. I just walked out of there that day and went to join an agency and gave up my job and then I landed up in an EMI home, had never been in one before. I didn't have a clue, didn't know anything really'. (DGH03/participant01)

A further example comes from a young support worker who as a teenager had a Saturday job washing dishes in a care home. Over the course of time she got to know the residents and noted unmet needs. The care of one man stuck in her mind:

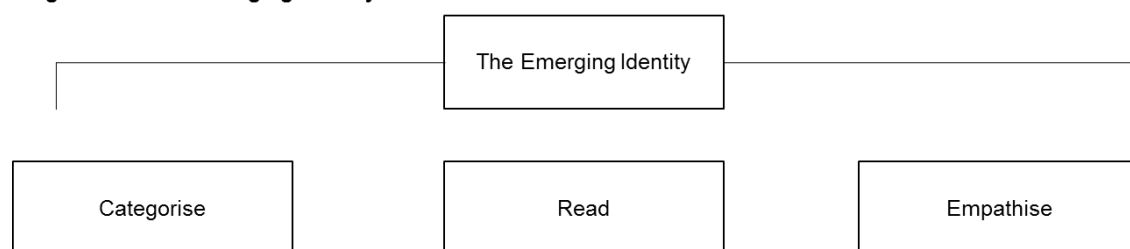
'I didn't like how he had been cared for. Even though I was only that age I didn't like how he was being cared for. He needed more attention, like things like after he had his tea he would be left with his dirty apron on like a baby. I would have taken that off him. It did make me do this kind of work'. (DGH01/participant02)

A high number of the participants (73.9%, n = 17) were coded for having had an inspirational encounter with nine of these participants also being coded for other types of encounters. The most represented staff group were dementia support workers who accounted for, 41% (n = 7) of all participants who had experienced an encounter of this kind, 50% (n = 4) of those who had only had an inspirational encounter and, such encounters involved 100% of that occupational group.

The Emerging Identity

The thematic analysis drew out three sub-themes (Figure 23) to determine the extent to which the participants acknowledged the patient with dementia as also being a unique, adult individual possessed of a greater depth of identity than that ascribed by their diagnosis.

Figure 23 – The Emerging Identity



Categorise

This sub-theme served to define a view of the person with dementia which revealed no great understanding of uniqueness and placed emphasis instead on the routine or physical tasks associated with that persons care.

Eight (34.7%) of the individual participants were coded for categorising people with dementia. The following two quotes are representative. The first from a recently qualified nurse the second from a hospital matron:

'I give them their medications about three times a day, morning lunch and evening, obviously not everyone, I just can't leave it on the table like I give to them. We speak to them, we have some with hygiene needs, we help them with their food and when they are ready to go home we make sure that they have got help at home or maybe they are going to a new home'. (DGH03/participant04).

'You just say a name, number and a time. You don't see the background (DGH01/participant01)

The act of getting to know the patient was acknowledged but as secondary to the routine or to the effective operating of clinical equipment as represented by the following two narrative segments:

'If we can get all the morning jobs done then in the afternoon I have got time to give to patients, speaking to relatives, getting to know the patient' (DGH01/participant 08)

'We had a phase when people were having their nails done but then the sats⁴ didn't work (DGH01/AI group01'Dream')

Underpinning the emphasis on physical care tasks was the importance to families of these things being seen to be done:

'We can reassure families that mum and dad have eaten and drunk, as they are the fundamental things that they are really worried about, that they have had a wash and that they have eaten and drank, so if we are able to demonstrate that, that stops them being worried properly and negates against any complaints' (DGH01/participant01)

Read

Within this sub-theme the nurse begins to understand that there may be a person as well as a patient. It is however only a beginning and there is still an emphasis around physical care and safety of the patient. The slight shift in emphasis is similar to the distinction between an empty and a brief encounter. The first representative narrative

⁴ Oxygen saturation levels measurement

segment from an Appreciative Inquiry workshop reflects the merest glimmer of understanding in an otherwise 'nurse knows best' statement:

'I think you can tell what people are going to be like, no disrespect but sometimes you know when their relatives get their clothes out you know they have pride, they are always hung up, ironed which is another sign isn't it and you can just tell' (DGH01/AI group01 'discovery')

Some nurses offered justification for maintaining the emphasis on the physical aspects of care:

'You know you may be empathizing that a patient is maybe distressed or agitated but you would know as well that you would need to do that set of observations so that you can assess that that patient is unwell, whether you need to call a doctor, whether you need to do any other interventions so some of your priorities may be very different from the patients or the relatives?'

You have to do that blood pressure to record if that lady's sick or not, and if that causes their increased confusion, do you know what I mean, it's part of your assessment isn't it, but that may well, you know you might have another nurse that might think "oh don't do that, it's going to cause them more distress" but in actual fact when it comes down to best interest and you are doing it in their best interest as a healthcare professional and you know that procedure needs carrying out'. (DGH02/participant01)

Some of the nurses alluded to the independence of the patient but were clear to show that and independent actions were permitted within a framework of maintaining safety and that as such safety would always trump independence. The following two narrative sections are representative of that:

'We allow her to do what she wants when she wants within reason to make sure she is safe' (DGH01/AI group01 'discovery')

'If they want to walk around they are allowed to walk around. If you know they are safe.' (DGH01/participant11)

Finally, for this sub-theme, is the finding that as some of the nurses begin to glimpse a person behind the patient they start to question their physical routine focussed actions:

'In the acute setting we tend to do everything for the dementia patients and as we know as you start doing things for the dementia patients they forget what they could do in the first place and it's always worse on the acute wards. You have got to get ready for the consultant' ward round, I wash them, I fasten their buttons instead of giving that patient time to wash themselves'. (DGH02/participant02)

Empathise

Within this sub-code the nurses make narrative statements which suggest that they had an understanding of the other and the world that he inhabits and, that the nurse was able to balance the physical and meta-physical aspects of care. Six of the nurses (26%) were coded for offering one or more pieces of narrative text which reflected these properties.

The first narrative segment suggests that the nurse concerned could view the care environment through the eyes of the other:

'Do you remember when we had a very smart lady? We had her and her husband and she thought she was on a cruise ship and I'd look around and think I can see how she thinks it is. You know the little windows at the top and the bars coming down. I could see in her mind's eye' (DGH01/participant10)

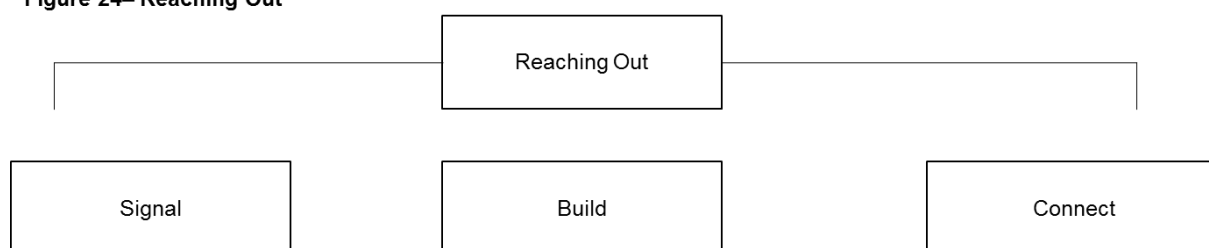
Another nurse offers a representative statement regarding how the other person must be feeling:

'Well they are scared, quite often you know. They are in this hospital, quite often had a fall and can't remember having a fall. They wake up and they are in this unfamiliar environment that they don't know. A lot of the time they haven't got family, they are elderly, and they might not know anybody at all'. (DGH01/participant02)

Reaching Out

This theme was about purposeful actions taken by the nurse to in some way engage with her patient who has dementia. Three sub-themes (Figure 24) were identified,

Figure 24– Reaching Out



Signal

Some nurses spoke about the importance of being attuned to the signals being transmitted by the person with dementia:

'I picked up on one of her words. This is what I do when someone is in a distressed response like that they will say a word that I can pick up on and then those words I will go with that and then they are like 'oh yes' and then you can go in from one of their words so they know I'm listening' (DGH03/participant01).

This participant picked up on language being spoken whilst her colleague offered an example of being sensitive to the signals coming from the silent person:

Interviewer – 'Was there something about her that drew you to her'?

'Yes, she was quiet and into herself while everybody else was sitting up, quite bright, she needed a bit more, er, care'. (DGH03/participant07)

Another nurse identified the silent tears as signalling an inner turmoil that could otherwise go unrecognised:

'I think sometimes it is not always what they say it's what they don't say, so sometimes you can go in and they look very lacking, withdrawn, sometimes they look very emotional, you see the tears and you know they have all this stuff going on inside' (DGH02/participant08)

The importance of acknowledging and responding to the signal was also available for coding:

'I think it is good if you can pass to a patient that, yes I am here for you, I am on your side, I am here to look after you and I will be your advocate and be whatever you want'. (DGH02/participant06)

Being engaged in sending or receiving signals was coded for eight (34.8%) of the nurses. The most frequently coded group was dementia support workers who accounted for 62.5% (n = 05) of all participants involved in this sub-theme and, 71% of all participating dementia support workers were sensitive to signals and signalling.

Build

This sub-theme describes the purposeful actions of nurses to construct a way of connecting to the other. There were five nurses (21.7%) who had narrative sections which were coded under this sub-theme. The whole is best represented by a lengthy narrative piece that will be discussed later in the thesis. It is offered by a dementia

support worker who describes building a bridge through the use of the Welsh language with a distressed and frightened person with dementia:

Interviewer – ‘Ok so you were listening to the sounds and they told you that this lady was distressed. So you didn’t walk by you decided to do something about that’?

‘Well yes because it can distress the harmony of the ward as well so it’s important because we have more than just one individual with dementia on the ward and the other people can’t understand what’s going on so to keep the tranquillity of the ward you have to make sure it’s settled’. (DGH03/participant01) -

Interviewer – ‘So was your main reason for going into that lady to create tranquillity on the ward or was there any other reason’?

‘Oh, no it was for the lady. I knew she would react well to me. (DGH03/participant01)

Interviewer – ‘And you then spoke to her in Welsh so you must have known she’s a Welsh speaker’

‘I picked up on one of her words. This is what I do when someone is in a distressed response like that they will say a word that I can pick up on and then those words I will go with that and then they are like ‘oh yes’ and then you can go in from one of their words so they know I’m listening’ (DGH03/participant01)

Interviewer - So you are picking up on one word and you are using that one word by saying it back to her so you are showing that you are listening to her

‘Yes and I’ll ask her if she’s sorted it out and I will go ‘Iscop’⁵ and agree with her and then it’s ‘Iesus’⁶ sort out the world’ (DGH03/participant01)

Interviewer – ‘So you’re making a connection to her through language and using that word as more than just a word, using that word as a symbol’

‘And my tone’ (DGH03/participant01)

Interviewer – ‘Tell us about your tone’

‘Oh I don’t know it (makes a kind of growling sound) that means something - It means something (makes the sound again). (DGH03/participant01)

Interviewer – ‘So there’s a cultural connection there, there’s a language connection, you are connecting with this lady. Ok, so you did that and you thought that would help you work with this lady. And then you said you went with her from her side room to your activity room, can you tell us about that journey’?

⁵ Welsh for Bishop

⁶ Welsh for Jesus

'Well we were walking and holding one hand like that and the other one is clamped so she's feeling close and this lady stoops her head and it's safe'. (DGH03/participant01)

Interviewer – 'She's feeling safe?'

'And I'm saying 'are you feeling safe?' (says it in Welsh) and she says 'do'⁷ so I'm making sure that she feels safe first and foremost before anything more happens and then we go 'Iscof' and then I put the Welsh music on' (DGH03/participant01)

Interviewer – 'So you're getting to the activity room, a non-clinical space, then what did you do when you got in here?'

'Usually the chairs are all in, I'll show the sofa but not all the time is she going to sit down straight away so we carry on walking then I'll put the radio on'. (DGH03/participant01)

Interviewer – 'Is she still distressed at this time?'

'No she's not distressed she's I can't call it distressed but she's unsettled at this point but she's saying she feels safe (DGH03/participant01)

Interviewer – 'Is she still aroused?'

'Yes and she's not sitting down at this point she's not in a relaxed state yet, I wouldn't say she's relaxed quite yet it takes a couple pf turns to reach the stereo then click it turns on, then you have to go around again then the music comes on then I can finally ask ...?... do you mind if I sit down and she goes 'oh, no you sit down' and I say do you want to sit with me and then its' (DGH03/participant01)

Interviewer – 'So you are almost turning it around and asking her to support you, ok, that's good. So then you sit down and you say that you were listening to the music and you say that you were cuddling, ok so tell me about that'

'It's a cuddle (DGH03/participant01) -

Interviewer – 'So you were close to her'

'Very close' (DGH03/participant01)

Interviewer – 'And she wasn't resisting that'

'No, no, she felt safe' (DGH03/participant01)

Connect

This sub-theme emerges when the nurse is seen to connect with the patient with dementia as a person. This is best represented by adding to the earlier narrative from DGH03/participant07 outlining her sensitivity to the signals inherent in the silent or

⁷ Welsh for yes

withdrawn patient. The context was of the patient sitting alone and apparently oblivious to a ward entertainment happening around her:

'I was holding her hand and stroking her and noticed that she wasn't doing anything then half way through she started to stroke back, opened her eyes and smiled and sadly had happy tears'. (DGH03/participant07)

The connection was frequently related to emotion and the act of being emotional in front of the patient was addressed:

'You know we are taught in nursing school that we shouldn't get attached to patients and that we shouldn't get emotionally attached and emotional in front of patients but at the end of the day it's hard not to, we are all human at the end of the day and we are going to get emotional' (DGH03/participant06)

Some went further in describing that attachment as friendship:

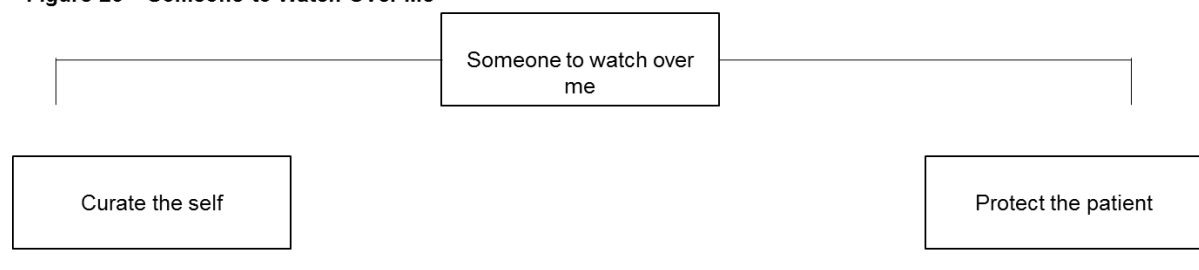
'... you do worry because you genuinely care for these people and I think because it is such a weird situation to be, in the friendships I have with people and the people that I speak to now and they have only been there a few days, these relationships just seem to form because people are frightened and are looking for support' (DGH02/participant08)

Eight of the nurses (34.7%) offered narrative sections that were coded for connecting to the other person. Six (75%) of these nurses were dementia support workers of whom 85.7% made connections with the person behind the patient façade.

Someone to watch over me

This theme was about two deliberate but very different actions taken by the nurse that represented a fundamental aspect of her belief system. Two sub-themes were identified (Figure 25)

Figure 25 – Someone to Watch Over Me



Curate the self

This was related to actions taken by the nurse to hold together the fragments of the sense of self of people with dementia. Nine (39.1%) of the nurses had narrative sections coded for engaging in this kind of action. The first representative narrative section is drawn from a ward sister talking about the important need to curate:

'You know these families are handing over their most precious gift for you to look after and they are very vulnerable and scared as well. And that person with dementia is handing over what's precious to them which is who they are, their whole sense of self identity is in your hands and that can be lost in hospital and you might never get that identity back again'.(DGH03/participant04)

Another ward sister offered this narrative on learning to see the person behind the patient:

'To us he was just a gentleman who was aggressive but actually he had a big history, travelled the world, spoke different languages and once you pick up on things like that you know, even something small like a job or something I think it just makes you think that person is a person'. (DGH02/participant03)

Knowing the fragments allowed the nurses to pass them on to others who in turn could act as custodians as evidenced through this narrative segment:

'We had a gentleman on XX ward when I was a sister and he used to work for the secret service years and years ago and he was Ghandi's right hand man so I asked him did he have any pictures of anything that would remind him of the happy times, pictures of Ghandi and pictures of him. Anyway ... eventually he went into a home and then I moved over to XX and I happened to see him on XX ward as an inpatient and I happened to be speaking to one of the student nurses and said she should speak to him about Ghandi and she did say she did not know who Ghandi is. And then I said to her, just go and ask him to talk about his previous life, what he did before he retired. I said go and speak to him and ask him about the secret service and ask him about working with Ghandi. So I saw her in the corridor and she said I spoke to him and he opened up, he had a massive smile when I mentioned Ghandi' (DGH03/participant03)

Protect the Patient

This sub-theme was related to the actions taken by the nurse to physically protect and keep safe her patient. Nine (39.1%) of the nurses were coded for this sub-theme. The concept of protection encompassed a number of areas. Some nurses narrated in very general terms about protection as perhaps a part of their role:

'We need to protect the more vulnerable in society and dementia patients come under that umbrella and if we get it right for those vulnerable patients then we will get it right for everybody really'. (DGH02/participant01)

Believes about the status of the person were commonly voiced as:

'Like a child really' (DGH02/participant03)

Some nurses moved away from the general and were more specific about recognising when to take direct action even if it did not relate to physical safety whilst admitting that they were not fully prepared for all aspects of that. This extract taken from an appreciative inquiry workshop is representative:

'We had that patient the other day whose family came in and were trying to get him to sign over some deeds or something and he clearly didn't have capacity and it's really difficult for us as nurses to intervene. But you know they were trying to get him to sign something, to know when to intervene and to know where we stand' (DGH01/participant10)

'A solicitor wouldn't take part in anything ... and you need a solicitor there' (DGH01/participant12)

'But what I'm saying is, the girls did intervene but where do we stand with that kind of stuff' (DGH01/participant10)

This broader safeguarding role was recognised:

'There are other things in place to protect those patients. There is a lot more emphasis and a lot more focus on making sure that if we carry out any procedures that we're gaining patients' consent, that we're looking at mental capacity, that we are completing best interest, and that the safeguarding side of things is a lot more robust.' (DGH02/participant01)

Associated with that seemed to be an acknowledgement of the nurse as confidante:

'They tell you things, they tell you that they are not happy at home or they are not happy when a certain relative comes round, you know this, that and the other and you don't know then how that is going' (DGH03/participant08)

Some of the nurses' narrative accounts suggested that they wanted to protect the patient from the effects of dementia as reflected in this account:

'The poor man doesn't want to hear that his wife has passed away at least ten times a day (DGH02/participant03)

The same nurse introduced an element of wishing she could make it all better:

'It's so hard, so difficult, so sad for them when you have got somebody who I don't know ninety five with two children who are in their fifties and yet this person believes that she is fifty and her children are nine and ten at home waiting

for her to cook tea and this person is here and we are saying “no you can't go home” and this person is saying “yes because the children need me”. It is so difficult, all you want to do is to take them home and let them feed these children. You want them to be where they believe they are’.
(DGH02/participant03)

The desire to protect the patient extended beyond the point at which that person was no longer in the care of the nurse. When asked if it was sometimes difficult to say goodbye to people one nurse answered:

‘Yes, because you always worry where they go next. You know they are going to as scared as they were when they came to us first, so it's just a vicious cycle.’
(DGH03/participant06)

8.2 Summary of Chapter Eight

This chapter has set out the finding that four relational themes emerged from within the data. It represents the starting point of conceptualising what compassionate dementia care may be and where it may reside. Chapter Nine which follows takes this considerably further by describing the conceptual properties identified by the nurse participants.

Chapter Nine

Findings – Part Two:

Positions Articulated and Compassionate Properties Identified.

9.0 Introduction

This chapter continues the presentation of the key findings of the research and moves to complete the setting out of conceptual findings and in particular to expose those properties which acute nurses identify as defining compassionate dementia care. This chapter therefore addresses the following findings,

Finding 2. Positions that reflect beliefs about people who have dementia are articulated by acute care nurses.

Finding 3. Acute care nurses conceptualise compassionate dementia care through a series of properties that are amenable to clustering.

Finding two is presented extensively as a number of positions were accessible and each is underpinned by representative narrative extracts. Given the nature of positions as being ephemeral and often contradictory some nurse participants articulated more than one position. As noted earlier the use of positioning theory to analyse qualitative or narrative data was a novel approach for which there was no previous standard to compare against or to frame the analysis. There was a reliance on the reflexive aspects of supervision focussed around viewing the video or transcribed narratives and that supervisory discourse became in itself generative.

Finding three is equally extensive and the conceptual properties that survived the analytical process are described and considered in terms of their coding frequency. It is those frequencies which determine the ranking of properties from which the central exemplar is drawn and others are assigned a status based on their proximity to what is termed the 'single spotlight' property. The eleven conceptual properties are then grouped into one of three clusters, physical, psychological and, meta-physical. This is

a device introduced here to identify the relevant interests of the nurse participants which will become important to the synthesis that follows in Chapter Nine.

9.1 Finding 2 Positions that reflect beliefs about people who have dementia are articulated by acute care nurses.

From within the narrative data it was possible to identify the positions adopted by nurses within each of the themes and sub-themes.

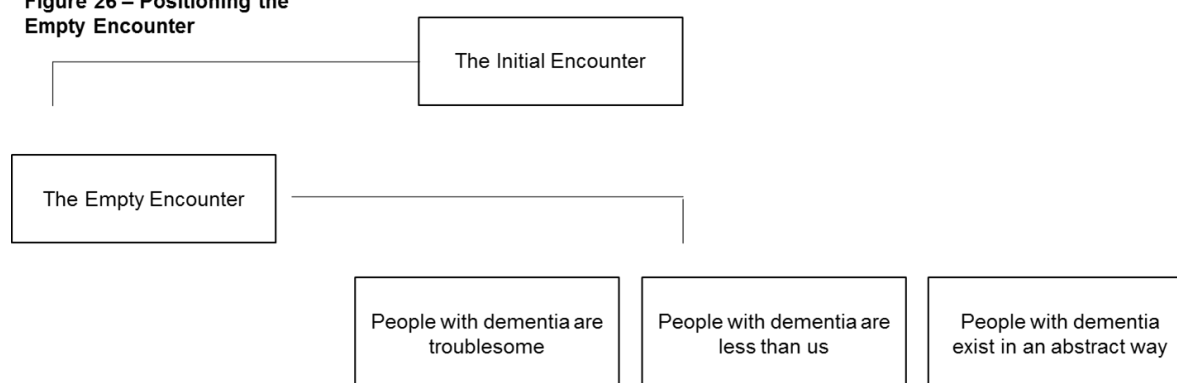
Positions Associated with ‘The Initial Encounter’

For the four sub-themes accommodated under this theme a total of forty-one narrative sections were selected as representative. From these representative sections eleven applied positions were identified. Nurses were seen to articulate more than one position at a time and often these were paradoxical. Findings from each sub-theme are addressed in turn.

Positioning the Empty Encounter

Fourteen sections were selected as representative and were owned by eight of the nurses. As set out below (Figure 26) these fourteen sections sired three applied positions.

Figure 26 – Positioning the Empty Encounter



People with Dementia are Troublesome

The commonest articulated position of nurses experiencing an empty encounter was that 'they are troublesome' which was voiced by 67% of those eight nurses. The position is set out in the following representative quotes:

'I don't think there are as many people with dementia who are the pleasantly confused as we would label them. They all seem to be progressively challenging people. We have had some extremely difficult patients' (DGH01/participant03)

'It is very hard for the staff to work with dementia patients and whatever training they have had goes out of the window. They get so frustrated ... because nurses tend to have poorly patients and they want to deal with that poorly patient but they have a dementia patient, who is poorly as well but being difficult when receiving treatment and things like that.' (DGH03/participant02)

People with Dementia are Less Than Us

This position was held in some way by three (37.5%) of the eight nurses. Often this was reflected in the linguistic device of reducing the whole person to be contained within a single label:

'And all these little dementia patients' (DGH01/participant11)

'Like a child really' (DGH02/participant03)

'Those palliatives' (DGH01/participant11)

The position also emerged as part of conversations between nurses. The following narrative extract is set in the context of a registered nurse losing an argument with a dementia support worker. That argument was essentially who met the needs of a specific patient best, nurses with a focus on the physical or the support worker with a focus on the meta-physical:

'He only liked it if it was me and him, one to one, if there was a lot more people in he just didn't like it.' (DGH01/participant09)

'Didn't he make cards? He made a hat once. We all sat there and put them on that was funny' (DGH01/participant10)

Finally this position once articulated reveals the place of the patient in the metaphorical pecking order within the ward, in this representative extract he and his psychological needs come lower than the completion of ward tasks and the need to help other nurses complete such tasks:

'I think if all the ward's work was done in all the sections of the ward, then maybe, yes. Then I think we need to be helpful to the other side of the ward if they are struggling' (DGH01/participant08)

People with Dementia Exist in Some Abstract Way

This position was held in some way by three (37.5%) of the eight nurses and suggested that whilst aware of people with dementia the nurses were somewhat removed from direct contact:

'I suppose the biggest area I look after is the elderly trauma group and we get a high volume of dementia patients. Some of my wards don't have a high volume of dementia patients' (DGH01/participant03)

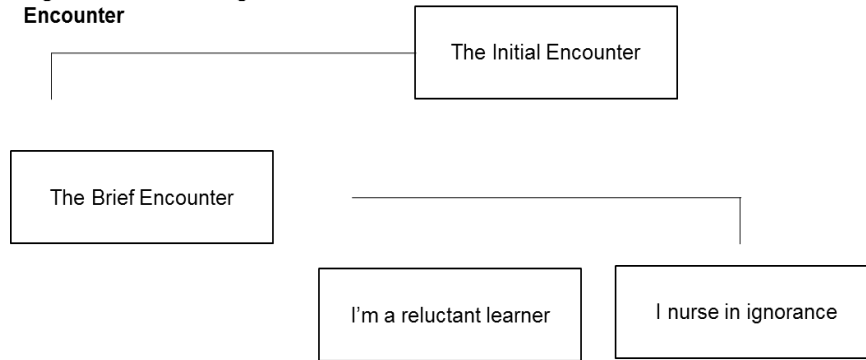
Interviewer – 'Do you actually have physical contact with the patients themselves?'

'I have done when there have been issues or problems but on a day to day basis I would not engage in any nursing care'. (DGH01/participant03)

Positioning the Brief Encounter

Overall for this sub-theme there were a total of seventeen coded sections from nine nurses. Three (34%) of these nurses had narrative sections coded under the brief encounter that were selected as representative. Four narrative sections were used and eliciting positions was affected by the low numbers. Despite that those sections that were selected as evidence produced two viable applied positions that are set out below (Figure 27),

Figure 27 – Positioning the Brief Encounter



I'm a Reluctant Learner

One nurse on promotion to matron found herself responsible for an area she previously knew little about and had previously little interest in:

'I feel that my knowledge and skills in dementia have changed dramatically because I was forced to not because I chose to'. (DGH01/participant01)

I nurse in ignorance

The three nurses who were coded for the brief encounter took up positions during their narratives which suggested that they and others did not know how to provide nursing care to people with dementia:

'You have the occasional patient with dementia, you would treat them with compassion but wouldn't know the level of service they required, you just do what you need to do for them' (DGH01/participant01)

Prompted by the interviewer to say what she and other didn't know, another matron stated:

'Things like their confusion, things that are real to them, they are angry, they are upset because we don't understand it as a general nurse' (DGH01/participant03).

Even after a prolonged admission when the nurses have developed understanding of the person a consequence of that overall lack of knowledge or skill to intervene could still be the exclusion of the person:

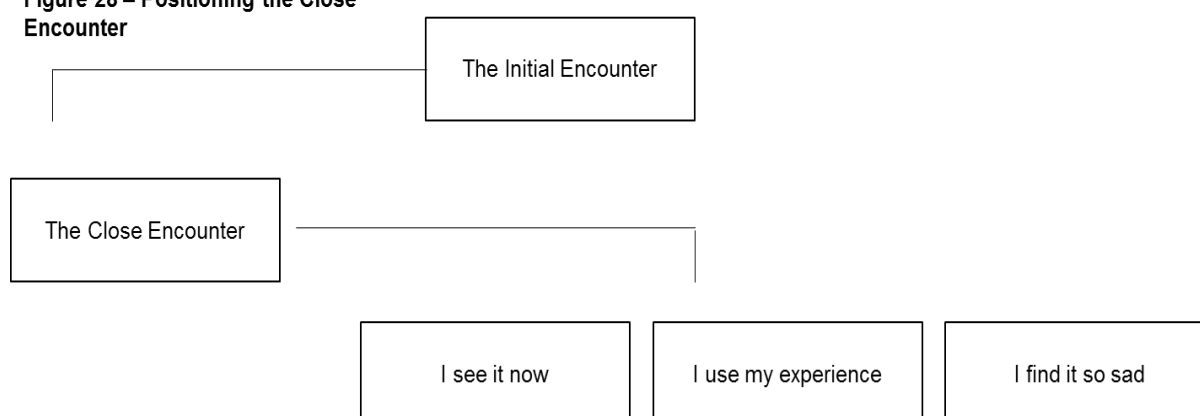
'She was still in the room because her behaviour was still inappropriate at times and she still needed to be isolated ... not isolated, in a single room away from other patients, but the ward staff had learned to manage her behaviour very, very well and she didn't need one to one'. (DGH02/participant02)

Positioning the Close Encounter

Overall ten narrative sections were coded as related to a close encounter. These ten sections came from the accounts of seven nurses. Eight narrative sections were selected as representative and this allowed six nurses to articulate three positions related to the close encounter.

These reflected the earlier finding that close encounters lead the nurse to view the experience of dementia through the eyes of family and carers. The three positions are as set out below (Figure 28),

Figure 28 – Positioning the Close Encounter



I See It Now

This position suggests that sometimes even when the nurse had a close encounter at a young age the import of that passed her by until later:

'Yes my dad's dad had Alzheimer's. He had it for about four years, it was quite rapid and he completely changed. He was a hardworking man and he could do anything, he could build anything and then he just stopped. He was aggressive with his dementia and took it out on the ones that was closest to him, like my dad would go every day to see him and yet my dad's brother who would go once in a blue moon. Every time my dad went he would say "you haven't been here, your brother comes here more than you" and that would always upset my dad. When his brother went he said "oh I am so glad you are here". We would be there

sometimes and we would think well you haven't been for months and that did upset my dad. I was only about sixteen, seventeen so I didn't have a great understanding and it's not that I found it funny but I did laugh at some of the things he said but now I realise why my dad was so upset to see his dad like this'. (DGH01/participant02)

I Use My Experience

This positioning reveals the nurse as being aware of her perceived advantage derived through personal experience:

'I understand from a relatives point of view and I think you go from having sympathy to empathy when you experience it yourself' (DGH01/participant06)

And for some nurses who had been carers their positioning was very closely aligned to and sympathetic of the family:

'... putting yourself in their position because I've been a terrible relative, it was someone I loved and I was around the clock' (DGH01/participant10)

'Sometimes the professional doesn't listen to what you say. Same as when my nana was in I said I want to bath my nana and wash her hair and I think they think they have to do it but its six o'clock at night and relatives don't do this do they?' (DGH01/participant11)

I Find It So Sad

The nurses narrated stories of their own experience to convey their belief in the inherent sadness that dementia brings to all concerned:

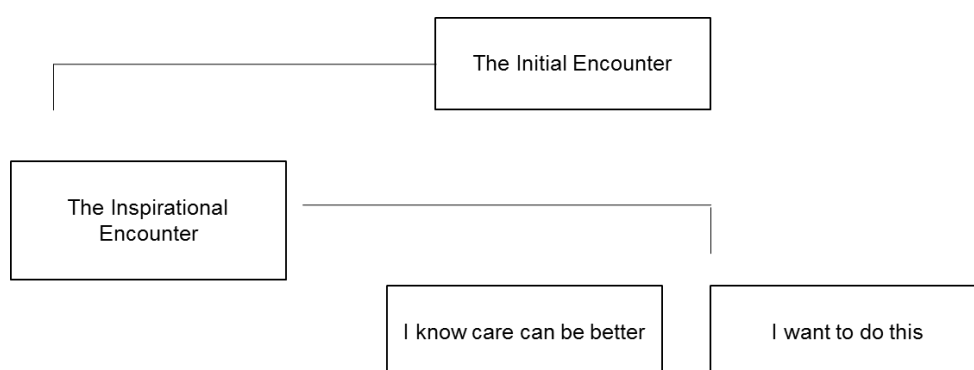
'My partner's grandfather suffered with senile dementia and my partner's mother died in a nursing home of dementia and to watch him struggle was hard because he had to watch this strong lady who was the head of the family rapidly deteriorate and that was hard for him. It was also hard to watch his granddad as well. Originally before we knew the diagnosis we would laugh at her and they would make a joke of it but then it got more severe and she would become a danger to herself. That was very sad because she was such a strong character'. (DGH01/participant01)

'Sad, really because that person that we knew was taken away, they were fading in front of our eyes'. (DGH02/participant06)

Positioning the Inspirational Encounter

Overall there were thirty narrative sections which attracted coding for the inspirational encounter. These thirty sections were owned by twelve nurses. Fifteen of the sections were selected as being representative of the whole and those selected sections accommodated all twelve nurses. Two positions were elicited from the selected narrative sections and are set out below (Figure 29).

Figure 29 – Positioning the Inspirational Encounter



I Know Care Can Be Better

At a young age two of the nurses had witnessed poor care and adopted this position which was articulated through their narrative account:

'Even though I was only that age I didn't like how he was been cared for. He needed more attention, like things like after he had his tea he would be left with his dirty apron on like a baby'. (DGH03/participant02)

I Want To Do This

Eight of the twelve nurses had in one way or another taken up the position that having been inspired by someone or, they had a desire to improve care, they wanted to work in dementia care:

'I think it comes from my gran, my gran was trained as a nurse when she was younger and I always as a little girl would hear about everything that she had done, people that she had helped. I used to go to the hospital with her sometimes, she used to take me in with her and I just loved it, absolutely loved and it was what I always wanted to do'. (DGH03/participant08)

*'My first experience in care of the elderly was working in a residential home in XXX and I absolutely loved it and I never wanted to be anything else. When I was doing my nurse training I always wanted to be a care of the elderly nurse. My first placement was care of the elderly, my first job was care of the elderly'.
(DGH03/participant03)*

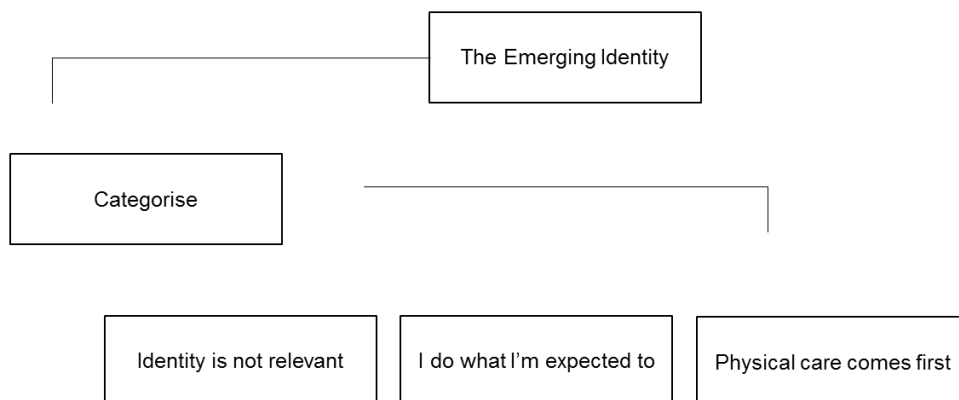
Positions Associated with 'The Emerging Identity'

For the three sub-themes under 'the emerging identity' total of 88 narrative sections were coded. From that total 34 sections were selected as representative and eight positions were articulated.

Positioning 'Categorised'

There were twelve selected narrative sections which were offered from eight nurses. Three positions emerged from this representative collection of narrative (Figure 30).

Figure 30 - Positioning 'Categorise'



Identity is Not Relevant

There were two narrative extracts within the selected collection which suggested a position being taken to describe a person as a series of negative labels with no regard for their uniqueness or any individual aspect of selfhood. This is representative:

'What was challenging for us was that she was under 65. She did have a diagnosis of dementia but she had other mental health problems which made her nursing quite challenging. She was schizophrenic as well. Some of her behaviour was very inappropriate so she had to be nursed in a cubicle so she was very isolated.' (DGH02/participant02)

I Do What I'm Expected

There were three narrative extracts from three nurses of which the one below was extremely representative:

'I am a professional and I do my job. I don't want to get involved too much' (DGH02/participant02)

Physical Care Comes First

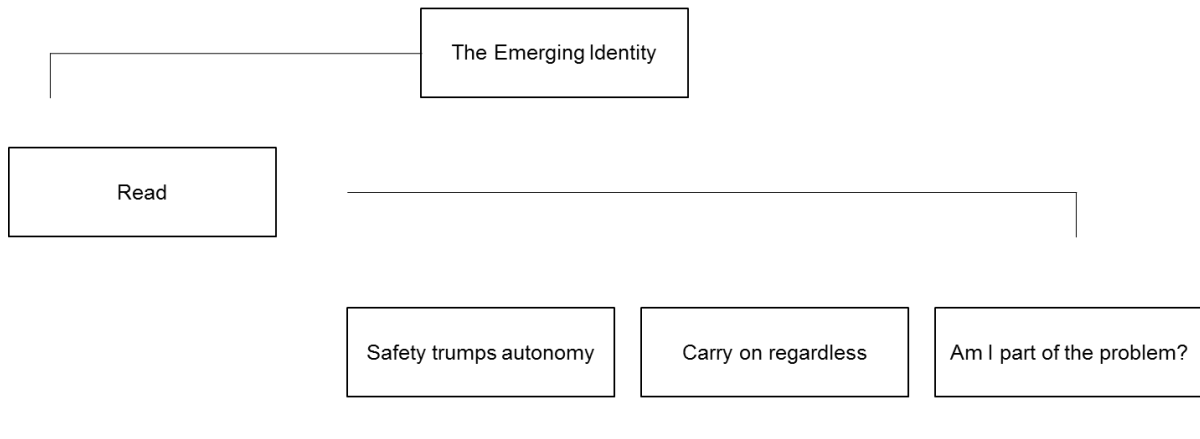
This was the highest frequency position adopted by nurses under this sub-theme with six narrative extracts being selected, the section below is again representative:

'A lot of the time things are happening for a reason aren't they, they have to happen because we need that to be done to you because otherwise if you weren't repositioned in bed then you would get pressure sores. Sometimes you have to understand that it still needs to be dealt with' (DGH01/participant12)

Positioning 'Read'

There were fourteen selected narrative sections offered by eight nurses which produced the three applied positions set out below (Figure 31).

Figure 31 - Positioning 'Read'



Safety Trumps Autonomy

Two selected narrative sections saw nurses articulating a belief that whilst the patient was entitled to a degree of freedom the boundary for that was still set by the nurse:

'We allow her to do what she wants when she wants, within reason to make sure she is safe.' (DGH01/participant11)

More senior nursing staff applied the same standard to juniors:

'If you like afternoon tea, let them have afternoon tea. What's wrong with a nurse having a cup of tea with a patient? If they are allocated to do that at that time.' (DGH01/participant03)

Carry On Regardless?

Recognising that physical care interventions could cause a person with dementia distress did not detract from the importance placed on carrying them out with no obvious attempt made to reduce that distress:

'You have to do that blood pressure to record if that lady's sick or not, and if that causes their increased confusion, d'you know what I mean, it's part of your assessment isn't it, but that may well, you know you might have another nurse that might think "oh don't do that, it's going to cause them more distress" but in actual fact when it comes down to best interest and you are doing it in their best interest as a healthcare professional and you know that procedure needs carrying out.' (DGH02/participant01)

Am I Part of the Problem?

Six of the selected narrative sections suggested that five nurses had positioned themselves as to some extent being at fault for the poor experience of care or the failure for it to be holistic. The narrative extracts below are representative of the whole:

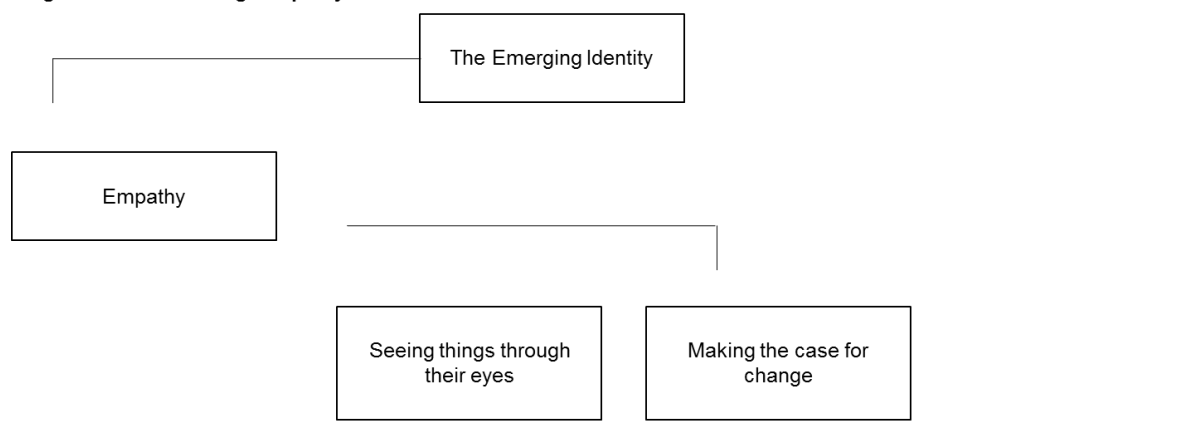
'In the acute setting we tend to do everything for the dementia patients and as we know as you start doing things for the dementia patients they forget what they could do in the first place and it's always worse on the acute wards. You have got to get ready for the consultant' ward round, I wash them, I fasten their buttons instead of giving that patient time to wash themselves.' (DGH02/participant02)

'You can care for somebody without knowing them but it's only physical care.' (DGH01/participant11)

Positioning 'Empathy'

Eight narrative sections were selected as representative. Those eight sections were owned by seven nurses and generated two applied positions (Figure 32).

Figure 32 - Positioning 'Empathy'



Seeing Things 'Through Their Eyes'

There were six of the selected narrative sections offered by five nurses which articulated this position. The nurses were able to take a step back and look afresh at the care environment and the behaviour of their patients within it:

'She thought she was on a cruise ship and I'd look around and think I can see how she thinks it is. You know the little windows at the top and the bars coming down. I could see in her mind's eye' (DGH01/participant10)

'They are appreciative of my role in terms of that it reduces significantly the amount of patients who wander because I think some of the times they do it out of boredom, it's not that they actually need anything, they just want a chat or they want something or they find an excuse to press the buzzers so that they can talk to somebody.' (DGH03/participant08)

Making the Case for Change

As the case for change in relation to dementia care is made in the representative sample below a number of voices contribute. They build to a consensus that holistic care is the most appropriate way to meet the patient's needs:

'If we think about dementia like we think about stroke services, somebody comes in with a stroke and the stroke team have to liaise with ...' DGH03/participant03

'They have a dedicated team.' DGH03/participant02

'Yes a team, they have to liaise within half an hour and be there within a certain time and that person has to be in a certain bed within four hours and that's it. If we thought about the mental state of the person as the same as the physical state then why not devise a similar plan' DGH03/participant03

'And their mental state will make their physical state get worse, they're not going to eat, not going to drink and if they are coming in with UTI's it's all going to get worse they'll go septic and it's just a never ending circle isn't it? So unless you address the mental health issues you're not going to be able to address the physical health issues' DGH03/participant04

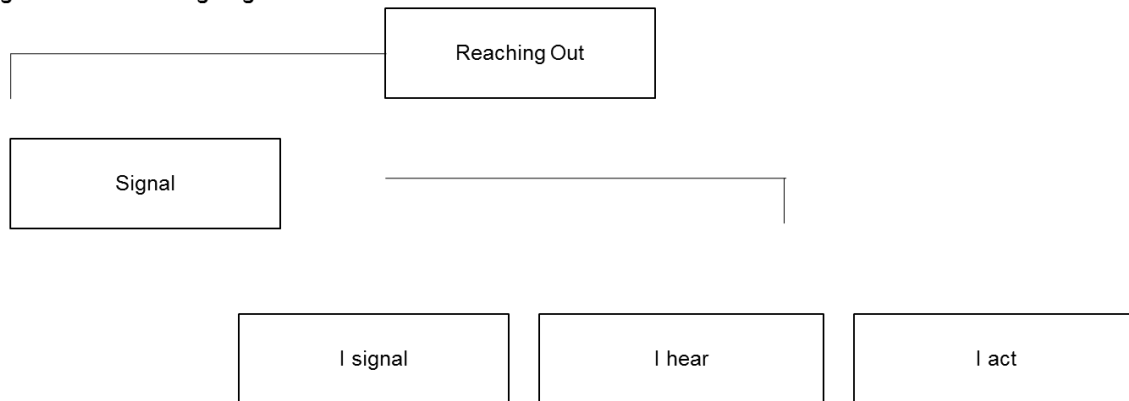
Positions Associated with 'Reaching Out'

There were a total of 56 narrative sections which were coded under the theme of reaching out. Of these twenty-six were selected as representative of the whole. From those selected sections the nurses articulated nine positions.

Positioning 'Signal'

Under this sub-theme there were a total of eleven narrative sections that were selected as being representative. These came from eight of the nurses who articulated the following three positions (Figure 33),

Figure 33 - Positioning 'Signal'



I Signal

Some of the nurses positioned themselves as sending out signals to patients with dementia and being receptive to those of that person. The importance of that was set out as:

'If you can pass to a patient that yes I am here for you, I am on your side, I am here to look after you and I will be your advocate and be whatever you want.'
(DGH03/participant06)

Predominantly this was seen as occurring through non-verbal mechanisms with touch being common:

'I would just sit and hold her hand at times, I would look in her face and smile.'
(DGH02/participant06)

'If you took hold of their hands while you are speaking to them they might give you a quick squeeze, that's recognition' (DGH01/participant04)

I Hear

Some nurses positioned silence as a viable signal and themselves as being sensitive to what lay behind that:

'I think sometimes it is not always what they say it's what they don't say, so sometimes you can go in and they look very lacking, withdrawn, sometimes they look very emotional, you see the tears and you know they have all this stuff going on inside.' (DGH02/participant08)

Interviewer – 'Was there something about her that drew you to her?'

'Yes she was quiet and into herself while everybody else was sitting up, quite bright, she needed a bit more, er, care' (DGH03/participant07)

I Act

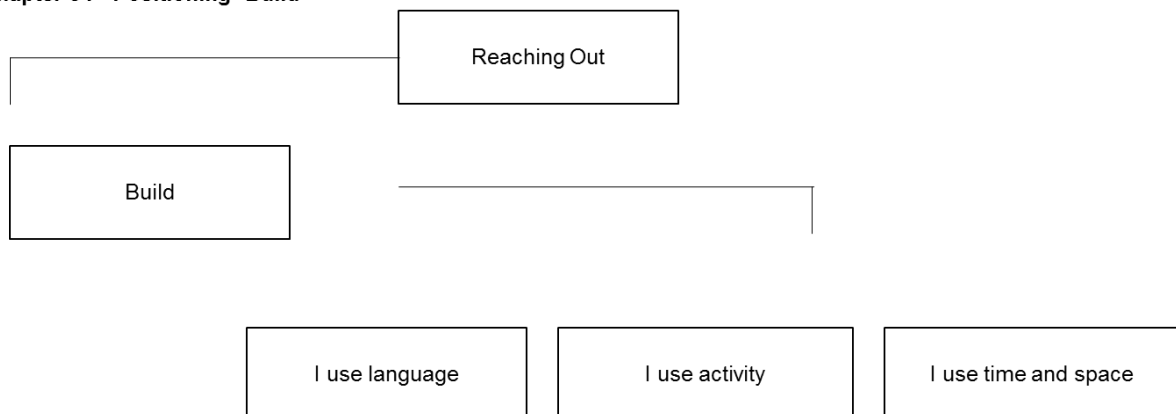
The nurses positioned taking some kind of action as important once the signal from the patient had been received:

'I picked up on one of her words. This is what I do when someone is in a distressed response like that they will say a word that I can pick up on and then those words I will go with that and then they are like 'oh yes' and then you can go in from one of their words so they know I'm listening.' (DGH03/participant01)

Positioning 'Build'

A total of seven narrative extracts, from six nurses, were selected as being representative. From those three positions emerged (Figure 34),

Chapter 34 - Positioning 'Build'



I Use Language

The Welsh speaking nurses in particular articulated this position:

'Because I speak Welsh and Miss XXX was Welsh speaking, it was an instant (connection), I was like her best friend' (DGH03/participant03)

As cited earlier, one nurse elaborated on this to convey the complexity of using a single word as the first step to start building a bridge to connect to the patient:

'I picked up on one of her words. This is what I do when someone is in a distressed response like that they will say a word that I can pick up on and then those words, I will go with that, and then they are like 'oh yes' and then you can go in from one of their words' (DGH03/participant01)

I Use Activity

Some nurses positioned engaging in a shared activity as a means of building a connection to that patient/s. the extract below from a dementia support worker is representative:

'When I worked on Sunday I washed four elderly lady's hair, put rollers in and you would have thought I had given them a million pounds.' (DGH01/participant02)

Interviewer - 'In the act of doing that, because the act in its self is just a physical task isn't, but in the act of washing someone's hair what's the interaction like between you and those ladies'

'Well you talk about things. Nearly everyone I did the other day they were saying about their mum's hair, my mum had long hair, curly hair, I had a curl in my hair when I was little, and I had ringlets in my hair. They were going back to their childhood and how their mother used to do their hair' (DGH01/participant02)

I Use Time and Space

Some nurses positioned the property of having sufficient time to allow the bridge to be constructed as important. The representative extract below aligns that with having an appropriate space for building a bridge to the person:

'I decided we weren't going to go back to the ward just yet. It was a nice day, the sun was out, so we went to sit in the garden and we were sat there for a good half an hour before we went back in. We got talking and she told me of all the lovely places she had been on holiday and she was sat with her eyes closed reminiscing, smiling' (DGH01/participant)

The opposite of this was the nurses looking afresh at their ward environments and positioning aspects of that as constructions that prevent the person being reached:

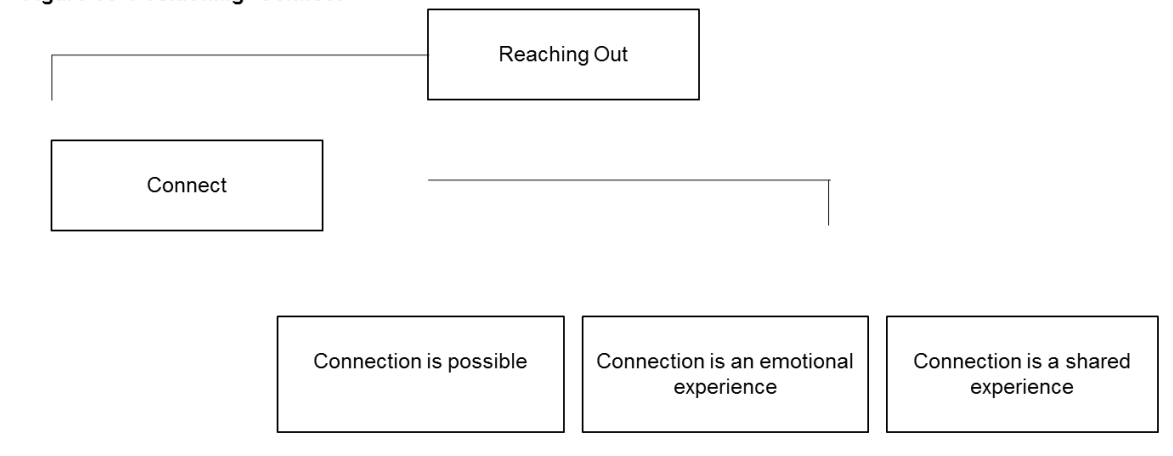
'We should incorporate a nurse's station in each individual bay rather than the one huge one that we have got which is nice, it's a nice welcoming position but

sometimes it does act as a barrier and there shouldn't be a barrier'
(DGH01/participant10)

Positioning 'Connect'

There were eight narrative sections available for this sub-theme. These came from eight nurses who together articulated the following three positions (Figure 35).

Figure 35 -Positioning 'Connect'



Connection is Possible

The nurses articulated the position that it was possible to connect with the patient. The point of connection being made was noted:

'She came here I was holding her hand and stroking her and noticed that she wasn't doing anything then half way through she started to stroke back, opened her eyes and smiled and sadly had happy tears.' (DGH03/participant07)

Connection is an Emotional Experience

The point at which a connection was established could be an emotional moment:

Interviewer – 'when did she start crying?'

'When she opened her eye's (DGH03/participant07)

Interviewer – ‘Ok so the emotion was there and needed to come out. Did she say anything?’

‘No, no. smiled, opened her eyes, tears.’ (DGH03/participant07)

Some nurses found the need to justify their involvement in this emotional moment:

‘You know we are taught in nursing school that we shouldn't get attached to patients and that we shouldn't get emotionally attached and emotional in front of patients but at the end of the day it's hard not to, we are all human at the end of the day and we are going to get emotional’ (DGH03/participant06)

Other nurses noted that establishing a connection that was emotional led to that nurse being remembered emotionally by the patient:

‘You can see the response on their face, you can see them smile when you walk in, they pat you cheek with both hands and I get that quite a lot.’
(DGH03/participant02)

This had an emotional impact upon the nurse,

‘I would say it made me feel proud that these patients have that connection with me and when those patients ask you ‘are you looking after me today?’
(DGH01/participant03)

Connection is a Shared Experience

The act of connecting was positioned as possible not only with the individual patient but with a group engaged in a shared and enjoyable activity:

Interviewer – ‘In the act of washing someone's hair what's the connection like between you and the patients ‘

‘Well you talk about things. Nearly everyone I did the other day they were saying about their mum's hair, my mum had long hair, curly hair, I had a curl in my hair when I was little, or I had ringlets in my hair. They were going back to their childhood and how their mother used to do their hair.’ (DGH01/participant02)

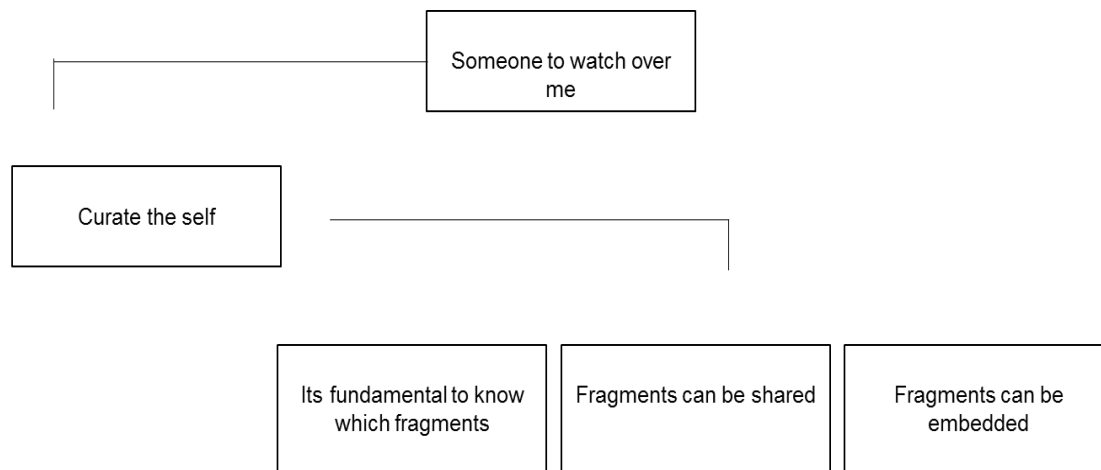
Positions Associated with ‘Someone to Watch over Me’

There were a total of 59 narrative sections which attracted coding under this sub-theme. They were generated from a total of nineteen nurses. Twenty-seven narrative extracts were selected as representative of the whole. From those extracts a total of six positions were articulated by fourteen nurses.

Positioning ‘Curate the Self’

For this sub-theme there were fourteen selected narrative extracts offered by eight nurses. From this came three applied positions as set out (Figure 36),

Figure 36 – Positioning ‘Curate the self’



It's Fundamental to Know Which Fragments

Some nurses articulated that if one is to hold the fragments of the others personhood together it would be important to know which pieces:

‘He smiled for the first time in weeks. And he engaged in a proper conversation with me and was telling me about the players and different things, past players, current players. He was engaged in a conversation whereas before he didn't really want to know anything, he was in a little side room and that was him really’. (DGH01/participant02)

'In a sense her suffering wasn't about being distressed about what could happen to her it was instead being distressed about how she would appear to others and that is the bit I was able to do something about'. (DGH01/participant04)

Fragments can be shared

Some nurses adopted a further position in that if one knew which fragments then these should be shared with others involved in that patients care:

'I happened to be speaking to one of the student nurses and said she should speak to him about Ghandi and she did say she did not know who Ghandi is. And then I said to her, just go and ask him to talk about his previous, what he did before he retired. I said go and speak to him and ask him about the secret service and ask him about working with Ghandi. So I saw her in the corridor and she said I spoke to him and he opened up, he had a massive smile when I mentioned Ghandi' (DGH03/participant03)

Fragments can be embedded

Some nurses articulated the position that fragments of personhood were to be found quite broadly and could be embedded in routines developed by people with dementia prior to the experience of becoming a patient:

'There was a patient in a little while ago, she used to Skype someone in Australia every morning and I used to make sure that she was up and dressed and had her make-up on as she did this normally (DGH01/participant04)

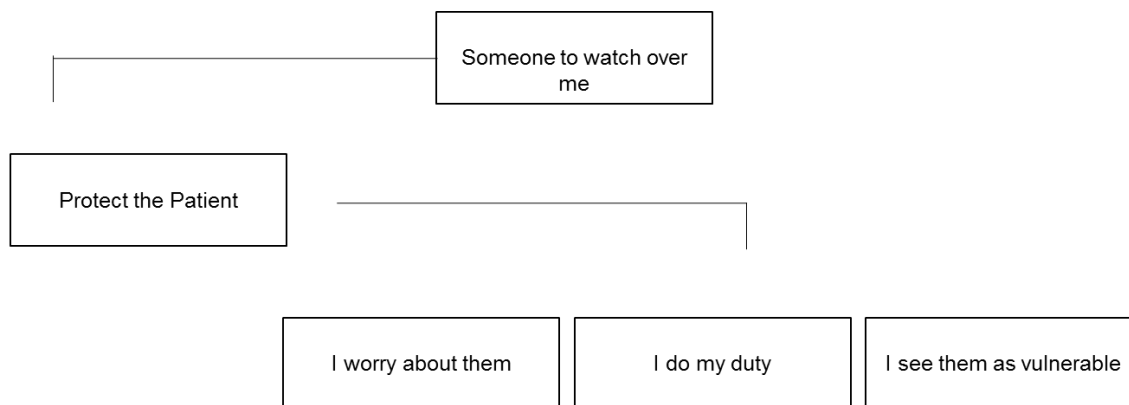
'They might say I usually get up at that time, you can then start maybe getting them up at that time so that they keep their routine. You are not getting them out of their complete routine, it's hard enough them being in hospital' (DGH01/participant07)

Positioning 'Protect the Patient'

For this sub-theme there were thirteen selected narrative extracts from a total of eight nurses.

Three positions were articulated (figure 37),

Figure 37 – Positioning ‘Protect the Patient’



I Worry About Them

Nurses were aware of the patient coming into the acute ward and being frightened or distressed. When they positioned themselves as worried about their patient it was solely in the context of that person being discharged to another care environment and becoming frightened and distressed all over again:

‘... that person comes in and they might be terrified and you form a relationship and do the best you can for that person and they come to trust you and to know you and perhaps not to feel so frightened and then you send them back out into the world again. So you always worry where they go next. You know they are going to as scared as they were when they came to us first.’
(DGH03/participant06)

‘It’s almost like you feel very protective of them as you would your family because it is almost like in a way they are their own person but you want to take care of them and make sure they are treated the same, not the same, everyone needs different things but the same standard.’ (DGH02/participant08)

I Do My Duty

The policy and process of keeping the patient safe was cited by some nurses as they positioned themselves as dutifully doing what was required by policy and process:

'There are other things in place to protect those patients. There is a lot more emphasis and a lot more focus on making sure that if we carry out any procedures that we're gaining patients' consent, that we're looking at mental capacity, that we are completing best interest, and that the safeguarding side of things is a lot more robust.' (DGH02/participant01)

I See Them as Vulnerable

A common thread running in the background of the narratives was articulated through the positioning adopted by the nurses as reflected here:

'They are so vulnerable and I think it's important that they can trust us so we do need to get that bond so that they are able to trust us as professionals' (DGH03/participant06)

And perhaps ultimately as:

'Like a child really'. (DGH02/participant03)

9.2 Finding 3. Acute care nurses conceptualise compassionate dementia care through a series of properties that are amenable to clustering.

The Properties of Compassionate Dementia Care

The data analysis process set out in Chapter Four led to the identification of eleven conceptual properties that defined compassionate dementia care. As stated earlier, those conceptual properties were ordered into three conceptual clusters and that ordering was based around their shared semantic field (Jackson and Ze Amvela, 2000). As such the clustering was language based and clusters denoted phenomena that could be symbolised by a set of related words where the relationship was that they shared common semantic properties (Brinton 2000), in this case the properties were meaningful so they were related to each other sufficient to fall under a dictionary definition of the term used to describe each cluster (Small et al. 1988). Finally, the reflexive ordering of properties was stylistically influenced by the 'centre stage

diagram' approach (Williams and Keady, 2012) which, although applied in a different context, allowed me to imagine what lay at the centre of the phenomenon of compassionate dementia care. From that the properties in relation to how strongly they were supported by the research data were labelled as,

1. The single 'spotlight' property
2. The "centre stage' properties
3. The 'off-stage' properties

The eleven properties are set out below (in alphabetical order) with representative narrative evidence.

1. **Acceptance of the Other**

The nurses identified that accepting the patient with dementia was an important aspect of delivering care:

'We are there to care and not to judge' (DGH01/participant08)

However, whilst generally accepted as an important principle it was acknowledged that circumstances in which the nurse felt threatened or vulnerable could impact upon that and possibly that the acceptance was not unconditional:

'I think where nurses' struggle is that patients are aggressive towards them whether that be verbally or physically, I think that can be really quite difficult for nurses to cope with. (DGH02/participant01)

Interviewer – 'Is it justified in that situation to be less compassionate towards that person, to be more cold, clinical and detached rather than engaging with that person?'

'It depends really, it does depend. I think it is difficult isn't it. If somebody is being really aggressive towards them, sometimes if we do show them compassion, they will actually respond to you and they may actually calm down, but equally if you have a nurse that is feeling quite vulnerable and is quite scared, it might be quite challenging to do that really. It is difficult to scenario. But yes you shouldn't be, but equally as well if somebody is being personal towards you or threatening, again it comes down to a human factor, and I think it is difficult to say'. (DGH02/participant01)

That same nurse on reflection articulated that being a nurse could itself be a mechanism to put that emotional reaction to one side:

'A staff member explained to me last night how he was verbally abused the shift before and his response to me was that "my reaction would be very different if I was out of work as I wouldn't let somebody speak to me like that", but as a nurse he remained professional and he remained looking after that patient and did what was needed to do. He was obviously very upset by that but he still continued to do his job. And I think all nurses would do that'.

(DGH02/participant01)

2. **Act**

The nurses stated that it was not enough to note in some abstract way that the patient was in need. Importance was placed on responding actively. In the same way that a soldier marches to the sound of guns so the nurse is drawn to the sights and sounds of distress:

'We can also have patients that are distressed, looking frightened and hitting out. I will go in and I will try to find out why they are distressed because usually they don't know what is going on.' (DGH03/participant01)

Other nurses identified that there were other actions which underpinned compassionate dementia care. These included the need to stand by the patient as an active advocate:

'I was able to go to the MDT meeting for this lady... it was the first time I had been and done anything like that, sitting in and being her advocate and saying, actually no, that's not right, that really she does need more care there. I am fighting for her needs and it's good to know that she and the family got what they wanted.' (DGH02/participant06)

Or to facilitate care that reduces length of stay and leads the patient towards an early discharge:

'I think compassion is not just sitting at the bedside with the patient it's about looking at nursing care, looking at the discharge plan and get things moving quicker to be able to get them back (home)'. (DGH01/participant11)

3. **Care Like I Want it For Me**

A number of nurses suggested that the highest quality of care which could help define compassionate dementia care was to nurse the patient in the way that the nurse would wish to be nurses if their positions were reversed:

'Just to treat people as you want to be treated yourself'. (DGH01/participant01)

'I always think that if I am doing something with anybody I always imagine if that person was me. How would I like it if somebody came up to me in a certain manner and how I would like it?' (DGH03/participant01)

4. **Create the Space to Be Me**

This related to the creation of psychological space in which personhood could be expressed. It involved the nurse having a willingness to create and share that space. The representative narrative extract below reflects the nurse respecting the expression of personhood and whilst she may not have shared his beliefs she allowed him to say them and to have an audience:

'He would open up to me about his past and what he did. I knew that he was a born again Christian which he did try and ask me to become one but that's a different story. But I did listen, I did listen.' (DGH01/participant09)

Another nurse having accompanied a patient to an out-patient clinic, at which she received a diagnosis of cancer, created the space for the lady to sit and reflect:

'It was a nice day, the sun was out, so we went to sit in the garden and we were sat there for a good half an hour before we went back in. We got talking and she told me of all the lovely places she had been on holiday and she was sat with her eyes closed reminiscing, smiling.' (DGH01/participant04)

5. **Familiarity**

Creating a sense of familiarity to underpin a continuity of care, providers of care and care environment were seen as a property:

'They will have lost their routine, lost the familiarity of their environment, different faces and they change so quickly. Somebody could be looking after them in the morning and somebody completely different in the afternoon. How are you going to gain trust when different faces are looking after you?' (DGH01/participant01)

6. **Friendship**

'Every patient that comes into the ward expects you to be friendly. People with dementia don't need a friend and there is a difference between the two. Being friendly is something as a nurse you do but perhaps being a friend is different.' (DGH03/participant06)

This was not the view of all and whilst some of the nurses talked about being friendly towards the patient and their families others took this further to consider the act of forming friendships:

'You get to know one another, you ask about things, you talk about everything to each other, they tell you things and you will try and help them if they are worried or you talk about happy times and things and they trust you, they know that you understand as though they were that individual, the person that they were before they had dementia.' (DGH03/participant07)

Friendships could develop that would leave some nurses experiencing a sense of loss on the death or discharge of that patient:

'I can think of three of the patients we have over the months and when the time comes for them to be discharged you are almost grieving for a few days afterwards. They are part of the ward aren't they, you develop a relationship.' (DGH03/participant03)

Despite this not all aspects of a friendship could be included such as the sharing of personal problems on the part of the nurse:

'Well I would be quite happy to share whatever I thought would help but I don't know that sometimes people are in a position where they wanted to hear, you know they already have got their own worries.' (DGH01/participant12)

7. Have the Time to Care

Most nurses identified a relationship between compassionate dementia care and sufficient time to be with the patient. It was suggested as being a balance to offset the strange and frightening experience of being in hospital:

'I think time really for patients I think is fundamental. It must be quite a scary place for a patient with dementia, even if they are in their home environment and they have a level of routine, you know we're taking them out of that environment, we're bringing them to an acute hospital, we're trying maybe to take bloods, put cannulas in, catheters, you know all of that needs time and explanation.' (DGH02/participant01)

It was seen as not only a precious gift to offer the patient but also a wise investment to make:

'It's about giving the patient your time and I know time is precious... If you don't invest that time, you are never going to get anywhere, you are never going to improve.' DGH01/participant03)

Some nurses suggested that less acute wards had the added advantage of prolonged length of stay which on its own provided more time:

'I think on this ward our patients are here a little bit longer and we get to know them a bit better so you're able to get to know their likes and dislikes, their routines, their favourites and, their sleep pattern and everything like that.' (DGH01/participant11)

Whilst in more acute wards time was a much more limited resource:

'Every moment counts, so you might not get the time to sit with somebody until when you are administering medication or when you are giving personal care, that's your quality time with that patient.' (DGH02/participant06)

And, ultimately nurses were very much aware of their lack of time to meet all the needs of that patient with some feeling embarrassed, upset or frustrate:

'We go home and worry about, those things we are not doing, I don't think it goes unnoticed that we haven't been able to meet this or that and it's probably one of our main frustrations.' (DGH01/participant10)

8. **Know the Person behind the Patient**

The nurses set out the relationship between knowing the person and compassionate care as these two representative narrative extracts show:

'I don't know how you can be compassionate without knowing more about the person or at least their experience. You can care for somebody without knowing them but it's only physical care.' (DGH01/participant01)

'Remember they are a person, they have memories, and they have got a background. You have to be compassionate towards how that person was rather than how they are now. They could be aggressive now but they have not always been like that, find out why.' (DGH01/participant02)

Some of the nurses identified the importance of this property by making reference to its absence from practice:

'The way he looked, obviously the way he dressed, if it was left to uncle he would have a suit jacket on with a tie and obviously he didn't. He always looked very clean and tidy but it would be just a shirt or a polo shirt with a jumper. Now uncle would never dress like that.' (DGH02/participant06)

'Every morning this week when I went into work I had to say why this man was distressed, because he didn't have his flat cap on. Every morning, and I wrote it in

his This Is Me. Five mornings on the run I walked into work and he was crying in his chair because he didn't have his flat cap on.' (DGH01/participant02)

Nurses narrated the importance of knowing the person as a means of understanding the behaviour of the patient:

'There was a man who always got up at four or five o'clock every morning and if we encouraged him to go back to bed and then he would get agitated and he would be medicated. When we actually spoke with the family we realised he always got up at that time of the morning because he was a farmer.'
(DGH01/participant06)

Some nurses spoke about coming to the realisation that knowing the person behind the patient was important and, as the representative extract below shows, had positive benefits for everyone involved:

'We stopped seeing this gentleman as a bed number, he wasn't such and such a bed 9c or such and such a cubicle or what have you. And doing things like that we built a better relationship with his family because we saw him as a person, as an individual. And from this everyone felt more positive on the ward because we could see the benefits of what we were doing by treating him as a person and not as a hospital number.' (DGH02/participant06)

It was also cited that this knowledge of the person was largely one way traffic:

'I think we get to know them a lot more than they get to know us really.'
(DGH03/participant04)

9. **Presence**

The nurses spoke about the nature of presence by which they meant the reassuring physical presence of a nurse with the patient during their time in hospital which they have acknowledged can be a frightening experience. The narrative extracts below are representative of the whole:

'They need someone to watch over them and need to know they're not alone'
(DGH01/participant10)

'We have a lady at the moment that screams all day but as soon as you are sat with her even for five minutes, give her a drink, comfort her she is fine.'
(DGH01/participant02)

'That person or that family member they want a person not a document they want a person they can talk to, explain their frustrations, explain their fears, explain how they are feeling without judgement without criticism, without reprisals.' (DGH02/participant06)

10. **Provide Comfort**

The nurses talked about the provision of comfort in a number of ways, firstly physical comfort:

'I think sometimes the medical model fails to you know touch on different aspects you know if somebody is stressed, how many times have we, you know, just had a spa day and it does make you feel better. It's not all about providing medicine and being clinical is it, people need to feel nice as well.' (DGH01/participant10)

Secondly, psychological comfort:

'It's the lady who doesn't speak in much in the other corner who doesn't understand where she is, who looks afraid and I am going to make sure she knows where she is and not necessary remembers why she is there but make sure she feels safe and maybe just to hold her hand.' (DGH01/participant04)

And thirdly, emotional comfort:

'In the activity room we have this thing. The only way I can describe it is like you know those dogs you see in a garden centre like resin things that go in the garden like a pottery thing? He actually liked the one we had and called it Jock and that was something he liked to carry as well so we would go and get it for him and he would carry it up and down with him, you know? He's actually going into the activity room to look for the dog and he'd sit with the dog on his lap stroking the dog. It helped him because it's a very frightening experience for a patient with dementia coming into hospital especially with like that increased state of confusion that increased state of anxiety and agitation but a little thing like that made a difference.' (DGH02/participant07)

11. **Understand the Situation of the Other**

A significant number of the nurses' narratives included sections which suggested that having understanding of the experience that the other finds himself in was important. There were common beliefs, across all three of the research sites, about the emotional aspects of that experience as set out in the representative sections below:

'You don't know how terrified these people are, what they are thinking, what their thoughts about the future are.' (DGH01/participant06)

'This ward is a very busy ward, the dementia patients are coming in needing surgery, broken hips, that kind of thing. They are in pain, they are having drugs and they are scared.' (DGH02/participant04)

'Just imagine waking up and you've blood, catheters and you don't know why they are there. I would be frightened.' (DGH03/participant01)

Nurses showed a degree of reflection about other aspects of that experience and their part in it:

'Where's my mum?' and they're 80 and you think gosh, how could ... it's unbelievable sometimes. It's hard for us to understand how they imagine where they are.' (DGH01/participant01)

'Yesterday I helped him with personal care and I have been trying to think about..... because for me he has that insight at that time and for me I could see that he was feeling, I think he felt less of a man low esteem and self-worth really and I am not sure what you can do about that. You know treat him as you would anyway because you know it's a massive what he has gone through himself and how he is feeling about that. If we talk to him any differently that's treating him like a child that would damage his self-worth even more.' (DGH02/participant07)

'I couldn't get out of my mind was that she was being told something really horrible, they weren't going to do anything, they could do something but they weren't going to. it wouldn't be sensible to do it but the fact is they still could and she wasn't bothered about that she was more bothered about how she was looking to everyone else, about how she appeared to everyone else rather than how long she has left.' (DGH01/participant04)

A number of nurses considered the importance of empathy in helping them to imagine the experience from the perspective of the other:

'I think empathy is very important. You can't understand what someone else is going through unless you can empathise, by putting yourself in that position.' (DGH02/participant04)

Some nurses were able to empathise and understand the broader impact of dementia on others:

'I think from having a relative with dementia you actually understand it from a relative's side. You understand the stress of trying to keep them safe at home, you understand the sleepless nights, you understand the feeling that you can't go home, the fact that you have constantly have to juggle work and home life, making sure there is food in the fridge. For me empathy is when you have lived that life that they are living, when you can understand it and I think for me that makes you that good nurse, you can actually relate to it.' (DGH01/participant06)

The Conceptual Clusters

The conceptual properties lent themselves to being ordered into three clusters namely, physical, psychological and meta-physical. These clusters were devices for placing together properties that shared a common linguistic base through their semantic field (Jackson and Ze Amvela, 2000). Distinctions could be made between the properties based on the broad shared meanings that connected some rather than others (Small et al. 1988). Being semantically driven devices it was possible to define each around a consensus from three recognised dictionaries.

They did offer some further organisation for the analysis outcomes and were inherently connected with the linear aspects of the earlier heuristic model and with the four relational themes.

The Physical Conceptual Cluster

Of the eleven final conceptual properties, four were contained within the physical cluster. Based on the dictionary consensus definition, the properties here were those that, related to body not the mind; involved bodily contact or activity and, related to practitioner behaviours that were real or tangible.

The four properties placed within this cluster were,

1. Act.
2. Presence.
3. Provide comfort.
4. Have the time to care.

The Psychological Conceptual Cluster

The three conceptual properties placed into this cluster were those that were more cerebral or cognitive rather than physical. So the property was not tangible like a physical property but rather it affected or arose in the mind. Those three properties were,

1. Care like I want it to be.
2. Familiarity.

3. Understand the situation the person finds themselves in.

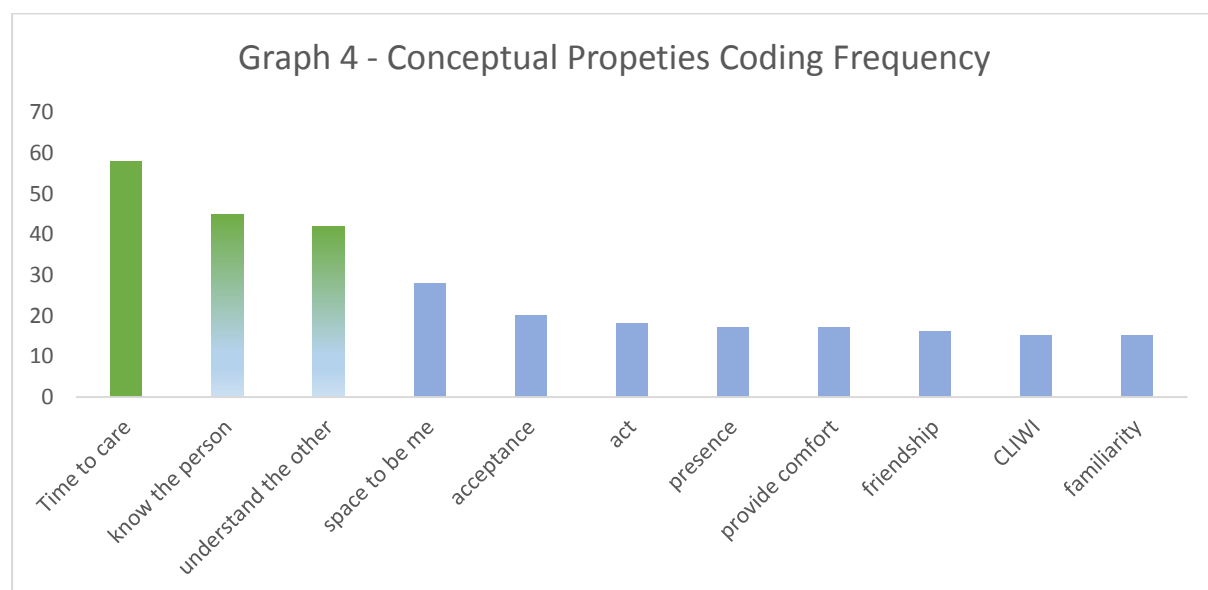
The Meta-Physical Conceptual Cluster

Properties within this cluster were those that dealt with concepts of being, knowing, and identity. There were four properties placed within this cluster,

1. Acceptance of the other.
2. Friendship.
3. Know the person behind the patient.
4. Create the space for me to be me.

9.3 The Ordering of Conceptual Properties

The data analysis interrogated each conceptual property in terms of how many nurses included it in their narratives and how frequently it was coded. What emerged from that exercise was an understanding of the relative importance of each property and its place within the overall emerging concept of compassionate dementia care. Ordering the properties (Nowell et al, 2017) in this way (Graph 4) allowed a very visual representation to emerge as to which property was dominant, which properties were supportive and which only played a passive role. In a sense it allowed the eleven final properties to be positioned so that a concept of compassionate dementia care could be brought into existence and stated as such.



The Single Spotlight Property

Having the Time to Care

This emerged as the conceptual property that achieved the greatest frequency of coding. As such it represents the central exemplar whose presence would define compassionate dementia care and which should be possessed by all nurses claiming to be compassionate. It was cited by nurses representing all of the initial encounter groups. As such it was seen as being important to those who had experienced an empty encounter as much as to those who had an inspirational one. This property accounted for 16.4% (n = 58) of all coded narrative extracts which were aimed at identifying the properties of compassionate dementia care. Eighteen (78.2%) of the nurses identified this as a property. The mean average was for each nurse to be coded 3.22 times for citing 'time to care' in their narratives.

The two Centre Stage Properties

Defined by this thesis as those properties that achieved a coding frequency of at least fifty percent of the spotlight property. The assignation of this cut off figure was subject to the reflexive supervisory discussions and review of the final coding frequency data. Based on that approach two conceptual properties were identified.

1 Knowing the Person behind the Patient

This property accounted for 12.7% (n = 45) of all coded narrative extracts which were aimed at identifying the properties of compassionate dementia care. Nineteen (82.6%) of the nurses identified this as a property. The mean average was for each nurse to be coded 2.36 times for citing 'knowing the person behind the patient' in their narratives.

2 Understanding the Situation of the Other

This property accounted for 11.8% (n = 42) of all coded narrative extracts which were aimed at identifying the properties of compassionate dementia care. Eighteen (78.2%) of the nurses identified this as a property. The mean average was for each nurse to

be coded 2.3 times for citing 'understanding the situation of the other' in their narratives.

The Off-Stage Properties

Defined by this thesis as those properties that achieved a coding frequency of at least a third of the centre stage properties. There were eight properties identified.

1 Creating the Space to Be Me

This property accounted for 7.9% (n = 28) of all coded narrative extracts which were aimed at identifying the properties of compassionate dementia care. Ten (21.7%) of the nurses identified this as a property.

2 Acceptance of the Other

This property accounted for 5.6% (n = 20) of all coded narrative extracts which were aimed at identifying the properties of compassionate dementia care. Five (43.4%) of the nurses identified this as a property.

3 Act

This property accounted for 5.09% (n = 18) of all coded narrative extracts which were aimed at identifying the properties of compassionate dementia care. Nine (39.1%) of the nurses identified this as a property.

4 Providing Comfort

This property accounted for 4.8% (n = 17) of all coded narrative extracts which were aimed at identifying the properties of compassionate dementia care. Eleven (47.8%) of the nurses identified this as a property.

5 Having a Presence

This property accounted for 4.8% (n = 17) of all coded narrative extracts which were aimed at identifying the properties of compassionate dementia care. Fourteen (60.8%) of the nurses identified this as a property.

6 Offering Friendship

This property accounted for 4.5% (n = 16) of all coded narrative extracts which were aimed at identifying the properties of compassionate dementia care. Seven (30.4%) of the nurses identified this as a property.

7 Care Like I want it For Me

This property accounted for 4.2% (n = 15) of all coded narrative extracts which were aimed at identifying the properties of compassionate dementia care. Twelve (52.1%) of the nurses identified this as a property.

8 Familiarity

This property accounted for 4.2% (n = 15) of all coded narrative extracts which were aimed at identifying the properties of compassionate dementia care. Nine (39.1%) of the nurses identified this as a property.

9.4 Summary of Chapter Nine

This chapter has presented the final two of the conceptual findings. A range of articulated and accessible positions were extracted from the data and represented findings for each relational theme and its sub-themes. Alongside this eleven conceptual properties were identified which taken together outlined those things that acute hospital nurses believed to be a part of compassionate dementia care. In particular three properties, heuristically termed the spotlight property and the two centre stage properties, were identified and represent those which the nurse claiming to deliver compassionate dementia care must possess as her own. A rich collection of findings and supporting data can now be taken forward to the next chapter where they will undergo a process of synthesis to draw out the meanings inherent in the collection as a whole.

Chapter Ten

Synthesis of the Research Findings

10.0 Introduction

This chapter draws the whole set of conceptual findings to a close through a clarification of the relationships between the relational themes, articulated positions and conceptual properties which emerged from the empirical process. In doing so the chapter acts to find a further layer of understanding within those findings. There is an inherent level of complexity contained within this chapter and it is prudent to begin by setting out to where it is the synthesis will take us to and how it will be presented before presenting the process.

The findings have led this thesis to a point at which a fundamental theoretical proposal can be introduced (see Section 9.1). That proposal will suggest that the impact of the initial encounter, with a person affected by dementia, is highly influential in shaping the nurses subsequent dementia care practice and, that her narrative related to this is potentially predictive. From that proposal the nurse participants will be identified as belonging to not only the collective of all twenty-three practitioners as a whole but, also to one of four sub-groups. Those sub-groups were related to the initial encounters experienced by the nurse participants and were;

1. The Empty group
2. The Brief group
3. The Close group
4. The Inspired group

A synthesis in respect of the collective and then each of these sub-groups will be undertaken within a framework which has been constructed around four factors:

1. The overall impact of the encounter.
2. The relationship between identified themes.
3. The relationship with the articulated positions.

4. The relationship with the identified properties of compassionate dementia care.

The fourth factor will be presented as a pictorial image showing at the centre the single property that the nurse participants identified as the dominant conceptual characteristic. Heuristically this has been termed the 'spotlight' property as most attention is focussed on it whilst the next tier of properties are labelled 'centre stage' suggesting that they too are important but not dominant, closest to but not sharing the spotlight. Emerging from the four factors as a whole, and acting as a representation of the collective or the sub-group, will be a number of 'framework statements' which allow comparisons to be made between groups.

Finally, this chapter will conclude with a revision of the dynamic heuristic model that was previously developed in absence of the findings (Figure 16,). The new model emerging from that revision is now an expression of the data itself. With the benefit of full possession of findings and, a thorough process of synthesis it presents as a more streamlined and elegant Six Space Model (Figure 39). It shows the different spaces from where individual nurses can claim they are delivering the same thing, compassionate dementia care. The emphasis on movement is muted and whilst there is still a journey towards incrementally higher levels of understanding that is now positioned as a background process leaving the foreground to focus solely on the conceptual. The nurse may come to rest at any of the six destinations and believe her practice to be compassionate. However, the further a nurse travels the more she is changed.

In leaving behind the spaces of restriction, where she sees herself purely within the constraints of her role, and ultimately arrives in the spaces of solidarity, where she is freed to be the kind of person she needs to be, the nurse has travelled a considerable emotional, spiritual and psychological distance. Whether the entire journey is necessary or indeed if one can travel too far; maybe to a point at which the focus shifts from the person with dementia to the nurse herself, will be discussed further in Chapter Twelve.

10.1 The Fundamental Proposal

The findings have demonstrated that the narratives of the nurse participants lead one to the view that initial encounters are highly influential. From that has emerged a fundamental theoretical proposal that is explored in this chapter. The proposal states that, the early symbolic representations formed by the nurse after having encountered a person or persons with dementia define the quality of the initial encounter. That in turn influences what happens next for her in respect of career choices, resilience and practitioner behaviour. Additionally those encounters play a significant part in how the nurse conceptualises compassionate dementia care and this further shapes her practice as she continues to encounter people who have dementia.

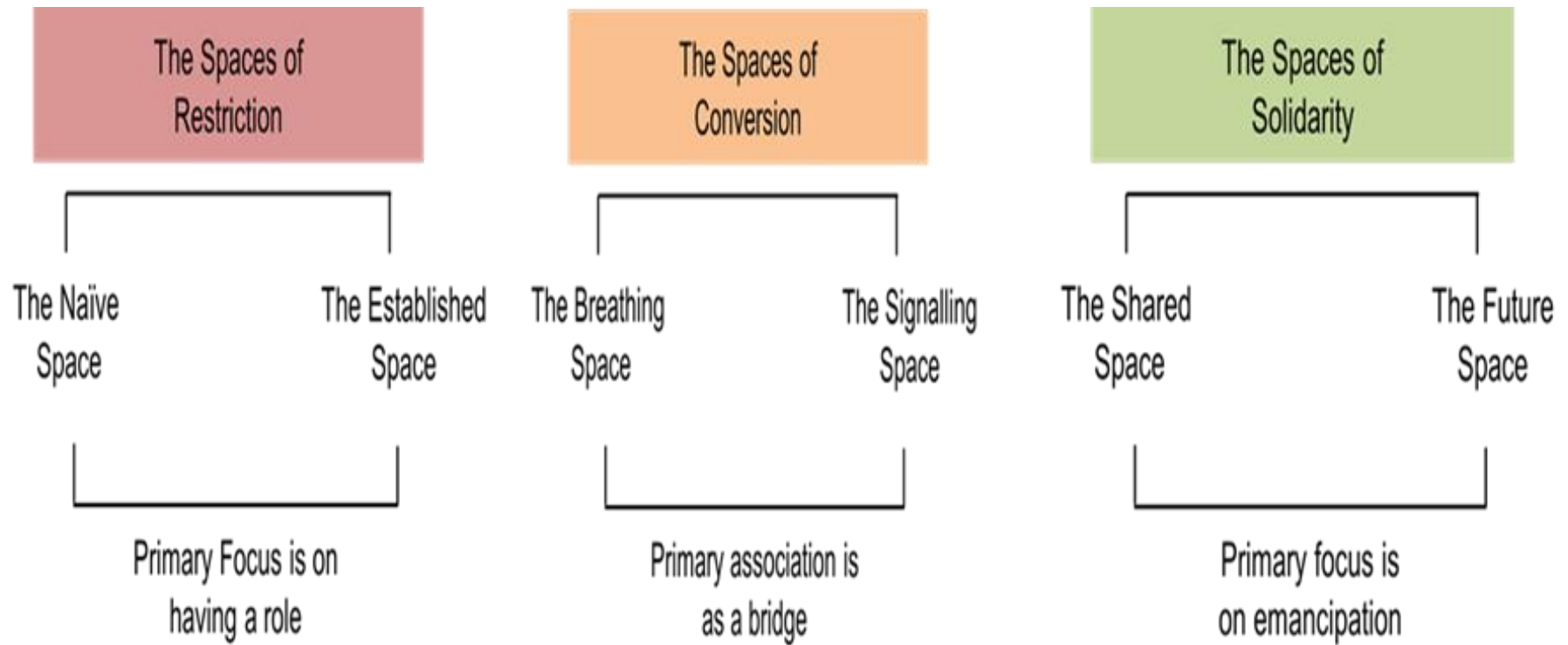
10.2 Compassionate Dementia Care - The Collective Conceptualisation

Twenty-three nurse participants were involved in this study. They came from across three district general hospitals and predominantly worked in care of the elderly or trauma and orthopaedic wards. They encompassed newly qualified nurses with less than a years' experience to those who had more than twenty five years and were coming towards the end of their nursing careers. Seven were dementia support workers which represents a new role in secondary care. As a collective the nurses had, of course, experienced the full range of initial encounters with 'brief being the least experienced, by three participants (13%) up to 'inspired' as the most experienced, by seventeen (74%). They populated every sub-theme the least being 'hear a reply' under the theme of 'reaching out' expressed by four (17.4%) of the nurse participants and, the most being 'curate the self' under the theme of 'someone to watch over me' at ten (43.5%). Together they articulated thirty-four positions. Of these the minority (thirteen, 38%) were negative in respect of people affected by dementia or dementia care generally whilst twenty-one (62%) tended to be more positive. In respect of the properties of compassionate dementia care their collective portfolio placed as the single spotlight property 'having or making the time to care' (Figure 38)

Figure 38 **Dominant Conceptual Properties (Collective)**



Figure 39 – The Six Space Model



Two centre stage properties followed that. The first, 'to know the person behind the patient', was related to identity whilst the second, 'understanding the situation of the person', related to having sensitivity to the individuals plight. Taken together they offer a set of three properties which must occur before the person affected by dementia can be included in his holistic nursing care. The challenges that dementia brings do mean that, for most people affected, it will take longer to understand what is happening and what is expected. Effective communication and rapport will be rooted in knowing the individual as a person with a full and varied life story. Finally, understanding the situation or plight of that person goes straight to the heart of compassion in that the nurse becomes aware of the other, she recognises his suffering as being more than physical (so, being in hospital, being in distress, at risk of losing his sense of self) and she is moved to respond to alleviate that.

Overall the collective have put first and foremost those things which will facilitate the person affected by dementia to be placed on an equal footing with others (who don't necessarily need this additional sensitivity) and, to meta-physically survive receiving care and treatment in a general hospital environment. However, within the collective group of nurse participants there are twenty three unique individuals with different life experiences, beliefs, views, attitudes and awareness of the needs of people affected by dementia. It is possible to explore differences within the collective by viewing them through the lens of the initial encounters they had with people or a person affected by dementia and seeing where that has shaped what has happened next.

10.3 The Implications of the Initial Encounters

Each initial encounter is now addressed. In support of this a synthesis matrix was utilised to test the relationships between the initial encounter and; the other emergent themes; the role, position, status, experience of the nurse participants, their articulated positions and, the patterns of property identification. Where more than one initial encounter occurred comparisons are made within that group to determine the extent to which mitigation occurs or where the greater influence lies.

The Impact of an Empty Encounter

There were seven nurse participants who had experienced an empty encounter. The group as a whole were all female (not unexpected in the context of the total sample) and all worked in clinical areas that regularly provided care to people with dementia, predominantly this was care of the elderly or trauma and orthopaedics. They were mature nurses aged between 31 and 55 years. Collectively they had more than 110 years nursing experience and a minimum of 83 years' experience of working with people affected by dementia. The group comprised of one matron, four nursing sisters, one staff nurse and one health care support worker. None of the nurse participants who had experienced an empty encounter had deliberately sought to provide care to people affected by dementia. Whilst the majority had decided to become nurses at an early age their surface motivations were quite simplistic ranging from 'I wanted to marry a doctor' to 'I wanted to look after people'. At least one was from an early point disillusioned and disappointed with nursing but had carried on practicing for more than thirty years.

Relationships between Themes

The relationship between the initial encounters experienced by this group of nurse participants and the other themes that emerged is set out (Figure 40). There were seven nurse participants who had not been presented with the opportunity to have encountered people with dementia in a positive way. Chapter One has discussed this, for example, in the context of professional socialisation (Chan and Chan, 2009). Student nurses find their encounters with patients with dementia challenging (Baillie et al. 2012) and they often occur within impoverished care environments where there is negative role modelling and inadequate support from mentors who lack the appropriate skills, knowledge or attitude (Brown et al, 2008). Whatever the cause there were almost a third of nurse participants involved in this study who had experienced an 'empty' initial encounter. This meant that they had, at some early point in the lives, encountered a person with dementia in a way which had no meaning or value. It was as if that encounter had never happened.

However, of those seven nurse participants five had also experienced other types of initial encounters. One nurse had, in addition to the empty encounter, also experienced

a close encounter which involved personal experience of a family member or other close person being affected by dementia. Two had had brief encounters which although similar to the empty experience did leave some slight trace of understanding with the nurse. One of those nurse participants had also had a close encounter. Two nurse participants had experienced inspirational encounters which were generally emotive and symbolically meaningful in their impact. As a whole the nurse participants in this group tended to approach the theme of 'the emerging identity' through the sub-themes of 'categorise' and 'read'. That is they displayed no evident regard for the possibility that behind the 'dementia patient' was a person of uniqueness and individuality. There was no clear mitigation for this from the presence of a close or inspirational encounter.

In terms of the theme 'reaching out', none of these nurse participants occupied the sub-themes in any substantial way. Only one of the group was identified as acting to 'build a bridge' whilst none aimed to 'connect to the other'. There was some very minor mitigation from those group members who had also had an inspirational encounter but this was not sufficiently adequate for those three nurse participants to connect and subsequently curate the others sense of self. Under the theme of 'someone to watch over me', the two group members who had only experienced an empty encounter were the only participants identified as acting to curate the self. However, neither engaged in any process of reaching out before attempting to do so and both speech acts, that reflected the concept of curating the self, did go against the overall flow of the discourse within which both nurses participated. Perhaps more accurately the more dominant outcome, expressed by three of the group, was the action of 'protect the patient' which was expressed predominantly as a defensive practice on the part of the nurse.

Relationship with articulated positions

As set out in the previous chapter under finding number two this group of nurse participants articulated three positions:

1. People with dementia are troublesome
2. People with dementia are less than us
3. People with dementia exist in some abstract way

These were not positive positions and they reflected underlying beliefs about those people with dementia in their care. The holding of those positions was not mitigated for by the experience of any other initial encounter that the nurse may have had.

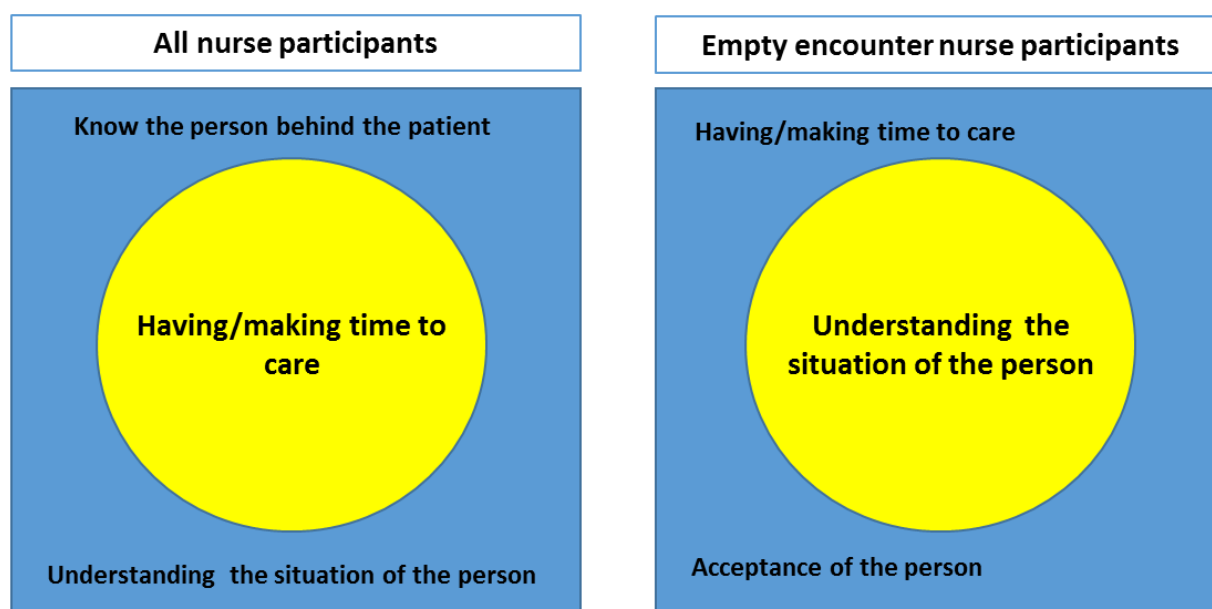
Figure 40 – Relationship between the Empty Encounter and Other Themes

ID	Role	The Initial Encounter				The Emerging Identity			Reaching Out				Someone to watch over me	
		Empty	Brief	Close	Inspirational	Categorise	Read	Empathise	Signal	Hear a reply	Build a bridge	Connect	Curate the self	Protect the patient
DGH01/N3	Matron	✓	✓	✓		✓	✓							
DGH03/N2	DSW	✓	✓			✓	✓	✓						
DGH02/N3	Sister	✓					✓						✓	✓
DGH01/N11	Sister	✓			✓				✓					✓
DGH01/N10	RN	✓			✓			✓			✓			✓
DGH01/N8	HCSW	✓		✓										
DGH02/N4	Sister	✓						✓	✓				✓	

Relationships with Identified Properties of Compassionate Dementia Care

The properties of compassionate care have been ranked previously in Chapter Eight to identify the spotlight property and those that sit centre stage and off stage. Taken as a whole the nurse participants who experienced an empty encounter would offer a different ordering of these properties compared to the collective. The spotlight property was not, 'having or making the time to care' but rather 'having an understanding of the situation of the person'. Sitting centre stage were the relegated property of 'having or making the time to care' and 'acceptance of the other' which was promoted from being an off stage property. The shift is represented below (Figure 41),

Figure 41 – Dominant Conceptual Properties (Empty Encounter)



Within the key properties portfolio of the empty encounter one is minded to consider that given the nurse participants rejection of, reaching out, of bridge building, of seeking to connect, and the articulation of positions that fundamentally devalue the person with dementia, there must be an illocutionary act involved. The surface meaning taken in the absence of this context is that the compassionate nurse must understand the potentially traumatic impact of hospital admission on the part of her patient. Legitimately one would then move to have acceptance of him as a person and adjust the time available so as to deliver the higher quality of care that his dementia

demands. However, in now having awareness of the malignant context one could position that spotlight property as having resonance with the Aristotelian construals. Before choosing to act compassionately one must make a set of judgements about the nature of the person, his relationship to his suffering and a measurement of degree or intensity of that suffering. Arguably these judgements are not only represented here but are given primacy under the spotlight. Alternatively and much more borne out by the findings associated with the empty encounter is the interpretation of 'situation of the person' as having nothing to do with dementia. Rather it relates to the physical health history and status associated with that person.

This thesis has acknowledged that compassionate nurses do not need to possess the full range of properties in order to practice compassionately. However, it has also been stated that a not unreasonable expectation would be for the compassionate nurse to possess the spotlight property and act in accordance with it. In accepting that here and, accepting the spotlight property as an illocutionary act, leads to a simple conclusion namely that; the nurse who experiences an empty initial encounter is more likely to place conditions on or around the compassionate care of her patient.

Framework Statements

All the elements of a framework are now in place and a set of statements can be made to suggest that the nurse who experiences an empty initial encounter is:

1. Highly unlikely to have made a conscious decision to nurse people affected by dementia.
2. Highly likely to approach the identity of a person with dementia through processes of 'categorisation' and 'reading', both reflect that the nurse has no obvious regard for the presence of a person existing behind the role of her patient.
3. Highly unlikely to purposefully 'reach out' and seek to connect to that other identity. This is a direct consequence of statement 1.
4. Highly unlikely that she will act to 'curate' the fragments of self that will have been shattered by the dementia which affects her patient. Again this is a further direct consequence of statement 1.

5. Highly likely to articulate positions suggestive of negative beliefs, attitudes and opinions about dementia and people affected by it.
6. Highly likely to underpin nursing practice with a need to make judgements about a patient and his relationship with his suffering.

Importantly, the presence of any higher order initial encounter (close or inspirational) is not sufficient to mitigate for the presence of an empty encounter. The personal reflection at the start of this thesis introduced the concept of redemption and one is minded to ask, if the empty encounter is so influential that even a higher order encounter cannot offer mitigation then where does redemption lie for these seven nurse participants?

Representative Narrative

The narrative (Box 1) was offered by a ward sister working in care of the elderly and with considerable experience. It was essentially empty and revolved around a scenario in which a lady with dementia stayed in her night clothes until later in the day when having had her hair 'done' she became happier. It was set in the context of the nurse being in control and permitting the 'difficult' behaviour of the patient. Despite the claim that 'we know this patient' there was little evidence of that and her pleasure from the attentions of the hairdresser were turned back on her as a criticism or judgement of her character.

Box 1 – Representative Narrative: The Empty Encounter

'My story is based on a patient we currently have on the ward. She has a diagnosis of dementia, Alzheimer's, she can be a little bit difficult at times. She loves animals, her sleep pattern is a bit to pot really but as a ward we know this patient and we allow her to do what she wants when she wants within reason to make sure she is safe.

There was one particular day she didn't want to get washed or dressed, she was still in her night clothes, and she was due to have her hair done in the afternoon for which she needed a little bit of persuasion. Eventually she went to have her hair done and that made her feel a little better so she got dressed ready to go out with her daughter. And once she was fully dressed and having all these compliments her mood came up and she was really pleased with herself, she was one of those 'look at me, my hairs done' she was proper clean and tidy.

To think that in the morning she didn't want to do nothing to in the afternoon the complete flip side of the coin she was really engaging. She was quite tired and sleepy that morning, she actually got up for breakfast then went back to bed which is something we would do anyway, 24 hour care, we allow our patients to be up at night. That's it really.'

The Impact of a Brief Encounter

Of the three nurse participants who had experienced a brief encounter there was one who had not also experienced an empty encounter. This nurse participant was a matron, with only one years' experience of dementia care in a career of more than twenty-five years. The relationship between themes for her is shown below (Figure 42).

Figure 42 - Relationships between themes

ID	Role	The Initial Encounter				The Emerging Identity			Reaching Out				Someone to watch over me	
		Empty	Brief	Close	Inspirational	Categorise	Read	Empathise	Signal	Hear a reply	Build a bridge	Connect	Curate the self	Protect the patient
DGH01/N1	Matron		✓	✓	✓	✓	✓	✓						

The outcome is the same as if this nurse participant had experienced an empty encounter. The inclusion of 'empathise' within the emerging identity indicates that some trace of understanding has occurred but nothing sufficient to see this nurse participant seek to reach out or connect. Again this is very similar to the outcome for nurse participants who experienced inspirational encounters along with an empty encounter.

Relationship with Articulated Positions

From all three nurse participants who experienced a brief encounter (plus any other) the two articulated positions, 'I nurse in ignorance' and 'I'm a reluctant learner' suggest some awareness of their lack of knowledge and skills to provide dementia care alongside a disregard for this. Within that is evidenced the modest difference which exists between an empty and a close encounter. 'Empty' positions act to locate any problem associated with care delivery as being located with the patient whereas 'brief' positions start to place emphasis on the nurse's inadequate knowledge or skills. The one nurse participant who had a brief but not an empty encounter reflected this through her articulated positions. Firstly, she didn't know what to do in terms of holistic care:

'You have the occasional patient with dementia, you would treat them with compassion but wouldn't know the level of service they required, you just do what you need to do for them.' (DGH01/participant01)

People can often hold more than one position at a time and often they can be contradictory. This occurs here as secondly, she claims to have developed the missing knowledge and skills:

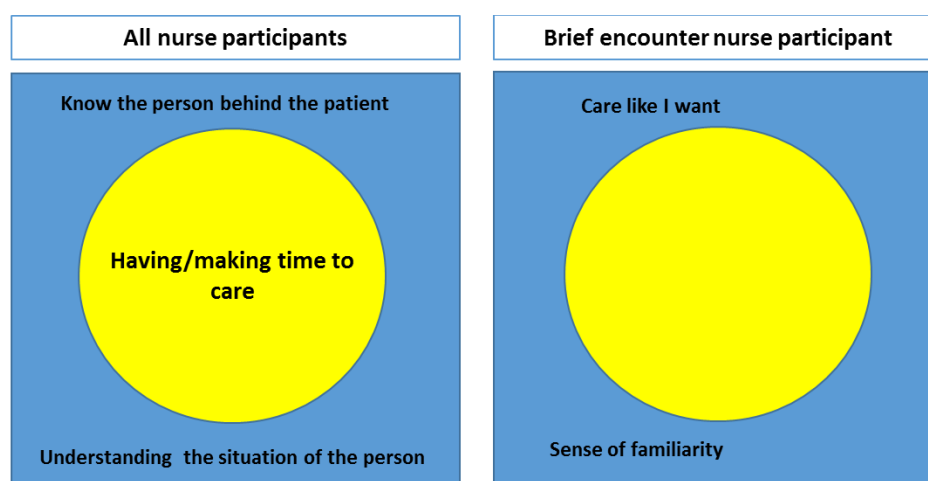
'I feel that my knowledge and skills in dementia have changed dramatically because I was forced to not because I chose to.' (DGH01/participant01)

The illocutionary act would stress the emphasis being placed upon *'I was forced to not because I chose to'* which perhaps makes the point itself without the need for further elaboration.

Relationships with Identified Properties of Compassionate Dementia Care

For this one nurse participant there was a poverty of coded narrative segments that made reference to the properties of compassionate dementia care. This became even starker when her dominant property 'heal the mind' was canned during the data analysis as not being sufficiently supported. Of the seven coded narrative sections for this canned property this nurse participant owned five (71%). Her two remaining sections, 'care like I want it' and 'a sense of familiarity' were each coded twice. Of note is the finding that there is no single spotlight property (Figure 43). When the illocutionary force is applied one can readily glimpse that here is a nurse out of her depth. She doesn't understand the person with dementia and it could be argued she owns no concept of compassionate dementia care. Almost helplessly she falls back on perhaps what she does know which is herself and her fear of change. She views the experience of dementia care through the lens of herself and again it can be said that the stance is one of standing in her own shoes rather than those of the other.

Figure 43 – Dominant Conceptual Properties (Brief Encounter)



Framework Statements

Taking into account that extrapolating anything from a sample of one is unwise it is possible to suggest that the framework statements which can now be stated are almost the same as those for the empty encounter. So, a nurse who experiences a brief initial encounter is,

1. Highly unlikely to have made a conscious decision to nurse people affected by dementia.
2. Highly likely to approach the identity of a person with dementia through processes of 'categorisation' and 'reading', both reflect that the nurse has no obvious regard for the presence of a person existing behind the role of her patient.
3. Highly unlikely to purposefully 'reach out' and seek to connect to that other identity. This is a direct consequence of statement 1.
4. Highly unlikely that she will act to 'curate' the fragments of self that will have been shattered by the dementia which affects her patient. Again this is a further direct consequence of statement 1.
5. Highly likely to articulate contradictory positions which suggest that she feels helpless about dementia and the care of people affected by it but does not wish to develop knowledge and skills.
6. Highly likely to underpin nursing practice with a need to not think outside of what she knows which means basing care on her own standard and rejecting change..

Representative Narrative

This nurse participant did not offer a narrative as part of the Appreciative Inquiry workshop 'Discover' phase but worked to support another to put hers together. As such there is no representative narrative.

The Impact of a Close Encounter

There were seven nurse participants who had experienced a close encounter. One had experienced this in isolation and her narrative suggests it wasn't an emotionally close relationship although it involved both an aunt and uncle. The remaining six had also had an inspirational encounter, exclusively with a grand-parent which given that as a group they were all aged in their early 30's is not unsurprising.

The group of seven were all female, four were dementia support workers and three were registered nurses, two staff nurses, one a ward sister, who had been qualified for between fifteen and twenty five years. All worked in care of the elderly or acute medicine and all were working with people affected by dementia. Three of the dementia support workers had less than five years' experience of dementia care, whilst the registered nurses had up to more than twenty five years.

Relationships between Themes

There is essentially no activity by this group of nurse participants in respect of 'categorise' or 'read' within the theme of the emerging identity (Figure 45). However, almost all members of this group are coded for 'empathy' within their narratives. In respect of 'reaching out' there is significant activity suggesting that this is largely a group who want to signal their willingness to connect with the other. The purpose of that connection is aimed very much at the desire to 'curate the self' and to capture the fragments of the shattered self and try to hold them and the person together.

Relationship with Articulated Positions

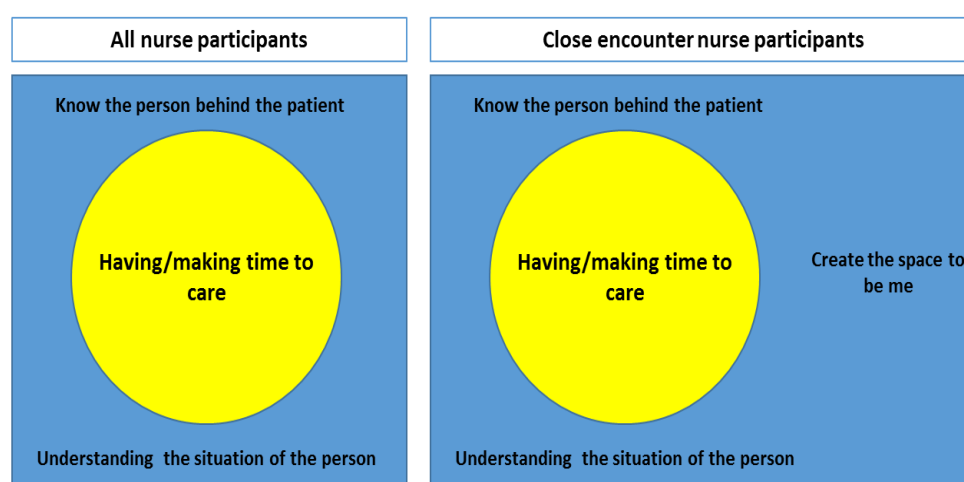
There were three positions articulated by those nurse participants who experienced a close encounter all of which are linked to the 'empathy' coding that dominated the theme of the initial encounter. Firstly, there was reflection captured under the position of 'I see it now'. This suggests that having had a close encounter as a young person the full emotional impact of that may not have been appreciated until that person enters nursing and comes across other families in similar situations. Secondly, there was action with the position of 'I use my experience' where that experience was of being a

carer for a family member with dementia and purposefully using that to both support and reassure carers and families of patients under their care. Thirdly, there was emotion captured within the position of ‘I find it so sad’ which commonly linked the nurse participants personal experience with her professional observations of the impact that dementia has on the person affected who is seen as slipping away. It is that perception which appears to motivate the nurse to intervene and to act to hold the fragments together and to support that person to be themselves as much as they can. Within this is to be found the very deep root of suffering (in the experience of dementia) as being the loss of the sense of self. Compassion is evidenced through the nurse recognising this and acting to minimise the impact.

Relationships with identified properties of compassionate dementia care

The portfolio of properties suggestive of compassionate dementia care are for this close encounter group almost the same as for the portfolio identified by the whole group. There is however one important difference (Figure 44) which is the inclusion of a third centre stage property which is closely tied to the sub—theme of ‘curate the self’ and is found at the heart of the representative narrative.

Figure 44 – Dominant Conceptual Properties (Close Encounters)



Framework statements

At this level the statements reflect a different stance to that seen before. The nurse who has experienced a close encounter (along with in most cases an inspirational encounter) is.

1. Highly likely to have made a conscious decision to nurse people affected by dementia.
2. Highly unlikely to approach the identity of a person with dementia through processes of 'categorisation' and 'reading', but rather to show 'empathy' and to have high regard for the presence of a person existing behind the role of her patient.
3. Highly likely to purposefully 'reach out' and seek to connect to that other identity.
4. Highly likely that she will act to "curate" the fragments of self that will have been shattered by the dementia which affects her patient.
5. Highly likely to articulate positions which reflective of her experience, influenced by emotion and which give her a defined priority for the nursing care of people with dementia.
6. Highly likely to underpin nursing practice with a focus on who the person is and how to maintain the others sense of self.

Figure 45 - Relationship between the Close Encounter and Other Themes

ID	Role	The Initial Encounter				The Emerging Identity			Reaching Out				Someone to watch over me	
		Empty	Brief	Close	Inspirational	Categorise	Read	Empathise	Signal	Hear a reply	Build a bridge	Connect	Curate the self	Protect the patient
DGH02/N6	RN			✓				✓	✓			✓	✓	✓
DGH01/N4	DSW			✓	✓			✓	✓		✓	✓	✓	
DGH03/N7	DSW			✓	✓				✓	✓		✓	✓	
DGH01/N2	DSW			✓	✓			✓			✓	✓	✓	
DGH01/N6	Sister			✓	✓			✓						
DGH01/N12	RN			✓	✓	✓								✓
DGH01/N9	DSW			✓	✓			✓	✓		✓	✓	✓	

Representative narrative

These statements are to be found embedded in the narratives of the nurse participants from this group. One participant, a dementia support worker based on a busy acute medical ward offered the following story (Box 2) as part of the Appreciative Inquiry 'discovery' phase of her workshop.

Box 2 Representative Narrative: The Close Encounter

'My story is about a lady with dementia who is still with us now on the ward, she's been with us now for a while and came in under various different specialities across the hospital. So after a while she needed to go to an ENT out-patient appointment and I took her down there as she's a Welsh speaker and I speak Welsh too.

The consultant in ENT had some quite awful news for her, they're not going to operate, and she has a tumour on her neck, they didn't say whether it was malignant or benign they didn't go into it with her but they did say that it was too complicated operation that would take about twelve hours to do and it was possibly within the blood vessels in her neck. She took it really well but she was bothered about how this tumour was making her look to other people. She's very proud, I mean she sleeps every night she puts her own rollers in her hair she dresses nicely, puts stockings on even though they are falling down with the weight loss, but she's always very proud of how she looks and she worries that she looks a mess and always asking 'do I look ok?'.

It was a nice day, the sun was out, so on the way back we went to sit in the garden and we were sat there for a good half an hour or so and shared a cup of tea. She sat there with her eyes closed in the sun and every now and again she asked me to turn her, 'turn me the other way now I need to warm the other side'. We got talking and she told me about her life, of all the lovely places she had been on holiday and she was sat with her eyes closed reminiscing, smiling.

I decided after work that day because of how worried she had been about how she looked that I was going to the shops to see if I could find a neck scarf. I gave it to her the next day she wore it for a while, she's worn it a few times since but she's forgotten it's there, I think she's forgotten that she was worried about that at all. It doesn't really bother her but I think on that day she was having a good day and retaining things better she was worried on the day but I think sitting with her out into the garden helped her to feel a bit better before going back on to the ward.'

The Impact of an Inspirational Encounter

There were six nurse participants who had experienced only an inspirational encounter. Three of these were registered nurses, two of whom were recently qualified staff nurses and one was a matron with more than fifteen years' experience. The others were dementia support workers with variable experience ranging from one year to almost fifteen. Five of these nurse participants had been inspired as teenagers, four had 'Saturday' jobs in care homes and one was a hospital cleaner. The sixth nurse participant had her first placement as a student nurse in a care of the elderly ward and was inspirationally moved by contact with people with dementia sufficient to seek a post there on qualifying. They had all encountered people with dementia who had had a profound impact on them and directly led them to work predominantly with people affected by dementia.

Relationships between Themes

Three of the nurse participants were coded for lower order sub-themes in the respect of the emerging identity which suggests that half of the members of this group displayed no evident regard for the possibility that behind the 'dementia patient' was a person of uniqueness and individuality (Figure 47). That is similar to the outcome for those nurse participants who experienced empty and brief encounters. The similarity does not flow across the theme of 'reaching out' which was essentially absent from the empty and brief encounters. There are however some inconsistencies within the theme in that; one participant signals but connects without holding out for a response or building a bridge, two listen for signals coming back without having sent any and two build bridges although one appears to go nowhere. Finally and surprisingly, given the participants descriptions of their inspirational antecedents, only two of the six nurse participants act to curate the fragments of self, whilst three act to protect the patient.

Relationship with Articulated Positions

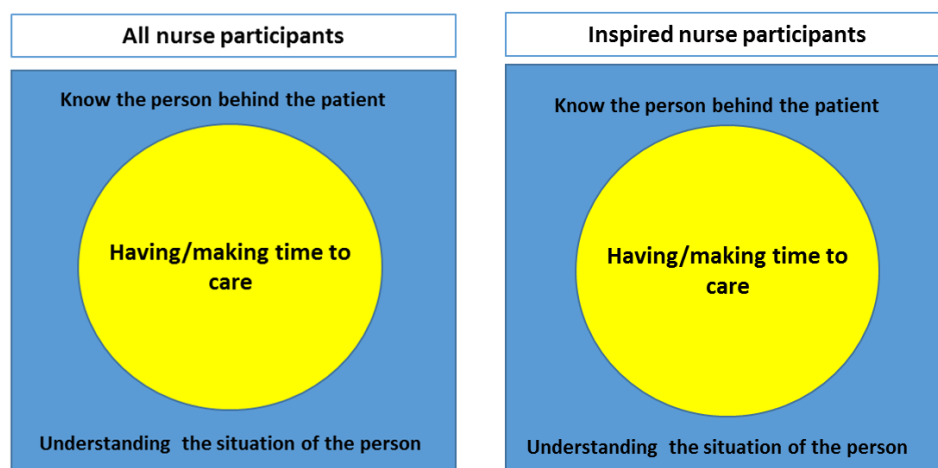
Two positions were commonly articulated by nurse participants who experienced inspirational encounters. Both were related to the impact of that encounter. Firstly, these participants had as outsiders to the situation witnessed care being delivered to

people affected by dementia. One had been a domestic on a hospital ward whilst others were washing dishes or helping out in other ways in care homes. They identified deficiencies in care delivery and adopted the position of ‘I know I can do better’. There are those for whom witnessing poor care in one speciality might encourage them to consider working elsewhere. But this group were able to see beyond that and in considering that care could be better they also articulated the position that ‘I want to do this’. One left her cleaning job the same day as gaining this insight and began working for a nursing agency. Another, as a student on her first placement decided this was where she would practice, she undertook bank shifts on that same ward and on qualifying took up a staff nurse post there.

Relationships with Identified Properties of Compassionate Dementia Care

The nurse participants experiencing an inspirational encounter held the same property portfolio as that for all nurse participants (Figure 46).

Figure 46 – Dominant Conceptual Properties (Inspirational Encounter)



A fourth property came close to making the criteria for a centre stage property but fell just short. That property ‘Friendship’ may help to understand the distinction between nurses who experience an inspirational encounter from those who experience both a close and an inspirational one.

Figure 47 - Relationship between the Inspirational Encounter and Other Themes

ID	Role	Inspirational	Categorise	Read	Empathise	Send signals	Hear a reply	Build a bridge	Connect to the other	Curate the self	Protect the patient
DGH02/participant08	DSW	√			√	√			√	√	√
DGH03/participant06	RN	√		√					√		√
DGH03/participant01	DSW	√	√				√	√	√		√
DGH03/participant03	Matron	√						√		√	
DGH03/participant02	DSW	√					√		√		
DGH03/participant04	RN	√	√								

The context of how the inspirational only group encountered people with dementia may have acted as an important learning event that has shaped their practice. At the time of the encounter the nurse participants were mostly young people who were not involved in delivering care but who had peripheral roles which allowed them to essentially become friends with the older people who inspired them. They also had no history with these inspirational actors before the chance meeting and no previous experience, personal or otherwise, of dementia. What seems to have occurred is an event of such emotional or psychological magnitude that their occupation of the spaces of restriction was blown apart and they were compelled to begin a spiritual like journey.

Framework Statements

1. Highly likely to have made a conscious decision to nurse people affected by dementia.
2. Unlikely to approach the identity of a person with dementia through processes of 'categorisation' and 'reading'.
3. Highly likely to purposefully 'reach out' and seek to connect to that other identity.
4. More likely that she will act to 'protect the patient' rather than "curate" the fragments of self that will have been shattered by the dementia which affects her patient.
5. Highly likely to articulate positions which suggest that she feels a sense of vocation about her practice.
6. Likely to underpin nursing practice with willingness to get close to people and form friendships.

Representative Narrative

The representative story (Box 3) was offered by a dementia support worker. Her narration was brief and affected by shyness and feeling uncomfortable speaking in English rather than Welsh. She was emotionally or empathically drawn to the lady and used touch to reach out and connect. She purposefully acted to get close to the person

who for two weeks had essentially placed herself out of contact. A connection was made and in that moment there was a release of emotion.

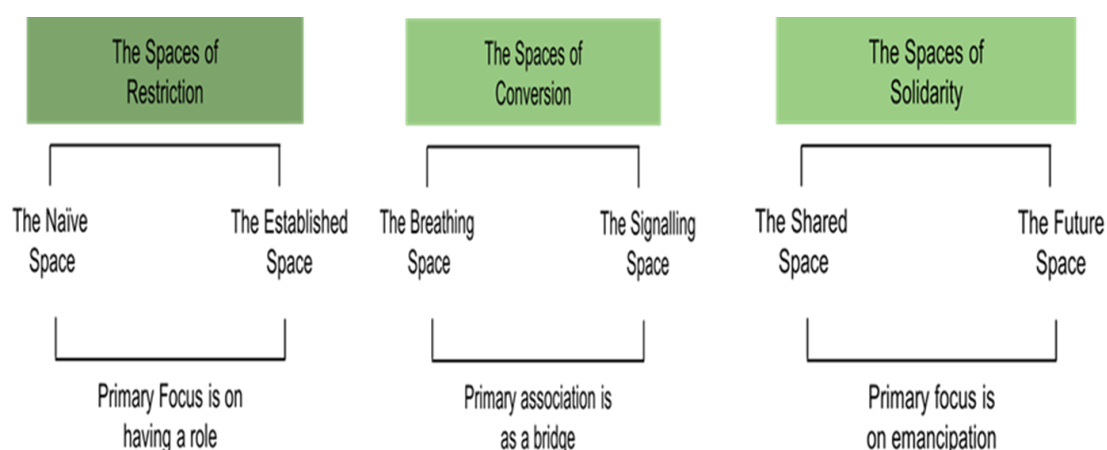
Box 3 Representative Narrative: The Inspirational Encounter

‘This lady was just in a chair. She hadn’t spoken even with her family since being in hospital, there was no expression, wasn’t saying anything, sleeping all the time, I can’t say that she was actually scared but she had closed her eyes, wasn’t talking or anything. And then we had an Elvis afternoon here that the patients had come to. I said hello and that Elvis¹ was here and things like that, held her hand a stroked it. There was nothing for a bit and then about halfway through she stroked my hand opened her eyes and smiled and then cried happy tears’.¹

10.4 Constructing the Final Model

The initial heuristic model (Figure 16, page 166) could now be revisited and reconstructed as something of greater validity than an intuitive, albeit reflexively driven guess. With the benefit of the empirical data having been analysed and synthesised it was possible to present the final ‘Six Space Model’ (Figure 39) as a new way of understanding the positioning of nurses in their practice.

Figure 39 the Six Space Model



In revisiting this, it is prudent to first summarise the key aspects of the heuristic model and then to consider how those aspects have been impacted upon by the findings. The initial model placed importance on its dynamic nature and heuristically this seemed right as authentic compassion is rooted in movement and action, the compassionate person must be moved to respond and the response must involve action. To facilitate that the metaphor of a journey was applied and, to enable progress the concept of points of conversion were adopted from the spiritual journey.

An opportunity to have a place of reflection (the breathing space) was an important consideration. What was offered through this was a space within which the nurse could safely move towards adopting a new stance with the option of retreating if she felt overwhelmed by the potential engrossment involved. It was also envisaged as a space for the nurse to listen to the voice of the person with dementia and respond to that by signalling an offer to connect and, support the individual's personhood and positive sense of self. As the journey progressed this desire to connect to the other would become an important deciding factor on how far the nurse would travel. The metaphors of the bridge and the wall (Halldorsdottir, 1996) were influential and offered points along the way where decisions could be made about both the direction and duration of travel. So, nurses who built bridges were positioned as more likely to travel further than a nurse who created a dead end.

It was proposed that travel was only undertaken to the point at which the nurse felt her journey was complete and had arrived at a destination from which she believed she was delivering the best care she could. However, what was implied was that 'compassionate dementia care' itself represented a single if not final destination that only some nurses would be capable of reaching. Those who did so were to be regarded as having broken free of the role related restrictions bound by 'what I do' and instead had achieved the more virtuous but challenging position related to 'who am I' or 'what kind of person ought I to be'. Those who had not arrived were regarded as practicing at a lower level of compassionate dementia care. Arriving at that final and desired destination was positioned as emancipatory for the nurse. She could legitimately think, feel and behave differently, in respect of dementia and those affected by it, in comparison to those other nurses she had left behind. Part of that emancipation was the freedom to take the risks presented by engrossment and to enshrine that within the concept of service and the giving of oneself to the other.

Now, with full possession of the literature and the data and, whilst much of that is shown to have been right, the heuristic may have represented too much an elitist model and devalued some important contributions to care made by nurses who had come to rest at earlier destinations. In addressing this it was evident that some aspects were in need of revision which inherently led to remodelling and a new fully informed Six Space Model (Figure 39) was constructed. The dynamic nature of the informed model occupies less of the foreground than was seen in the heuristic. The narratives have demonstrated that there is movement and action involved and, that conversions occur, but these are processes that occur in the background and are peculiar to each participant. The drivers behind action are articulated through the initial encounters, and this is evident in the framework statements. The emphasis has shifted exclusively to the spaces themselves which represented the varied destinations arrived at by nurses and from which they can claim to practice compassionate care to people with dementia.

Each space is a valid place from which to support a person with dementia. The naïve space continues to largely represent the uninformed position. The term 'naïve' may still be open to future revision and one is minded to reflect on initiatives such as 'dementia friends' facilitated by the Alzheimer's society which has shown six million people (mostly sitting in the naïve space) across the UK how to effectively support a person with dementia to live well. Empirically I have demonstrated that some nurse participants remain in and practice from this emptiest of places whilst most acquire some understanding from training and experience to root them in the established space. In the context of this study those nurses were those who had predominantly experienced empty or brief initial encounters.

The 'established' space represents the current view on compassionate nursing care although the quality of that care will be variable. Caught up in the world of her own experience and without the benefit of looking beyond that each nurse participant residing here has argued that they strive to provide 'good' care to 'dementia patients'. Frequently they claim to be thwarted in doing more than they do; there is no time, there are too few staff, there are too many demands, there is no training, they are not supported by managers, are all frequently cited in the narratives, if only these things were there then the claim is that everything would improve. Their narratives at one level identify that all is not well with the care of people with dementia whilst at the same

time the nurse participants absolve themselves of any blame for maintaining a status quo and accepting the established position that this is just the way things are.

These nurse participants place emphasis on that which they have understanding of and that which is logical in terms of procedure and policy, namely the physical health condition. Dementia is less understandable, less logical and less easily managed, and these nurses distance themselves from that by allowing themselves to be seduced by the reductionist view of dementia. In doing so they shift responsibility for inadequate care as much onto the person with dementia as they do to others in the organisation. Good care is therefore physical and contains nothing over and above anything that any other person would expect. These nurses have become thoughtless in the very way meant by Arendt (1992) and as such they become uncomfortable when asked to confront their thoughts as evidenced through the 'discover' phase of the 4-D model. Without belittling the experience one is minded to consider their experience as analogous with the opening lines of Winnie-the-Pooh:

'Here is Edward Bear, coming downstairs now, bump, bump, bump, on the back of his head, behind Christopher Robin. It is, as far as he knows, the only way of coming downstairs, but sometimes he feels that there really is another way, if only he could stop bumping for a moment and think of it. And then he feels that perhaps there isn't.' (Milne, 1924, page 1)

The discomfort experienced by these nurse participants as they confront the fact that there may be another way shows how the generative properties of the Appreciative Inquiry approach can open up a normative discourse through which the status quo can be challenged (this is addressed further in Chapter Eleven).

All spaces beyond those that are 'restrictive' represent incrementally different views of dementia, those affected by it and how care should be shaped. The space of conversion is the most grounded of all. It represents a place where nurses who wish to connect can create the circumstances to do so. The act of building bridges and connecting to people are tangible and the actions of the nurse can be seen, heard or felt by the person they are aimed at. Equally real are any responses, or otherwise, to the nurses attempts at connection. These too are heard, seen or felt and they act as forces of conversion which reinforce and sustain the nurse as she realises that connections are possible and mutually beneficial. This is therefore a very practical space predominantly occupied by those nurse participants who had a close encounter

with principally a parent or grand-parent who had dementia. The day to day caring for a loved one with dementia is an unavoidably practical experience with the greater effort being devoted to the act of trying to stay connected to that person. For these nurses the personal influences their professional practice and they naturally act to make a connection as it is only through this relationship that nursing care can be delivered more effectively.

The space of solidarity is different in that it may be as much the representative of an ideal as it may be the highest form of dementia care nursing. It is a place to which the nurse is led by an inspirational encounter which is almost evangelical. The main characteristic is that it represents spaces which are rooted in the emancipation of the nurse from the constraints of her role. Rather than maintaining a relationship based around rights and responsibilities it emphasises much more the equality between the person delivering care and the person receiving it as fellow human beings. It also finds roots in virtue ethics and the nurse is almost compelled to question her own identity which may unwittingly place attention upon her rather than the person with dementia, in short, understanding who she is rather than who he is, which makes this space somewhat contradictory. Whilst the philosophy underpinning the space is without doubt laudable the act of solidarity itself may be beyond the capabilities of the person or, just a mirage on the part of the nurse who wants to believe it can be so.

The three spaces are highly distinguishable from each other. In the first, dementia is not really understood, the person affected is expected to conform to the system of an acute hospital and the way it is ordered, connections are superficial and the focus is exclusively on the physical health problem. As the framework statements show the nurse practicing in these spaces of restriction has never enjoyed more than an empty encounter. In the second space the nurse may well be influenced by a close encounter and have experiences of the challenges associated with caring for a close relative with dementia. Through that she may have learnt to be pragmatic and very practical whilst constantly striving to remain connected to the person beneath the dementia. She brings that experience to her practice and seeks to build bridges and make connections knowing that this will make the delivery and receipt of care more satisfying for both. This new space of conversion moves the concept of conversion away from that set out by the spiritual journey towards it being the act of converting what the nurse has learnt at home and using it to inform and influence her practice. Unlike in

the heuristic model the nurse is not faced with making a choice as to where to go next because here in the final model she has arrived at her destination. All that she wishes to do can be done in this space even though she is potentially surrounded by an organisational and social culture that will constantly challenge her to do so. The danger to the nurse is not so much engrossment but rather exhaustion.

In the third space the actions of the nurse have moved beyond connecting and caring towards something that is almost political. The space of solidarity is not associated with humanitarian solidarity (taking care of the other who can no longer take care of himself) which is to be found across the model in the space of conversion. Solidarity in this third space is firmly rooted in the mutuality of 'being with' (Nairn, 2014, p80) the other and standing up for each other (Jaeggi, 2001). It is the language and the world of dementia activism towards which the nurse through her inspirational encounter is drawn.

Compassionate dementia care can be claimed to be delivered in all three of these spaces. However, the average patient with dementia in an acute hospital ward is over eighty years of age, has moderate to severe cognitive impairment, multiple co-morbidities and may well be in their last year of life. In the spaces of restriction the person is viewed from a frail and vulnerable perspective, their individual needs generally disregarded and there is no real holistic care whilst in the spaces of solidarity adopting the activist posture required is unlikely however much the nurse may wish it so. Pragmatically it can only be in the spaces of conversion that the person with dementia is truly invited into their care by a nurse who wishes that care to be holistic and individualised. As such compassionate dementia care as conceptualised by the collective of twenty-three nurse participants can only sit in this second space.

10.5 Summary of Chapter Ten

This chapter has reached some important conclusions, Firstly, that the collective conceptualisation of compassionate dementia care in the context of the acute hospital is a set of three properties which must occur before the person affected by dementia can be included in his holistic nursing care. The first is that the nurse must have or make the time to care, the second that the nurse must come to know the person behind the patient and, the third that the nurse must have sensitivity to the individual's plight

and, an understanding the situation he finds himself in. Alongside that there are alternative conceptualisations which explain the inconsistency in the quality of care provided whilst allowing nurse practitioners to claim they are delivering the same thing. The model of Compassionate Dementia Care has moved from its original heuristic design towards a more elegant model that is informed by the empirical data and, shows the spaces where the nurses and their alternative conceptualisations sit. That new Six Space Model raises a potentially controversial position that whilst a nurse can travel to spaces of higher understanding it is only in the pragmatic spaces of conversion that the acute care conceptualisation of dementia care can satisfactorily rest.

Chapter Eleven follows. In that chapter there is a return to the methodology and explore the contribution that Appreciative Inquiry has made and how the methodological findings act to support and validate the findings thus far.

Chapter Eleven

What Did Appreciative Inquiry Contribute?

11.0 Introduction

A premise of this study was that the chosen research methodology should be sufficiently generative to draw out from the discourse a nursing narrative from which the elements of compassionate dementia care could be identified. Generativity was accepted as set out by (Gergen, 1968) as a potent force capable of stimulating normative discourse through which the status quo could be challenged and potentially overturned. The products of that generative approach have been set out in Chapters Eight, Nine and Ten. This chapter acts to provide the assurance around Appreciative Inquiry (Cooperrider & Srivastva 1987) as being a legitimate generative methodology capable of transforming practitioners. In particular it demonstrates how participation in the 4D process (Cooperrider, 1996) influences practitioner views on dementia and those affected. Additionally this chapter shows how the provocative propositions which emerge from the 4D process are themselves illocutionary narratives made up of themes which act to reinforce the collective conceptualisation of compassionate dementia care set out in finding three.

This chapter therefore sets out the two methodological findings as,

Finding 4. Appreciative Inquiry, in the context of this research study, possesses generative capacity

Finding 5. Provocative propositioning related to the Appreciative Inquiry 4-D approach is an illocutionary mechanism. Analysis of the meaning behind the propositions reveals key conceptual properties of compassionate dementia care

11.1 Finding 4. Appreciative Inquiry, in the context of this research study, possesses generative capacity

The conceptual findings outlined earlier have indicate that not only does Appreciative Inquiry have the potential to be a model for organisational change but that also it is a

valid model for democratic research. The bringing together of twenty-three nurses working in district general hospitals to work through the 4-D model generated a significant amount of research data. The analysis of that data has allowed a new way of looking at compassionate dementia care to emerge and arguably a positive epistemological contribution has been made. However, the primary focus of this study was on the conceptual and, one limitation (discussed in Chapter Twelve) is the lack of an assured longitudinal change in practitioner behaviour as a consequence of participation in the Appreciative Inquiry process. What has been shown is that in respect of those nurses who experienced an empty encounter engagement with the approach led them, by the fourth phase, to voice more positive views and as part of a collective, commit to positive changes in practice. That outcome is reflective of the concept of generative capacity outlined as being:

‘The capacity to challenge the guiding assumptions of the culture, to raise fundamental questions regarding contemporary social life, to foster reconsideration of that which is ‘taken for granted’ and thereby generate fresh alternatives for social action’ (Gergen 1982, p109).

The case of DGH01/participant10 was previously used, in the data analysis chapter, to show the analytical approach that was taken to question generativity. Five of the other six nurse participants were subject to the same analysis and outcomes for another two participants are briefly summarised here in support of finding four. The seventh, DGH01/participant03, did not fully complete the 4-D process and has not been included in the analysis. The two additional nurse participants selected as representative of the seven as a whole are now presented.

DGH01/participant11

Discovery

The narrative offered by this nurse participant was more fully discussed in the previous chapter (Box 1). It was set in the context of the nurse being in control and permitting the difficult behaviour of the patient. Despite the claim that ‘we know this patient’ there was little evidence of that and the lady’s pleasure from the attentions of the hairdresser was turned back on her as a criticism or judgement of her character.

Dream

During this phase there were times where DGH01/participant11 made positive contributions for example, she made use of her personal experience of a family member being in hospital to challenge comments of others about families and carers and in suggesting that mental health nurses should work on the ward she opened up an opportunity for others to reflect on their knowledge and skills.

However, she frequently couched her contributions in language which detracted from the positivity. For example, she suggested building a walled community of some kind where:

'... all these little dementia patients live in there in their little houses where they are all safe' (Appreciative Inquiry Dream phase/DGH01/group01 line 77)

Design

DGH01/participant11 made more positive contributions during this phase. She spoke strongly about the nature of the nurses' station:

'it does act as a barrier and there shouldn't be a barrier between relatives and staff'
. (Appreciative Inquiry Design phase/DGH01/group01 line 28 - 29)

In respect of the knowledge and skills needed for dementia care she questioned whether this collective (and by extension the ward team) possessed sufficient and adopted an important position:

'We could be making things worse.' (Appreciative Inquiry Design phase/DGH01/group01 lines 109 - 110)

Deliver

DGH01/participant11 shaped the provocative propositions for this collective and brought to that some of the positive contributions she had made earlier in the workshop.

Overall, there is one clear indication of the generative capacity of Appreciative Inquiry around which more modest examples ebb and flow. She began the 4-D process with a narrative within which 'dementia patients' were labelled as being responsible for their 'difficult' behaviour and that generally this was tolerated because ultimately the nurses had control and authority over the situation. She ended the process by questioning

whether the nurses themselves could have been the problem and made things worse by their lack of knowledge and skills.

DGH02/participant04

This nurse participant was a young and dynamic sister from a trauma and orthopaedic ward who whilst sat in the empty group had unusually been coded for, empathy, signalling and curating the self. She had been in this post for six months prior to the research commencing and had no previous meaningful experience of providing dementia care.

Discovery

DGH02/participant04 arrived late for the start of the workshop and did not offer a narrative of her own although she strongly supported others in her group. Her pre-narrative interview had shown that she believed individualised care was important although this had not been thoroughly articulated. She also had an awareness of the need for sensitive care to be extended to not only her patients but also their families who may be distressed:

'They come here because they have a major injury, they have to have major surgery. They have poor mobility, are elderly, frail and unable to communicate, unable to express their needs so their families anxiety can manifest in that way that they have left their vulnerable relative in their care.' (DGH02/participant04)

Dream

Her positioning of people affected by dementia changed as she progressed through the dream phase. To begin with she claimed that nursing staff were at risk of burnout because:

'It's not just physical it's mentally exhausting especially if you've got quite a few dementia patients who are quite challenging on the ward.' (Appreciative Inquiry Dream phase/DGH02/group01 lines 20 - 21)

However, she made a number of positive contributions and by the close made a truly powerful and highly empathic statement:

'You know these families are handing over their most precious gift for you to look after and they are very vulnerable and scared as well. And that person with dementia is handing over what's precious to them which is who they are, their whole sense of self identity is in your hands and that can be lost in hospital and you might never get that identity back again.' (Appreciative Inquiry Dream phase/DGH02/group01 lines 121 - 125)

Design

DGH02/participant04 was fully involved in this phase of grounding into reality all that had been imagined in the previous phase. She brought a real growth in her understanding to that as shown through perhaps her most powerful contribution:

'It's not all about the fancy things is it, it's about you as a person, you as a nurse, you as a carer' (Appreciative Inquiry Design phase/DGH02/group01 line 125)

Overall, DGH02/participant04 reflected the generative capacity inherent in Appreciative Inquiry. Whilst at the start of the 4-D process she was expressing a degree of understanding by the close she was transformed and voicing very powerful and empathic statements suggestive of a change in her thinking.

Of the seven nurse participants who formed the empty encounter group, six produced narrative data that could be analysed and explored. Of those six participants, five could clearly be shown to have changed as a consequence of working through the Appreciative Inquiry 4-D approach. That change was of a magnitude to suggest that Appreciative Inquiry as set out by (Cooperrider and Srivastva, 1987) does possess generative capacity as defined by Gergen, (1978).

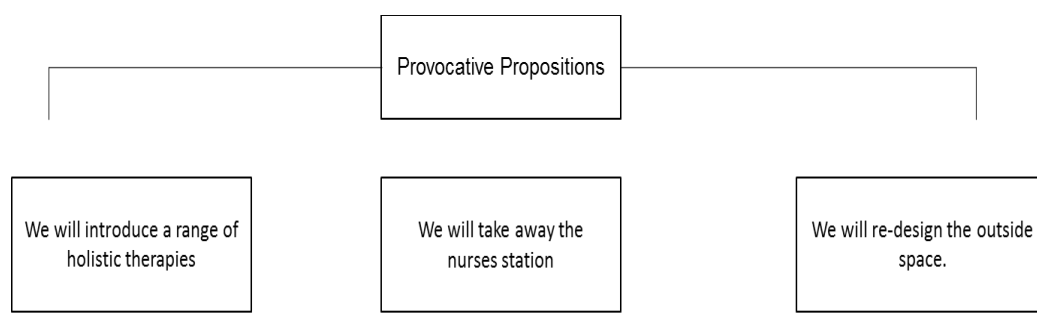
11.2 Finding 5. Provocative propositioning related to the Appreciative Inquiry 4-approach was an illocutionary mechanism. Analysis of the meaning behind the propositions revealed key conceptual properties of compassionate dementia care.

Within the Appreciative Inquiry methodology the 4-D cycle was run in each of the three research sites⁸. Whilst the first three elements; discovery, dream and design involved creating small sub-groups, the final phase, deliver, brought all participants at the site together as a collective. From that collective emerged a series of three provocative propositions. The expression of each proposition taken at face value was the locutionary force suggesting real actions that the nurses were committing to undertake to improve dementia care. However around that locutionary expression was the illocutionary force (Halliday 2006) which was exerted to discover the meaning behind the words used (Levinson 1983). The approach to linguistic analysis adopted by this thesis has been set out in Chapter Three. As part of that exposition one provocative proposition was worked through as an example. The same analytical process was applied to each proposition. The findings of that process are presented for the collective at each research site.

DGH01 Collective 1

The nurses as a collective offered three provocative propositions (Figure 48):

Figure 48 – DGH01 Collective 1 Propositions

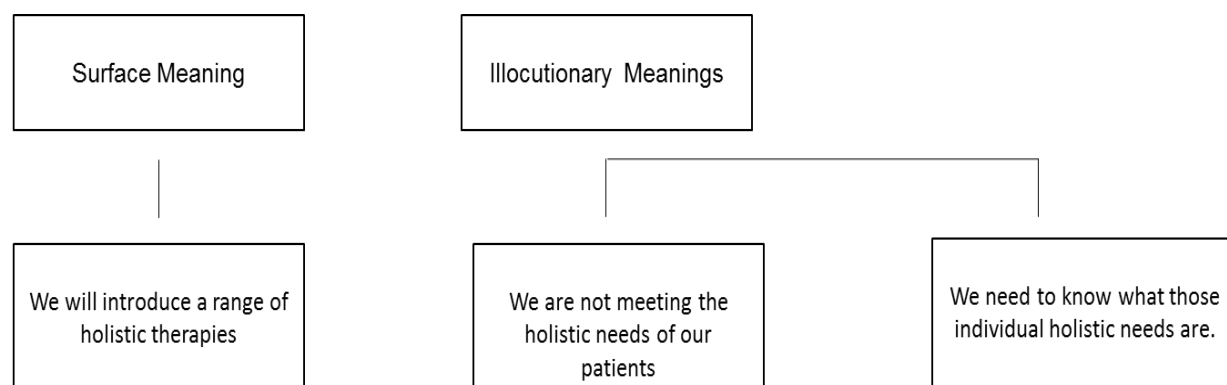


⁸ The site DGH01 was split into two workshops to accommodate a larger number of nurse participants. The site DGH03 was split into two groups but within one workshop. As such there were five sets of provocative propositions, fifteen propositions in total.

The findings which emerged from the linguistic analysis are presented in turn.

We will introduce a range of holistic therapies.

Figure 49 Meanings Associated with Propositions (1)

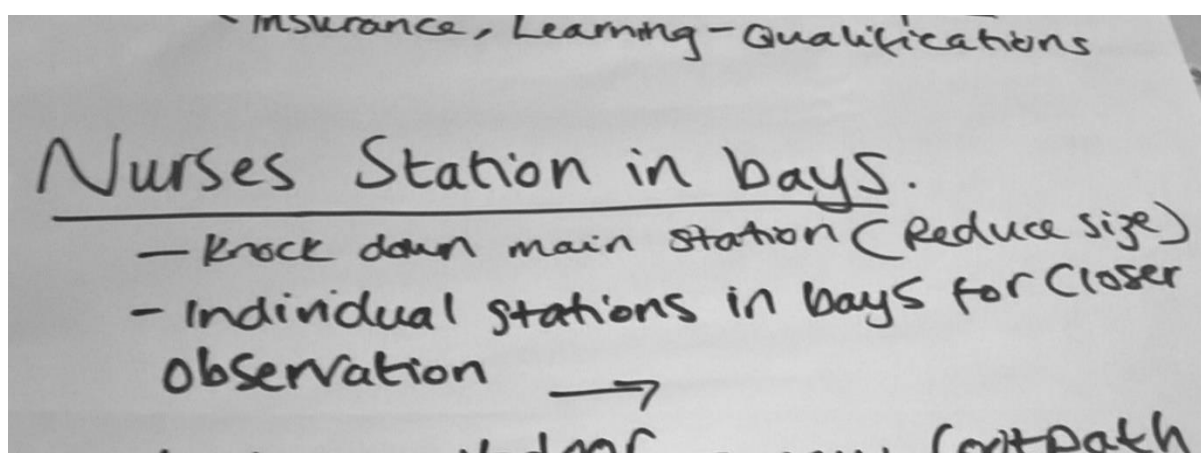


Both surface and deeper illocutionary meanings were analysed (Figure 49). The surface meaning behind this arose from a normative discourse that initially focussed around the importance of providing comfort then moved to the limitations of the medical model and ultimately back to the provision of comfort. Overall that discourse served to question the established order, the culture of care and the value placed on recognising and meeting a person's holistic needs. The concept of 'holistic therapies' finally served as a metaphor for recognising that something more than business as usual needed to be introduced. The reflective element suggested that whilst recognising the existence of broader patient needs, the nurses questioned whether they knew what those needs were in individual cases. As such the true meaning behind the proposition was not to introduce a range of holistic therapies but rather to know the individual well enough to determine what his additional needs would be.

We will take away the nurses station.

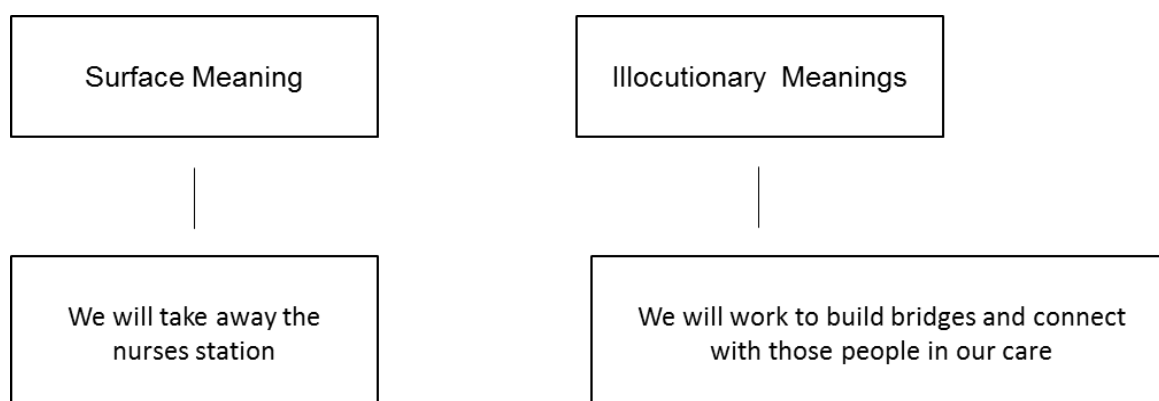
This proposition (Image 4) was worked through (Figure 50) as the example in the previous data analysis chapter.

Image 4 Workshop Flipchart Extract – ‘Nurses Station’



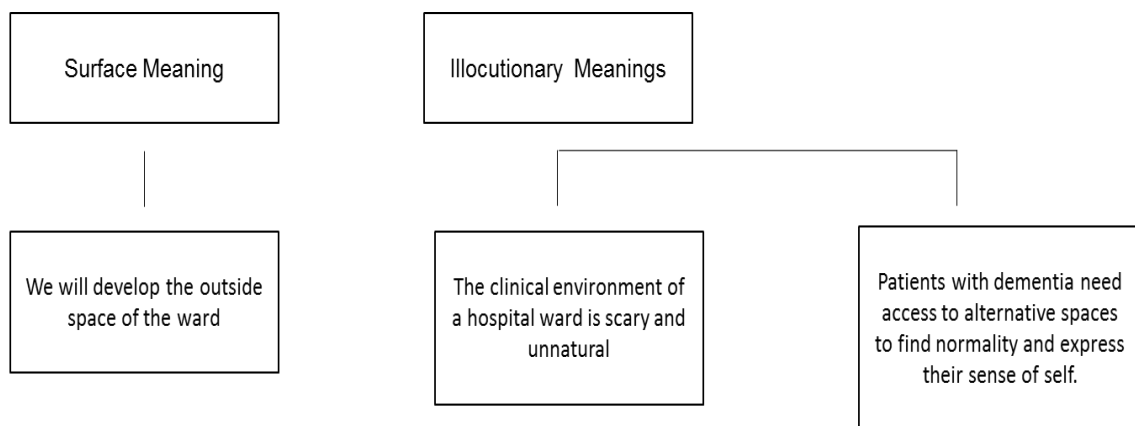
That analysis showed that the subject of the proposition, the nurse's station, as a physical structure dominated the ward. In some sense it could be said to define the ward and the definition being offered was 'unfriendly'. However, the ward was seen as more than a physical structure. It is a social organisation comprised of social agents and the most visible social agents are nurses and patients. The physical structure says something about the relationship between the two and in particular what is inferred is that 'we (the nurses) are not friendly'. The proposition is therefore not about the clumsy unfriendly physical structure of a nurses station but rather is about the nurses and the quality of the relationship they have with patients on their ward. By committing to take away that physical object they are implicitly communicating that their identity and practice needs to change and they need to remove barriers and connect more with those in their care.

Figure 50 Meanings Associated with Propositions (2)



We will develop the outside space.

Figure 51 Meanings Associated with Propositions (3)



Having confronted the unfriendly nature of physical structures within the ward the nurses engaged in discourse that challenged further meta-physical aspects (Figure 51). They articulated an awareness of how the clinical space impacts negatively upon people with dementia and contrasted that with their perceptions of this patient group as this extract of the discourse shows:

'They're from a generation of having been outside aren't they'
(DGH01/participant08)

'Our patients are mostly local people they're familiar with the views, from war time when self sufficiency was the thing they were growing their own veg'
(DGH01'participant11)

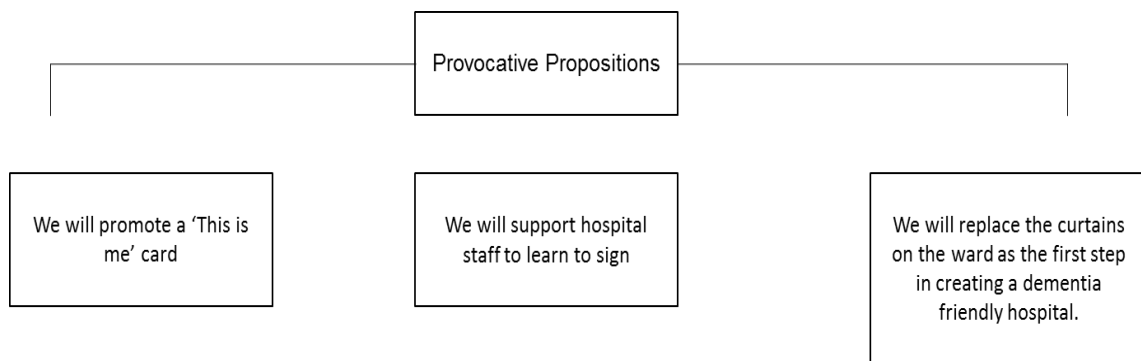
'I can't imagine what it must be like, can you? To not be able to go outside'
(DGH01'participant10))

The interpreted meaning of the nurses proposition is that they are conveying a change in their identify as practitioners and reflecting an awareness of the unnatural situation the person with dementia finds themselves in when being a hospital in-patient. That change compliments the previous two propositions and gives coherence and cohesion (Halliday and Hasan 1976) to the set. The nurses therefore used their propositions to state that they were aware of unmet needs on the part of individual patients, that the way to identify those needs was to know more about those individuals and to seek

ways to build bridges and connect. They further articulated that having insight into the way that individual perceives their situation reveals that the clinical space may be a further barrier to connecting and as such non clinical, natural, social spaces should be available.

DGH01 Collective 2

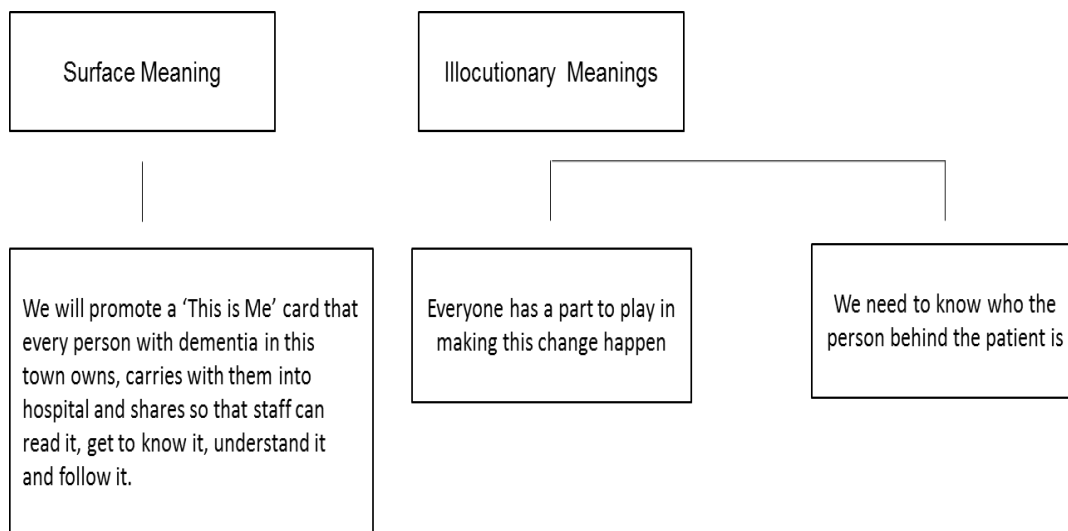
Figure 52 – DGH01 collective 2 propositions



The findings which emerged from the linguistic analysis are presented in turn.

We will promote a 'This is me' card

Figure 53 Meanings Associated with Propositions (4)



The discourse within this group of nurses was increasingly reflective of a simmering frustration. Despite engaging with the affirmative nature of Appreciative Inquiry the nurses could not lose sight of a need for change that they felt should be more widely shared by others. The nurses expressed through the latter part of the proposition (Figure 53) that everyone involved had a specific role to play in bringing this cultural change about. The presence of a 'This is me' card (Alzheimer's Society, 2019) alone could not achieve this as set out in the narrative section below:

'Every morning this week when I went into work I had to say why this man was distressed, because he didn't have his flat cap on. Every morning and I wrote it in his This is Me. Five mornings on the run I walked into work and he was crying in his chair because he didn't have his flat cap on, and it's there' (DGH01/participant02 – AI Delivery phase)

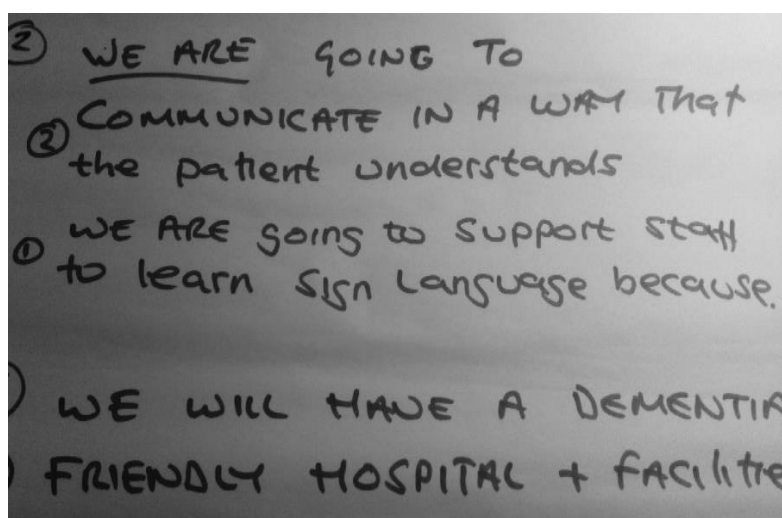
Fundamentally the nurses were outlining that what was required to promote compassionate dementia care was the understanding of the identity of the person behind the patient. Secondary to that was the importance of the person himself being involved in that process and having some degree of responsibility (although in essence this might fall to a proxy).

2 We will support hospital staff to sign

The surface meaning (Image 5) arose from within one of the narratives of this group:

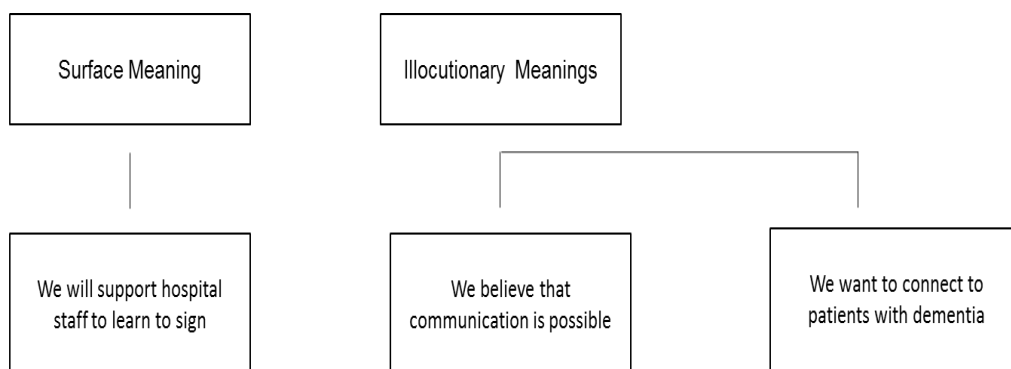
'A couple of weeks ago we had a deaf person with dementia. He's been deaf since eleven because of meningitis. So he signs, theres no-one on our ward who signs so I got an app for the i-pad I can choose the word and it shows me the sign for it. Eventually we got communicating with each other and he wasn't as far along as everyone thought it was just people were shouting at him... he's got dementia, he's deaf and everyone is shouting at him so that he can hear them, he can't hear you he's deaf, completely deaf' (DGH01/participant04 – AI Delivery phase)

Image 5 – Workshop Flipchart Extract ‘Sign Language’



The proposition (Figure 54) was unanimously adopted. However, it was infeasible that the nurses involved had the ability, resources, time or authorisation to achieve what they were suggesting and at some levels was quite naive.

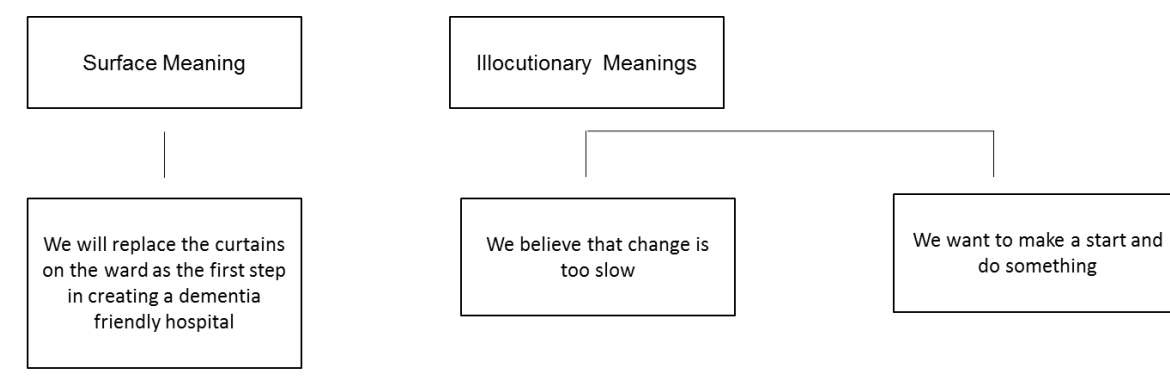
Figure 54 Meanings Associated with Propositions (5)



The passion within the discourse was evident and overall the proposition lent itself to an interpretive approach to analyse the non-natural aspects of meaning, namely that this was not about sign language but about communication itself. What was being expressed was a frustration at the poverty of communication with patients who have dementia. The expression around shouting at a deaf person who can't hear was metaphorical in the context of failing to communicate in a way that connects to people with dementia.

- 3 We will replace the curtains on our wards as the first step in creating a dementia friendly hospital

Figure 55 Meanings Associated with Propositions (6)

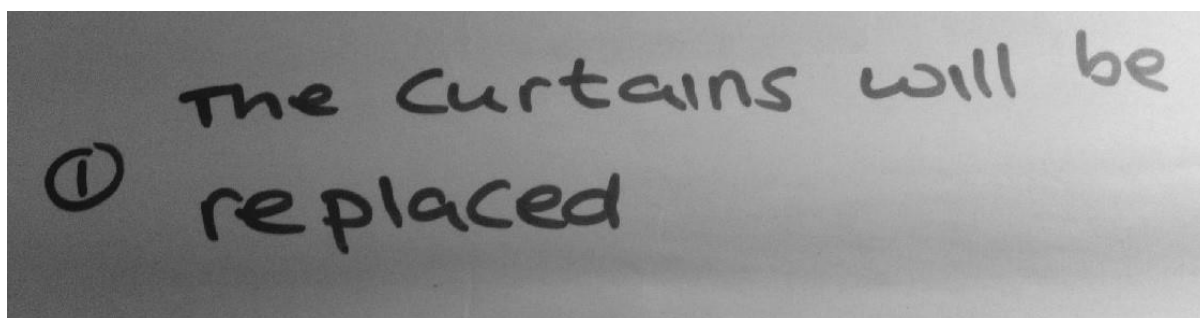


The underlying frustration was again behind this provocative proposition and in a sense the surface meaning here is quite close to being illocutionary. One of the nurses talked about the lack of change in the physical environment and its décor. She recalled giving birth in the hospital some years before and stated that throughout the wards the same bed curtains were still in use and were perhaps no longer appropriate:

'They are vile, absolutely vile, all stained. The patterns absolutely do nothing for the person with dementia' (DGH01/participant02 – AI Delivery phase)

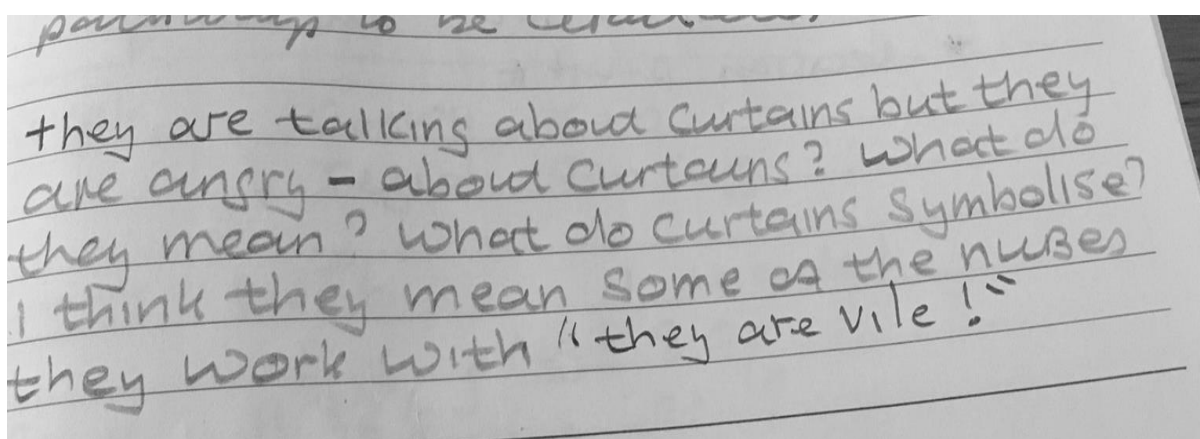
That they were still being used the group thought acted as an indicator of the slow pace of change and the interpretive analysis found meaning attached to cultural change around dementia care.

Image 6 – Workshop Flipchart Extract ‘Change the Curtains



The nurses had elected to use the curtains as a symbol for this (Image 6) and therefore the commissive act of changing the curtains became something else. In this case that something else was to communicate a desire for change and to do something within the realm of influence where those nurses positioned themselves. I questioned with them my field note (Image 7) that, given their anger and frustration at the poor care they saw being delivered, ‘curtains’ might stand as a proxy for ‘staff’ who they might regard as ‘vile’ and who, in their view ‘absolutely do nothing for the person with dementia’. Whilst denied by the members of the collective this remains as a potentially potent metaphor.

Image 7 – Field Note Extract ‘Change the Curtains’

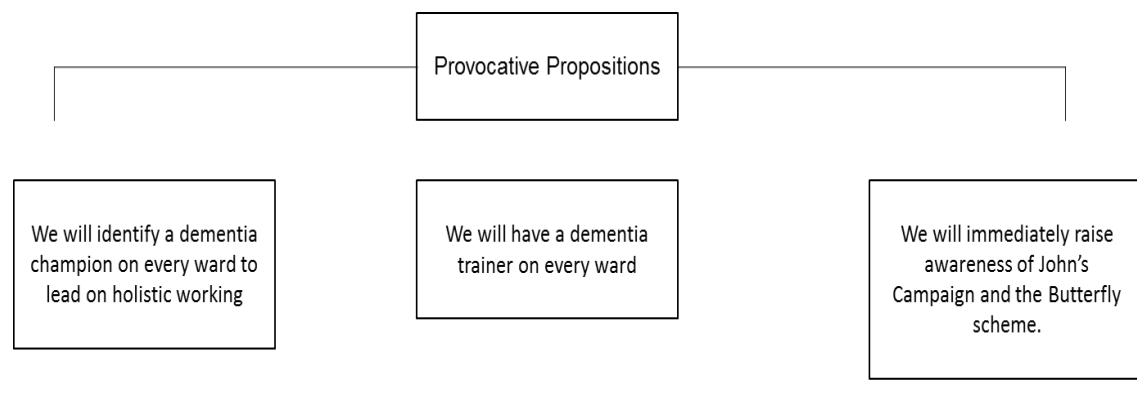


Overall, this second collective had expressed through an interpretation of their three provocative propositions that they felt coming to know better the person behind the patient was important and that everyone involved had some degree of responsibility for bringing this about. Secondly they believed that communication transcended the

verbal and that there were alternative approaches which could be used to connect with individual patients, and thirdly, that changing the culture of care (perhaps to facilitate the first two propositions) was too slow a process but had to start somewhere.

DGH02 Collective 1

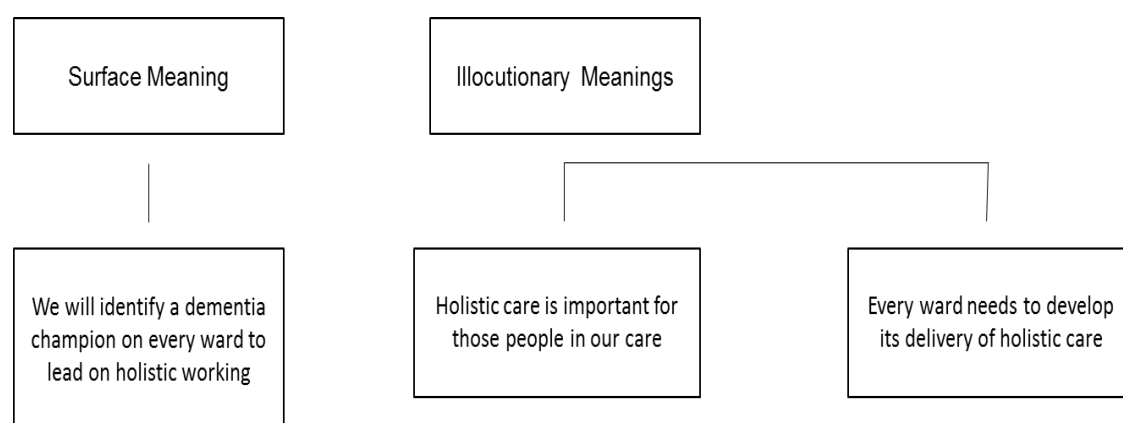
Figure 56 – DGH02 collective 1 propositions



We will identify a dementia champion on every ward to lead on holistic working

The concept of holistic working was previously highlighted by the DGH01/collective1 which also inferred that hospital staff may not have sufficient understanding of what that means. This collective from DGH02 research site built on that (Figure 57) by positioning holistic care as an unmet need that required championing. The inclusion in the proposition of ‘every ward’ suggested the scale of that unmet need.

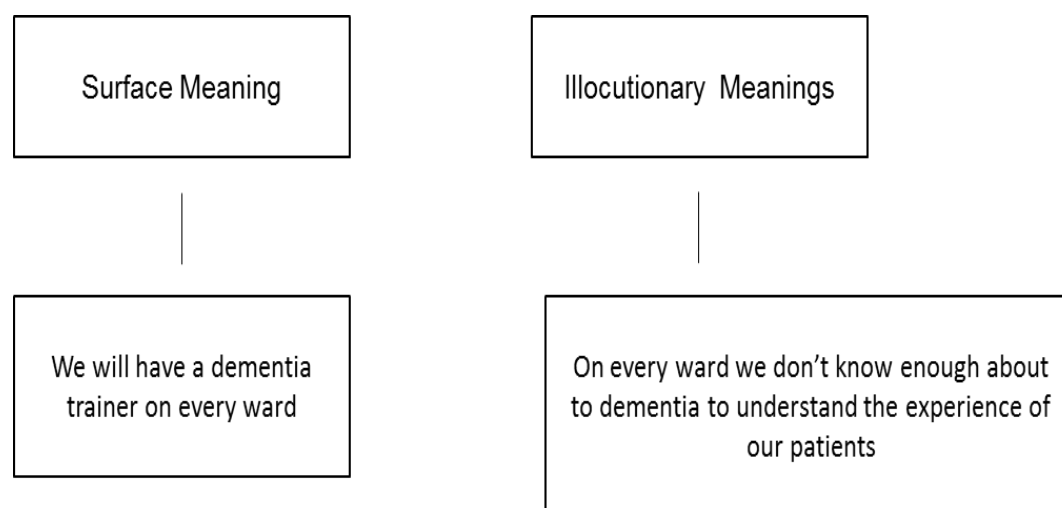
Figure 57 Meanings Associated with Propositions (7)



We will have a dementia trainer on every ward

The collective strengthened its position that acute hospital staff lack sufficient understanding of the individual needs of patients with dementia (Figure 58). Whilst that was set out in the first of the collectives propositions with the need to champion holistic care this went further and recommended that staff needed to be trained to understand the patient experience and to determine those needs.

Figure 58 Meanings Associated with Propositions (8)

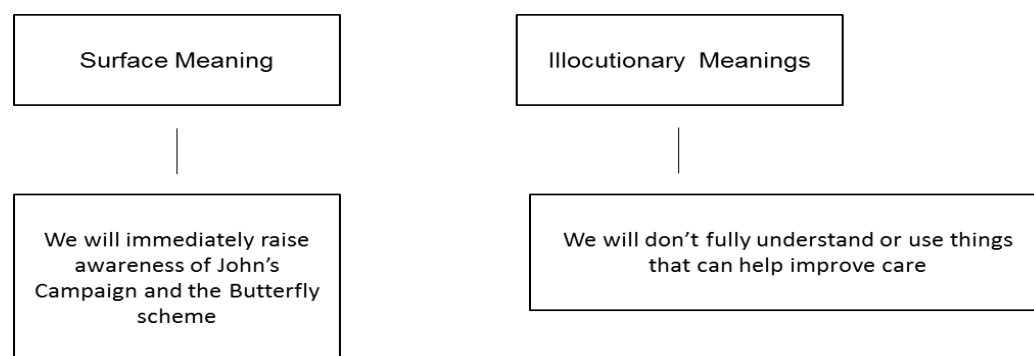


We will immediately raise awareness of John's Campaign and the Butterfly scheme

The third of the propositions continued the theme (Figure 59). The two cited approaches were not unknown to the members of the collective but the emphasis was

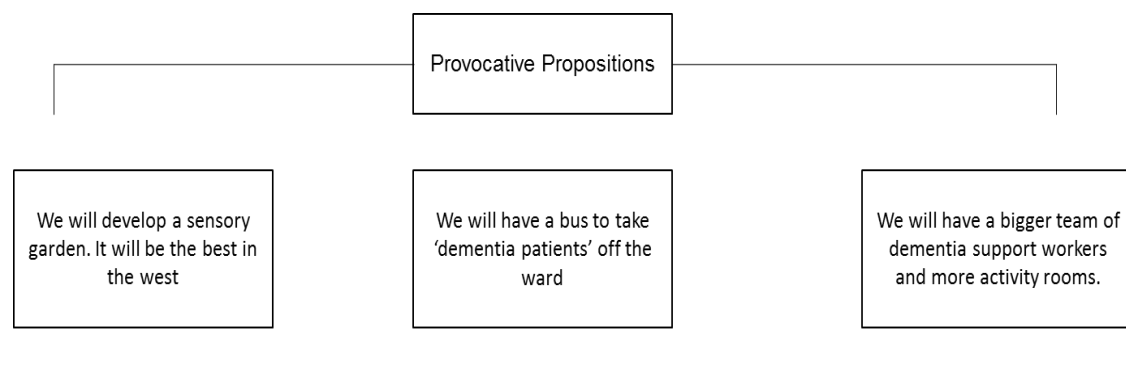
placed on raising awareness. This suggested that acute care nurses were either not fully conversant with these approaches or did not use them. As both were aimed at improving the patient experience this was a further reflection of ‘business as usual’ as not including regard for knowing who the person is or appreciating the individuals situation sufficient that mandatory tools would be familiar and utilised.

Figure 59 Meanings Associated with Propositions (9)



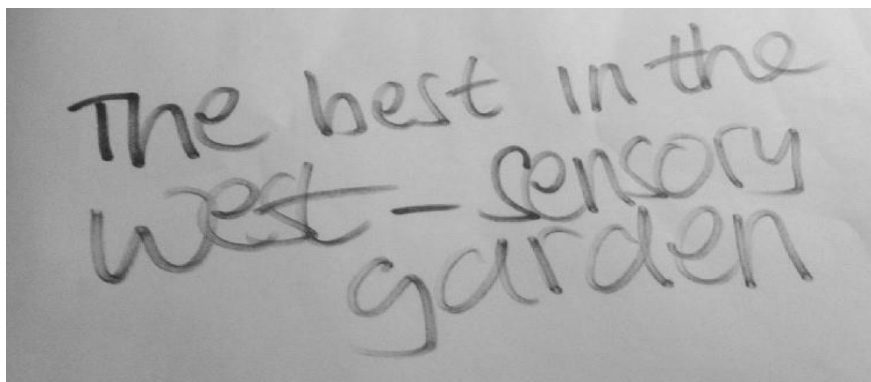
DGH03 Collective 1

Figure 60 – DGH03 Collective 1 Propositions



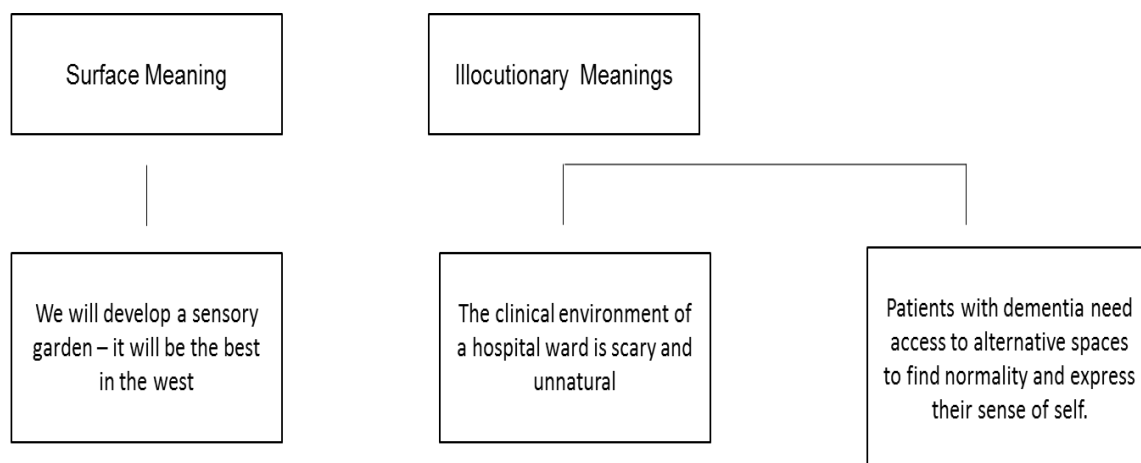
'We will develop a sensory garden. It will be the best in the west'

Image 8 - Workshop Flip Chart Extract 'Best in the West'



There was again a similarity with another collective (DGH01/collective1) with both articulating an awareness of how the clinical space impacted negatively upon people with dementia. Again the surface meaning acted as a partial antidote to that with a further expression of a commissive propositional act, this time to build a sensory garden (Figure 61).

Figure 61 Meanings Associated with Propositions (10)



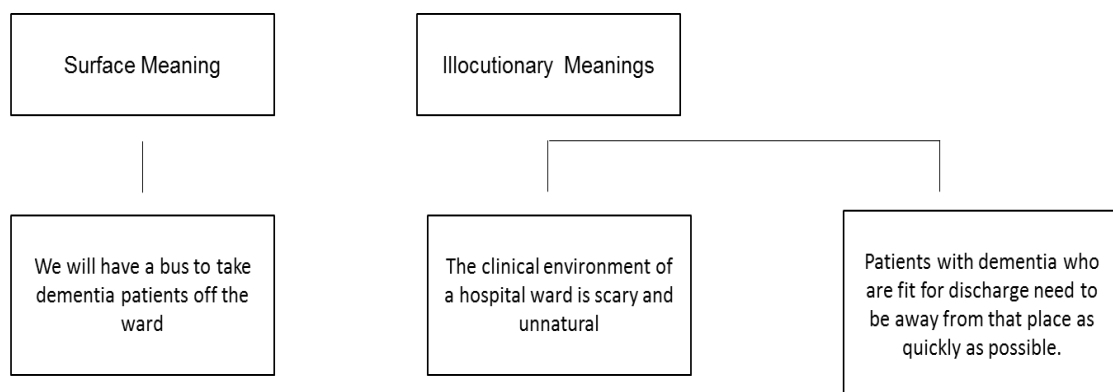
The collective fuelled this further with a sense of pride in undertaking the change, it was to be the 'best in west' (Image 8). So, not only would the patient with dementia have access to a space to find or feel 'normal' away from the abnormality of being in hospital but it would be a better space than anywhere else. That is unlikely so from an

analytically interpretive perspective there is an illocutionary force at play here, their pride does not come from building the best garden but from acting to connect and facilitate selfhood.

We will have a bus to take dementia patients off the ward

This second proposition was related in some ways to the first but possessed a much stronger illocutionary expression (Figure 62). This again reflected the evidence that hospitals as clinical spaces are somewhat toxic to their patients who have dementia (Dewing and Dijk, 2014). That is particularly the case for those who are fit for discharge but with nowhere to go. This proposition was about more than just a 'normal' space but was about the need to move people with dementia away from the ward and the hospital as soon as possible. It was a reflection of the collective having an understanding of the plight of the person and a desire to offer something.

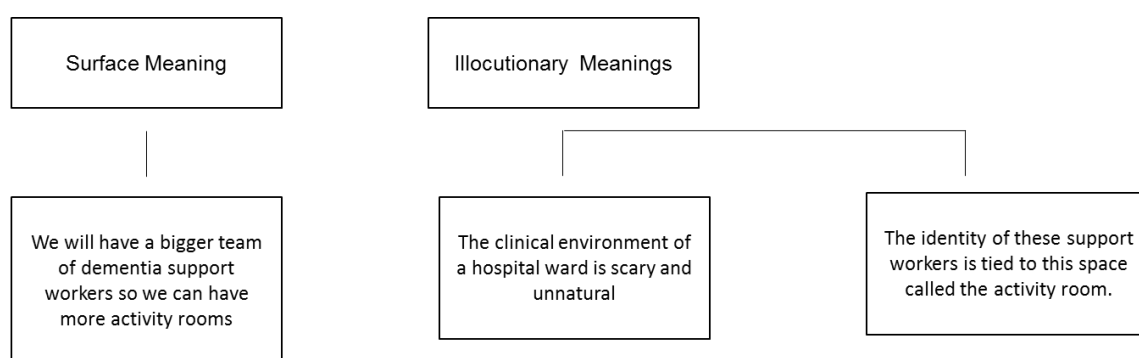
Figure 62 Meanings Associated with Propositions (11)



We will have a bigger team of dementia support workers so we can have more activity rooms

The theme continued into the third proposition where this time the surface meaning was about increasing the size of the team in order to create more physical spaces that would be non-clinical refuges (Figure 63).

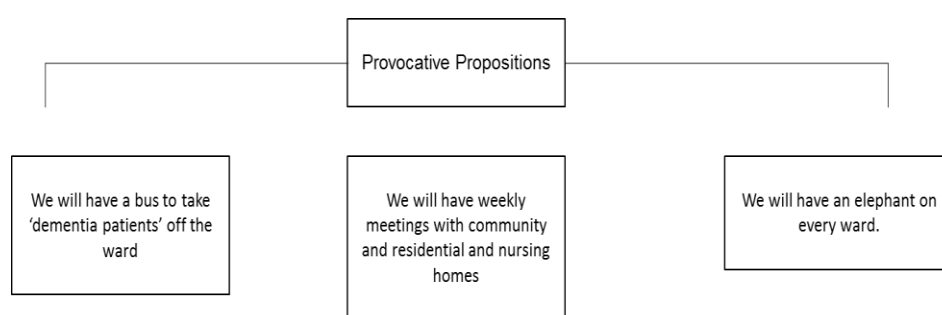
Figure 63 Meanings Associated with Propositions (12)



By semantically tying the space to the team it said something about identity and the collective members (which was predominantly dementia support workers) positioned themselves as the only ones who could create such space. This carried the illocutionary meaning that the collective were the only ones who were promoting normality and selfhood. Ultimately the illocutionary force draws out that it was not about more workers or spaces but about greater understanding of the situation the person with dementia finds themselves in once admitted to hospital.

DGH03 Collective 2

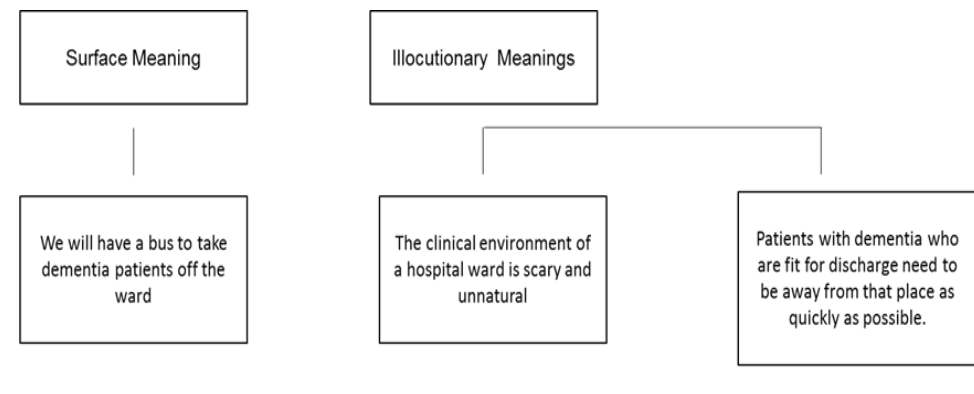
Figure 64 – DGH03 Collective 2 propositions



We will have a bus to take dementia patients off the ward

This proposition (Figure 65) was identical to the proposition made by the first collective at this site. And given the homogeneity of the group it was not unexpected that the linguistic analysis derived the same conclusions regarding the meaning behind the surface.

Figure 65 Meanings Associated with Propositions (13)

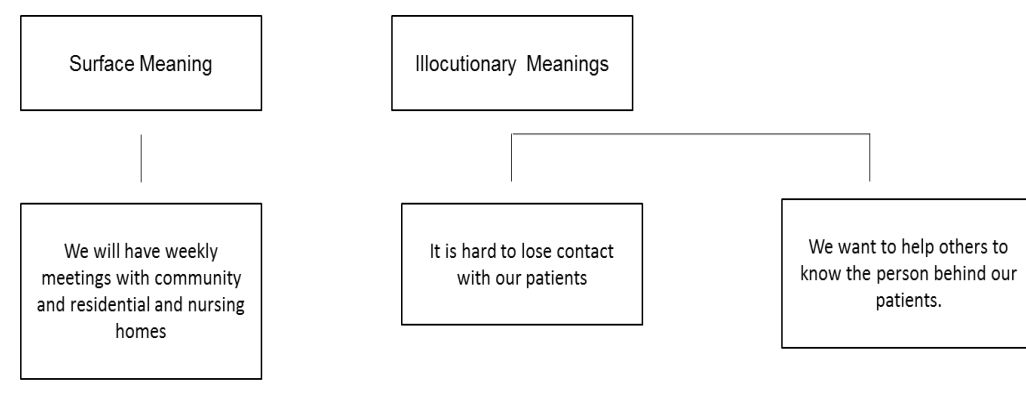


We will have meetings with community and residential and nursing homes

For a team of predominantly dementia support workers, junior staff nurses and a matron all working mainly in acute medical wards for older people, to suggest meeting weekly with care homes (Figure 66) seemed unusual enough to be questioned:

Interviewer 'I don't quite understand that one, I do apologise, talk us through it again, am I missing something? What is that one about again? So you are having a weekly meeting...'

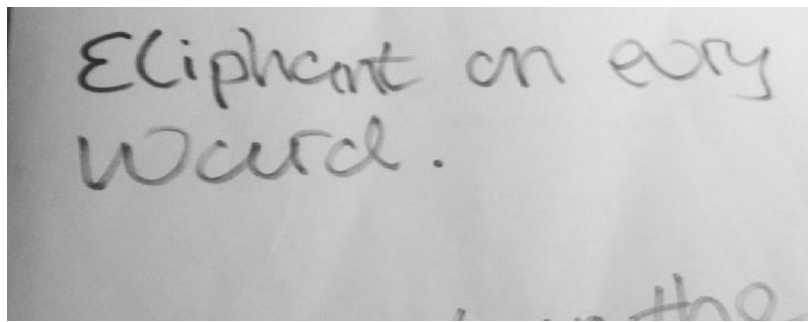
Figure 66 Meanings Associated with Propositions (14)



The surface meaning needed to be elaborated and on this point the collective seemed a little inarticulate but what came across was that this was rooted in the team having taken on the mantle of understanding the patient, appreciating his situation and, providing a space for him to feel his normal self. Having done all of that it was then hard to say goodbye to him and send him into the care of others who might not do any of that. The propositional property of knowing him as a person was therefore being expressed as fragile enough in hospital but even more so following discharge when everything this team had learnt would be lost.

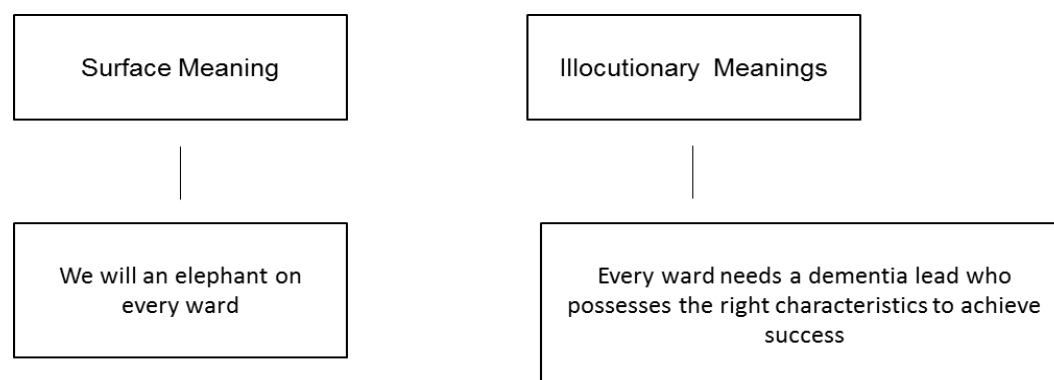
We will have an elephant on every ward

Image 9 Workshop Flipchart Extract ‘Elephant’



On the face of it this proposition (Image 9) challenges the conventions around the definitions of text (Halliday, 2006). Situational coherence requires that each part of the language of the text can logically sit together. ‘Elephant’ and ‘ward’ contextually do not fit and clearly from the outset the introduction of an elephant into a hospital ward can only be metaphorical. As such this proposition as soon as it was uttered needed to be subjected to interpretation and analysis (Figure 67).

Figure 67 Meanings Associated with Propositions (15)



'An elephant never forgets, they are very caring and strong and compassionate'
(DGH03/participant07 – AI group 2 Delivery phase)

As the whole was illocutionary it was clear that the collective were thinking in terms of the alleged properties of an elephant but relating these to the properties of the dementia champion. Elephants are without question significant physical entities but are also seen as empathic, friendly, dignified and possessed of the ability to communicate through different modes including the non verbal (Bates et al. 2008). In some senses this was similar to the propositions from site DGH02 related to every ward identifying a dementia champion and having a dementia trainer. It was an acknowledgement that change requires leadership and leaders require certain qualities. Such is the scale of cultural change required then the illocutionary meaning behind this proposition was that the right leader of the right kind was required on every ward.

Finding Two Summary

Fifteen propositions were outlined by five collectives across three research sites. Each was subject to an interpretive analysis of the language used to express meanings that were both explicit and more importantly implicit. The hypothesis behind this is that the implicit meanings shaped by the illocutionary force will reveal properties of

compassionate dementia care. This exercise revealed the following properties which suggested that to be practicing compassionate dementia care one would need to,

1. Determine individual holistic needs by sufficiently knowing the individual patient as also a person.
2. Connect to the person by building bridges through a range of communication strategies.
3. Understand the plight of the person and have awareness of the situation he finds himself in.
4. Provide non-clinical 'normal' spaces of refuge.

11.3 Summary of Chapter Eleven

This chapter has demonstrated that Appreciative Inquiry as a methodology for democratic research made a definite contribution to the research process. Its democratic nature held the nurse participants together as they progressed through the phases of the 4 – D model sufficient that by the point of deliver they could agree a number of provocative propositions aimed at improving dementia care on their wards. The added value contribution from this came as the propositions were subject to linguistic analysis and the illocutionary aspects revealed a series of properties that acted to validate the conceptual properties drawn from the bespoke triadic model of analysis.

The generative capacity of Appreciative Inquiry was tested and found to have redemptive properties. By this I mean that the cohort of nurses who had had empty encounters and were somewhat dismissive or negative about dementia care underwent a process of transformation during the workshops. By the close they had begun to question themselves and their practice and some made significant contributions to the outcomes of the research.

These findings have by themselves made an epistemological contribution and shown the potential that Appreciative Inquiry has for use in health care research that does more than just explore organisational change. The final chapter follows and draws the whole thesis to a close by revisiting the key aspects of all that has gone before whilst looking to the future and considering the potential implications of this research.

Chapter Twelve

Discussion

12.0 Introduction

This thesis has made a contribution to the understanding of compassion in the context of dementia care and, within the setting of acute hospital nursing. It has found that acute care nurses, working collectively within a democratic research methodology, can conceptualise the properties of compassionate dementia care. In particular they can identify a triad of key properties which must be at the forefront of practice if there is to be parity in the care experienced by people affected by dementia. In this final chapter I shall rehearse again what the specifics of that contribution are. In addition to that, and with the whole of this doctoral work now laid out, this chapter essentially draws things to a close by restating the original focus of the research, its aims and questions, and evaluating what has changed along the way. My overall approach for this chapter is to fall back on the traditional and refer back to what has been read, written, researched, synthesised and found, as well as pointing forwards to where the findings may influence future research, policy and practice.

The chapter offers a summary of the findings and discusses again the four initial encounters that are at the core of this thesis. In doing so, and in the absence of any substantive previous research, the alignment of the findings to the broad literature base is discussed. That not only takes us full circle but is a concluding act to support the validity of the fundamental proposition that was made in Chapter Ten, that the quality of the initial encounter influences everything else that follows. I close the chapter with my personal reflections having lived with this topic for the past five years and then set out a series of recommendations for research, policy and practice.

12.1 Restatement of the Research

I began this period of study about five years ago in the midst of the Tawel Fan investigation⁹. I have steadily studied whilst around me my work has been dominated

⁹ See personal reflection, page 12

by the ebb and flow, twists and turns of the post Tawel Fan world. The original focus of my research was to look at compassion through its absence and to link that to the abuse of elderly and vulnerable people within the NHS. Whilst making that link was relatively straightforward it was somewhat naïve to think, as I did, that this doctoral work would remedy that or, to position the research in terms of the ‘this must never happen again’ agenda. Fundamental to that initial naivety was the belief that democratic research had the potential to address the absence of compassion. In small groups or learning sets practitioners could look afresh at their practice, rediscover those things they may have lost, discover the positive core of nursing and return with a new set of practitioner behaviours. This somewhat aspirational approach focussed early attention upon Appreciative Inquiry (Cooperrider and Srivastva, 1987) as the methodology which would make these things happen.

Over time the focus changed and as both I and the project as a whole academically matured new questions emerged that shifted the emphasis away from the methodological towards the conceptual. In particular the shift was been away from the absence of compassion towards a more essential understanding as to what it actually might be and, how nurses could describe its relationship to the care of a person with dementia. Whilst this shift relegated the context of abuse to the deep background it still exercised an influence over the direction of the research. In exploring every serious service failure, in the past fifty years, which involved the care of older or vulnerable people a clear trend emerged. To begin with the failures and abuses occurred in mental health or learning disability settings but, as time moved on, these became much less (albeit with one or two notable exceptions) whilst those involving acute care settings increased, and most notably the events at Mid-Staffs NHS Trust (Francis, 2010) exploded the discourse around compassion and care into the public domain. I decided upon research questions which reflect all of these factors. My attention would be conceptual, it would focus on compassion, it would involve nurses working in acute hospital care and its primary context would be dementia care. So, essentially the research asked how those nurses conceptualise compassionate dementia care and, it asked whether that could be distinguished from a much broader concept of compassionate nursing care. The first question has been answered but perhaps not in the way that I expected it to be. The collective group of nurse participants was able to identify an entire portfolio of conceptual properties associated

with compassionate dementia care and to isolate the most important of those. Yet, in doing so a series of alternative conceptualisations also emerged depending on which group within the collective the nurse belonged to. These alternatives served to act as one of a number of distinctions between groups which have a bearing on practitioner behaviour.

This second question was important. The scoping review and the three tier scaffold built to support it showed no lack of literature related to the general concept of compassion or the relationship between compassion and nursing care. However, on entering the third tier (compassion and dementia care) there was a surprising emptiness and in all honesty the papers selected for my review, whilst the best on offer, were somewhat peripheral. The position seemed to be that in respect of the nursing literature, which I positioned as a reflection of nursing's interest at that point in time, there was no significant body of work questioning if compassionate dementia care was different to compassionate nursing care. That seemed counter intuitive as the literature has been comfortably endowed with evidence that dementia brings additional challenges that most people without dementia do not experience. It would therefore not have been unreasonable to expect to find previous attempts to disentangle a 'dementia component' from within the broader concept of compassionate nursing.

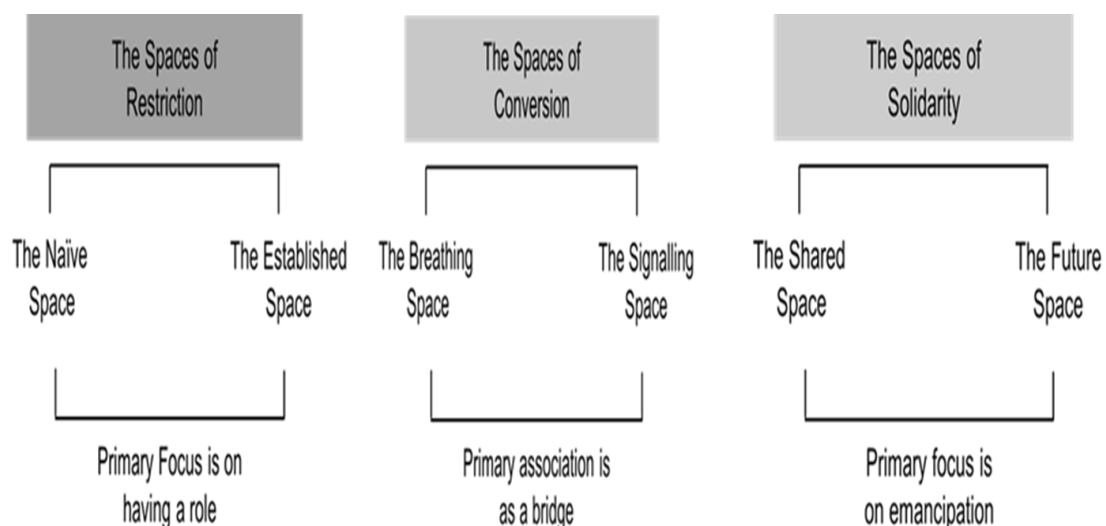
One of the contributions of my research is the serious attempt to identify this concept and its distinguishing properties and, to ask how one might model that to explore it further. In particular it was asked if there were in some way differences between the nurses delivering the same kind of care, in the same kind of places and, surrounded by the same kind of pressures. This question moved to adopt a more dominant position in the thesis and led to a fundamental proposition that the quality of initial encounters shaped all that happened next. This outcome was completely unforeseen in the early months of the doctorate and its emergence from the data was one of the clear contributions made by the research.

That modelling itself was subject to change as the research progressed. The first blueprints were heuristic (see Figure 16), they were guesses which intuitively felt right as they were driven frequently and rigorously through a highly reflexive process involving supervisors and others. Driving the design was the literature which whilst not

outlining compassionate dementia care had left some quietly expressed suggestions as to what might be found there. Those suggestions (standing in solidarity with the other (Perry, 2009) finding a breathing space within which to listen to the voice of the other (van der Cingel, 2011) and, signalling the invitation to engage (Halldorsdottir, 1996)) were all included in the heuristic model because of a chance encounter with a Sister of the Daughters of Charity of St. Vincent de Paul. That led me to an exploration of the spiritual journey, removing it from the context of her orders work with the poor (Wiesner, 1987) and, applying it to dementia care practice. In many ways it also fitted with the work of Travelbee (1971) and her emphasis upon the importance of finding meaning in suffering.

The heuristic model that came out of this was still largely subjective but reassurance was found in reflexivity allowed a sense that in many ways it felt right to be legitimised. However, as the research progressed and more understanding was gained it began to look unnecessarily clumsy. In particular the nature of conversion was revisited (as described earlier) and its dynamic properties secularised and relegated to a background process. What became different about the final Six Space Model (Figure 39) was that foreground dynamic action was no longer the movement *between* the spaces but rather related to the acts undertaken *within* the spaces.

Figure 39 the Six Space Model



So, over the course of time much changed. The focus moved away from abuse towards compassion and, from the methodological to the conceptual. This led to a

revision of the research questions which have been answered producing a number of key findings which are now summarised.

12.2 Summary of Research Findings

The findings have been presented in full in Chapters Eight, Nine and Eleven respectively. In short there are three conceptual findings, two methodological findings and, the development of the previously mentioned Six Space Model (Figure 39). What these collectively have told us is that acute hospital nurses were able to theorise a concept of compassionate dementia care and that it was distinguishable from a broader concept of compassionate nursing care. That broader concept was well represented in the nursing literature and this thesis has told its story using the Meleis-milestones of nursing theory (Meleis 2012) as episodes. It has been stated that whilst nursing theory could generally be aligned to these fixed points, its thoughts regarding compassion have twisted and turned across, around and amidst those milestones.

Nursing compassion is comprised of a number of elements that have allowed this thesis to identify a working conceptualisation. It is principally characterised by dynamic action that is initiated by benevolence towards the other (Lutzen and Nordin, 1993) sustained through sympathetic equanimity (Boleyn-Fitzgerald, 2003) and driven by the positive energy that benevolence generates (Tuckett, 1998). The nurse acts to do good for the other not from any emotion but because both she and he are part of a greater ontological whole (Orem, 1985). In doing good she is aware of the other and his suffering and whilst understanding this she is not so engrossed that she becomes overwhelmed and paralysed by it so as to no longer be capable of the rational decision making that underpins the prescribed nursing care that aims to alleviate his suffering.

Compassionate dementia care is conceptualised by my research as being different. It acknowledges the impact that the general symptoms of the dementia syndrome have upon the person's resilience to hospital admission. The nurse participants have collectively argued that before compassionate nursing care can be delivered it is necessary to act to increase the individual's resilience and establish the conditions within which that person is as anxiety free as possible. From eleven conceptual properties (of compassionate dementia care) three emerged to exemplify that distinction and to create a level playing field from which the person could comprehend

a quality of care that others may otherwise take for granted. These three properties are essentially relational and involve the nurse taking time to deliberately act to better understand who the person behind the patient is and to look at their situation through their eyes. Whilst this does not open the door to engrossment it certainly moves the nurse from a position of sympathetic equanimity towards something more like an empathic friendliness.

Supporting the collectives conceptual properties were findings associated with Appreciative Inquiry as the chosen methodology. They showed that Appreciative Inquiry possesses the generative capacity to engage a group of nurses in a normative debate through which they question the status quo and aspects of their own practice. Data drawn from that and from the provocative propositions produced a secondary set of characteristics which acted to validate the eleven conceptual properties.

Perhaps the unexpected but fundamental finding from the narrative aspect of the research was that the initial encounters that nurses had with people with dementia had a significant impact, which could be either positive or negative. Whilst all the identified themes were relational the initial encounters were very much starting points from which the nurses beliefs about dementia could remain in a fairly static space of restriction or be propelled forwards towards something more. Their interaction with the other relational themes set the tone for understanding how individual nurses cared for people with dementia on their wards. That understanding was sufficient to identify who were the bridge builders, who were acting to hold the others fragmented self together, who were becoming activists and, those who didn't want to get involved and focussed on task completion and adherence to role. This understanding facilitated the improvement of an early heuristic model into a more robust data led explanatory model to show the six spaces of practice in respect of dementia care. It was then possible to infer from each nurses individual pattern of interaction between the initial encounter and the other themes alongside, her subsequent conceptualisation of compassionate dementia care which space she would most likely inhabit. A point was reached at which it was possible to use the model to show where such care was likely to be lacking, where it could be at risk of turning into activism or focussing on the nurse and, where pragmatically compassion sat.

The methodological findings reflected the stance taking in Chapters One and Two that a different approach was needed to influence practitioner behaviour and that approach needed to reflect the participatory, inclusive or democratic properties of knowledge translation (Sudsawad 2007). Appreciative Inquiry as envisioned by Cooperrider and Srivastva (1987) was shown in this study to have the generative capacity (Gergen, 1978) to stimulate a discourse from which conceptual properties of a compassionate dementia care could be elicited. The extent to which this participation changes practitioner behaviour remains unclear however two phenomena were noted which imply a strong possibility of positive change. First, each collective identified through their provocative propositions that change was required and that in many ways that they needed to change. If one considers the example of the proposition made by DGH01 Collective 1, to remove the nurse's station then one can see change as it happened. One of the collective members (DGH011) first introduced the nurse's station as part of her own generative journey which culminated in significant change in her beliefs, attitude and language. That the size and position of the station made it an unfriendly barrier was recognised at a deeper level of meaning as a physical object standing as a representation of the nurses themselves. The leap from 'it is unfriendly' to 'we are unfriendly' is the cognitive move needed for behaviour to change. In committing to take away the physical object the nurses were committing to personal change and communicating this.

Second, change was observed through the tracking, using linguistic analysis, of the generative journeys undertaken by most of the 'empty' nurses during this project. The 4-D approach allowed them to be fully involved, respected and sufficiently emotionally secure to put to one side the daily demands of their roles and to experience the 'wonder' of discovery from research rather than the usual problem identification and action planning (Cooperrider and Srivastva, 1987). Essentially what was seen in the workshops were nurses who were responding to the implied permission of the approach to stop being 'mechanics' and instead become 'explorers' (Cooperrider and Srivastva, 1987) and experiencing a style of research which reflected the original Lewinian vision to be adventurous, refreshing and revitalising (Lewin, 1951).

12.3 Alignment to the Literature

Whilst the literature related to compassion and dementia is sparse it is possible to look at the findings through the lens of nursing's more general discourse and in particular to consider where the initial encounters and their impact resonate with that. As set out in the framework statements the nurse who experiences an empty encounter is highly likely to underpin nursing practice with a need to make judgements about her 'dementia patient' and his relationship with suffering. This statement acts to position the 'empty conceptualisation' in a place that is influenced by one aspect of the Aristotelian view of compassion (the construals) which allows the 'empty' nurse to assume sole authority on the entitlement to care, the nature of which she alone will determine. Alongside that is the empty view of suffering as being an experience resting solely with the patient although, again reflecting the construals, the nurse can measure the extent of that suffering in order to make informed judgements about it. The suffering of the patient is one dimensional and related to the physical and although the fear of being in hospital is frequently acknowledged it is not seen as legitimate suffering. Because of this there is a limited understanding of an individual's behaviour serving a communicating function. It may be argued that as behaviour can function to communicate unmet need and, as unmet needs are identified in every inquiry into serious service failure, it is unsurprising that dementia becomes associated with 'difficult' or 'challenging' behaviour and that some nurses are pejorative about this:

'I don't think there are as many people with dementia who are the pleasantly confused as we would label them. They all seem to be progressively challenging people. We have had some extremely difficult patients' (DGH01/participant03)

Here there is no consideration that behind the behaviour may lie a message. There is no attempt to find meaning in his suffering as suggested by Travelbee (1981) as the cause of physical pain is obvious. Any other forms of suffering are inconceivable in the context of a patient who is seen to have no valid emotional world. There is no attempt to stand in his shoes or to feel his pain because empathy is regarded as being dangerous to the nurse who must learn to function with equanimity in the face of suffering (Boleyn-Fitzgerald 2003). This cultural stance has significant implications for the 'patient', who in addition to the physical health problem, is also affected by dementia. That person has less opportunity than others to have his voice heard and

as such less opportunity than others to influence or be involved in that care. In this situation his personhood is not only vulnerable but distinctly threatened. If, as demonstrated, the 'empty' nurse has no regard for there being an individual person behind the role of 'patient', has no desire to connect and no understanding of the need to curate the fragments of self, that threat is significant.

Whilst it is reported (Lundgren and Berg, 2011) that there is no expectation on the part of the 'patient' for his nurse to be empathic and no call to share his pain, there is a need for him to at least be known by his nurse and to feel included. For this to occur the Aristotelian rules state that firstly the nurse must be aware of the other. This should be taken as a given but in this empty context the quality and willingness of that awareness are both questionable. The empty conceptualisation places the person with dementia firmly into the social role of 'patient' (Parsons 1951) and boundaries this with expectations for the rules of the role to be obeyed irrespective of the cognitive ability to do so. Beliefs about non-compliance with the rules are captured in the articulated position of 'people with dementia are troublesome'.

If one draws these factors together it can be seen that 'empty' nurses undertake their practice in spaces of restriction. That restriction applies to the person affected by dementia who is denied his voice, his individuality and inherently his sense of self. They are places of restriction for nurses who bound by rules, expectations, and simplistic definitions of nursing are blinded to the possibilities of a richer way of working with people who have dementia. The first of the spaces of restriction (the naïve space) is essentially the lowest order of understanding. Whilst it is accepted that this is a bald generalisation it remains a fact that the greater majority in society have little or no understanding of dementia, they are 'dementia naïve'. The language used in this space is not as people affected by dementia and activist organisations would advocate for (The Dementia Engagement and Empowerment Project, 2014). Most commonly the person is described as a 'dementia patient' or a 'sufferer', and in effect the whole of the person is reduced to a label of illness or disease.

Moving away from the naïve to the established space is based on a deliberate decision of the individual to enter nursing. For the nurse participants in this study, who experienced an empty encounter, the simplicity of that decision making has already been described. Additionally Chapter One demonstrated how this is represented within

the literature and the role played by professional socialisation which often exposes the nurse to negative attitudes about dementia early in her career (Scerri and Scerri, 2012, Baillie et al, 2012, Chan and Chan, 2009). Those negative inheritances passed on through generations of nurses may anchor a nurse in the naïve space where she may still believe that she provides compassionate care to people affected by dementia. That belief becomes valid in part because she has developed compliance to an assurance driven health care culture (Roberts and Ion, 2004) that has taken away her ability to think (Arendt, 1992) and she, as a well-meaning person, unconsciously equates her acts of malignant social psychology (Kitwood 1997) to compassionate care.

Those who practice more in the established space have moved away from the naïve view but instead hold to a certain, perhaps simplistic, understanding of nursing. This was again captured throughout the literature but particularly by nurse theorists establishing the components of meta-theory, which was set out in the analysis by Meleis (2012), and again may be aligned to the Aristotelian construals. Those rules are reflected in the belief that awareness of her patient is grounded in the nurses perception, judgement and measurement of his needs (Griffin, 1983) and, that the role of the nurse is to 'observe, reflect and reason' (Orem, 1985, p26) before acting. As such the alleviating of suffering is reserved for those judged to have a legitimate need for nursing in that they have suffered enough.

In the established space the nurse follows a culturally determined set of rules to guide her actions rather than being moved to act:

'I am a professional and I do my job. I don't want to get involved too much'
(DGH02/participant02)

One might argue that 'I don't want to get involved' is so far away from the act of signalling, so bereft of empathy, and so distanced from compassion that it must be a misrepresentation of nursing. However, it has been suggested that such a stance reflects the reality that because sympathetic equanimity itself ought to be seen as the ideal rather than the expectation it would be unreasonable to condemn those who fall short of even this minimum standard (Boleyn-Fitzgerald, 2003).

In circumstances where the motives of the nurse are not questioned there is a seductive simplicity that comes with acting within her socially determined role. This is underpinned by a naïve view of nursing which reflects the mantra from Leininger (1984) that, 'Nursing is caring, and caring is nursing' (p83) and that the concept of caring is sufficient to accommodate all the attributes of nursing (Roach, 1987). Where the nurse states:

'I give them their medications about three times a day, morning lunch and evening, obviously not everyone, I just can't leave it on the table like I give to them. We speak to them, we have some with hygiene needs, we help them with their food and when they are ready to go home we make sure that they have got help at home or maybe they are going to a new home. (DGH03/participant04),

then one is reminded of the allegation by Kitwood, (1997) that the person could experience all the aspects of care that society deems appropriate without ever encountering an I-Thou relationship. If one likens this to the spiritual journey the individual by virtue of entering the nursing profession has entered on the 'way of appreciation'. She has, to innovate Wiesner (1987), become aware of the sick, observed their suffering, heard their cry and, responded. The patient has become the *object* of nursing effort but it is in that objectification where malignancy lies. That malignancy is not an intent to do harm or to disempower or to disable, but it has that effect:

'In the acute setting we tend to do everything for the dementia patients and as we know as you start doing things for the dementia patients they forget what they could do in the first place and it's always worse on the acute wards. You have got to get ready for the consultant' ward round, I wash them, I fasten their buttons instead of giving that patient time to wash themselves.' (DGH02/participant02)

This may be unacceptable to some who may question whether this is how it must be and whether there is another way. In starting to question the nurse has already moved into the breathing space. As she does so she has already distanced herself away from the restrictions of the past and moved towards a new and more balanced way of practising. Care becomes more holistic and the nurse is motivated towards allocating her time to understand the predicament of the other from his perspective and, acting to determine his needs rather than those she believes him to have (Scott, 1995). It is not a given that this understanding occurs as quickly as sometimes the decision to

pursue it and, it is not free from risk as it exposes the nurse to a broader appreciation of health care provision. This is reflective of the second conversion (Wiesner, 1987) through which one becomes aware that inadequate care¹⁰ is a structural problem and, that one is very much part of that.

Those structural problems will be viewed clearly in terms of the quality of connectedness between the carer and the one who is cared for. Halldorsdottir, (1996) set out that the nurse can either work to build bridges or walls and in the breathing space the nurse will decide what it is that she wishes to construct. In seeking to move forward she must build bridges and this thesis has demonstrated how that occurs through language and a range of actions which act as signals to the other that the nurse wishes to connect. In choosing to build a dead end she will not move back to the restricted spaces but will find that she never really left.

For those who stay, the spaces of conversion can be positions from which the nurse learns to deliver compassionate dementia care or, in some cases, spaces where she is learning what else might be possible and what she might be advocating for in the spaces of solidarity. This thesis has stated that compassionate dementia care sits firmly in the spaces of conversion but it must also be considered that these spaces can, for some, also be important stops on the way to and from somewhere else. The nurse passing through is in a state of uncertainty but also open to discovery. In the language of Cooperrider and Srivastva, (1987) the nurse has ceased to be mechanic and has become explorer. Whilst in dementia care there is a need for both, the way of dialogue provides an opportunity for exploration and learning as she builds relationships with the person affected by dementia, understands his needs and comes to regard him as wiser than her and as an expert in his own meta-physical needs. That nurse is now person centred and as far as possible will seek to involve him in his care. Others driven by the forces of an inspirational encounter, may be on their way to the spaces of solidarity where there are 'now no longer distinctions, we stand together, our relationship and stance has fundamentally and permanently changed' (Wiesner, 1987 p217).

¹⁰ Again I re-frame the spiritual journey

For some who are deeply inspired and moved, the decision can be made so quickly that the spaces of conversion are bypassed. Conversion still occurs but this is through the encounter itself:

'I was a domestic I just walked out of here that day and went to join an agency and gave up my job and then I landed up in an EMI home, had never been in one before. I didn't have a clue, didn't know anything really' (DGH03/participant01)

This nurse participant jumped straight from the naïve space to the shared space where as a dementia support worker she exemplifies the building of bridges and seeking to connect to the other. For others there is a tipping point at which the nurse relocates from the signalling space to the shared space and finds her destination to circumscribe a whole new concept of compassionate dementia care. Dietze and Orb (2000) captured this and argued that compassion did not reside in any single act on the part of the nurse but instead it was to be glimpsed in the way that the nurse carried out the act. If the intention was to do 'good' then that act was itself virtuous and benevolent.

The desire to undertake the act arose not from any duty expected of the nurse but because both she and the other are part of a shared humanity. In respect of the background process of the third conversion the nurse has come to see that he, the person affected by dementia, is no different to her and that they are no different to all other human beings. There are no distinctions and whilst each brings something different to the relationship they stand together. The nurse is freed from restrictions of role and in fully closing the circle the final piece of the Aristotelian philosophical legacy fits neatly here as what has been found through the process of exploration is *philia*, the natural friendship that connects all humans. There is much in this space that dovetails with the fifth, sixth and seventh of the Meleis milestones (Meleis, 2012). The fifth documents nursing's focus on epistemic diversity and its impact upon both nursing research and theory. In placing emphasis on, and embracing, culture, ethnicity, language, beliefs, values and geography as well as understanding more about the diversity of individual experiences of illness. This opened the way for the empowerment of nurse researchers to break away from positivistic science and pursue methodologies better suited to that which they wanted to explore. In a sense taken collectively the literature in the substantive review is not only representative of this

period but directly informed the heuristic model. That it continued to reflect the empirically derived final Six Space Model shows that the two are inherently connected.

The final Meleis milestone saw nursing moving onwards into the future and in many ways the future space of the model is still being written. Whilst it is potentially an uncertain future with the literature questioning the sustainability of compassion in a technical 21st century health care system. In such a world nurse explorers may become technicians (Fry et al, 2013) and increased demands see newly qualified nurses stating that they do not have time to be compassionate (Curtis et al, 2012) whilst the perils of compassion fatigue (see Joinson, 1992 and Figley, 1995) assume a stronger voice than that celebrating its potential for good. Overall the nurse is attempting to practice differently because she feels compelled to do so. As she occupies the signalling space and is firmly engaged with the way of dialogue (Wiesner, 1987) the influence of virtue ethics comes to the fore. The question is asked 'what ought a nurse to be?' (Tuckett, 1998, p220) and the nurse may reflect on asking 'what kind of a person do I want to be?'

As considered in Chapter Ten, this may be a point where it goes too far, becomes too evangelical and too meta-physical. A point may be reached where the emphasis is moving away from the person with dementia and his needs towards the nurse and her self-development. At the human level the nurse and the person are equal but he has a need for physical care or treatment not because he has dementia but in addition to his dementia. He has a right for the need to be met and in some senses this is reflective of the possession of a legitimate need for nursing (Orem, 1985). That is problematic and contradictory for the relationship in this space. At one level what is espoused is that they are fundamentally equal whilst at another that is not possible. He has a legitimate need for nursing which suggests that he has been judged, measured or assessed and, the legitimacy is accepted because he has a deficit in meeting a known self-care need.

This is the relationship found back in the established space where the nurse doesn't question who she is or what kind of person ought she to be. Such questions would be regarded as distractions from implementing the nursing process, there is no need for reflection the nurse in 'not getting involved' is thoughtless and inconsistently there is no place for thoughtlessness in the spaces of solidarity. So these two spaces cannot

be everything to everyone. They only work for those who move away from delivering nursing care, take up advocacy and become friends with a relationship untainted by the physical aspects of care. It is of note that every dementia support worker involved in this research, experienced an inspirational encounter, practices in a way that distances them from physical care, passionately advocates for the rights of people with dementia, sees no problem in forming friendships as part of their practice and occupies either the higher end of the spaces of conversion or the spaces of solidarity.

12.4 What Contribution has this Research Made?

The scoping review found that literature related to a unique, stand-alone concept which could be labelled compassionate dementia care was essentially absent. Over the five years of undertaking this course of study the position has not changed in any meaningful way. This research will start to fill that void. It does not offer a universal conceptualisation of compassionate dementia care but one that is drawn from the world of the district general hospital and from those nurses who practice therein. It is a concept that is quite clear, before one can deliver compassionate nursing care one must first acknowledge the importance of three specific conceptual properties. Firstly, people with dementia need more time allocating to them and the compassionate nurse must act to find that time. For those people without dementia who are admitted for care and treatment having limited (but hopefully quality) time with their nurse is understood and acceptable. For people with dementia the absence of that time can be devastating and if additional time is not included for any nursing activity then understanding and meaning may be quickly lost and regained with difficulty

Secondly, the nurse must know who the person is behind the role of 'patient' – this is crucial for building the bridge necessary for connecting to that person. For those people without dementia who are admitted for care and treatment there are many opportunities to project their sense of self and to select which aspects of the self they wish to share. For people with dementia the self has been shattered by dementia and for many it becomes almost impossible to project themselves as they wish to be seen by others. Thirdly, the nurse must appreciate and be sensitive to the plight of this person who finds himself in an alien place within which at every turn his selfhood is threatened. For those people without dementia who are admitted for care and

treatment the hospital can be a strange place outside the scope of one's everyday experience but it will still be largely fathomable. For people with dementia it is less so and this can lead to distress responses that others find challenging and which significantly interfere with care delivery and to negative labelling of the person.

The preservation of the sense of self then becomes the context within which all aspects of nursing care can gather around. By doing so time is liberated as every 'task' becomes an opportunity to strengthen the triadic intervention, time has been found and time is used to understand the person and his situation whilst simultaneously all other aspects of nursing care are delivered. Alongside this collective conceptualisation the research has influenced the development of a Six Space Model that shows the spaces from which nurses' practice and within which alternative conceptualisations of compassionate dementia care can reside. That model is much more a universal product than the acute care conceptualisation. It can apply as a benchmark or a guide for all nurses who deliver dementia care.

Finally, the finding that the way in which a nurse first encounters a person or persons with dementia can be a highly influential experience and set the nurse on course towards practicing in any of the six spaces in the model. In respect of dementia care this is a new way of thinking that is supported by the data and its analysis. The narrative as told by the nurse may offer a novel insight into her beliefs and relationship with dementia care far better than any psychometric test.

12.5 Personal Reflections

Over the course of five years this research has changed in its focus and approach and I believe that validates the time taken to complete the course of study. There have been short and enjoyable acts of gathering the participants together which was about more than just collecting the data as those nurses were offered an opportunity to, stop, reflect, work together, laugh, and talk about compassion in the context of dementia. I see these nurses regularly as part of my role and there is something different about our relationship now, an acknowledgement that we shared something and I can see that each of them has been affected in some way by the process. There have been painful periods of scoping the literature, transcribing data (around 120,000 words) and painstakingly analysing that data step by step. There have been productive periods of

writing and trying to find the right word or craft the perfect sentence or remember how important signposting is to the reader who has not lived these five years with me. Most importantly there have been long reflexive periods of thinking and talking whilst I tried to link up or find insights in the literature or the data or the direction of a chapter if not a whole thesis.

The time to think has been invaluable and has influenced the refocussing of what it is that this study has been about. Abuse of the vulnerable has motivated me but any grand designs of discerning a new approach to change that are at one level pompous and at another too early to contemplate. Certainly Appreciative Inquiry has the potential to change practitioner beliefs and behaviour and through that to change culture but this has not been the time to fully test out on the grand scale. The contribution of five years' work lies in the conceptual and I am happy with that. Five years ago one of my supervisors (JRM) asked me what I thought compassionate dementia care was, I didn't know. Now I do and, even though it may not be the same thing as the twenty-three nurse participants in this study say it is I'm content with my view, I respect theirs and I'm comfortable with knowing where both I and they sit within the Six Space Model.

Although I believe this study to have achieved its aims there have been some unavoidable limitations. Firstly, the research was undertaken within one Health Board and as such the findings may represent a set of outcomes that are culturally or organisationally unique to North Wales. Accepting that limitation from the start was mediated by the reality that each of the research sites was at least fifty miles from the others, there was limited contact between the nurses from each site and, the organisation (following a process of restructuring within NHS Wales) was sufficiently immature to have not yet acquired a standardised approach across its breadth of clinical services.

Secondly, I have claimed that the study has demonstrated the generative capacity of Appreciative Inquiry. That claim is made on the basis of analysing the change experienced by some of the nurse practitioners as they underwent the 4-D process. Whilst I stand by that finding it is acknowledged that the lack of a longitudinal follow up, to further assess practice change, is a limitation. Thirdly, there is innovation within

this study and I believe there are novel findings which make an epistemological contribution. However, because new ground is trodden key aspects of the analysis had to be reflexively developed. In particular there was no model for using positioning theory as an analytical tool and, I have had to draw out from the discipline of functional linguistics the sufficient basic tools to assign meanings beyond the surface. Whilst I believe that I have approached that in as rigorous a way as possible within the time constraints I acknowledge that others could interpret the analytical model in their own way.

Fourthly, the nurse participants were a self-selecting group whose motivations for taking part in the research I have not explored. A significant number had an interest in dementia care (although it is evident that some clearly did not) and for many that may be a reflection of their initial contacts with either a family member affected by dementia or an early inspirational encounter. Whatever their motivation, I accept that it could interfere with the final conceptualisation but also choose to accept that as a collective, self-selected or otherwise, they had much to contribute. Finally, in respect of limitations, there is a paucity of literature related to other interpretations of what compassionate dementia care may be. Whilst the literature review has included literature only up to 2016 I have kept an eye on it since then and there continues to be an inadequate number of contributions.

12.6a Primary Recommendations

For Research

Further narrative research is needed to further explore the predictive properties associated with initial encounters and practice development.

This research has found that the initial encounters were important events in shaping the practice of the twenty-three nurses who participated. This is potentially a very important finding which can enhance the contextual understanding of the nursing care for those with dementia. There needs to be further and more focussed exploration of this to establish if there is a correlation to be found within larger groups of practitioners in different areas of practice and at different locations.

For Policy

The education of health and social care undergraduates must include reflections on the concept of compassion and students must be exposed to a balanced critique as to its risks and benefits.

The vulnerability of compassion in the face of increasingly technological 21st century health care has been cited in this thesis. As a consequence of that the questioning by academics as to the value of teaching compassion to nursing students has also been seen in the literature. However, this draws nursing away from its fundamental function as a human and social endeavour whose ontological essence cannot be replaced by technology. Compassion as the core of nursing practice transcends technology and nurses should have opportunities to reflect upon its benefits to patients, potential risks to themselves and the recognition of compassion fatigue in themselves and others.

For Practice

Senior managers need to consider the importance opportunities offered by taking nursing staff out of practice to reflect and review with others aspects of practice.

This research has shown that offering nurses the opportunity to step out of practice and be part of research provides them with an opportunity to reflect upon and change practitioner behaviour. In the pressurised and frequently chaotic world of the acute hospital there is limited time to reflect or engage in the normative discourse required to question or challenge practice sufficient to identify or set new standards.

12.6b Secondary Recommendations

For Research

1. It should be explored whether the impact of restricted initial encounters can in some way be mitigated or that such schemas are indeed fixed.

This follows from the point above and is of equal if not more importance. If it is established from replication or further narrative analysis that the initial encounters are important then the impact of later encounters must be explored. My research has suggested the schema is formed at the first encounter and consequently that later encounters lack generativity. This however makes me uncomfortable as it leaves the nurse with nowhere to go and intuitively one feels that there must be some other mechanism available to offer a pathway to change. A close encounter at a later point may be such a mechanism but this needs to be tested over a larger cohort of nurses. It also seems too deterministic that the two restrictive encounters condemn the nurse to a career of restricted practice (even though this is commonly and anecdotally suggested). As many of restricted encounters involve people with dementia who are frail, vulnerable, unwell and possessed of complex and challenging symptoms then, the potential for deliberately arranged positive encounters with different cohorts of people with dementia could be explored.

2. The suggestion that the spaces of solidarity may be a step too far and lead to ambiguities in practice for the nurse should be tested further with a larger or less homogenous cohort of participants to determine if this is a generalizable finding.

The Six Space Model is book ended by two distinct poles. The first of restriction where there is little or no value for those with dementia and, secondly the spaces of solidarity where the nurse immersed as she is in fellow feeling associates herself very closely with those affected. The first spaces are potentially, but not definitively, associated with inadequate care, serious service failure and abuse. However, the practice of the nurse in the spaces of solidarity is much less explored and understood in terms of its impact on those involved. There are good reasons therefore to pursue this through post-doctoral narrative enquiry.

3. There should be a longitudinal follow up to a study of this kind to assess the extent to which the commitment to practice change translates into real action. Allied to that would be an exploration of the forces which shape or inhibit that action.

This relates to the identified limitation that once collectives made their provocative propositions the process stopped. As such there was no action to determine if the nurses had followed through on the proposition and made the changes. Whilst this thesis has accepted the functional linguistic stance, that uttering the proposition is enough to indicate change within the practitioner, this may, outside of academia, be inadequate. If the nurses state that the nursing station is an unfriendly barrier and the illocutionary force shows that it is not the station but the nurses themselves that is being described, then removing the station becomes a symbolic act which represents change in practitioner behaviour. By failing to undertake the physical act the nurses undermine the message they are otherwise trying to communicate and one could be justified in questioning whether Appreciative Inquiry had been sufficiently generative. This may be a challenge too far in respect of 'an elephant on every ward' but post-doctoral work could otherwise be valuable.

4. In this study a bespoke analytical model was constructed around positioning theory. This may, or may not, be transferable to other research. It was however of utility to this research and there should be an opportunity to develop positioning theory as a valid and reliable method for analysing qualitative data.

Introducing positioning theory as part of the analytical tool box was a gamble but it has added a new dimension to the interpretation of narrative data. The identification of specific positions being adopted by the nurse participants aligned well with other analytical outcomes and strengthened the framework statements. The positions gave a useful insight into the beliefs of the nurse participants about dementia and those affected by it. However, positioning theory is not commonly used as a mechanism for qualitative data analysis. Given the potential found in my research it is suggested that it be explored further and that a set of guidelines be developed to support researchers to use it more widely.

For Policy

1. Compassionate care of people with dementia can be facilitated by the triad of identified conceptual properties (the spotlight and centre stage properties). Attention should be placed, by policy makers, on supporting those delivering care to develop adequate knowledge, skills and motivation to support these key properties.

The concept developed through my research shows that there is a triad of three conceptual properties which must be present if nursing care for the person with dementia can be considered to be compassionate. These properties concern themselves with entering the world of that person and seeing the experience through his eyes. Current policy in respect of learning outcomes from dementia training address this in part but need to go further and to emphasise that practitioners must be provided with opportunities to acquire and reflect on these properties.

2. There should be support for the concept of meaningfully including people with dementia and carers as co-educationalists in the development of undergraduate and post graduate health and social care students.

Nurse participants in this study had encountered people with dementia at various levels of symptom severity however, the dominant encounters were with those who were their patients of the acute hospital. This meant that the nurses were overwhelmingly encountering people with dementia who matched the stereotype, older, frailer, acutely ill, distressed, and vulnerable and out of touch with reality. In breaking through the stereotype there is a need to expose nurses to people with dementia who present differently and who are able to articulate what dementia means to them in daily life. In part this fits with recommendation 12.6b1 above and the greater inclusion of people with dementia in training and education could be a means of providing those positive encounters.

3. Health and social care undergraduates should be exposed to appreciative and affirmative research methodologies that focus on those things within social organisations that work well. They should graduate with a skill set that includes the ability to facilitate this kind of approach towards change.

Appreciative Inquiry was an effective methodology for this research. It was non-threatening to the participants who readily participated and its generative potential with that cohort has been demonstrated through my research. It is a methodology that can be applied to many areas of practice and organisational development and I advocate that it be part of the skill set for nurses.

4. There needs to be action to develop and introduce policy drivers aimed at addressing negative socialisation related to dementia care in the workplace.

It is unacceptable that generations of nursing have been allowed to maintain the poor attitudes and beliefs which drive inadequate care and which can ultimately lead to serious service failure. In addition to actions related to recommendations 12.6a1 and 12.6d2 there needs to a stronger focus on nurses finding the courage to challenge poor practice and for supervision in relation to dementia care to be offered by those with an understanding of best practice.

5. Policy makers should emphasise the importance of building relationships between people who use services and those who develop them. This should be one mechanism by which health and social care staff can be presented with opportunities to enjoy positive experiences with people affected by dementia and carers.

Health care organisation, institutions and facilities are social organisations. They are made up of people traditionally divided into social roles predominantly associated with those who need care and those who deliver care. This thesis in its exploration of positioning theory has shown that roles can be regarded as defeasible and open to reinterpretation. The voice of those using services is becoming increasingly prominent and service development increasingly rooted in meaningful engagement. As that increases the concept of stepping outside of

socially ordained roles and working together in collaboration increasingly becomes accepted as the norm then this will act to build further on recommendations 12.6b2 and 1w2.6d2 and create those positive opportunities that may mitigate for earlier restrictive encounters.

For Practice

1. Provocative propositions made at the close of an Appreciative Inquiry workshop must be owned by the participants and management support is needed to turn these into reality.

Recommendation 12.6a4 addressed the longitudinal monitoring of nurse practitioners follow through on collective provocative propositions. As the wider view may be that actions are more important than words then such propositions are meaningless without the participants genuinely being motivated to carry them out and, their managers providing whatever support is required.

4. Listening to the person with dementia should be regarded as a legitimate use of a nurse's time and given priority.

As the spotlight property of compassionate dementia care time is needed to learn who the person is and to appreciate the plight that he finds himself in as only then can care be effectively and compassionately delivered. Nurse participants suggested that they often do not have the time to talk with and get to know people in their care beyond the superficial. Whilst this is open to challenge as nurses spend a lot of time with patients whilst undertaking care tasks but choose not to use that time to good effect. That said, part of the cultural shift in nursing people with dementia (as also outlined in recommendation 12.6b5) involves thinking differently about what is important to dementia care. Repositioning making time to get to know the person and understand his experience as the key to providing compassionate dementia care is the appropriate place to start.

12.7 The Welsh Context

Welsh health and social care policy sits within a broader National agenda that resonates in many ways with this thesis and the findings reported therein. The overarching political program is captured within 'Taking Wales Forward' (Welsh Government, 2016) which aims to ambitiously look beyond Brexit to question what kind of country Wales should be and how can that be achieved. The emphasis is placed on working together, building stronger communities, improving and reforming public services, supporting people when they need it most and overall seeking to be a country characterised by confidence, equality, skills and resilience.

Articulating this macro policy and allowing it to be operationalised across all public services was set out in 'Prosperity for All: the national strategy' (Welsh Government, 2017) and buttressed by 'The Well-Being Statement' (Welsh Government, 2017). Within both can be found a focus on the delivery of policy and, in respect of health care, it is the future state of services and the promotion of good health which is stressed whilst the whole is driven by involvement, collaboration and integration. Within the policy program lies a fundamental existential question as to what kind of nation should Wales be and what needs to be done to achieve that?

There is resonance here with the discourse around the positioning of the nurse as she travels the compassion focussed journey. That nurse moves away from thinking 'what do I do?' towards 'how do I do it?' and ultimately to asking 'what kind of a person should I be?' As she enters the spaces of Conversion and of Solidarity she too is finding the emphasis for her practice being placed on improving services, supporting the other and finding her confidence, skills and resilience to remain distanced from the Naïve spaces. Consequently what is found deep within 'Taking Wales Forward' (Welsh Government, 2016) and front and centre of this thesis is the same existential stance and ambition. Understanding the Six Space Model offers the nurse an opportunity to not only position herself in comparison to her peers but also to view the quality of her practice as a contribution to the health and prosperity of Wales.

Even deeper within the Welsh policy agenda is found the emerging view of the change required by health and social care services. That change is set in the context of episodic, but serious, service failure involving the abuse of vulnerable people including

those with dementia. Historically that has included the inquiries into Eley hospital (Robb, 1967) and St. David's (Walshe, 2003) and, more recently, Tawel Fan (Ockenden, 2015), Bridgend, Port Talbot, Brecon and, Mountain Ash hospitals (Andrews and Butler, 2014). These abuses occurred across Wales and a response was required. So, before the publication of 'Taking Wales Forward' (Welsh Government, 2016) Wales, unlike all other countries around the world, chose initially not to have a dementia strategy but rather a vision (Welsh Assembly Government, 2011). That vision reflecting the welsh sense of community and its bardic culture aimed at building dementia supportive communities within which people with dementia could participate as equal and active citizens for as long as possible. In short, as the historical abuses had occurred within a context of exclusion, objectification, denial of rights and rejection of citizenship, the response was to deliberately framed within an existential and culturally influential context of 'Welshness'.

The National Dementia Vision for Wales (Welsh Assembly Government, 2012) sits comfortably with the tone, flow and findings of this thesis. Such supportive communities must be compassionate or fail to live up to the spirit of the vision and, their conceptualisation of compassion must be aligned to that set out by the collective of nurse participants in my research. That is they must take the time to be aware of the other (their fellow citizens with dementia), they must come to know each person beyond the label of dementia and, in order to be supportive, they must understand the situation that he or she finds themselves in. Effectively they must view the world of their town, village, church or shop through the eyes of the other and make reasonable adjustments to facilitate inclusion and participation.

That there are alternative conceptualisations should not go un-heeded. Whilst the National Dementia Vision remains the primary influence it is of note that the most serious service failures have occurred after the vision was launched. Those failures encompass four of six Health Boards and have involved the direct abuse and in some cases criminal assault of vulnerable people in hospital care. The policy response to this is for the National Dementia Action Plan for Wales (Welsh Government, 2018) to emerge from within 'Taking Wales Forward' (Welsh Government, 2016) and whilst retaining the cultural ties of the National Vision for it to be much more direct in respect of the improvement expected.

One could argue here that the need to set out and monitor expectations reflects a loss of legitimacy in Welsh health and social care services to be safe, effective and compassionate providers of dementia care. At the heart of the actions which lead to this loss of legitimacy is my finding that four relational themes circumscribe and influence the practice of people working with those affected by dementia. As an example, those who have experienced empty encounters articulate positions which predispose towards poor care and potentially towards abuse. If people with dementia are seen as troublesome or less than us then our behaviour towards 'them' can legitimately be different than towards others. No positive change can be expected from those who experienced brief encounters and who go on to deliver care reluctantly and in ignorance of holistic needs of that person. For both there is a clear need to state what is expected from practitioners, how those expectations will be evidenced and reported by health and social care organisations, how they will be monitored and ultimately how progress will be made public.

There is therefore a relationship of sorts between the policy agenda and this thesis although it is a relationship developed in isolation. The findings offer a new layer of understanding about how individual practitioners may be influenced and how those influences impact on the care of people with dementia. More importantly the findings align to the unwritten aspects of policy and in particular the challenge for organisations to mitigate for practitioners who have little regard for people with dementia and low individual absorptive capacity for change. This thesis has found that there is help to be found within the generative potential of a democratic research method such as Appreciative Inquiry and, that by bringing practitioners together a process of redemptive mitigation is possible. The relationship between policy and research findings needs to be articulated and published so as to acknowledge the link but also to continue the normative discourse and move it into a third level of policy making.

Where the first level was vision and strategy and, the second was improvement planning, reporting and monitoring then the third level will be more highly reflective of positioning theory and particularly of rights and duties and the argument from Harre (2015) is worth rehearsing again here. Duties, he argued, are always oriented towards the other who has a vulnerability and are assigned to one who can overcome that vulnerability whilst rights are what one exercises as a result of ones vulnerability with the expectation that the other will fulfil his responsibility towards one. This expectation

is possible because of the process of socialisation and yet Chapter One highlighted how workplace socialisation led to empty encounters, negative role modelling and a rejection of rights and responsibilities in respect of people with dementia.

The third level of policy making aims to address this but has only reached the position of doing so because policy makers have increasingly lent towards the increasing influence, involvement and participation of people living with and affected by dementia in the political sphere. As such the process has already been generative and stimulated the kind of transformative discourse sought by Gergen (1982) which has led to the third level of dementia focussed policy emerging as the, yet unwritten, Welsh Dementia Constitution is constructed through normative discourse aimed at establishing National quality indicators different to those set for England.

In many senses my involvement with that national project is this research brought to life. It sees me and others occupying the Spaces of Solidarity with one foot firmly rooted in the Shared Space whilst the other tentatively reaches out to the blank page which is the Future Space. It is an experience that aligns strongly to the view of the Spaces of Solidarity as being a political place but also one of emancipation as again in the language of Cooperrider and Srivastva, (1987) the nurse has ceased to be mechanic and has become explorer. That policy is being shaped by practitioners, carers and people affected by dementia and brings with it the echo of the spiritual journey which whispers that the destination is a place where there are 'now no longer distinctions, we stand together, our relationship and stance has fundamentally and permanently changed' (Wiesner, 1987 p217).

12.8 Final Thoughts

At the risk of repeating myself I believe that my research has made a positive contribution in the field of dementia care and has added something new to the understanding of compassionate care. It has addressed the 'what, where and how' of compassionate dementia care and offered a template of expected practitioner behaviours which underpin the concept.

The findings have shown that democratised research has an important part to play in encouraging narrative, challenging assumptions and shaping future practice. These

are important as I believe I have demonstrated that redemption is possible for those who practice in the spaces of restriction where the concept of compassionate dementia care is most misunderstood. The choice of the word 'redemption' is deliberate and implies that there is something, perhaps not sinful, but certainly malignant about those spaces of restriction. Whilst the naïve space is populated by almost everyone in society their superficially, sympathetically and sinful views of people affected by dementia are understandable as rooted in ignorance and largely forgivable. However, this position is shifting as society at large is subject to such things as 'the Prime Ministers challenge' or the Alzheimer's society's dementia friends project and, the voices of dementia activists arguing for changes in language used to describe dementia and those affected by it. It is not outside the bounds of possibility that as the increasing number of people affected by dementia impacts upon society that the inherent properties of the naïve space may become less amenable to absolution. In taking the view that the spaces of restriction are ones from which the nurse can be saved suggests that the initial encounter may not be as deterministic as this thesis has implied. Given opportunities for development the nurse can be redeemed and can undergo something close to the conversions found in the spiritual journey. This takes the nurse away from restriction towards emancipation but ideally settling midway in a space of conversion where she is continually refreshed by each encounter.

Redemption in the context of this thesis lies in the generative capacity of Appreciative Inquiry as a legitimate methodology for democratic research. It has been demonstrated that five out of six nurse participants who entered the 4-D process with beliefs reflective of the restrictive spaces exited as committing themselves to positive change in practice. Attached to this was an increased understanding of the other not as a 'dementia patient' but as a person caught up in, and trying to make sense of, difficult and challenging circumstances. I have very high regard and stand in solidarity with each person affected by dementia who is plunged without warning into a place that is alien, uncomfortable, frightening and incomprehensible. I have great respect and fondness for those nurses who day after day return to the strange world of the big district general hospital and do the best that they can for others in need. If this research can support nurses to better understand the particular needs of a person with dementia then their best care will become even better and I will be satisfied with that.

Appendices

Appendix I - Serious Service Failure – a fifty year history

Appendix II – Study Information Sheet

Appendix III – Consent Form for Participation in the Research Study

Appendix IV - Ethical Approval Letter – Healthcare and Medical Sciences Ethical Committee

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Appendix VI – Scoping Review: search results

Appendix VII - Scoping Review: charting the data

Appendix VIII – Aligning the data to Meleis milestones

Appendix 1 - **Serious Service Failure – a Fifty Year History**

Date	Place	Issues	Outcomes
1968	Banstead Hospital – Surrey	Following publication in 1967 of ‘Sans Everything’ 7 hospitals cited by the book were investigated. Allegations encompassed ill treatment, wilful neglect, physical abuse, psychological abuse, unkind, unsympathetic attitudes and lack of staff training.	7 formal inquiries of which only one upheld allegations of physical abuse and ill treatment of elderly vulnerable patients at Springfield Hospital. Inquiry outcomes generally regarded as biased.
1968	Cowley Road Hospital – Oxford		
1968	Friern Hospital – London		
1968	St. James Hospital – Leeds		
1968	Storches Hall Hospital – Kirkburton, Yorks		
1968	St. Lawrence’s Hospital – Bodmin		
1968	Springfield Hospital - Manchester		
1969	Ely Hospital - Cardiff	Ill treatment, abuse and neglect of long stay patients. Isolated hospital. Closed culture. Poor staff training no nurse had attended	Traditional inquiry with recommendations. Introduction of national monitoring system.

Date	Place	Issues	Outcomes
		training for 20 years. Older patients nursed on back-wards with no medical involvement.	Management team replaced. Additional staffing resource
1971	Farleigh Hospital - Somerset	Physical abuse of elderly mentally ill patients within a culture of indifference from nurses.	Traditional inquiry
1972	Whittingham Hospital	Allegations of cruelty, ill treatment, theft, callous, cruel and incompetent nursing care	Traditional inquiry and police investigation
1972	St. Augustine's Hospital - Kent	Poor care of patients on long stay ward. 70 cases of abuse of vulnerable people, neglect and derogatory practices.	Traditional inquiry all allegations upheld. Criticism of senior staff. No disciplinary action.
1974	South Ockendon Psychiatric Hospital	Physical abuse of elderly mentally ill patients within a culture of fear and intimidation. Relates to events from 1968	Traditional inquiry
1975	Brockhall Hospital, Blackburn Lancashire	Physical abuse of patients with learning disability	Traditional inquiry
1976	Memorial Park Hospital - Darlington	Involved allegations of poor care in the psychiatric unit of a district general hospital leading to deaths of patients	Traditional inquiry

Date	Place	Issues	Outcomes
1976	St. Ebba's Hospital - Epsom	Physical abuse of patients with learning disability	Traditional inquiry
1976	Bolton General Hospital – Psychiatric Unit	Cited in the comprehensive list by Munson-Barker (1981) but report no longer available	Traditional inquiry
1977	Mary Dendy Hospital – Great Warford	Two male nurses investigated for ill treatment of mentally ill patients	Traditional inquiry
1978	Normansfield Hospital - Middlesex	Poor care of patients with learning disabilities some with severe vulnerability and physical health needs. Breakdown and conflict in working relationships.	Traditional inquiry
1979	Church Hill House Hospital - Bracknell	Allegations of assault and abuse by staff on vulnerable patients.	Traditional inquiry
1979	St. Mary's Hospital - Gateshead	Cited in comprehensive list by Adams (2002) but original report no longer available	Traditional inquiry
1980	Brookwood Hospital – Guildford, Surrey	Cited in comprehensive list by Adams (2002) but original report no longer available	Traditional inquiry

Date	Place	Issues	Outcomes
1980	Newchurch Hospital	Cited in comprehensive list by Adams (2002) but original report no longer available	Traditional inquiry
1981	Sandhill Hospital	Cited in comprehensive list by Adams (2002) but original report no longer available	Traditional inquiry
1982	St. David's Hospital - Carmarthen	Series of reports dating back to 1974. Deplorable standards on some wards with little regard for privacy or the preservation of human dignity.	Traditional inquiry
1999	Beech ward – St. Pancras Hospital	Allegations made by whistleblower of physical and psychological abuse of 13 elderly mentally ill patients from 1993 to 1996.	Traditional inquiry. Allegations upheld. Ward closed. Recommendations made.
2000	Whipp's Cross Hospital - London	Allegations raised by undercover reporter of neglect, psychological abuse and inhumane practices towards vulnerable elderly patients.	Traditional inquiry – all allegations upheld. 41 recommendations made.
2000	Lakeland NHS Trust - Cumbria	Appalling abuse of elderly people with degrading, cruel and unprofessional behaviour	Traditional inquiry by CHI. Allegations upheld. Recommendations made.

Date	Place	Issues	Outcomes
2000	Garlands Hospital - Carlisle	Allegations of physical and psychological abuse of elderly vulnerable patients with mental health problems.	Traditional inquiry by CHI. Allegations upheld. Recommendations made.
2000	Epsom and St. Helier NHS Trust	Increased mortality amongst elderly vulnerable patients	Traditional inquiry by CHI. Allegations uphold. Resignations by senior management team. Recommendations made.
2002	Gosport war memorial hospital - Hampshire	Concerns expressed by the police around the care and treatment of frail older people including the potential unlawful killing of a patient in 1998. Concerns about quality of care and inappropriate use of medicines.	Traditional inquiry by CHI. Allegations upheld. Recommendations made.
2003	Rowan ward - Manchester	Whistle-blower allegations of physical and psychological abuse of patients with advanced dementia.	Traditional inquiry – police investigation, all allegations upheld. Recommendations made.
2011	Stafford Hospital – South Staffordshire	Allegation dating from 2005 of neglect, indignity, poor care, uncaring attitudes and lack of compassion.	Traditional inquiry – the Francis report with 200+ recommendations.

Date	Place	Issues	Outcomes
2011	Winterbourne View – South Gloucestershire	Undercover filming by BBC Panorama revealed physical and psychological abuse of vulnerable people with learning disability.	Led to CQC investigation and 132 inspections of similar institutions.
2011	<p>Ealing Hospitals NHS Trust</p> <p>Royal Bolton NHS Foundation Trust</p> <p>Southampton University NHS Trust</p> <p>Heart of England NHS Foundation Trust</p> <p>Oxford Radcliffe Hospitals NHS Trust</p> <p>Ashford and St. Peters Hospitals NHS Foundation Trust</p>	Report by the Health Service Ombudsman into ten investigations into care of older people in hospital.	Commissioners' conclusion is that the reasonable expectations that older people may have for quality care are not being fulfilled and that the NHS is failing to respond compassionately.

Date	Place	Issues	Outcomes
	Surrey and Borders Partnership NHS Foundation Trust Northern Lincolnshire and Goole Hospitals NHS Foundation Trust		
2012	Tawel Fan ward – North Wales	Allegations of physical and psychological abuse and uncaring attitudes and lack of compassion	Traditional inquiry. Police investigation. Removal of senior management team.
2014	Gosport war memorial hospital - Hampshire	Unexpected deaths of 92 elderly patients. Inappropriate use of tranquilising medication. Allegations date from 1988	Traditional inquiry reopened following earlier CHI Inquiry
2014	Princess of Wales hospital - Bridgend	Allegations of poor unacceptable care for older vulnerable patients with loss of compassion	Traditional inquiry leading to the Trusted to Care report with recommendations.
2014	Neath hospital – Port Talbot		

Date	Place	Issues	Outcomes
2015	Princess of Wales hospital - Bridgend	Inappropriate medication and elderly patients	Police inquiry
2015	Brecon War Memorial Hospital	Physical abuse by HCSW. Drunk staff on night duty. Lack of food for patients.	Internal and Police investigation
2015	Ysbyty Cwm Cynon – Mountain Ash	10 staff suspended following death of elderly patient with unexplained bruising.	Internal and Police investigation
2018	Tawel Fan ward – North Wales	Second investigation of events from 2013. Undertaken by the Health and Social Care Advisory Service.	Traditional inquiry leading to comprehensive report with significant priorities for change.

Appendix II – Study Participant Information Sheet



***Conceptualising Compassionate Dementia Care in the Acute
Hospital – an appreciative inquiry***

Participant Information Sheet

The Study

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Sean Page is an honorary Senior Lecturer in nursing and a Consultant Nurse in North Wales. He is completing research at the School of Healthcare Sciences as part of his PhD.

What is the purpose of the study?

This study examines the way that acute hospital nurses understand the concept of compassion, the meanings that it has for them and how those

meanings influence the way in which care is delivered. In particular it examines what compassionate care means in the context of patients who have a dementia and what that might look like in practice.

The study also aims to test a novel approach or methodology that is called Appreciative Inquiry. This approach suggests that change can be brought about by looking at what works well and talking to each other about why this is. As that conversation is developed, stories are shared and images emerge about what possibilities there are for the future. It is a method in which those being researched are fully involved in the research process.

A sample of thirty nurses and healthcare support workers will be recruited from areas of the district general hospitals that provide care to patients with dementia. The aim is to establish a learning set of ten nurses at each of the three main acute hospitals.

Why have I been chosen?

You have been approached because you are either a registered nurse or a health care support worker who provides care to patients who have dementia. You are part of the group from whom we wish to learn what the understanding of compassionate dementia care is.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and, in time, be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

Although Sean Page is a senior nurse in the health board, he is for the purposes of this research to be regarded only as a post graduate student

of Bangor University. If you decide not take part in this study your relationship with Sean Page as a senior nurse will not be affected.

What will happen to me if I take part?

If you express an interest in taking part, Sean Page will make a convenient appointment to see you at your place of work. The aim of the study will be explained to you once more and, if you are happy to proceed after this visit, then you will be a participant in the study.

In the first part of the study Sean Page will ask if he can interview you about your experiences of nursing patients who have dementia and what, from your perspective, makes for good care. This interview will be tape recorded.

In the second part of the study you will be invited to join a learning set of about ten people, all nurses from your hospital. A learning set is a group of people who work together to understand something. In this study we are trying to understand what compassionate dementia care means.

The learning set will meet twice. Each meeting will be a three hour workshop that will follow the stages of the Appreciative Inquiry approach. At the end of these workshops it is hoped that you and the learning set as a whole will have identified a model of what compassionate dementia care is. At that point you will be asked to see if there are changes you can make to the care of patients with dementia that fit with this model that you have helped to create.

In the final stage of the research Sean Page will ask you if he can interview you again. That interview will explore your views on having taken part in the research and if any changes have been made to the care of patients with dementia.

All information that you contribute to the research will be strictly confidential so that only those involved in the research will know exactly what you have said. Your name will not be used on labelling of the audio recordings or in any report. The audio files will be stored in a secure place at Bangor University. Any information collected about you in the course of the research will be kept strictly confidential and destroyed at the end of the study in accordance with the data protection act, unless you consent to the data being kept as part of an archive in an anonymised form. Otherwise, the record of the interviews on tape will be erased as will the stored transcripts held on computer records.

What if there is a problem?

Sean Page is an honorary member of the teaching faculty at Bangor University and registered as a post graduate student but is not employed by the University. Any complaint you have about your involvement in the study should be made directly to:

Professor. J. Ryecroft-Malone
Head of School, Professor of Implementation, University Director of
Research
School of Healthcare Sciences
Bangor University
Bangor
Gwynedd, LL57 2EF

Also as part of the study there is a procedure in place which deals with disclosures of malpractice or abuse reported by participants and in such instances Sean Page will be required to break confidentiality.

What will happen to the results of the research study?

On completion of the study the results will be analysed and incorporated into a PhD thesis that will be submitted to Bangor University. It is anticipated that the doctoral thesis will in whole or part be shared with others and presented either verbally or as a written paper for publication. You will not be named in any of these.

Contact for further information

Thank you for taking the time to read this information sheet. If you are interested in being considered as a research participant in the study please email Sean Page or contact him via the details below.

School of Healthcare Sciences
College of Health and Behavioural Sciences
Bangor University
Fron Heulog
Ffriddoedd Road
Bangor
Gwynedd, LL57 2EF

Email: s.page@bangor.ac.uk

Telephone number: 0788 0044220

Appendix III – Consent form for participation in the research study



Participant Consent Form

Researcher's name SEAN PAGE

Title of Project - Conceptualising Compassionate Dementia Care in the Acute Hospital – an appreciative inquiry

Please read each of the statements below. If you agree to participate please initial each box in turn.

1	I confirm that I have read and understand the participant information sheet dated 6 th September 2015 for the above study.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.	
3	I confirm that I consent to my interviews being tape/audio recorded by the researcher as part of the study.	
4	I give permission for the researcher to use anonymised quotes from the interviews and workshops and for anonymised interviews to be shared with any other researchers.	

5	I give permission for the researcher to store anonymised quotes from the interviews and workshops as data archives in Bangor University according to its regulations.	
6	I understand that as part of the study there is a procedure in place which deals with disclosures of malpractice or abuse reported by participants and in such instances Sean Page will be required to break confidentiality.	
7	I agree to take part in the above study.	

Name of person	Date	Signed
Name of researcher	Date	Signed
Sean Page		

This form will be produced in duplicate. One copy should be retained by the participant and the other by the researcher.

Appendix IV – Ethical Approval Letter – Healthcare and Medical Sciences Ethical Committee

COLEG IECHYD A GWYDDORAU YMDDYGIADOL
COLLEGE OF HEALTH AND BEHAVIOURAL SCIENCES

YSGOL GWYDDORAU GOFAL IECHYD
SCHOOL OF HEALTHCARE SCIENCES

Healthcare and Medical Sciences Academic Ethics Committee



24 October 2016

Sean Page
c/o School of Healthcare Science
Bangor University

Dear Sean

**Re: Compassionate Dementia Care in the Acute Hospital – an appreciative enquiry
Request for ethical approval of amendment to PhD study protocol**

Thank you for your application to the AEC which was subject to an expedited review as requested. All of the necessary documentation was provided and appropriately completed.

I am therefore able to give approval for your study on behalf of the AEC, and this letter constitutes evidence of that approval should it be necessary for any applications to other RECs.

Please note that approval from this AEC does not convey automatic authority to proceed with your study. You are formally advised that it is essential to confirm with the relevant authorities whether you are required to submit your proposal to any other Ethics Committee(s), such as Local NHS Research Ethics Committee, and NHS Research Governance Departments, prior to commencing your study.

Should you need to make any substantial amendments to your study protocol during the lifetime of the research, you are required to submit notice of these to the AEC for further approval, including major amendments requested by an external REC or R&D Commit

If you have any queries, please do not hesitate to contact me for clarification.

Yours sincerely

Dr Sion Williams
Chair, HCMS AEC

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Registered charity number: 1141565

HCMS AEC approval letter V2 July 2013

Appendix V – Ethical Approval Letter – NHS Research and Development Internal Review Panel



Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

**Panel Arolygu Mewnol Y&D
R&D Internal Review Panel**

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Mr Sean Page
Consultant Nurse for Dementia
Ablett Unit
Ysbyty Glan Clwyd
Bodelwyddan
LL18 5UJ

s.page@bangor.ac.uk

Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
Email: rossela.roberts@wales.nhs.uk
Debra.slater@wales.nhs.uk
sion.lewis@wales.nhs.uk
Tel/Fax: 01248 384 877

30 August 2016

Dear Mr Page

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title Compassionate Dementia Care in the Acute Hospital: An Appreciative Inquiry
IRAS reference 203492

Thank you for submitting your R&D application and supporting documents. The above study was eligible for Proportionate Review and was reviewed by the R&D Manager and Chairman of the Internal Review Panel.

The Panel is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The Proportionate Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The documents reviewed and approved are listed below:

Documents Reviewed:	Version	Date
R&D Form	-	-
SSI Form	-	-
Protocol	1	03/09/2015
Participant Information Sheet	1	29/06/2016
Participant Consent Form	1	29/06/2016
Interview Schedule	1	29/06/2016
Study Poster	1	29/06/2016
CV of CI/Student	-	06/07/2016

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009).

An electronic link to this document is provided on the BCUHB R&D WebPages.

Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database. To apply for adoption onto the NISCHR CRP, please go to: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979>.

Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at:
<http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571> and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:

http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.

Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office. If you need any support in uploading this data, please contact debra.slater@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Panel, may I take this opportunity to wish you every success with your research.

Yours sincerely,



Dr Nefyn Williams PhD, FRCGP
Associate Director of R&D
Chairman Internal Review Panel

Copy to:

Principal Investigator Ms Alison Griffiths
Assistant Director of Nursing
Ysbyty Glan Clwyd
Bodelwyddan
LL15 5UJ alison.griffiths4@wales.nhs.uk

Sponsor: Huw Roberts
Fron Heulog
Bangor University
Bangor
LL57 2EF huw.roberts@bangor.ac.uk

Academic Supervisor: Dr Sion Williams
School of Healthcare Sciences
Fron Heulog
Bangor University
LL57 2EF sion.williams@bangor.ac.uk

Appendix VI – Scoping Review: search results

Search Results

Search terms and limits	Database (provider) and number of results					Total results used in review
	JSTOR (Bangor University)	Medline (EBSCO host)	CINAHL (Bangor University)	PubMed	Philosophers Index (EBSCO host)	
Search 1						
((compassion)) AND la:(eng OR en)	291	442	344	599	152	23
((compassion)) AND (conceptualised)) AND la:(eng OR en)	02	02	0	0	0	
((compassion)) AND (concept)) AND la:(eng OR en)	163	92	186	06	12	
((compassion)) AND (concept)) AND (perspective)) AND la:(eng OR en)	112	03	68	02	02	

Search terms and limits	Database (provider) and number of results					Total results used in review
	JSTOR (Bangor r Univer sity)	Medline (EBSCO host)	CINAHL (Bangor University)	PubMed	Philosophers Index (EBSCO host)	
Search 2						
((compassion) AND (nursing)) AND la:(eng OR en)	3 201	249	587	05	09	47
((compassion) AND (nursing)) AND la:(eng OR en) AND disc:(medicinealliedhealth- discipline)	711	867	NA	-	-	
((compassion) AND (nursing)) AND (acute)) AND la:(eng OR en)	647	52	32	153		
((compassion) AND (nursing)) AND (acute hospital)) AND la:(eng OR en)	1 682	09	03	97	894	

Search terms and limits	Database (provider) and number of results					Total results used in review
	JSTOR (Bangor University)	Medline (EBSCO host)	CINAHL (Bangor University)	PubMed	Philosophers Index (EBSCO host)	
((compassion) AND (nursing)) AND (acute hospital)) AND la:(eng OR en) AND disc:(medicinealliedhealth-discipline)	589	NA	NA	-	-	
((compassion) AND (nursing)) AND (conceptualised)) AND (acute hospital)) AND la:(eng OR en)	05	00	00	00	00	
((compassion) AND (nursing)) AND (perception)) AND (acute hospital)) AND la:(eng OR en)	480	00	07	00	00	
Search 3						

Search terms and limits	Database (provider) and number of results					Total results used in review
	JSTOR (Bangor University)	Medline (EBSCO host)	CINAHL (Bangor University)	PubMed	Philosophers Index (EBSCO host)	
((compassion) AND (dementia)) AND (nursing)) AND la:(eng OR en)	119	18	70	140	00	07
((ab:(compassionate dementia)) AND (care)) AND (concept)) AND la:(eng OR en)	94	00	06	00	00	
((ab:(nurses understanding)) AND (compassionate)) AND (dementia)) AND (care)) AND la:(eng OR en)	08	01	06	02	00	
((compassionate) AND (dementia)) AND (care)) AND la:(eng OR en)	179	12	11	30	00	

Appendix VII – Scoping Review: charting the data

Data Chart 1

How is Compassion Conceptualised?

Search 1: the Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
Definition	Aristotelian	1989	Review of Aristotelian philosophy of emotion virtues such as compassion.	Roberts, R.C	C1
		2000	Sets out her view of Aristotelian concept of compassion	Nussbaum, M	C2
		2000	Sets out Aristotelian concept of compassion and critiques then develops Nussbaum's stance.	Carr, B	C3
		2005	A conceptual framework for integrating research related to the physiology of compassion and the wisdom of Buddhist teachings	Wang, S.	C4
		2010	Addresses evolutionary theory of compassion and integrates three evolutionary arguments to show the complexity of response.	Goetz, J.L et al	C5
Awareness of the other					
	Fellow feeling	2003	In a post 9-11 world compassion is threatened. Particularly in relation to the other who is distanced from us or not like us	Nussbaum, M	C6

Search 1: the Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
	Theory of mind	1994	Supports the concept that compassion is largely reserved for those from the same social group and that there is an order to this.	Burnstein et al	C7
		1995	Evolutionary theory further proposes a theory of mind to help explain one's ability to understand the other and to have insight into what he may be thinking or feeling about an experience	Byrne, R.W	C8
		2007	Measured the degree to which research participants would be sensitive to the needs of others under different circumstances. Suggests that social group membership brings benefits one of which is access to compassion from other members.	Oceja, L, and Jimenez I	C9
		2010	Explores and validates the relationship between compassion and social ties. The nearer the other is to you the more you will be compassionate.	Oveis, C, et al	C10
Awareness of suffering					
	Universal theory	1982	Comprehensive review of the concept of suffering and its relationship to personhood – suffering is experienced by persons not merely by bodies. Failure to understand that can by itself cause suffering.	Cassell, E.J	C11
	Theological	1938	Sets out a new discourse around the relationship between mercy and Christianity.	Aquinas,T.1938 edition of 1256 .Summa Theologica	C12

Search 1: the Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
		1995	Sets out the role of theological doctrine in holding together religions as non kin social groups	Durkheim	C13
		1997	Commentary on Aristotelian pity and the compassion of Christ.	Walton, D.N	C14
		2012	Addresses uncomfortable realities of compassion.	Malpas, J	C15
Responding					
		2004	Limitations on compassion are set out and relate in part to Aristotelian construals.	Altran, S and Norenzayan, A	C16
	Empathic	1979	Discusses the imagination required to be empathic and to imagine oneself in the position of the other.	Shott	C17
		1980	Sets out the concept of compassion and its relationship to compassionate empathy. Suggests response to alleviate the suffering of the other is based upon some understanding of what the other is experiencing.	Blum, L	C18
		1991	Defends the rationality of compassion. Builds on Blum, and other philosophers who argue that identifying with the other is achieved through imagination. Echoes Aristotelian view that similarity to the sufferer and vulnerability to the same suffering will evoke a compassionate response.	Snow, N.E	C19

Search 1: the Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
		2006	Discusses the absence of empathy from compassion and the implications associated with that	Frost et al	C20
	Self-serving /hypocritical	1991	Discusses the self-serving nature of compassion. Being motivated by being seen to do good.	Himmelfarb, G	C21

_Data Chart 2

How is Compassion Conceptualised within the Nursing Literature?

Search 2: the Nursing Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
General understanding Related to -	Definitions				
		2007	Concept analysis to clarify the meaning of compassion and examine its relevance to nursing practice.	Schantz, M.L	N1
		2012 a	Explores the concept of compassion and its implications for nursing as it is positioned as a core or fundamental value.	Straughair, C	N2
		2012 b	Builds on earlier paper and acknowledges that the concept of compassion has been ill-defined and sets out ways to strengthen compassionate care.	Straughair, C	N3
		2014	A discursive view aiming to understand the meaning of compassion. Study results lead to a challenging stance regarding the beliefs and values that underpin compassion. Claims to bring a greater clarity to the subject.	Dewar, B, et al	N4
		2015	Considers whether humanitarian values such as care and compassion can be taught. Sets out a discursive review of caring, compassion and empathy. Results suggest such	Richardson, C, et al	N5

Search 2: the Nursing Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
			concepts are ill-defined but that they are amenable to education.		
		2017	Considers compassion as a professional intention with dual purposes that benefit both the recipient and provider of health care. But its sustainability is seen as vulnerable as the 'flow' of compassion can be defended or depleted by a range of factors.	Tierney et al,	N53
	Dimensions				
		1992	Outlines a discourse around empathy and challenges the uncritical integration into nursing theory	Morse et al.	N6
		1993	Offers a concept clarification of the phenomenon of respect and stated it had never been adequately defined in the nursing theory or literature.	Browne P.L	N7
		1997	Meta-synthesis of qualitative analyses of caring.	Sherwood	N8
		2001	Offered a concept clarification of empathy and revealed increased diversity in the nursing literature regarding its conceptualisation.	Kunyk and Olsen	N9
		2004	Explored the semantics of core concepts of nursing.	Sadler, J.J	N10
		2006	Exploration of the concept of compassion amongst nurse educators. Sets out nine themes.	Peters, M.A	N11

Search 2: the Nursing Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
		2008	A philosophical inquiry to determine common characteristics associated with nursing care. Overlaps with other work on Christian compassion and explores concepts of suffering.	Austgard, K.I	N12
		2008	Identifies compassion as one of seven universal dimensions of caring.	Hudacek, S.S	N13
		2011	Sets out the key attributes of compassion and identifies barriers and methods to overcome such barriers	Cole-King, A, Gilbert, P	N14
		2009	Describes compassion as perceived within the relationship between nurses and older people with chronic conditions. Identifies seven dimensions that combine to produce compassion.	Van der Cingel, M	N15
		2013	Explores compassion as a core nursing value through the experiences of emergency department nurses.	Fry, M,	N16
		1997	Sets out a broad consensus of agreement regarding nursing's phenomena of interest	Fawcett, J	N51
		1983	Suggests that core concepts must include the interplay between the nurse, the patient and the situation	Newman, M.A	N52

Search 2: the Nursing Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
	Caring				
		1983	Considers the place of compassion within a broader analysis of the caring relationship	Griffin, A.P	N17
		1983	Outlines an overview of caring in the literature but identifies limited interest in the concept.	Gaut, D.A	N18
		1984	States that caring cannot be divorced from nursing.	Leininger	N19
		1985	Caring is a deliberate activity of one who knows nursing and is based upon a deliberate cognitive process	Orem, D	N20
		1987	Identifies compassion as one of five core aspects of nursing but does not elaborate further in her own words preferring to accept a theological based definition	Roach, S	N21
		1988	Finds that compassion is only one aspect of caring and that it is not the most important	Ray,	N22
		1990	Argues for the clarification of the concept of caring if it is to be retained as the essence of nursing.	Morse et al	N23
		1995	A conceptual analysis of caring in health care practices that directly discusses compassion	Scott, P.A	N24

Search 2: the Nursing Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
		1996	Outlines a narrative research study exploring perceptions about care and finds compassion is related to both actions and attitudes.	Czerwiec, M	N25
		1996	Jorm1.	Halldorsdottir, S	N26
		1999	Offers a literary meta-analysis of caring and showed the concept was not yet fully understood in nursing theory.	Swanson, K.M	N27
		1999	Explores and validates the relationship between empathy and caring. Offers a comprehensive review of empathy in relation to nursing.	Reynolds, W and Scott, R	N28
		2003	Distinguishes compassion as being one type of caring, explores its relationship with pity. Sets out a particular way in which nurses should care about patients.	Boleyn-Fitzgerald, P	N29
		2005	Comprehensively considers the concept of caring from a phenomenological perspective.	Spichiger, E, et al	N30
		2009	Critical examination of the relationship between compassion and care from number of perspectives.	Bradshaw, A	N31
		2011	Undertook a phenomenological exploration of the meaning of receiving care	Lundgren and Berg	N32

Search 2: the Nursing Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
		2012	Critical examination of the literature outlining the concept of caring.	Sargent, A	N33
Principles	Care ethics				
		1989	Considers the place of caring in a theory of nursing ethics. Adopts a feminist stance to analyse models of caring and to challenge masculine models of decision making and ethical analysis.	Fry, S.T et al	N34
		1998	Comprehensive overview of the ethics of caring. Links well to MSP and to compassion	Tuckett, A	N35
	Morality				
		1993	Considers the moral dimensions of caring. Grounded theory study looking at benevolence. Significant links to compassion particularly to sensitivity towards the other and being motivated to respond.	Lutzen, K, Nordin, C	N36
		2000	Focus is upon compassion and its meaning for nursing. Argues that compassion is a moral choice rather than just a natural response to suffering in the other.	Von Dietze, E, Orb, A	N37
		2005	Positions compassion as one of eight attributes that indicates moral competence within nursing practice.	Jormsri, P, et al	N38

Search 2: the Nursing Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
Process	Sensitivity				
		2008	A concept development of sensitivity in nursing.	Sayers, K.L, de Vries, K	N39
		2013	Sets out the 'absolute necessity' of compassion to reflective practice and summarises a decade of work by the author to reach this conclusion. Proposes a theory of compassion within an emancipatory paradigm to guide further nursing research.	Georges, J.M	N40
		2014	Qualitative exploratory descriptive study. Patients see compassion as contained within a nurses actions the smallest of which can convey something meaningful to others.	Bramley and Matiti	N41
		2015	Considers the role of compassion in the development of person centred care.	Van Lieshout, F, et al	N42
	Suffering in the other				
		2014	Explores the meaning of compassion to nursing practice. Results suggest that the emotional connection between the nurse and the suffering other is the grounding of nursing practice. Three relational themes are set out and interpreted.	Dunn, D.J, and Rivas, D	N43
Threats to -					

Search 2: the Nursing Conceptualisation of Compassion					
Category	Sub-category	Date	Main contribution	Citation	Number
	Dissonance in socialisation				
		2012	Demonstrates that socialisation in compassionate practice is compromised by dissonance between idealism and reality.	Curtis, K, et al	N44
		2013	Addresses concerns that nurses are not being adequately prepared to meet the expected professional standard of compassion. Highlights the dissonance experienced by students between expectation and reality of practice.	Curtis, K	N45
		2013	Develops the understanding of dissonance experienced by student nurses exposed to non-supportive environments in which to develop their compassionate care. Outlines that compassion is often conceptualised by what it is not.	Horsburgh, D, and Ross, J	N46
	Compassion fatigue	2015	Theorised the dynamic nature of compassion in nursing but also identified fragility.	Borgstrom and Wallter	N47
		2009	Explores the concept of compassion energy and its relationship to compassion fatigue.	Dunn, D.J	N48
		1992	Offered the first articulation of compassion fatigue as a concept and an illness.	Joinson, A,	N49

Data Chart 3

How is Compassionate Dementia Care Conceptualised by Acute Hospital Nurses?

Search 3: the Nursing Conceptualisation of Compassionate Dementia Care					
Category	Sub-category	Date	Main contribution	Citation	Number
Understanding					
	As a concept				
		2012	Considers the conceptualisation of compassionate care for older people.	Dewar, B, Nolan, M	D1
	Dimensions				
		2011	Explores compassionate as perceived by nurses of older people with chronic conditions. Results reveal a seven dimension model of compassion.	Van der Cingel	D2
		2015	Narrative descriptive study of care staff in Ireland, Netherlands and Sweden. Participants discuss caring and compassion in relation to the long term care of older people.	Eldh et al	D3
Process					

Search 3: the Nursing Conceptualisation of Compassionate Dementia Care					
Category	Sub-category	Date	Main contribution	Citation	Number
	Awareness of the other	2008	Considers the identify of a person with dementia when viewed as the demented other. Places limits upon awareness of the other and their suffering when the label of dementia is imposed.	Naue, U, Kroll, T	D4
		2011	Considers the awareness of the other where the other is perceived as having dementia and the label gives them nowhere to go. Critiques earlier paper by Naue and Kroll (2008) and asks for language to be reconsidered and reframed in dementia care.	Sabat, S, et al	D5
	Suffering				
		2009	Explores the ways in which nurses let older people know that they sense their suffering and are willing to try to alleviate it. Paying attention to the little things gave a message of the other person being valued.	Perry, B	D6
	Being moved to respond	2012	Explores nurses' experiences of working with hospital patients with dementia. Being touched by the vulnerability of the demented patient was a common experience and indicates compassion.	Bryon, E et al	D7

Appendix VIII Alignment of data to Meleis Milestones

Alignment to Nursing Theory Development (as set out by Meleis, 2012)

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
<p>1981-1985: emergence of domain concepts</p> <p>Acceptance of the value of nursing theory and the demand for more.</p> <p>Existing theory re-examined.</p> <p>Central concepts of nursing identified</p>	<p>05-S2</p> <p>00-S3</p>	<p>N17-1983 (Griffin)</p> <p>Sets out a philosophical understanding of caring in relation to nursing. Outlines that nursing judgement and perception are important.</p> <p>N18-1983 (Gaut)</p> <p>Outlines that historically limited interest has been shown in the term 'compassion' and emphasis has been upon caring.</p> <p>N52-1983 (Newman)</p> <p>Introduces the concept that core dimensions of nursing must be understood in the context of an interplay between the nurse, the patient and the</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>situation they find themselves in.</p> <p>N20-1985 (Orem)</p> <p>Sets out caring as applied to nursing is relational in that care givers and cared for must be in contact with each other as they share an experience. Usually that experience is one in which the caregiver compensates for those things that the cared for cannot do.</p> <p>N51-1997 (Fawcett)</p> <p>Sets out a broad consensus of agreement regarding nursing's phenomena of interest</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
<p>1986-1990: from metatheory to concept development</p> <p>Increased publication of papers focussing on concept development.</p> <p>Theory-practice gap noted.</p> <p>Concept development seen as bridging the gap.</p>	<p>05-S2</p> <p>00-S3</p>	<p>N16-1989 (Fry)</p> <p>Considers caring from a feminist perspective and criticised paternalistic nature of medical ethics.</p> <p><u>Theme</u> – first steps</p> <p>N19-1984 (Leininger)</p> <p>Offers the view that nursing is caring and caring is nursing. Caring in this context may be seen as a proxy term for compassion. View is latter regarded as reductionist and that not all nursing care is compassionate or caring</p> <p><u>Theme</u> – first steps</p> <p>N21-1987 (Roach)</p> <p>Stated that nursing is unique because all of its core attributes are</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>found within the concept of caring.</p> <p>N22-1988 (Ray) Undertook a philosophical analysis of caring. Argued that the re-examination had identified a number of constructs within which compassion was the most important.</p> <p>N06-1990 (Morse et al) Outlined concerns that nursing could not reach consensus agreement regarding its core components or process.</p>	
1991-1995: development of middle range theories	03-S2 00-S3	<p>N07-1993 (Browne) Considers problematic nature of conceptualising care</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
<p>Conceptual focus on nursing values.</p> <p>Focus on specific nursing phenomena that either emerge from or reflect practice.</p>		<p>Offers a review of sociological literature to suggest that the concept of care is lacking clarity and has been through the 1980's inadequately defined. Examines original characteristics of care by deconstructing and comparing them.</p> <p>Argues that care is not a theoretical category but rather a descriptive term for something that has many forms.</p> <p><u>Theme</u> – thinking again</p> <p>N36 -1993 (Lutzen and Nordin)</p> <p>Grounded theory exploring moral dimensions of nursing.</p> <p>Identifies nurses having sensitivity towards those who are</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>vulnerable and the desire to be benevolent, virtuous or to do good acting as a central motivating factor. The empirical approach used allows findings to emerge from practice.</p> <p><u>Theme</u> – learning from practice</p> <p>N23-1992 (Morse et al) Challenged nursing's uncritical adoption of empathy. Argued that whilst it was being regarded as crucial to the nurse-patient relationship it was not fully understood.</p> <p>N24-1995 (Scott) Explored what is required for the nurse to fully understand the predicament of the</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		patient. Uses the term compassion from the outset.	
<p>1996-2000: evidence means research not theory</p> <p>Nursing literature focused upon identifying best evidence and translating that into practice.</p> <p>Initially influenced by biomedical model that reduces acceptable evidence to positivistic and empirical</p> <p>Later opening up a critical dialogue to challenge this and to suggest that evidence may legitimately include</p>	<p>07-S2</p> <p>00-S3</p>	<p>N08-1997 (Sherwood)</p> <p>Recognises the need to move to new more developed models of caring. Current models are just the beginnings of theory development. Critiques existing models and pulls together a decade of qualitative studies to better understand what caring is.</p> <p><u>Theme</u> – thinking again</p> <p>N25-1996 (Czerwiec)</p> <p>Series of narratives that setting out the nursing relationship as individual expressions of meeting human needs. Argues that it is</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
components more congruent with nursing science.		<p>practice which creates best practice and practitioners who everyday are redesigning services, developing ways to anticipate unmet need, mitigating failures and cautions that nursing must not lose sight of that.</p> <p><u>Theme</u> – learning from practice</p> <p>N26-1996 (Hallsdorsdottir)</p> <p>Sets out her theory of nursing and metaphorical descriptors of theory that reconceptualise caring. Nurses positioned as building bridges to connect or walls to distance themselves</p> <p><u>Theme</u> – thinking again</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>N27-1999 (Swanson) Exploration of nurses views on empathy and its importance to nursing. Argues that nursing is so mired in positivism that it cannot correctly understand phenomenology or apply that to nursing's understanding of empathy. <u>Theme</u> – thinking again</p> <p>N28 -1999 (Reynolds and Scott) Comprehensive review of empathy in relation to nursing. <u>Theme</u> – thinking again</p> <p>N35-1998 (Tuckett) Comprehensive overview of care ethics.</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>Identifies that nursing is inherently associated with the practice of caring and that compassion should underpin caring and expressed through the nurse-patient relationship. A caring nurse is a virtuous person who acts out of compassion.</p> <p><u>Theme</u> – first steps</p> <p>N37-2000 (Dietze and Orb)</p> <p>Explores the meaning of compassion for nursing.</p> <p>States that compassion is often considered to be an essential component of nursing and argues that it about more than a response to suffering.</p> <p>Positions compassion</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		in nursing as a moral choice and discusses the implications of that. Concludes that compassion is greater than just an ingredient of care and represents the core of nursing. <u>Theme</u> – thinking again	
<p>2001-2005: epistemic diversity</p> <p>Two discourses accepted as equally valid. The scientific and the post positivistic. Diversity frees nurses to transform nursing and make it reflective of those that nurses serve.</p> <p>Critique of the status quo</p>	<p>05-S2</p> <p>00-S3</p>	<p>N09-2001 (Kunyk and Olson)</p> <p>Offered a concept clarification of compassion through major review of the literature. Identified a point at which empathy and compassion diverge.</p> <p>N10-2004 (Sadler)</p> <p>Discussed semantic context of literature associated with compassion and suggested that proxy</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
Places reconceptualization in context		<p>words had previously been used and that compassion had not been absent from the earlier discourse.</p> <p>N29-2003 (Boleyn-Fitzgerald)</p> <p>Argues that nursing's conceptualisation of care is incomplete and there is a need to distinguish compassion as one type of caring and distinct from aloof pity and fearful pity. Sets out a particular way for nurses to care about patients.</p> <p><u>Theme</u> – thinking again</p> <p>N30-2005 (Spichiger et al)</p> <p>Comprehensive consideration of concept of caring from</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>phenomenological perspective. States that one needs to move away from positivistic science to understand the concept of nursing. Her views on caring reflect the process and vulnerabilities of compassion.</p> <p><u>Theme</u> – liberated discourse</p> <p>N38-2005 (Jormsri) Highlight three levels of competence, clinical, general and moral and that the patient values clinical competence and expect moral competence.</p> <p><u>Theme</u> – thinking again</p>	
2006-2010: liberation of nursing theory	<p>10-S2</p> <p>02-S3</p>	<p>N1-2007 (Schantz) Concept clarification to determine the meaning of compassion and its</p>	<p>D3-2008 Considers the identity of a person with dementia when viewed</p>

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
Nurses empowered to distance themselves from the biomedical model and theory development now being guided by alternative paradigm.		<p>relevance to nursing. Set in context of beliefs that compassion has been assumed to be important to nursing but never well-defined or promoted in everyday practice. Concerned that at best it has become optional and at worse dismissed.</p> <p><u>Theme</u> – thinking again</p> <p>N11-2006 (Peters)</p> <p>Qualitative phenomenological inquiry exploring the concept of compassion from perspective of nurse educators. Seven essential and two incidental themes identified.</p> <p><u>Theme</u> – liberated discourse</p>	<p>as the demented other. Places limits upon awareness of the other and their suffering when the label of dementia is imposed.</p> <p><u>Theme</u> – liberated discourse</p> <p>D5-2009</p> <p>Explores the ways in which nurses let older people know that they sense their suffering and are willing to try to alleviate it. Paying attention to the little things gives a message that the other is valued.</p> <p><u>Theme</u> – re-focus</p>

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>N12-2008 (Austgard)</p> <p>Hermeneutical philosophical inquiry to determine common characteristics associated with nursing care. Sets out that care remains unclear in definitional terms and subject to more than one conceptualisation. Considers why similar nurses practice in very different ways.</p> <p><u>Theme</u> – liberated discourse</p> <p>N13-2008 (Hudacek)</p> <p>Qualitative, philosophical study that analyses 200 nurses' narratives and identifies compassion as one of seven universal dimensions of nursing.</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p><u>Theme</u> – liberated discourse</p> <p>N39-2008 (Sayers and de Vries) Argues that changes in nursing's stance towards patients has created vulnerability in the protection of patients. Cites Engelhardt's concept of moral friends and moral strangers and discusses the value of using this to analyse nursing.</p> <p><u>Theme</u> – thinking again</p> <p>N15-2009 (van der Cingel) Comprehensive review of Aristotelian construals for compassion and the relationship with professional care. Asks</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>if compassion cannot take away suffering why then is it seen as fundamental to nursing and nursing care. Sets out a coherent answer after a thorough review of the concept generally.</p> <p>N31-2009 (Bradshaw) Critical examination of the relationship between compassion and care. Claims that a UK emphasis on measuring compassion is a parody. Sets out that compassion as an aspect of nursing can no longer philosophically or practically be expected. <u>Theme</u> – thinking again</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>N32-2011 (Lundgren and Berg)</p> <p>Restates the key attributes of compassion for health care. Identifies barriers and ways to overcome them.</p> <p><u>Theme</u> – pause and reflect</p> <p>N48-2009 (Dunn)</p> <p>Discusses the vicarious suffering that sits at the core of compassion fatigue. Offers a critique of Figley's earlier discourse around compassion fatigue in particular the protection to be found in the therapeutic relationship.</p> <p><u>Theme</u> – thinking again</p> <p>N49-1992 (Joinson)</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		Offered the first articulation of compassion fatigue as a concept and an illness.	
<p>2011- onwards: into the future</p> <p>Increasing aged population and those affected by chronic conditions leads to a need to develop theories that are relevant to a more defined population group.</p>	<p>14-S2</p> <p>04-S3</p>	<p>N2-2012a (Straughair)</p> <p>Explores the implications for nursing now that compassion is identified as a core value.</p> <p><u>Theme</u> – pause and reflect</p> <p>N3-2012b (Straughair)</p> <p>Sets out that the concept of compassion has been ill-defined and identifies ways to strengthen this as a core value.</p> <p><u>Theme</u> – pause and reflect</p>	<p>D2-2011</p> <p>Qualitative analysis across different care settings. Explores compassion as perceived by nurses of older people with chronic conditions. Sets out the seven dimensions of compassionate care.</p> <p><u>Theme</u> – re-focus</p> <p>D4-2011</p> <p>Critiques earlier paper (D3) and advocates for language to be reconsidered and reframed in dementia care. Argues that the</p>

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>N14-2011 (Cole-King and Gilbert)</p> <p>Defines compassion as it is perceived within the relationship between nurses and older people with chronic health conditions.</p> <p><u>Theme</u> – re-focus</p> <p>N44-2012 (Curtis et al)</p> <p>Demonstrates that socialisation in compassionate care is undermined by dissonance between idealism and reality.</p> <p><u>Theme</u> – pause and reflect.</p> <p>N45-2013 (Curtis)</p> <p>Addresses concerns that nurses are not adequately prepared to meet expected</p>	<p>label of dementia negatively impacts upon awareness of the other.</p> <p><u>Theme</u> – pause and reflect</p> <p>D6-2012</p> <p>Qualitative study involving 21 Flemish hospital nurses. Explores nurse's experiences of working with patients who have dementia. Being touched by the vulnerability of each individual patient was a common experience indicative of compassion.</p> <p><u>Theme</u> – re-focus</p> <p>D1-2013</p> <p>Appreciative inquiry approach to consider the conceptualisation</p>

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>professional standards associated with compassion.</p> <p><u>Theme</u> – into the future</p> <p>N4-2014 (Dewar et al)</p> <p>Challenges nursing's view of compassion and looks to reconceptualise the meaning. Actively involves older people in an appreciative inquiry approach to define compassion in the general hospital.</p> <p><u>Theme</u> – into the future</p> <p>N16-2013 (Fry et al)</p> <p>Explores compassion from the perspective of ED nursing.</p> <p><u>Theme</u> – re-focus</p> <p>N40-2013 (Georges)</p>	<p>of compassionate care for older people. Builds a model based upon 'appreciative caring conversations' that promote compassionate relation centred care.</p> <p><u>Theme</u> – re-focus</p>

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>Proposes an emancipatory theory of compassion to guide future research and practice.</p> <p><u>Theme</u> – into the future</p> <p>N33-2012 (Sargent)</p> <p>Undertook a critical review of conceptual analyses of compassion. Stated that nursing must review its relationship with the concept of caring and challenged Leiningers earlier mantra.</p> <p>N46-2013 (Horsburgh and Ross)</p> <p>Built upon the work of Curtis to demonstrate that support for new nurses to achieve</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>compassionate care was largely absent.</p> <p>N43-2014 (Dunn and Rivas) Recognised the demands felt by nurses to deliver compassionate care in the context of increasingly demanding and technological health care system.</p> <p>N41-2014 (Bramley and Matiti) Explored compassion through the eyes of the patient. Findings echoed others that were commonly reported in other literature. Patients valued nurses taking time to be with them.</p> <p>N5-2015 (Richardson)</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3
		<p>Addressed how nurses are educationally prepared to deliver compassionate care and described development of an undergraduate module focussing upon compassion, care and empathy.</p> <p>N47-2015 (Borgstrom and Walter)</p> <p>Continued the critique of compassion in the changing world of health care.</p> <p>N42-2015 (van Lieshout et al)</p> <p>Outlined the value of the person centred approach to supporting compassion in the face of challenges from 21st century health care.</p>	

Characteristics of period of development of nursing theory	Number of search 2 or 3 papers	Characteristics of selected literature from search 2	Characteristics of selected literature from search 3

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