Conversations within a nursing home. An ethnographic study of the lived experience of residents, visitors and staff

Thesis submitted in accordance with the requirements of the University of Chester for the degree of Doctor of Education

Kate Mansfield-Loynes

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Declaration

I declare that the material being presented for examination is my own work except where otherwise identified by references and that I have not plagiarised another's work. I also declare that this work has not been submitted for any other award of the University of Chester or that of any other Higher Education Institution.

Signed: ....

Dated: 30/09/2021

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Finally, this thesis is dedicated to all nurses who think they are not capable of studying at doctoral level and, especially, all the hardworking staff within the social care sector; you are enough.

Abstract

This thesis uses an ethnographic study to explore the lived experience of those living, working and visiting a nursing home. This tripartite has traditionally been hidden from view, given no forum to voice experiences in a meaningful way within a sector which is seriously underfunded.

By using the work of Erving Goffman as a foundation I utilise a therapeutic reflective Marxist lens to explore the lived experience of the tripartite and examine the neo-liberal practices that abound within health services. I relate the tripartite voices through a series of narratives that underline that care, in and of itself, is significant and that it is emphasised through the everyday-ness of their experiences that cuts through the institutional practices and power imbalances inherent within the social care arena. There are complexities that arise when attempting to understand the messiness of the nursing home and wider social care arena but, as a nurse that has spent the majority of their working life within it, I have been able to navigate and draw some conclusions around what it is to live, work and visit this marginalized sector.

I have explored what it means to age in today's society and the inherent ageism, discrimination and stigma that accompanies the ageing process. I have reviewed what 'home' is and that an individual's personal history of 'home' supports an individual's sense of belonging and continuity which is integral to well-being and thus a literal place and an ideal. However, the legislation and regulation that wraps itself around elderly care inexorably leads to a sense of surveillance which provides a power imbalance. This power imbalance is reviewed against Goffman's work around Total Institutions (1961).

By thematically analysing my data I have realised that the conversations and observations were part of a greater map which, due to its subject matter, was complex but interconnected. Ultimately, there were three themes that took precedence: Death (of self; social death and of life as we know it); Personalization of care and expectations and; Environment and business policy.

All the statistical evidence points to a future where there is an ageing population with increasingly complex co-morbidities which will be situated within the reality of a decreasing younger population. I conclude that there is a need to reframe sickness to health-care within the rhetoric around older people and their requirements from a healthcare system, coupled with a necessity of educating the wider population on societal prejudice and discriminations to an ageing population. There is also a need to engage further with the current conceptualizations of care at a deeper and philosophical level.

Table of Contents

List of Tables and Figures

Conversation Codes:

I made the decision at the beginning of this thesis to colour code the conversations that are noted within this work. This was to enable the reader to pay particular attention to the voices that have enabled me to write this thesis and appreciate that the themes usually embraced everyone that resides within the nursing home arena.

Light green	**Ancillary staff**
Orange	**Residents**
Blue	**Unregistered care staff**
Brown	**Professionally registered care staff**
Purple	**Visitors**
Pink	**Observation diary**
Burgundy	**Informal conversations**

Confidentiality

In order to maintain the confidentiality of the physical home and the overall Company, there are no references included within this work which could identify them. Should any reader wishing to enquire about the source of information, please do contact me directly. Within the thesis itself, the reader can be guided to a Company document by the brackets indicating: (confidential, refer request to author).

Chapter 1

Introduction and background

This thesis is an exploration into the lived experience of those living, working and visiting a nursing home. This signals a significant tripartite who have a rich lived experience to share as these are individuals put together, through little choice of their own and who have little control over their lives. They live separately but come together within the arena of the nursing home. This tripartite has traditionally been hidden from view, given no forum to voice experiences in a meaningful way within a sector which is seriously underfunded. There is a disconnect because of the neo-liberal rhetoric around caring for the whole population and what actually happens to this disregarded community of older people. The World Health Organization [WHO] (2015) outline that whilst there is considerable indication "that older people contribute to society in many ways, they are instead often stereotyped as frail, out of touch, burdensome or dependent" (p. 10). Old age has become a tool for disabling people and is historically contingent on society not being inclusive to those in older age groups. Rather than enabling people to live productive lives, older people are disabled by the social barriers constructed to ensure that the younger and fitter generation may thrive.

There is a shifting demographic that is favouring an ageing population within Western societies (WHO, 2015) which forces the urgency of making known current experiences of the tripartite to inform the future of aged care. No matter what the popular press tries to impress upon us in regards to '60 is the new 40' (Beech, 2015), '70 is the new 50' (Knapton, 2015), ageing is inevitable and the process starts from the day we are born. However, whilst other phases of life are celebrated there appears to be nearly universal issue with the life phase classed as old age. Old age has a label of being disagreeable, objectionable, and undesirable, laden with expectations of illness and deterioration of the body with Dening and Milne (2011) outlining that our aging society are a "profoundly marginalised group" (p. 3). In no other age of life is there a mass migration, forced or elective, to a place where a person has

minimal options on choice of habitat, is enforced to live with others and is dependent upon others for personal care.

The conception of care homes is steeped within the history of the UK with the first Alms Houses being created in 936AD (Munson, 2020). However, it was not until the Nursing Homes Registration Act in 1927 that formalised, regulated and inspected care was provided for the elderly. In 1948 the Labour government of the time created the National Assistance Act which placed the requirement on all local authorities to provide care for the elderly, disabled and ill people firmly at their door. The seminal work of Townsend (1962) identified that elderly care continued to see remnants of the workhouse culture remaining within care homes and institutions. There was no central heating, multiple shared occupancy was the norm and a plea was put forward of employing staff who were trained within care of the elderly. From reviewing the history, the difference within the structure is down to the tripartite. Whereas the resident and staff have very much followed a duel dependency, from the latter part of the 20th Century, the visitor has become increasingly important and thus a tripartite is configured. Within this analysis, a nursing home is viewed as a final dwelling place for older people and a key component of our healthcare system. In 2018/19 there were 841,850 adults (The Kings Fund, 2019a) residing within 14,171 care homes (Care Quality Commission [CQC], 2017a) registered within England alone with 4,168 (CQC, 2019) of these classified as nursing homes. This only underscores the awareness that there are thousands of older people who are relatively powerless within our current system of healthcare. Whilst there are differences between nursing and care homes, and this is discussed further in chapter two, the terms are often used interchangeably. As I undertook the study within a registered nursing home, any direct link to my research or registered nurses will use the term nursing home. The terminology of care home will be used when discussing the wider social care arena as this is where most data sets live. It is predicted that by 2036 those aged 65 years and over will account for a quarter of the United Kingdom [UK] population (Office for National Statistics [ONS], 2017), thus care homes will certainly be an essential and omnipresent component of the healthcare system within the UK. With an ageing population, and with the current crisis in healthcare intensified

by Covid-19, there is need for discussion around public responsibility to enable a fulfilling and safe environment for elderly people to live. Debate needs to encompass how care homes may prove to be an essential service for those elderly unable to live safely on their own. The loss of a person's home can be a de-humanising experience with the person themselves losing control of their decisions over the mundane, such as where, what and when to eat. Autonomy, throughout our lives, is an important factor in who we are and this loss of self-governance can deeply affect an individual's values and beliefs regarding who they are. As outlined by Avsar (2008, p. 3) "Neoliberal autonomy seems to stand on the advocacy of freedom of individuals to make their own decisions" so while autonomy may be one of most revered in a neo-liberal economy, those with the least –the older generation – have the least ability to be themselves. This has resulted in the situation where the physical representation of a persons treasured items, as a reminder of the past can be lost, as there is a need to 'fit' into the new habitable space provided.

In contemporary society, the older person has been neglected as a valuable member with enduring experience and, once admitted to a care home, there is little focus on the gerontological perspective of care and little belief of a discharge back into the community. I will explore what the role of institutionalising the elderly is and, whether there is an inter-dependence on the rise of the nursing homes and/or demographic changes of notions of family. Health systems overall focus on the medical model of care where each illness or disability is countered as a separate problem with little consideration of the whole person approach to care. As Illich (1976) outlines "The ritualization of stages in life is nothing new; what is new is their intense medicalization" (p. 89). From Illich's (1979) quote to the WHO's (2015) outlining that wherever there is a medical problem it is sought out and there is an attempt to fix it, it would appear that the medical model has not developed to incorporate the psychosocial and emotional needs that people may have. Furthermore, there appears to be a desire to medicalise old age in a way that does not allow a person to 'live' with old age, rather there is an encouragement to polarise efforts in curing the many ailments associated with old age but, as Illich (1976) considers, there is potentially little that medicine can do to manage old age. Coyle (1999)

expanded in her study that the medical profession can stereotype people according to their perceived age. Coyle (1999) explained in her study that it was especially women who were persuaded that their undiagnosed health condition was not due to a specific biological issue, but rather that it was old age that was their cause of ill health. This medicalization (Illich, 1976) of the ageing process is, in itself, institutionalising and can only reinforce the current societal thinking that medical intervention is required. Within my experiences, it can be the basic nursing care that needs to occur in order to reduce medical interventions at a higher level. For example, the offering of fluids regularly, oral care and correctly fitting footwear can decrease any number of larger medical interventions due to infections, dehydration and falls. The reason there is a concentration on the medical approach is that it assists both society, and those who undertake the caring, to be able to label people in a systematic way rather than in a relationship-focused way. As outlined by Salsberg and Quigley (2017), there is a need to rethink modern health policy to "require a goal of maintaining functional ability rather than curing disease" (p. 52). If we are more successful in the neo-liberal rhetoric around care provision we can realign conversations around what constitutes a care home to promote choice and autonomy in the decision-making process.

Against my initial prejudices, I became increasingly convinced that some of the broad arguments Marx presents around capitalist exploitation, alienation and, objectification of other people's lives, were a compelling theoretical perspective. A Marx theoretical perspective gave a convincing argument to understand the experiences of the tripartite. However, this thesis is not a detailed and subtle reading of Marxist theory (McLellan, 1976/1980; Claeys, 2018). This is not due to any reservations about the close and elegant argumentations, but my thesis is about something which is much starker and does not require that form of analysis. Instead, what I am taking from Marx are ideas about class, marginalization, exploitation and, the idea of a system or a structure. The area that I am going to concentrate on in terms of structure is a nursing home and what I want to do is take those key ideas as I believe they explain the experiences that happen there. By using ethnographic methods and utilising a Marxist lens I believe that the approach is therapeutic as I am searching for 'the human' -

the human side of the nursing home from the perspectives of those that live, work and visit it. It has therapeutic value to those who gave me their stories as it allowed them time to reflect, however fleetingly, and be listened to. It has supported me to explore the stark contrast to a traditional medical model, where medical ideology helps to maintain class structure and these patterns of domination and, the economization of elder people's care from neoliberalism. Marxism enables explanation of the marginalized, including those care workers as victims of an economic way of viewing the world. As outlined by Claeys (2018) "The loudest voice at any given point reflects the values of the dominant class…" (p. 101). The arguments that I am going to present are not complex, that is not because I am against complexity, it is because the issues and experiences presented are stark. Each of the chapters contained within this thesis outlines starkness and the context of the starkness. By using a Marxist critically reflective approach, which involves understanding the structural positions that actors are forced to take because of how they are situated within a neo-liberal market, I endeavour to rescue the lived experience from simple accounting and make present the experiences of those that I see as marginalised from the important discussions about how they live their lives in old age and work within a struggling social care system.

Humans are social beings and one of the most important expressions of this sociality is that we live, and have evolved to live, in social groups. These social groups are usually built when we relate to social entities that impact on our lives - family and friends, work, community, religion, sports - we do not necessarily see the members of the group as other but routinely express our involvement as us. The thesis critically analyses residents residing within the nursing home, how they have adapted to the enforced habitation with others. I will explore with relatives how they have, or have not, built relationships with staff within the nursing home and what the transfer of their loved one to someone else's care has been like. The arguments in the thesis gained momentum with the analysis of the inter-dependency of the tripartite upon each other and whether a sense of one's own autonomy and agency is reduced due to this need for reciprocity.

Eight per cent of nurses registered on the Nursing and Midwifery Council's [NMC] register are known to work within nursing homes, this equates to 55,500 (Munn, 2017). These nurses often feel overlooked by their regulatory bodies, Unions and, feel looked down upon by both fellow professionals and the public as being seen as second rate nurses (Learner, 2015). The labelling of care provided outside of the National Health Service [NHS] is directed by the media and is usually unfavourable and negative, as seen in a plethora of popular press articles (Bodkin, 2017; Campbell, 2017; Hardy, 2015; Matthews-King, 2019; Russell, 2017). According to research literature (DeForge, et al. 2011) the lived experience of nurses and carers who work within a nursing home is that of multiple stressors that do not empower them to provide person-centred care. Although the setting for this research by DeForge, et al. (2011) was Canada, there are many similarities to that of the British care system revolving around the standardization of care rather than addressing policy to encourage person-centred care. Whilst I propose that aged care within this country stigmatises older people, the social care system itself can be seen to marginalise those that work within it. There are issues with both economic and social protection afforded to those who work within the social care arena. Inherently there are lower wages, minimal sick pay and fewer holidays for social care staff compared to those working within the NHS. The professional status of those involved in the tripartite are similarly marginalized. This is not just cultural but also includes fiscal and professional opportunities which are diminished; they are downgraded to a disregarded community. This Marxist understanding caused me to start and understand myself. I have worked within the private sector for the majority of my career and I have felt, as a qualified nurse, that I have had little professional representation and that the people who have used a nursing home service have not been acknowledged as a member of the wider society, or indeed recognised within a healthcare community. If ideologies are utilised to define or construct a world as it is (Jost, et al., 2009), this experience allows me to be more politically and ideologically reflexive – political as my position today is a result of history and ideologically as there is a pluralistic approach to nursing. As Erikson and Tedin (2003) outline, ideology is a "set of beliefs about the proper order of society and how it can be achieved" (p. 64).

The intention of this study is to contribute to and expand the knowledge on the tripartite lived experience of residents, staff and relatives who live, work in and visit a nursing home. Through this study I will be exploring the notion of ageing in today's society from the perspective of those actively engaged within the nursing home arena through the lens of lived experience. This thesis is obsessed with the mundane as the realities of this tripartite experience occur. Relationships that are newly and pre-formed will be examined alongside the nursing home as a physical space that all interactions and life occurs within. The mundane will be structured for this tripartite within policy, over which they have no control which, in Marxist terms, is about the economic ends rather than the rhetoric of care. Policy will be interwoven throughout the themes in a way that examines how nursing homes and the staff are governed and the impact that this can have on relationship-based care as an inherent requirement for true collaborative care. Towards the end of the writing of this thesis came the global pandemic of Covid-19. Whilst the research and the analysis were all completed prior to this, it would be negligent of me to ignore this situation, especially due to the integral part social care had to play within the care of the nation. Therefore, I have included a sub-chapter directly linked to this topic at the end of this thesis.

Scope of the study

Throughout the course of this doctorate I have been introduced to many new theorists, one of whom is Erving Goffman. Realization of Goffman's work having relevance to today's concept of nursing homes was a true phenomenon in my journey to considering my thesis. The rich description that Goffman (1961) provides, which is essential in Goffman's work, is also key in understanding the nursing home tripartite put forward within this work. I had always known that this body of work would be around the concept of nursing homes but I struggled to identify the specifics within my thought processes. Goffman's body of work has provided some invaluable insights into the experiences within a mental hospital environment (1961) and how the idea of total institutions applies to prisons and

correctional facilities. Goffman (1961) identifies that his goal was "…to try and learn about the social world of the hospital inmate, as this world is subjectively experienced by him" (p. ix). Whilst reading his work I started to question myself and the current practices that I have been emerged in and started to think that this was an area I wanted to explore more. Goffman's work could be described as a catalyst for my reflection on both a political and ethical level. The issues that I have reflected upon are probably moral questions, but they are also distinctly political as well, as they raise the whole "whose side we are on" question (Finch, 1993, p.77). I do think that elder care is about sides, although the question on who the enemy is, is not always clear. Whilst considering my experiences on working within social care, was I reflecting upon why I did what I did or was I examining the reasons why I did it – the requirements placed upon me by governing policies and legislation. It is apparent than in order to provide care it has to be legislated for, therefore, to understand what care currently is there is a need to explore governmental policies. Any action, or in-action, that is undertaken can be seen as political in nature and this is what initially led me to question the lens that I was looking through when examining my research.

Coupled with the work of Goffman, I was encouraged to read the book *In a different voice* (Gilligan, 2003). Reading this was a revelation to me as this book reframed using voices to really place qualitative research into a more meaningful alignment with reality. As within my previous work (Mansfield-Loynes, Morris-Thompson and Marks-Maran, 2016), which was written whilst studying my doctorate (see appendix two for full paper), there is a risk that older people within nursing homes do not have their voice heard. This is due to the prejudice surrounding meaningful interactions placed onto older people, especially those who may have a cognitive impairment. By utilising the term 'voice' I am meaning the ability to speak and be heard. There is research to show that this loss of voice can be partnered with "learned helplessness and instrumental passivity" (Ice, 2002., p. 346). These voices equate to experience, perspective, and the re-establishment of the right to be regarded, rather than simply the words that are spoken. By searching for and giving a platform for this tripartite to be heard is not through misdirected sympathy towards them; it is to use the idea that the peculiarities of a

person's story can shape their life course in a way that is unique to them but impacts upon their social circumstances. The marginalised within our society, whether this be the elderly or those working within the social care sector, are often not listened to. Their ideas and requests are brushed over as meaningless or too difficult. Thus, the basic premise of this thesis was constructed.

As discussed, the enduring tradition is that people residing within a care home environment have been a silent presence and, if we do hear their voice, it is predominantly through others. This includes family, carers and academics (McColgan, et al., 2000) enunciating a perception of a person's life story and, doing so with the legitimacy of expertise, which I attribute to living within a capitalist society where an individual cannot be viewed as 'free'. Within Marxist theory (Marx, 1894), classes which are dominant are correspondent with autonomy and therefore rights. Consequently, when you take an older person away from their home, a diminution of all that was occurs. This, in turn, marginalizes this vulnerable sector of society and places them within an exclusion zone, namely the nursing home and they also become a commodity which satisfies capitalism; "…under capitalism, the ultimate aim was to turn commodities into money" (McLellan, 1976, p. 52). This is partly due to older people being admitted to nursing homes with failing health, whether that be physical frailty, cognitive deterioration or a mixture of both so, this lack of voice may be due to their lack of power derived from a reliance upon others for their care needs including social, psychological, emotional and physical support. Older people within nursing homes have traditionally had little or no control over their care and trajectory through the system thus this instrumental passivity (Ice, 2002) is built through the repetition of routine and an encouragement, from staff and relatives, to become dependent rather than independent.

Although the data collected has been focussed within one nursing home as there is a desire to reflect rather than represent. I believe that the themes and issues raised within this thesis will have significance for most other healthcare workers and healthcare environments.

Research aims and questions

The aims of this research are to:

- Explore, describe and interpret the perspectives of lived experience of residents, relatives and staff within a nursing home environment.
- Generate understanding and insight to inform, empower and assist future residents, relatives and organisations
- Promote debate on current practices to provide insight and incite improvements, both within the micro and macro environment, for the care of nursing home residents

These aims will be met through:

- Semi-structured audio-recorded interviews with residents, relatives and staff who were living, working or visiting the nursing home
- Non-participant observations within the nursing home environment
- Presenting findings to inform and improve the practice of health professionals through education and organisations engaged with older people and nursing homes via policy.

These aims will deliver on answering the following research questions:

- What are the lived experiences of residents, staff and relatives who live, visit and work within a nursing home?
- How does policy impact upon elderly care within the United Kingdom?
- What does the future of elderly care look like for an ageing population?

Chosen methodology

Ethnography was selected as the most appropriate methodological approach as the setting of the nursing home was intrinsic to the resident, staff and relatives. An overt and emic approach was undertaken throughout the fieldwork given the desire to explore the lived experience and the consequent emotions and denotations from the tripartite. By utilising Marxism (Claeys, 2018; McLellan, 1980) as a way of understanding the lived experience of the tripartite and understand meaning from the discourse, it allowed those participating not only to have a voice but to become an

agent of power and thus get their voices heard within wider society. As outlined by Jones and Smith (2017), ethnography is frequently used within healthcare research as a way of understanding a patient's perspective and their lived experience within a given situation. The joy of ethnography to me was the iterative way in which meaning was appropriated through the conversations that occurred. Meaning making was expanded and checked-out through many conversations. This layering of conversations allows for a deeper understanding that is required when commenting on the lived experience of another. This way of using ethnography as a methodology relates to what Jerolmack and Khan (2017) identify as "character driven ethnography" (p. 6). Jerolmack and Khan (2017) go on to explain "The focus is on getting the person right, and in so doing, challenging general accounts of social relations. Relatedly, work in this tradition also often shows how places embody singular traditions and meanings that shape local culture and social identities in particular ways" (p.6). Whilst this research was based on the tripartite of lived experience, there was the physical place to be considered, that of the nursing home instead. Thus, this methodology was deemed to meet the needs of this research study. Further expansion on methodology will be located in chapter five.

Chapter summary

This chapter has endeavoured to give a sound reasoning of why this particular research study is important. The lived experience of those engaged and using nursing homes is vital. If we do not ask to hear their experiences and thoughts, there is little chance of reconceptualising the social care sector and we would remain in an oversimplified dichotomy of old versus young and healthy versus ill, NHS versus private care. There is a need for the redesign of social care policy to move away from institutionalization of a vulnerable group to that of supporting self-determination. In an attempt to reduce the discrimination to those working within nursing homes, there is also a need to reconstruct the image of nursing home care delivery.

Chapter 2

An ageing society

Introduction

As outlined in chapter one, policy is interwoven throughout this thesis and needs to be examined to review how it has affected the ageing population. The policy that controls social care is, in Marxist terms, an economic end, rather than concerned with the physical act of caring. The way fiscal and social policy in today's capitalist society has reduced people to their economic market worth. The first term I will be looking at is the concept of "societal ageing" (Copper, 1986, p. 52). What this concept identifies is that all people are reduced to an almost economic husk which means that individuals themselves hold no importance, their only value is that of what economic value they can generate. As Marx (2020) outlines "Money is the universal, self-constituted value of all things. It has therefore robbed the whole world, human as well as natural, of its own values" (p. 67).

Chronological age can be seen as a misnomer with Eckert (1997) contending that to undertake research there needs to be a direction of focus "away from chronological age and towards the life experiences that give age meaning" (p. 167). In my personal experience as a nurse, lecturer and member of society, there is little dialogue about the age of somebody specifically and more rhetoric around what Copper (1986) calls "societal ageing" (p. 52) which is supported by how people look and its difference to a person's own self-image. Due to the expansion of the life cycle, there is an increased heterogeneity towards people over the age of 65 years. The relatives of residents that I interviewed were mainly the same age group as the resident yet there was a marked contrast between the two which indicates that chronological age is only required when it is salient to use it. As YouGov (2018) demonstrate in Table 1, it is more difficult today to identify those with an age greater than 65 years. This concept of society's view on aging links with the Marxist view of power being absolute under a capitalist government. For many years, capitalist ideologies have been rooted within the structures

of society. For example Marx and Engels (1884) describe societies as always being about class struggles. As Marx went on to state; "The consuming power of the workers is limited… partly by the fact that they are used only as long as they can be profitably employed by the capitalist class" (1894, p. 351). Marx explains that social power, the way that society, in this case describing and notating ageing, is the productive force of individuals being diminished (Claeys, 2018). Under capitalism, the ruling class hold the power (Marx & Engels, 1848), and this power is distributed through policies and legislation. This means that instead of individual autonomy, people who reach society's view of old age, are directed towards accepting it rather than free to determine their own thoughts.

Table 1: How young are young people? (YouGov, 2018).
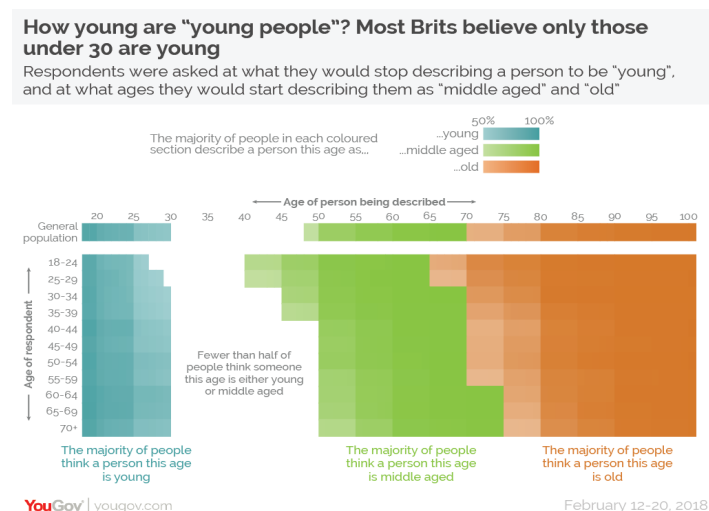
What Table 1 indicates is that the majority of people questioned thought that young age finished at 30 years of age, middle aged started around 48 years of age and that old age began at 70 years of age. What is an interesting variant is that between the age of 30 years and around 48 years of age there is no consensus on what part of the life cycle a person is "the age with no name" *(*YouGov, 2018. Para. 6). The WHO (2002b) identify that in most Western developed societies there is a consensus of 65 years old chronologically being classed as old age. However, despite what surveys and statistics denote regarding when old age starts, WHO (2015) outline that there is an increasing level of discrimination and stigma attached to being old. Age then, is socially constructed and affects attitudes which lead to the discrimination and stigmatisation of older people.

Discrimination and stigma

Goffman (1963) made shockingly clear that stigma is a phenomenon where an individual, who has a certain attribute, is excluded or rejected by society as a result of that attribute. Stigma is placed firmly within a society's belief, attitude and value system and thus can be difficult to quantify and address. Attempting to alter ingrained perceptions is difficult. Goffman (1963) details how individuals that are stigmatized can accept those labels placed upon them which results in an on-going self-stigmatization. This self-stigmatization can manifest itself in various ways, but commonly, this is exhibited through shame, self-hatred, isolation and depression. Conversely, discrimination is the action that results from stigmatization which are much more easily identifiable and can include behaviours such as bullying, harassment and lack of opportunity. Thus, discrimination is a result of stigma. Dobbs, et al. (2008) provide some excellent insight into the how stigmatization evolves into discrimination and I have taken the liberty of compiling their ideas into a Venn diagram (Figure 1) to aid in further discussion of their ideas.

Figure 1: The inter-related components of stigma (adapted from Dobbs, et al., 2008).
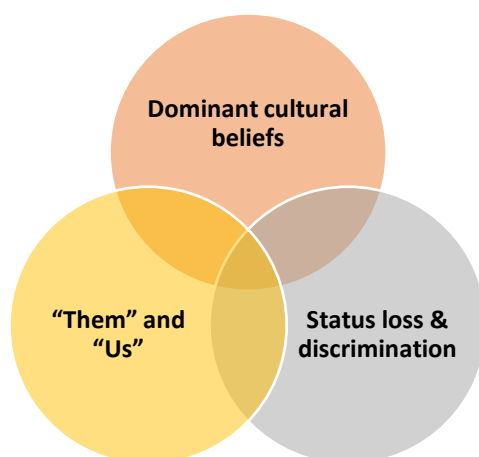
These interrelated components are dependent upon one another but have their basis within societal attitudes towards a certain group of people which are ingrained and become 'normal' and thus self-perpetuating. There is a homogenization of the elderly which is usually characterised by memory loss, inabilities, and dependency upon others which is seen as undesirable. The opinions that lie behind

culture and beliefs manifest themselves into both attitudes and behaviours which enable a 'them' and 'us' situation. This has a consequence of social exclusion or alienation from the society in which a person inhabits which, results in a loss of status. Whilst this is not always intended; **"**Normals really mean no harm; when they do, it is because they don't know better." (Goffman, 1963, p. 116), there are societal behaviours that underscore this divide. For example, Goffman (1963) discusses how people are stigmatized due to a physical disability where they are "…politely and clearly excluded from certain setting…" (p. 163). This happens within ageing care where people are excluded from work or decision-making around their own care. By placing the 'them' away from general society supports self-stigmatization (Goffman, 1963) as well as perpetuating the initial dominant culture and beliefs. By placing the older person within institutional living, for example a care home, Goffman (1963) suggests that further de-personalization occurs due to certain features that occur within group living. Goffman (1963) identifies that conducting all aspects of life within the same place under a single authority, the need to follow schedules and rules and having one's daily activities witnessed by other members of the institution are largely responsible for de-personalization. Institutional depersonalization is the natural logic of neo-liberal economics which Marx discusses in terms of alienation

Whilst Taylor (2011) outlines that Marxists believe there is an inseparable link between racism and capitalism, the same could be said for the interdependency of discrimination and capitalism. The separation of the elderly into a separate class of citizen can be seen as a case of them being stigmatized to the extent that only other stigmatized people can have contact with them. The positioning of the elderly within the public agenda needs to be addressed by ensuring that policy meets the needs of a diverse group of individuals with an emphasis on appropriate health and care systems being in place. Only when discrimination, whether it be covert or overt, is addressed can we move on to reducing the stigma that is attached to old age. It is interesting to note that discrimination and stigma have been on the agenda for 20 years with the WHO (2002a) urging immediate action to redress the issues that "stigma is destructive and obstructive" (p. 18). They highlight areas that need to be considered when tackling both stigma and discrimination (Table 2).

Table 2: A strategic approach for action against stigma and discrimination (adapted from WHO, 2002a, p.17)

Examining our own attitudes and practices;
Increasing awareness;
Supporting empowerment;
Stopping exclusion;
Ensuring appropriate treatment and care;
Credible advocacy;
Effective public and professional education;
Equitable allocation of health, welfare and research budgets ;
Effective planning for projected changes in national demographics.

Stigmatization is reproduced and circulated through the everyday-ness of language. The over-simplification of language is patronizing but occurs because people are placed within a patronizing position. Terms of endearment and over-simplification of language when talking with older people adds to individual self-stigmatization, as already discussed. Whilst this use of language is implicit rather than explicit stigmatizing behaviour, due to the socially constructed reality for an older person within a care home, there is a risk for the maintenance of personal identity due to the stigma, discrimination and stereotyping that society and, potentially the care home itself, perpetuates (Goffman, 1963; 1961).

Demographics of an aging population

Whilst stigmatization marginalizes this section of society (Marx and Engels, 1884), it also produces another truth. This truth is to do with the way the older person can be transformed into a commodity and thus, valuable. True value lies with a mass of elderly habituating in the same area (the nursing home) which, potentially, removes the individuality of a person as there is a need to homogenize the population through regimentation of care. By examining the ageing population data and its economic consequences there will be a demonstration that despite knowing what needs to be done, neo-liberalism cannot transform itself. Despite really good evidence of what needs to happen – greater

resources, a different understanding of what care is, the impact on families because of the strain placed upon them as carers – the response has been to try and find the solution through the greater neo-liberalization of the sector.

Commodification, according to Marxist traditions, is when people or services become commodities or goods for exchange (Claeys, 2018). There is a dichotomy between care, as an act in and of itself and, the market place or commodification of care. The logic of this is inexorable; it is not only the actual payment that is the paramount issue when discussing nursing homes but also the bureaucratization of care though the political and managerial control of the sector. The fact that the provision of care is needed to have a contract in place for the exchange of money ultimately means that the care itself is commodified. If the contract is in place to allow for an agreement on the type of care one is agreeing to, where is the individualized, person-centred care situated? As outlined by Claassen (2011) "Contracts purport to make care into a good with transparent and well-specified boundaries. Contracts therefore fail to accommodate caring obligations, which by their very nature are unspecified and without clear boundaries" (p.11). There is a need to provide care that incorporates the intersectionality of old age. Old age, is and of itself, is not an illness or disease that can be cured, instead it can be represented in very different ways. For some older people it is the psychological arena of depression and anxiety that forms the need for care. For others it is the co-morbidities that old age can exacerbate. Neoliberal capitalist society reduces old age to a commodity it can exploit.

It is important to highlight that there are two different types of care home that cater for differing patient requirements. Firstly, there is the residential home that provides care from unqualified care staff where patients' needs in regards to washing, dressing, safety and nutrition are catered for and the home is usually quite small. Secondly, there is the nursing home which provides everything that a residential home does with the addition of 24-hour medical care from a registered practitioner (usually a registered nurse). In previous years, nursing homes traditionally admitted residents with chronic conditions but this has changed over the past decade with residents being admitted in sub-

acute conditions, usually following a hospital stay. The resident population has changed in regard to dependency and cognitive impairment and this will continue to become the new norm for nursing homes.

The majority of data is a combined total for all English care homes – both residential and nursing – as this is how it is represented within the public reporting systems. According to the CQC (2019) there are 14,171 care homes registered, with 4,168 classified as nursing homes. The CQC monitor, inspect and regulate health and social care services. The data that the CQC are concerned with is data that could be translated into a profit and loss accountability agenda which again links to older people being placed into nursing homes becoming a commodity. According to the CQC (2019) two per cent of all nursing homes were rated as inadequate, 22 per cent require improvement, 72 percent are good and four per cent are outstanding. In 2018/19, these care homes cared for an estimated 841,850 adults (The Kings Fund, 2019a) requiring long term care. Added to this, there were another 223,605 short term care package episodes (The Kings Fund, 2019a). There has been a reduction in nursing homes, totalling six per cent (or by 236), between 2013-2019 (CQC, 2019). Whilst the CQC (2019) promote this as a positive move as more people are being cared for in their own home, instead there is greater evidence that recruitment and retention is the main issue with Skills For Care (2020) advising that there are 1.6 million vacancies within the social care sector.

Being employed within a care home is viewed as low-skilled and low paid whilst being physically and emotionally challenging. Working hours are long and, due to recruitment and retention issues, there are shifts when there are not enough staff on duty and overtime is expected to be filled by the current staff. This will contribute to the documented turnover rate of 40 per cent for care staff and 34 per cent for registered nurses in the adult care sector which, if compared against the NHS acute services as 11.9 per cent registered nurse turnover indicates as a worrying statistic (CQC, 2019). Taylor (2011) outlines that the Marxist perspective maintains that poverty, like wealth, is an inexorable consequence of a capitalist society. Marxist thought outlines that poverty profits the ruling class, as it

ensures that there is always a workforce willing to accept low wages (Marx 1894; Marx & Engles, 1848). Likewise, the existence of unemployment and job insecurity means that there is always a reserve army of labour able and willing to take their place if they are not happy. Capitalism and the bourgeoisie therefore benefit from the existence of poverty (Cunningham, 2007). Accompanying the potential for keeping wages low is an associative stigma. I have been informed many times throughout my career that nurses working within nursing homes are deskilled, leading to feelings of isolation and not being qualified enough (whatever that means). Supplement these feelings with caring for older people who are already potentially stigmatised due to being elderly or living with a mental health illness and there appear to be little incentive for people to see this sector of healthcare as being important or rewarding.

With the rising costs of agency staff and a year on year reduction on fees, paid for by the council, smaller nursing homes may well struggle with the financial burdens and ultimately decide to close. This does not support the notion of a more liberal approach to domiciliary care within the community. There is also a potential time bomb for a loss of overseas staff to the United Kingdome leaving the European Union [EU]. According to Baker (2019) 16 percent of registered nurses (49,501 people) and 10 per cent of un-registered care workers (33,156 people) are European nationals who are essential in maintaining the NHS. I am not able to locate any current data on the EU national's workforce within the care home sector but it is likely that these percentages will be at least replicated if not significantly higher. Due to care work within British society being culturally devalued due to being a female dominated workforce, meaning low status with a resultant low grade of pay, the loss of European workers will impact on the ability to provide person-centred care to an increasingly ageing population. This cultural appropriation of care work being for women indirectly affects the wages that are common within this work. Women have routinely served significant functions within a capitalist society as reproducers of the labour force and undertaking the role of primary carers, and continue to be over-represented in low wage occupations (Brown, 2012; Fraser, 2016; Gimenz, 2018; Smith, 1979). As the government remains a patriarchal system with an ideology that serves to normalise gender

inequalities as inevitable and necessary, this impacts on the views of society in regard to women and their value and place within it – it is almost the legitimization of care work being only fit for the women in society to undertake. Patriarchal relations place limitations on women and it is a hard fight to move beyond the status of a second class citizens. It should be noted that these relative low wages are not indicative of the human capital and essential skills that care workers imbue into their daily work (Hussein, 2017; Ravenswood & Harris, 2015). The fact that this sector of care workers provide the best care they can despite the negative connotations and lack of funding is testament to them.

What is presented next is data, very often from the government, which would ordinarily suggest that a different course of action was required. However, the remarkable thing is that alternative courses of action are not being taken or possibly being considered. The overall population within the UK is growing due to increased life expectancy and we have entered what Salsberg and Quigley (2017) outline as a "demographic transition" (p. 54). According to the ONS (2017) in 2015 there were almost an equal number of those aged up to 15 years as there were over 65 years which, by 2025, will have tipped towards there being more elderly people than under the age of 15 years, which is due to there being less births than deaths (ONS, 2019). This statistic, in itself, raises the obdurate future challenge around the adequacy of a workforce to provide long-term care for an increasingly ageing population. Those, people aged 65 years and older have increased between 1975 and 2015 from 14.1% to 17.8% of the population and, as identified in Table 3, there is a further growth projection that predicts that those aged 65 years and over will account for a quarter of the UK population (ONS, 2017). What has been noted from the data from 2016 (ONS, 2019) is that the life expectancy has decreased due to the reduced growth of life expectancy that has occurred over the last few years. However, the ONS (2019) still prospectively outline that those above the age of 85 years will almost double over the following 25 years, from 1.6 million people in 2018 to nearly 3 million by 2043 (see Table 4).

Table 3: Age distribution of the UK population, 1975 to 2045 (projected) (ONS, March 2017).

Year	UK Population	0 to 15 years (%)	16 to 64 years (%)	65 years and over (%)
1975	56,226,000	24.9	61.0	14.1
1985	56,554,000	20.7	64.1	15.2
1995	58,025,000	20.7	63.4	15.8
2005	60,413,000	19.3	64.7	15.9
2015	65,110,000	18.8	63.3	17.8
2025	69,444,000	18.9	60.9	20.2
2035	73,044,000	18.1	58.3	23.6
2045	76,055,000	17.7	57.8	24.6

Table 4: Age structure of the UK population, mid 2018 and mid 2043 (ONS, 2019)
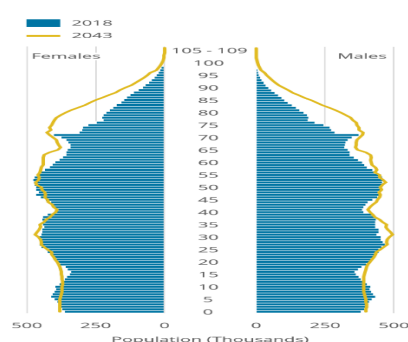
Life expectancy data is important to inform policy and future planning of services and whilst these statistics propose a growth in life expectancy, it is important to underline that there is a difference between length of life and length of healthy life. The ONS (2018a) identify that there is "healthy life expectancy" and "disability-free life expectancy" (para. 7) and whilst this is self-reported this differentiation between healthy and disability free life expectancy is viewed as "important high-level measures of a population's health status" (ONS, 2018b, para. 3). According to the ONS (2018a) men will live, on average, 63.1 years, or 79.7%, in good health while women will live 63.6% years or 76.7%. For each gender, the time spent within what is termed at "Not Good" health (ONS, 2018a) has risen due to life expectancy rising more quickly that healthy life expectancy (see Table 5).

Table 5: Healthy life expectancy at birth, years lived in "Not Good" health and the proportion of life spent healthy, by sex. UK, 2009 to 2011 and 2015 to 2017 (ONS, 2018a).
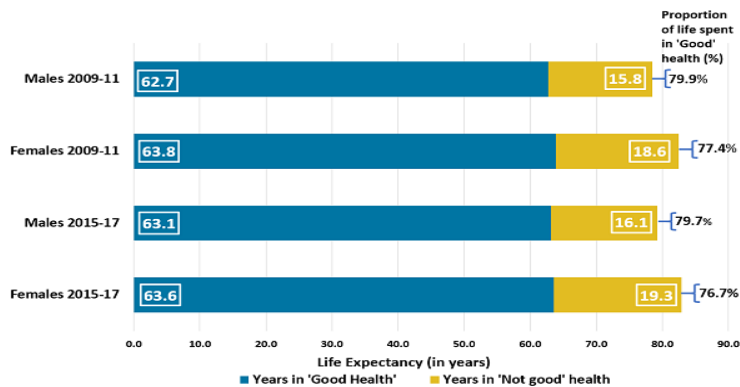
"Not Good" health (ONS, 2018a) will give rise to an increasing number of vulnerable people within our society. Due to the increasing number of people within this sector of vulnerability we can no longer ignore the fact that social care is seriously underfunded, leading to the potentiality of detriment of care to many thousands of people within our society. As outlined by Folbre (2001): "the increased cost of care … means that more people, especially children, the elderly, and other dependents, cannot always afford the care they need . . . [and] increased pressure to cut costs leads to reductions in the quality of care…." (p. xv). The quantitative data that is provided demonstrates that there is a fixed mentality to caring for older people. Politically and sociologically this data is seen in terms of financial implications – how much having an increasingly elderly population will cost. We are a long way off the rallying cry of "The goal should be nothing less than the creation of a new system that ends exploitation by vindicating life-making over profit-making" (Nilsen, 2020, para 18) in terms of providing elderly care, there is a need to move away from the capitalist form of accounting where worth is understood only in economic affordability within hegemonic institutions and instead engage with a person-centred and relationship-focussed approach to care. The latest statistics for nursing homes (ONS, 2014) indicate that there is an important demographic shift of patients with those over the age of 85 years representing 59.2% in 2011 compared to 56.5% in 2001 (see Table 6). This increase of age could be seen as one of the major success stories of the last half of the twentieth century but,

just because people are living longer, as indicated above, this does not necessarily mean they are living

better.

Table 6: Proportions of the resident care home population aged 65 and over by age in England and Wales, 2011. (ONS, 2014).
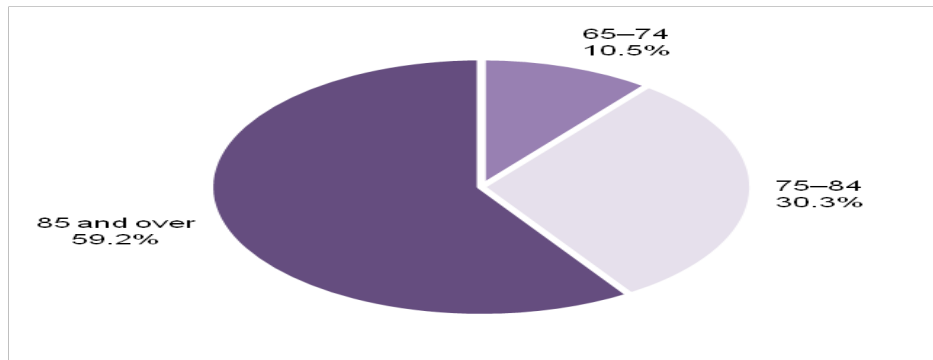
Unsurprisingly, a person's use of health services increase with age due to progressive chronic

conditions, increased co-morbidities and polypharmacy, so these statistics are an important

consideration for the provision of health and social care services that are provided, especially when

the cost implication is considered. In 2014, Alzheimer's Society published a major study on the social

and economic impact of dementia in the UK which gave a cost estimate of £26.3 billion pounds. The

NHS is credited with providing £4.3 billion and social care with £10.1 billion but £5.8 billion is paid

by families for everyday care from professional care workers for tasks such as washing, dressing and

eating (Alzheimer's Society, 2014). Care home fees are adjusted according to a means test entitled

the Care Needs Assessment. If a person, requiring nursing home care in England, has more than

£23,250 (The Kings Fund, 2019a) in assets the cost of the care is the responsibility of that person,

with those people who have less than £14,250 in assets being funded totally by local authority. A

person who is classed as having ongoing and substantial care needs may be eligible for NHS

continuing healthcare funding and this does not take into account whether the person has over the

£23,250. It was intended following the Care Act, 2014, which came into force April 2015, that the

government would increase the maximum amount of assets to £72,000 from April 2016 but this was

not implemented, and appears to have been delayed until at least 2020. The Government had

advised that it was to publish a green paper (probably in 2018) that would provide the basis for new

legislation on how to plan and pay for social care (Age UK, 2017) as well as tackling the issues of an ageing population (Gov.UK., 2017). This was only published in the autumn of 2021, revised in March 2022, yet will not come into effect until October 2023 (Gov.UK, 2022). Currently, local authority (LA) payments are capped at £500 per week (UK Care Guide, 2018) but many care homes charge significantly more than this. According to the Competition and Markets Authority (CMA, 2017) this basic payment is insufficient to secure the long-term running of a care home and care homes that are LA funded have no monies to enable re-investment into the service leading to sub-standard care homes. The worrying data provide by the CMA (2017) is that around a quarter of all care homes (approximately 3,543) have a 75 per cent rate of LA funded residents. The CMA (2017) advise that these homes are at risk of failing and, on average, this level of funding is ten per cent below the required minimum level to cover costs. According to Killett, et al. (2013) the closure of smaller nursing homes could be a portent through which oligopolistic control of the nursing home sector will appear with a few larger companies running their own type of social care in which decisions of "profits prioritised over people in decision making" (p.44) would become more apparent. There is almost a feeling of the private sector "legitimising the importance of care'" (Budig and Joya, 2008., p. 11). An older person can decide to live in a care home of higher cost but the difference must be met by another person – friend or relative, and this is termed a third-party top-up. In 2017/18, the cost of these third-party top-ups was estimated to be £2.9 billion (The Kings Fund, 2019a). This disparity between LA funded, top ups and private funders is unjust and until a person and their relatives need to investigate going into a nursing home there is little awareness in the general public over this inequality. There are a minority of people who are classed as 'wealthy' within the population of residents within nursing homes and this measure ensures that anybody with their own home and who lives on their own (no spouse or dependant) will end up paying costs which far exceed what the LA provide (CMA, 2017). This is another example of women being penalised, in this case for living longer than men and, as outlined by Bajekel (2002), women are statistically more likely to be admitted to a nursing home from living alone. A decade ago, the Dilnot Commission (2011), which was set up

to examine the measures required to allow a fair and equitable approach to funding care home places and care packages, revealed that an estimated 50 per cent of people aged 65 and over will spend up to £20,000 on care costs and that 10 per cent would face costs of over £100,000. In recent statistics provided by The Kings Fund (2019a), throughout 2018/19 the total expenditure on adult social care by local authorities was up by £800 million from 2017/18 to £22.2 billion. This amount does not just cover care home fees but a whole raft of requirements as set out in Table 7:

Table 7: 2018/19 Gross current expenditure in England by primary support reason. (The Kings Fund, 2019a).

The figures discussed here demonstrate that there is an increasing demand for services but this demand is becoming more expensive. Whilst this obviously can be attributed to the factor of demographic change, with a rising number of people over the age of 65 years with increasing co-morbidities, I believe there are other factors that influence this situation that are situated within the family structure as well as a refusal to accept that social care policy needs reviewing to meet the needs of 21st century older care. However, there are counter beliefs around the need for increased funding from scholars such as Allan and Scruggs (2004); Bradley, et al. (2003) and; Esping-Anderson (2006) who disagree with the state needing to fund welfare projects for older people. Esping-Anderson (2006) goes as far to state that a: "…focus on spending may be misleading. Expenditures are epiphenomenal to the theoretical substance of welfare states … by scoring welfare states on spending, we assume that all the spending counts equally" (p. 161). Whilst this point of view suggests there is a need to quantify what older care consists of, there is a difficulty around measuring what 'sufficient' consists

of especially when the biomedical approach remains the overriding method within a paradigm of conceptualizing care (Filer, 2019). There is a confusing lexicon around the ideology of what care is and there are preconceptions (and misconceptions) around what is paramount for social policy surrounding the care of the older person. It would serve us all to be engaged within these conversations in order to structure a humane structure to funding for the older person.

Contemporary research by Vaismoradi, et al. (2015), suggests that the major influence for a person being admitted to a nursing home was due to the person not being able to care adequately for their own needs due to a deterioration of physical or cognitive skills, with the second reason being due to the inability of the persons family members to manage the care of their relative. There are increasing demands upon and changes within the structure of families which can influence the ability to care for an older relative. Davis and Nolan (2003) outline that there is no one reason for placing a relative in a nursing home but a potential driver can be the need for employment by the potential carer. This is agreed upon by Yeboah (2015) who outlines that the family-based care of the older generation and "intergenerational reciprocity" (p.239) is waning. This inter-generational care is impacted upon by emerging family structures. Compared to the 1970's, there is an extensive rise in employment for females, who are traditionally thought of as being the care giver, up from 53% in 1971 to 67% in 2013 (ONS, 2013). The 'traditional' family structure has evolved and many parents now have relationships with step-children which, as implied by Ferguson (2004) can adversely affect the demand and reliability of care at times of greatest need. The age at which a child now has their first child is also rising, from 27 to 30 years between 1990 and 2012 (ONS, 2014), which can affect the ability of a child to care full time for an ageing relative – commonly referred to as the 'sandwich generation' (The Kings Fund, 2019b). There is also what is labelled 'beanpole families' (Bengtson, et al. 1990) where a family structure has many generations (due to longevity) but fewer people at each generation, thus reducing the number of people to care inter-generationally. Bertram (in Hoff, 2015) devised the term "multi-local multigenerational family" (p. 17) where families are located across large geographical areas and potentially across the world. This multi-local multigenerational family may have infrequent face to

face contact and rely more upon social media to connect on a regular basis. This increasingly diverse geographical area will impact on the ability to provided inter-generational physical care. Whilst there is a thought that the care of a relative is usually from a child (Evandrou, et al., 2018), the biggest increase of informal care is actually from spouses (Hoff, 2015). With increased longevity for both genders there are now demands placed upon spouses to provide much of the informal care, which can impact on their mental and physical health also. It is interesting to note that global research undertaken on behalf of the WHO (Buchan, et al., 2017) identifies that by having family members undertake the care required at home actually bolsters the inefficiencies of the health care system and policies. This informal care is not always gender specific however, it does tend to involve females in the main caring role and it does sustain the inequalities that exist in a hierarchical society based upon discrimination and prejudice in regards to income, class and race (Magar, et al., 2017).

Chapter summary

This chapter has provided a conceptualization of and a demographic perspective on ageing within society today. I have explored the issues of stigma and discrimination, not only for older people but for the workforce in general. I have provided statistics that support the theory of an every growing older population that will not, necessarily, live longer with a better quality of life. The role of family has been explored and discussion around the evolving nature of how families are no longer able to burden the care work that may have traditionally been undertaken within the home in recent decades has been outlined. The ongoing expectation of family (especially spouses) taking on the burden of care appears to be the final exploitation in the neo-liberal ideology. When a neo-liberal capitalist government cannot squeeze anything further out it does not take responsibility, instead it off-loads responsibility to those with an ethical, moral and familial connection.

Chapter 3

Concept of Home and Total Institution

It is in the space of the care home, which is a strange kind of amalgam of what a home should be, and its neo-liberal reduction as a form of a money-making enterprise, that the tripartite within this thesis is bought together. When one discusses their own home, you would not be the 'resident'. As soon as you bring in the resident to the home it then becomes an institution. If the home in which they are living is not theirs, it becomes an institution. When a person visits someone else, becomes the visitor to their home, they are not imbued with regulations that visitors to a care home are governed by, which again infers institution.

There are two principle reasons why I am looking at the concept of a home. The first is because, in a way, home is symbolically the idea where someone belongs and where someone has a right to be. Secondly, within a capitalist system the home also represents autonomy and individual power (Avsar, 2008). The way that care is being operationalised means that the care homes very often take the home and substitute it in order to make money out of it. This substitute inevitably becomes the institution. However, a home goes beyond the physical, the bricks and mortar of a building and the notion of home engages with the emotional psyche of a person. Home as a notion, specific place and entity, consumes a substantial proportion of individuals' incomes, preoccupies their day-dreams and their leisure time. Home is imbued with a myriad of emotional, physical and psychological thoughts and feelings which are dependent on the individual, which indicates that a person's history is entangled with the home. This personal history through the home supports an individual's sense of belonging and continuity, to both their family and wider community, and, through the act of ownership a sense of agency and independence. Through time we have co-produced our own ideology of home that is reflective of a cultural consensus and includes; safety and protection against an outside world, a place to be a part of a chosen social unit; autonomy and privacy, thus the concept of home is multi-

dimensional. There are psychological aspects that are attributed to home which include belonging-ness, permanence and community. An older person's home can be viewed as integral to their emotional well-being (Musselwhite, 2018) with attached meaning of neighbourhood (Sixsmith et al, 2014). It would appear that there is a symbolic merger then between the home and one's own self and thus the home can be seen as a literal place and an ideal. Therefore, to move away from a home, especially if it is not a personal choice, can result in negative psychological impacts due to loss whilst also marginalizing further the older person. This removal of a person from their own home identifies with what Marx (in Westmoreland, 2019) calls "Bourgeois property" (para. 5). In order to pay the nursing home fees the house is held in trust or sold thus meeting what Marx & Engles (1848) outline as the natural neo-liberal logic through which institutions acquire the personal property of individuals. The ultimate gain is for the capitalist structure as the person moves to a place where the care has to be paid for, at the cost that is demanded.

As home can be considered as a layered phenomenon nursing homes are viewed as being both a concrete place and an image (Wellin & Jaffe, 2004) which embodies cultural ideals of independence and comfort. The two may subjectively be congruent or not! The Company's website (where the research was undertaken) proffers the following in regard to their care homes:

> The environment we live in has a significant impact on our happiness and well-being. Each [company name removed] home has a unique look and feel but all are designed to be warm, comfortable and stylish places to live in. Where homes have outdoor spaces, they are kept beautifully maintained and set up for both relaxation and summer activities (citation confidential, refer request for reference to Author).

The nursing home embraces the feel of a domestic home and yet is the antithesis of it – people who are unable to be at home can only be cared for within this type of institution. Therefore, it is not the physical place where people live (as it is like home) but those who work within it that make the individual live a comfortable life. It is almost a narrative process of undermining a person's confidence in their agency to live an independent life in their own home with the only alternative to move into a nursing home. This process of undermining is coupled with a typical marketing tactic that implants the

idea that the individual's own home is lacking in some way by suggesting that "the nursing home is beautifully maintained, warm and comfortable" (citation confidential, refer request for reference to Author). The ideology of home, and thus family, is also aimed at the recruitment of staff "We aim to create a family environment in all our homes, hospitals and offices" (citation confidential, refer request for reference to Author). This identifies that the feeling of home is aspired to whether as a resident, relative or a member of staff. It appears that home is the panacea within care – to be at home means that this is where the care is best.

Environmental gerontology (Wahl & Oswald, 2010) has been discussed since 1960's and this ideology has attempted to conceptualise the move between a medical model of care into a multidimensional approach of quality of care within a quality of life setting. This is more than an attempt at a cultural shift, this is also an attempt to reverse the values of neo-liberalism. According to Vaismoradi, et al. (2015) people considering a move into a nursing home expect the environment to be similar to their current home. The architectural language that is used to express space ordinarily forefronts a preconceived idea of what on older person's space needs to look like with Fairhurst (1999) identifying: "For architects, then, the manipulation of space is a logical process, dependent upon technical and standardised notions of the amount of space needed to place possessions. For older people, though, this relationship is reversed; their possessions predate the space created by the architect so that objects are logically prior to space" (p. 96). This idea or ideal of home, prior to moving into it, may be unrealistic and there becomes an inevitable tension between the ideal supposition and organizational rules and norms that are associated with nursing home care. These rules and norms can (or will) ultimately restrict flexibility and expectations but, this does not mean that the care is less than competent; instead there is a need to review the understanding of an older person's lifestyle and start to move away from the typical stereotyping of what and who an elderly person is - it is not as restrictive or prescriptive as imagined. There is a facade of home placed onto what is essentially a concept of what Goffman (1959) succinctly outlines as a social establishment with the description:

"…any place surrounded by fixed barriers to perception in which a particular kind of activity regularly takes place" (p.238) highlights the need to culturally alter the perception of what a nursing home is, or could be, by removing the fixed barrier. Only by altering the distal stimulus will perceptions be altered.

The ownership of nursing homes has relocated over recent decades, and certainly since the 1990's, from government run to private sector ownership, with 64% of residential and nursing home beds being provided by local authorities or the NHS in 1979; by 2012 it was 6% (ONS, 2017). Health care in general, with social care being most affected, was part of the neoliberal privatization drive in the 1980s under Thatcher. What this meant was that there was a privatization of space; space was sold in order for it to be re-ordered as institutionalized space. Mercille (2017) outlines that due to neoliberal policies "the needs of older people have been increasingly treated as a commodity from which investors can profit" (p. 2). This changing of organizational ownership from government to a for-profit business model ultimately brings an emphasis to the commoditization of care and the possible side-lining of those older people unable to pay for the privilege of being housed in a reputable nursing home.

Nursing homes are inevitably shaped by policy and this is outlined within The Care Homes Regulations Act, 2001/2003 and the most prominent influence is regulation. The regulator, since 2009, of all care facilities is the CQC, who has the brief to regulate, inspect and ensure care in care homes meets the fundamental standards (CQC, 2017b). This regulation inexorably leads to a sense of surveillance mainly for the staff and owners of a nursing home but this can also be felt by residents and their family, as the CQC inspect all functions and spaces of a nursing home and award a rating which is placed on their portal (https://cqc.org.uk/). This system of surveillance serves to provide a power imbalance in favour of the CQC and there has been an increasing culture of compliance to meet regulatory requirements rather than a desire to meet resident's personal requests and needs. Even though the CQC (2017b) outlines the need for person-centred care as one of its fundamental standards there is a disconnect between the amount of written notes that are required to allow person-centred care and that of the

actual action of providing person-centred care. The commonly heard misnomer that if it is not written down then it has not happened promotes a litigious view of nursing home care that is supported by the power of compliance at its core.

There have been recent attempts to re-determine nursing homes into places where people live and experience their lives, however, unless there is a much more radical approach to care this heritage of what Goffman (1961) entitles total institutionalization will continue to perpetuate. There remains a definite public perception, and a possible reality, of nursing homes maintaining the characteristics of the total institutions, namely those of loss of privacy, limited boundaries, adherence to uniform treatment and fixed schedule and, a loss of choice (Goffman, 1961). The placement of those who are 'deviant' due to old age or through physical or mental deterioration into nursing homes is viewed as social rejection (Reidy, 1993). The very act of placing people within a nursing home is stigmatising through the rejection of deviance within a 'normal' community. This idea was further supported by Rowles (1978) who outlined that older people became prisoners of space with the consequence of psychological withdrawal. As Meisen (2006) outlines, a care home needs to address and support both the emotional well-being of the people residing there, as well as their relatives and friends, to reduce pathological grieving and feelings of seclusion. There is a dichotomous nature to living and working within a nursing home which is characterised by the symbolic nature that the nursing home has to relatives and residents as a place of loss - a final resting place before the inevitability of death and to the staff as a place of living, caring and employment. However, many individual places, whether within big organizations or small and independent may develop its own particular culture. Those people who live and work within the nursing home will combine, through social interaction, their values, beliefs and assumptions as part of the everyday-ness of living and working together. This leads to a dualism within culture where the individual influences the culture and the culture influences the individual.

As previously outlined, I was introduced to Goffman whilst undertaking the taught part of this Doctorate and immediately became intrigued on his ideas around institutions. Having worked within

nursing homes for the majority of my nursing career to date and feeling passionately not only about the people I had nursed but also the view (perceived?) of nursing homes and the staff which worked within them. There is discourse in general around nursing homes being institutions both within the realms of health but also within media coverage and I was keen to further engage within Goffman's ideas within *Asylums* (1961) in part to debunk what he had written. After reading the book – four times – I started to bring in some of the ideas that he discussed within my teaching for post-registration qualifications. When we engaged in conversations around admitting patients to hospitals I described to the students about Goffman's (1961) portrayal of admission procedures and the degradation of rectal examinations that were undertaken. What I did not expect were nurses reporting that this does, in some way, still occur. They described to me how, when some patients were admitted to their wards, a skin assessment needed to be undertaken and this could include the patient's buttocks being opened to ensure no pressure areas had developed there. This one instance highlighted to me that the practices and themes of the 1960's were still in play in today's health care practices. How humiliating it must be to have these type of checks undertaken and how submissive we are when entering a place, like a hospital, to undress and submit to these types of examination. There is a conceptualization of power in that the medical profession remains omnipotent in regard to all areas concerning health and well-being. There is a power differential when people (patients) are vulnerable and needing help and thus trust is implicit when entering into a place of perceived safety. There is a trust that whatever is asked of the patient that it is for their own good and no more than surface questions are asked. This precarious power, based on trust, is interesting as in no other situation within normal life would we submit to this type of invasive treatment with full agreement. Thinking about power and how it is displaced when getting older and what is removed from our ageing population in terms of self-determination has become one of the main stratums throughout this thesis. As outlined by Peters (2007, p. 2) "… depending on the focus and the "rawness" of a critical incident, it may feel uncomfortable to undertake a critical reflection because it highlights our assumptions, views and behaviours" however, the notion of a Marxist critical reflection would enable

me to reconstitute different parts of my experience into a human whole. As Jones and Bradbury (2018) outline, a Marxist critical reflection approach will allow me to look at the familiar world of social care but also challenge me to "…reassess what we tend to accept as normal" (p. 35). By undertaking this approach, it is anticipated that I will be able to inform practice in order to facilitate change, therefore addressing the challenge stated by Marx (1888, in Barker, 2018, p. 67): "The philosophers have only interpreted the world, but the point is to change it". Care is significant and by utilising the lived experience there is an emphasis on the everyday-ness in contrast to the institutionalised setting in which this research was undertaken. Whether this approach is philosophically tenable is not the argument here as it is about the dignity of an echelon of our society that is overlooked and undervalued. The act of listening itself can be constituted as care so it becomes therapeutic to the individual doing the talking. It gives people the time (and permission) to reflect, however fleetingly.

Mali's (2008) case study opens up a cleft in our understanding of care and provides a devastating critique on the current care system. There is a clear focus between Goffman's (1961) writings and real-life examples within a contemporary society. This has provided a tool by which I will measure both observed actions and oral discussion from evidence undertaken during the data collection and will be reflected upon in the discussion chapter.

Figure 2: Dimensions and variables of total institutions (adapted from Mali, 2008., p. 436)

Dimensions of the total institution	Variables of the total institution
Isolation from the outside world	Contact with the outside world Visits by friends, relatives and acquaintances Defining life 'inside' and 'outside' the institution
Process of mortification	Admission procedures Personnel's assistance in solving residents' problems Personnel's assistance in adjusting to institutional life
Strict control of authorities over the individual's life	The way of entering a room Respect for the privacy of residents Calling residents by their names

	Way of communication with residents
Comprehensive care for all aspects of an individual's life	Residents access to information on the performance of services, events in the home
	Residents influence on the performance of services (time, mode, form kind)
Bureaucratisation of life	House rules
	Residents rights
	Adjustment to institutional life
Non-everyday life	Stage of independent care
	Performance of activity of the home environment in the institutions
	Consideration of individual wishes, interests and needs of residents
Disciplinary system	Violations of the house rules and their sanctions
Spending of free time	Employment activities
	Influence of the activities on adjustment to institutional life
Secondary adjustments	Ways of adjusting to institutional life
	Withdrawal into oneself
	Search for a sense of life in the institution
The world of residents - the world of staff	Relationship between staff and the residents
	An involvement cycle
Atmosphere and culture of the institution	Atmosphere and culture of residents
	Atmosphere and culture of staff.

Chapter summary

This chapter has explored the concept of home, not just as a physical place but where an individual's emotional and psychological well-being is built and maintained. To be at home is to feel included within the community where you are based. The nursing home environment may purport to be home but, due to the mass of people housed within it and the subjection to regulation and policy, it is an institution. The nursing home is viewed dualistically between staff and the residents and their visitors. On one hand it is viewed as a final place before death (residents and visitors) whilst staff view as a place of life, care and employment. This is a potential are for conflict both between the parties as well as within the self.

Chapter 4

Literature review

Introduction

As explored within the introduction to this thesis, I was introduced to the work of Goffman in the taught aspect of this doctorate. The reading of his work inspired me to reflect upon the nature of care homes. This chapter will evaluate the specific literature that informs the use of Goffman for studies within nursing homes. The reasoning behind the type of literature review will be outlined and the search criteria will be explained to indicate how the literature review was realised.

Scoping and conceptual literature review

There is a need for a literature review within any research and, according to Grant and Booth (2009), there is usually a chapter within any thesis or research paper to alert others to what connected research has already been undertaken, how this research informs the thesis and how the potential thesis adds value to the research field.   However, as this research was theory-generation, or an inductive approach, I was keen not to engage in this traditional format, therefore, a scoping and conceptual review of the literature was undertaken which, as suggested by Peterson, et al. (2017), can be relevant within the field of health research. As outlined by Kirby and McKenna (1989) there is a need, depending on the type of research you wish to undertake, to free oneself from what has gone before:

> **It is an experience in thinking freely and reflecting upon how you think**. Being free to this means getting rid of the 'shoulds' that tell you how you *should* think, what you *should* gather and where you *should* go for information. It also means understanding that you think differently than anyone else and that is it precisely this unique understanding that enables you to do different research than others. **You** are important to your research task. No one else can do it as you would. If you invest yourself in the research process, and if you do a thorough and honourable research, it will be good research" (p. 55. bold and italics in original).

This was liberating to me for this work. The majority of all research books, the internet and indeed other theses that I read all talked about the in-depth literature review that needed to occur prior to starting. I could not appreciate how undertaking this in-depth review would free my mind and not influence what I looked at, what I saw as important or prejudice my plans for this work. The voices of others could influence my own and my participant's voice and this research was important to me.

A scoping review of the literature has no definition which is universally accepted (Peterson, et al. 2017) and, as such, there is some controversy surrounding its application. This is due to the analyses of a scoping review not being based entirely upon the quality of the articles utilised and there being no exacting criteria for undertaking it (Levac, et al., 2010). However, Grant and Booth (2009) suggest that a practical application of a scoping review is useful for a: "Preliminary assessment of potential size and scope of available research literature. Aims to identify nature and extent of research evidence" (p. 92). This was exactly what I needed to understand – the use of Goffman, within a qualitative paradigm and situated within a nursing home. This would allow me to review the literature to date and utilise it to inform my own study whilst ensuring that this work would indeed be a new addition to the research field.

At the beginning of my Doctoral studies I had not really encountered Goffman therefore, a preliminary search was undertaken in September 2016 in an attempt to connect with the wider relevant literature. What is interesting is that there have been no additions to the original scoping literature review within the past four years which indicates that there is a scarcity in research that directly utilises Goffman in regard to nursing homes and long-term care facilities.

There may be some criticisms regarding the depth of this literature review, using only Goffman within my search criteria initially, however an ongoing gathering and reviewing of literature has been undertaken to ensure that any and all current research was included. In fact, over 500 journal articles, books and websites have been chronicled within a personal bibliography that have informed my

thinking and understanding. Much of this was undertaken within the data analysis stages when I was making sense of the themes that were coming through my work. Some have been incorporated within my reference list at the end of this thesis but many remain as bibliographical evidence.

Results

ProQuest, PubMed Health, Elton B. Stephens Company [EBSCO] and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases were all utilised within the search. There were no dates applied as I believed that older research may well have been in abundance and have some interesting points to consider. It would also be useful to compare the outcomes from older research to those that may be uncovered within this thesis. The only exclusion criteria was that of publications not written in English. The Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) tool (Cooke, et al., 2012) was adopted as a way of engaging more fully with qualitative literature (Table 8).

Table 8: Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) tool (adapted from Cooke, et al., 2012).

Sample	older people OR aged OR older OR elderly OR geriatric OR elderly people OR senior
Phenomenon of **I**nterest	nursing homes OR long term care OR residential care AND Goffman
Design	observation OR interviews OR focus groups
Evaluation	experiences OR attitudes
Research type	qualitative, mixed method, scoping reviews

The outcome from this scoping literature review highlighted the scarcity of research that utilised Goffman's work directly in regard to nursing homes. There were seven full text research papers (Table 9).

Table 9: Literature identified.

Title	Type of study, country and sample	Findings	Strengths	Limitation	Recom-mendations
Mali, J. (2008). Comparison of the characteristics of homes for older people in Slovenia with Goffman's concept of the total institution. *European Journal of Social Work. 11*(4). 431-443.	Qualitative Slovenia	Adjustment to institutional life is a long process Emotional labour is integral to staff's ability to care for residents Strict control by the institution is ever present and seen as the only way to allow a large group of people to live together harmoniously	Table on dimensions and variable of a total institution Sample of homes = 61 for questionnaires	Overseas institution examined Articulation of methodology minimal	Flexibility to rules governing an institution Increase staff awareness of depersonalization
Parker Oliver , D.., Porock, D. & Oliver, D. B. (2006). Managing the secrets of dying backstage: The voices of nursing home staff. Omega. 53(3) 193-207.	Secondary analysis of a project USA	Backstage behaviours conflict with public reality presented by long-term care institutions	Use of interviewee's voice to clarify themes	Funded research Overseas study Use of Goffman's Presentation of Self rather than Asylums as a basis for the study Secondary analysis Staff interviewed were all experienced practitioners	De-mystify the process of death Palliative care needs to become a legitimate option of nursing home care
Rohlfsen, L. (2003, December 8th). *Institutions to community-based care facilities: The continued dehumanization of the chronically mentally ill.* Paper presented at the American Sociological Association, Arizona State University, USA	Conference paper USA	Goal congruence between facility's goals and that of the individual Individual's control of their own life The necessity of specific facilities for mentally ill people	Focus on a non-hospital setting which is easier to transpose to a nursing home setting	Based on long-term facilities for the mentally ill Overseas study	Move from institutions to community-based mental health care services Re-evaluation of mental health facilities goals
Owens, C. (2004). The glass-walled asylum: A description of a lay residential community for the severely	Ethnography using participant observation	Full social integration may not be possible	Only UK study to utilise Goffman's	Based on long-term facilities for	Re-examine the concept of asylum and recognise that

mentally ill. *Journal of Mental Health. 13*(3). 319-332	and semi-structured interviews. UK	Normalization conflicts with need to keep vulnerable people safe	*Asylum* as a basis for work Sample of participants Participant observation Use of interviewee's voice to clarify themes	the mentally ill All staff interviewed were non-registered Business operated small domestic homes as the place of care	for some people it is needed
Dupuis, L. S., Smale, B. & Wiersma, E. (2005). Creating open environment in long term care settings: An examination of influencing factors. *Therapeutic Recreation Journal. 39*(4). 277-298	Self-administered questionnaire Canada.	Recreation and leisure programme enhance quality of life Increase the numbers and families and friends involved in the facility	Response rate to questionnaire (36.3%),	Overseas study Concentrated on recreation programmes	Foster a view of long-term care that is a place of continued life and thriving Include residents in the selection, planning and implementation of recreation programs
Mclean, A. (2006). From commodity to community in nursing homes: an impossibility?. Ageing & Society. 26. 925-937.	Forum article Based on author's Ethnography that compared two older people's units for dementia USA	Relational interaction between staff and resident must take precedence over task Efforts needed to maintain resident identity	Based on 18-months project Daily observations throughout the 18-months at different times Large sample	Research conducted with a grant from the Alzheimer's Association of America No voices from participants utilised	Institutional obstacles need to be reviewed Radical overhaul of funding of nursing homes Reframing of the social perceptions on values and priorities for long-term care
Zweig, S. C. & Oliver, D. P. (2009). Returning from the total institution to a home environment: A journey for birthing and dying. Journal of Housing for the Elderly. 23. 116-129	Review of literature: birthing and dying rooms USA	Home equates to a place where a person-environment relationship can be maintained for the benefit of both	Regard for the dying environment and the use of space and architecture	No indication of how literature review was undertaken	Need to create environments that are based on the individual patient not the organization's requirements

Including the forum article and conference paper this literature review has assisted in providing some context for the use of Goffman within long-term care facilities in this under-researched area. There was only one ethnographic study (Owens, 2004) and whilst this was within the realms of long-term care involving people living with longstanding severe mental illness. This identifies that this study, utilising Goffman, within the realms of the nursing home will contribute to the wider research community.

Whilst there was a dearth of research pertaining to the use of Goffman within the realms of nursing home literature, there were some interesting themes that occurred from the articles that have been reviewed.

Theme 1: Staff

McLean (2006) proffers a reasoning for the high rate of turnover or staff within a nursing home setting, that of being disillusioned with the care they are 'allowed' to administer which is ultimately dependent upon the type of organisational image of care they work within, the accompanying rules and regulations and the environment that their employment is based in. If an individual care worker's vision of care surpasses that which they are encouraged to give, there is a clash of ideology leading to staff dissatisfaction and finally burn-out which forces the care worker to leave, as Mali (2008) identifies within her work, staff are automatically bound, by the very nature of the work, to be driven within an involvement cycle. This is a really pertinent point that I had never considered before. When I reflect upon my career this is exactly what has happened within a couple of places that I have worked, mainly within the hospital setting. The turnover of patients, the hierarchies that are ensconced as a part of the management structures and the lack of relational care has led me to feel that the patient themselves were very low down on the list of priorities. Rohlfsen (2003) states that staff, who are constricted by an organizations goals, rationalise the care they give and, occasionally, this can lead to what Goffman (1961) contends to be "dehumanization" (p. 78). Due to the requirements of the organization and compliancy to both organizational and regulatory requirements there is a pressure for staff to behave in a certain way. Staff are judged against a list of organizational requirements and key performance indicators and non-conformation is disallowed. In my experience, the use of appraisals and inductions are a way of monitoring and managing behaviours that do not conform to the organizational goals with the goals being set by management with no input from residents or their families.

Theme 2: Physical place

The majority of the literature reviews started by explicating an overview around what previous concepts of institutions were and how, in order to meet today's societal expectations, there needs to be an ideological shift in the thinking about where we place people for long-term care. Indeed, Mali (2008) outlines that we are "witnessing the development of a new philosophy" (p. 432). What is unfortunate is that there is no real discussion over what this new philosophy entails and how it could be implemented! Dupuis, et al. (2005) outline that the physical environment of a long-term care facility can cause substantial damage for residents as they engender a closed-environment where residents are shut off from their past life and the community at large. Within the forum article from McLean (2006) there was an attempt to identify the use of the terminology of "community" (p. 927) when describing long-term facilities as inappropriate within its current usage. For a community to exist, all members need to have an input into the governing of the system that underpins the decision-making (McLean, 2006) with Mali (2008) adding that it may be impossible for any institution to realise being a true community. What McLean (2006) eloquently highlights is that few of the people who reside within the nursing home are there through choice but rather through the "involuntary circumstances" (p. 927) that have placed them in need of nursing care. McLean (2006) suggests that it is the staff who are employed and the organization that runs the home that superficially utilize the term community to engender a feeling of togetherness and possibly engender palatability as a marketing ploy. However, it is a partisan usage of the term as it is imposed on the residents who reside their rather than a partnership of decision-making through choice.

Zweig and Oliver (2009) outline that a "dying space" (p. 124) is becoming increasingly defined both within hospitals as well as within community care. Whilst Zweig and Oliver (2009) articulate their research around separate rooms within a larger environment, it feels that this "dying space" (p. 124) could be perceived as a nursing home in its entirety. There is a perception that people are admitted to a nursing home to die which, of course, is mainly true however, there is a need to remember that

the nursing home is a place to live in also. Many people make an informed choice to move into a nursing home for personal reasons such as company, planning for their future and unwillingness to burden their relatives and can live there for many years. There is a perception that nursing homes are a waiting room for death but, in my experience, they are so much more. These are places where friends and family can come together to celebrate their loved one's life without the stress of the intimate care that may be needed. There is opportunity to engage with new people, try new experiences and perhaps regain some of the lost abilities due to polypharmacy or lack of personalised physiotherapy.

Theme 3: Commoditization

McLean (2006) identifies that all organizations who own long-term facilities have to keep them full with paying residents as far as is possible, obviously good fiscal sense! With this in mind, there is a need to continually 'sell' the facility to potential users; the local community, other health care professionals who may guide potential residents to the facility and prospective families and residents. However, McLean (2006) utilises the work of McKnight (1995) to underline the thought that commodified communities cannot provide care in its truest form as there is a dependency upon routine and task-orientated activities that are undertaken at a person rather than with. Rohlfsen (2003) outlines that goals which are set by an organization are rarely for the good of the individual resident, rather they are set to meet the needs of regulators and increase the potential to sell the services to new families. Parker Oliver, et al. (2006) go further and suggest that part of the marketing for nursing homes is based around promoting life with no mention of death and, that there is a "pretence that this is not a place where death occurs" (p. 195). They suggest that this also assists family members in making the decision to place their loved one in a place for living rather than on a basis that a nursing home can provide a good death. Death, apparently, does not sell beds!

Theme 4: Identity, Control and Mortification

According to McLean (2006) there is a need for residents to be able to control their own behaviours when a part of a long-term facility with Mali (2008) outlining that these prescribed behaviours are structured by the standards and roles determined by the overall organization. What is missing here is that institutions tend to be highly regulated and thus it is not just the parent company but the regulators themselves that set the standards. Either way, ultimately, this compliance to the norms set will be difficult for many residents as the whole reason they are admitted to a home is due to the very fact they cannot care for themselves without the support of nursing staff. For those people who live with dementia, it would prove to be facile to expect them to observe even simple rules or regulations that can govern an institution. McLean (2006) highlights that when a resident cannot control their own behaviour, there is a risk that staff will attempt to regulate behaviours and even emotions of those that they care for. As a juxtaposition to staff control comes the suggestion from Zweig and Oliver (2009) that control must lie within the hands of the resident and only then will the resident feel secure within the nursing home. What was interesting to me was that Mali (2008) suggests that once a person is admitted to a nursing home they are "not human in the true sense of the word" (p. 433) as an individual no longer "presents the integrity and human nature of human life" (p. 433). This is a fatalistic idea that may well be the case of historical institutions rather than the nursing homes of today. This is an area that I will pay attention to when analysing the data. The idea of patient control is echoed also within Rohlfsen's (2003) conference paper and, whilst directed at mental health institutions, can be readily recognised within nursing home environments. The call for the congruency of goals or outcomes between an institution and the individual is important for empowerment and a sense of and individual's control over their own life (Mali, 2008; Rohlfsen, 2003). Rohlfsen (2003) and Mali (2008) both identify that if control is taken away from a person, whether intentionally or not, there is a risk to the maintenance of an individual's identity which is already in jeopardy due to the stigmatisation of being placed within an institution. Dupuis, et al. (2005) echo this sentiment and outline that the very fact that a person has been relocated to a care

facility engenders feelings of reduced self-worth and produces dissonance with self-concept. Rohlfsen (2006) utilises Goffman's (1961) work on secondary adjustments that demonstrates the enablement of a resident to evidence that their identity as an adult still exists. This includes actions such as black market activities and trading between residents.

Rohlfsen (2003) outlines the ways in which people who live within long-term facilities are exposed to the process of mortification. She outlines the many acts of mortification which include "requesting permission or supplies for minor activities they can usually execute on their own" (p. 7). The many ways Rohlfsen (2003) summarizes are areas that I have never considered that I have removed adulthood from a resident. I have often mailed letters for people, telephoned on behalf of someone and arranged for money that was held within the administrator's office, to be given. These activities were undertaken through kindness rather than an awareness to control another. However, as Goffman (1961) outlines "'disculturation' occurs – that is the 'untraining' which renders the resident incapable of managing features of daily life on the outside" (p. 12). The very act of telephoning for a doctor's appointment, on reflection, was undertaken to please the doctor's surgery as there were set times for a nursing home to ring and, the need for us to know when and where the appointment was to inform the writing of care notes as a regulatory exercise. There is a need to be continually mindful around the maintenance of resident choice as well as mainlining abilities, rather than undergoing tasks to meet the needs of regulation and the staff. Rohlfsen (2003) proposed within her conclusion that only by empowering residents to take control of their own lives could dehumanization be annulled.

Theme 5: Medicalization

Dupuis, et al. (2005) propose that staff routinely medicalise residents within their care and thus constrain the everyday choices a resident can make and impact on the judgements made by staff to allow residents freedom in movement. These constraints, perceived by staff, impact on residents by

making life choices a series of risk averse actions rather than allowing full immersion with individual life choices. There is a limiting consequence, for the resident, with these risk averse strategies and Dupuis, et al. (2005) question whether acting on just staff perception is unjustified for quality of life to be achieved.

According to Zweig and Oliver (2009) the process of dying has been medicalised to a point where it is viewed as a failure within care environments with Mali (2008) and Parker Oliver, et al. (2006) expanding that medicalisation is inherent within all aspects of a nursing home. The process of dying conflicts with an organization's goal of maintaining life, perhaps at the cost of quality for quantity (Parker Oliver, et al., 2006). This theory is supported by McLean (2006) who outlines that the promotion of curing a person is a priority of all institutions with Mali (2008) suggesting that by a curative only stance being adopted all routine care and tasks are taken over by a wish for longevity rather than quality driven outcomes. What is worrying is what Parker Oliver, et al. (2006) suggest occurs within the recognition of the dying process in that staff are aware that a resident is entering the dying phase of life but it is not discussed and it is kept backstage rather than being openly discussed. This is due to a perceived need, from the organization itself and the relatives of the person dying, for ongoing life-sustaining treatments rather than palliative care however, the dying person themselves often recognise that further treatment will not help (Parker Oliver, et al., 2006). Within the nursing home arena, it is more likely that an older person is admitted for the remainder of their life rather than with a goal of being cured and discharged back into the community thus, according to McLean (2006) "custodial management" (p. 931) is enforced. This custodial management (McLean, 2006) is required as there is never really a fixed point as to when a person will die (Zweig and Oliver, 2009). It is usually difficult to predict an exact time a person will die when they are within a nursing home, couple this with a reluctance to discuss death openly and honestly and this can be a challenge when attempting to provide the 'perfect' death. However, the suggestion proffered by Zweig and Oliver (2009) of "physicians and patients…must agree that the expected prognosis of the patient is 6 months or less" (p. 126) provides a starting point for discussions to be had.

An interesting finding, that was highlighted within the work of Owens (2004), was the perceived difference that employing only non-registered professionals within the caring role had upon the non-medicalisation of care within small domestic homes where people living with long-term mental illness resided. Owens (2004) interviewees suggested that an experimental approach to care whereby working alongside residents rather than providing prescribed care, was the best foundation for enabling people living with mental illness to feel normality on a daily basis. By spontaneously responding to the resident in front of them there was collective ownership of the care process. Unfortunately, there is no explanation within the research that outlines how regulators of services react to this provision of non-expert care but it is certainly a thought-provoking and novel way of providing long term care. However, there appears to be incongruence between what the interviewees outline and the reality. Owens (2004) goes on to report that although this is the perceived foundation the reality is somewhat different with staff actually structuring residents daily lives, being governed by crisis management policies and actually adopting what was outlined as a parental role. There was an intensive amount of staffing required to maintain this appearance of normality which, within private companies, is fiscally difficult to operate and maintain. Ultimately, there was a collision between the desire for normalcy and the need to protect a highly vulnerable member of society which could result in a breakdown of patient-staff relationships.

As I have outlined, the scoping review resulted in a scarcity of research. Throughout the remaining thesis, I will undertake to weave other literature throughout my work as a way of supporting and exploring my themes.

Chapter summary

This literature review has uncovered a scarcity of research that applies Goffman's work to long-term care in general and nursing homes specifically. Much of the research critically appraised came from the mid-2,000's and not earlier as I had expected. This could be because there was a slight resurgence

of interest into what long-term facilities were offering at the time. Whatever the reason, there is minimal research to be located. Themes from the research reviewed have included: the medicalization of old age, staff perceptions of working within a long-term facility, how control, identity and mortification are interlinked and, how commoditization can impact upon the lives of those within a long-term facility setting. There were areas within the research where I have indicated that I felt a personal awareness of. These included the hierarchies inherent within care that tend to overshadow the needs of the patient; the perceptions of nursing homes as merely being a place to await death and; lack of choice and individual patient control over their own lives. Whilst the literature reviewed is disparate in regard to the methodology and the institutions where the research was conducted, what is resonant throughout are the major themes discussed within the chapter as well as a feeling that care is in a state of flux with no clear way to overcome the barriers that permeate throughout the care system to promote a more relationship-focused ideology of care.

What is clear is that the voices of older people, their families and the staff caring for them, remain unheard in a tripartite way. This triumvirate are not separate voices, they work together to enhance the nursing home setting and they are interwoven in making the culture of care for a particular home. The focus of my work will be on the lived experience of those within the nursing home arena and the emphasis will be on telling their stories. This will emphasise a different narrative from the literature reviewed but will complement the research that others have undertaken.

Chapter 5
Methodology

Introduction

> To have a voice is human. To have something to say is to be a person. But speaking depends on listening and being heard; it is an intensely relational act. (Gilligan, 1982. p. xvi).

In the previous chapters I have analysed how the commodification of older people works, what that means to the tripartite and, how it links into the wider neo-liberal agenda. In this chapter I want to explore methodologically how I use Marxism and ethnography to understand how commodified people experience and respond to this institutionalization, which they have no control over.

Research has often been conceived of as being paradigmatically opposed with the use of positivist and interpretivist approaches (Bowling, 2000). As I wish to foreground voice I have chosen to concentrate and emphasise the following critical, ethical and methodological approach to the lived experience that it represents, paying attention to the contexts in which is uttered and heard. The relationship between the researcher and the researched are contingent and relational and, how I am positioned as a Marxist gives me a particular perspective as a researcher. In respect of positionality, there is often a classic distinction identified between 'insiders' and 'outsiders'. An insider can assist with the ability to ask more meaningful questions and, claimed as most important, be able to "project a more truthful, authentic understanding of the culture under study" (Merriam, et al 2001, p.411). Naturally, there is the converse to this thought - that of being inherently biased (Bowling, 2000). Researcher positionality also has implications for knowledge construction as a position can influence the issues that the researcher focuses on. Previous experiences shape how we feel about situations into which we enter which, in conjunction with situated knowledge from being an insider, allows a certain confidence in one's own ability. However, this does not mean you are given carte blanche to enter and undertake research within the environment. What must be remembered by the researcher who believes they

are an "insider" is that positionality is not a unitary concept, but a multidimensional process, in which a researcher may be closely positioned on some aspects and not on others (Lusambili, et al 2020). There needs to be an acceptance of the fluidity in which the researcher works in regards to the insider/outsider positionality and this can be decided by either the researcher or the participant. Therefore, the management between both insider and outsider positionality needed to be undertaken. My positioning as a registered nurse who had spent time in a senior position within this very nursing home needed to be handled with discretion. There would be many differences in the nursing home today than when I worked there thus, as the researcher, I needed to ensure that tensions did not arise between myself and the research participants by carefully wording questions as part of the conversations and actively listening to both verbal and non-verbal cues.

Reynolds (1999, p. 539) outlines that "Critical reflection, therefore, whether its underlying influences are from critical theory, liberationist pedagogy, feminism, Marxism, or postmodernism, treats all generalized observations and prescriptions on society and social behaviour (…) as interested rather than neutral". The use of Marx was a considered one as a feminist approach was debated also. There are similarities within Marxism and Feminism such as the gendering of caring roles and the division of labour (Kennedy, 2013); the call for revolution with Feminist writings (Barratt, 2014) advocating that sexism only leads to other divergent types of oppression and; alienation where the subjugation and repression of women through class-orientated capitalism due to patriarchal societies is situated (Lane, 2015). It is the differences between the Feminism and Marxism which was important for this research. Whilst Feminist theory aims to increase gender equality through the abolishment of patriarchal systems and societies, Marxism rails against capitalism due to the authority of the ruling classes thus alienating the middle and lower classes. Despite both Marxism and Feminism having social dimensions, Marxist theory is more concerned about the economic system of society (Mouffe, 2014) which is where the philosophy of this research sits. By encapsulating the tripartite within this work, and seeking to represent each voice, Marxist theory was the obvious choice. By utilising a critical reflective Marxist reflective approach (Claeys, 2018) to this research I was buoyed by the words of

Therborne (2008) who states; "Critical thought depends on cultural soil to grow. In order to make sense, a critique must depart from certain assumptions or principles" (p. 35). I have used the work of Marx and utilised the areas which have meaning for my work to promote an understanding of the lived experience (Marx 1844/2019; Marx, 1894; Marx & Engles, 1848). By undertaking this approach it is proposed that I will be able to interpret my own experience and describe my understanding of culture, policy and economics, which lead to the inevitable warehousing of people deemed no longer useful to society. It will also assist in explaining the position of those people who work within the social care sector.

The choice of subject for this research has been based upon my own experience of working within social care. There has been a political unwillingness over successive governments to solve an ever-growing litany of issues that directly affect social care including; underfunding of the social care system and disparity for workers compared to those working within the NHS (for examples see Bayliss & Gideon, 2020; Dilnot report (2011); Maynard, 2017). Coupled with this is a societal and cultural shift that now appears to disregard the elderly population leading to a sub-sector of the population who suffer loneliness and sub-standard care.

 This links into social theory as Harrington (2005) explains:

> Social theory arises first and foremost from everyday life from an enormous variety of contexts of conversation, discussion and interaction between ordinary people…it is our action and participation in the social world that is the source of our ability to gain knowledge of history and social processes. (p. 6).

The choice of a data-driven, or bottom-up approach was elected due to having, as outlined above, an interest or motivation within this area.

Social constructionism

Utilising a social constructionist approach to this narrative exploration will assist in producing an overview of a tripartite perception of social reality and knowledge. As Brown (1995) outlines: "by studying how illness is socially constructed, we examine how social forces shape our understanding of and actions towards health, illness, and healing" (p. 35). Adopting this approach will emphasise how the meaning and experience of being old, caring for the older person or being a relative of an older person is shaped by the social and cultural systems that are in place. Writing in 1985, Gergen and Davis outline that "Social constructionism may be defined as a perspective which believes that a great deal of human life exists as is does due to social and interpersonal influences"(p. 265) with Conrad and Barker (2010) adding "… social constructionism examines how individuals and groups contribute to producing perceived social reality and knowledge" (p. 67). Marxist critiques of medicine and health (Cohen, 2013; Navarro, 1983; Waitzken, 1978) have largely concentrated on inequity and power disparities within health institutions which are a part of and support capitalist enterprises and the methods of ideological and social control within health care practices (Cohen, 2013). In chapter two I analysed how older people are turned into commodities and what I am interested in is what the tripartite, as a whole, experience in relation to this commodification. Therefore, the critical reflective Marxist lens by which to view this thesis is ideal as I believe there will be conversations that discuss an imbalance of power and how control of all people within the tripartite is endemic. By undertaking a social constructionist approach, it is anticipated that an understanding will be formed of how the social influences both collective and individual life and experiences. Respecting and paying careful attention to the residents, visitors and staff as primary sources of information will assist in examining how they themselves perceive their own reality.

The predominant conceptual framework for this study is derived from Goffman's (1961) work within long-term mental health institutions, found within the book *Asylums: Essays on the social situation of mental patients and other inmates*.

Research method: a naturalistic approach.

Ambert, et al. (1995) outline that qualitative research provides new information, which potentially, reflects new practices or behaviours; new forms of social organization or structure and; new ways of thinking or interpreting processes of socialization or change. Punch (2010) highlights that there are developments within qualitative methodology that underscore the political nature of social research: "…the recognition that social research…is a human construction, framed and presented within a particular set of discourses (and sometime ideologies)" (p. 135). Punch (2010) continues on to outline that research styles are never neutral but instead are influenced by and ultimately embody implicit models of what the social world is, what it should be like, of what counts as knowledge and how this knowledge is sought. From this new knowledge; for example in chapter six my attention was drawn to death not just being about the physical ending but also about the death that occurs through diagnosis or living and working within a nursing home, existing ideas could be completely redirected, modified or added to (Ambert, et al. 1995). Therefore, the choice of ethnography is theoretically the most powerful methodology to undertake to gain these insights and, as Fetterman (1989) suggests, the emic viewpoint - an insider's perception of reality – is at the core of this form of research.

With the setting of the nursing home being intrinsic to the tripartite, ethnography is the prevailing methodological approach in an attempt to fully comprehend those lived experiences and, as Goffman (1961) highlights, there is a need to "…try to learn about the social world of the hospital inmate, as this world is subjectively experienced by him (p. ix). Through undertaking interviews, the discourse that occurs can be a way of affecting how we think, act, speak and write (Cherryholmes, 1988; Davies and Harre, 1990). Fetterman (1989) expands on this by stating that ethnography "…is instrumental to understanding and accurately describing situations and behaviours…" (p. 30). As a professional who has spent the majority of their career to date within a nursing home setting there is a resonation with Woods (1986) and his description of ethnography:

> [Ethnography] is concerned with what people are, how they behave, how they interact together. It aims to uncover their beliefs, values, perspectives, motivations, and how all

these things develop or change over time or from situation to situation. It tries to do all this *within* the group, and from within the perspectives of the group's members. … This means learning *their* language and customs with all their nuances. … The ethnographer is interested in what lies beneath – the subject's views… The ethnographer thus aims to represent the reality studied in all its various layers of social meaning in its full richness. (p.4-5; italics in original)

Therefore, ethnography is more complex than a simple reporting process and instead takes on the mantle of being an inquiry process (Wolcott, 1990) with the researcher themselves being "...the research instrument *par excellence"* (Hammersely & Atkinson, 1983; italics in original). There is caution about the use of ethnography from Carspecken (1996) who suggests that no matter what the researcher does, that no one can conquer the precise view of another's reality. However, this recognition of the researcher being an active participant was essential to my ontological beliefs as I would be the interface for the data collection and those people being researched. Holmgren, et al. (2012) suggest that a caution needs to be in place when considering this method as traditional ethnographic studies within nursing homes tend to focus on nursing home nurses and not those of the relatives in combination. Van Maanen (2011) indicates that there is a political negotiation that comes from using ethnography as "the power of one group to represent another is always involved" (p. 5). Van Maanen (2011) goes on to suggest that the researcher is one step ahead on those actually being studied. For these reasons, you should not study one sector of a nursing home without the consideration of other aspects as there is an interplay and a friction between the relationships and actions of the three groups studied which, without reflection on all viewpoints, would not be at the forefront of the discussion.

I was known to the Company and some of the staff where my interviews were undertaken, thus situating contextual and historical relations which promoted some enabling possibilities which, promoted cooperation and collaboration between myself as researcher and the interviewees essentially as co-participants. It was noted that the staff interviewed were familiar with me and used terminology that another researcher may not have understood. Whilst this was viewed as a positive, there was a need to remember that even though there was a mutual etymology between the staff

and myself I needed to remain vigilant for the possibility of misunderstanding where terminologies may be unfamiliar (Harrowing, et al., 2010). I needed to remind myself that this was not the nursing home of 20 years ago when I started there! I was able to reflect, in a timely manner, within the conversations both internally and within dialogue. There appeared to be a level of trust in me, as the researcher, where sensitive issues were talked about openly.

Stacey (1988) explained that it was impossible to have a fully unbiased ethnographic account but a partial account was possible. In part this was due to what Stacey (1988) outlines as the researcher needing to create a research product and this leads to the researcher potentially imposing meanings on situations. In order to support the robust nature of my observations, I kept a journal. The journal entries were an important part of both the observation and interview process and served as a point of reference throughout the data analysis stages. Data analysis included looking at policy, investigating cultural practices as well as interpreting, through thematic analysis, the data from the tripartite interviews. The data analysis was systematic and the acknowledgement of my own values and beliefs assisted in the negotiation of meanings rather than the imposition of meaning and promote understanding of the conversations (Harrowing, et al., 2010; Stacey, 1988).

It is important to highlight that although there are occasions where the term interview is used within this work when, in reality, conversations occurred. Due to a data-driven approach, and as outlined by Hamilton (2008), conversations are much more fluid than interviews. There is a need to fully involve oneself within the conversation, bringing with this a myriad of skills for listening, interpreting body language and engaging with another person's linguistic abilities, which is an important consideration within the remit of older age conversations. By engaging with conversations, the topics were not constrained, as they might have been within interviews. As Hamilton (2008) states: "…conversational contributions can be windows on emotions and reflections that would probably have gone unnoticed within a more constrained context" (p. 575). The nature of the conversations reflected the material and emotional conditions of the tripartite. Whilst some conversations were pre-planned there were

opportunities throughout the observations where I could listen-in on day-to-day conversations as they happened. Whilst not a direct part of these interactions, between residents and their visitors or staff and residents for example, I am not influencing the discourse. It was essential to observe, and listen in to, conversations where people chose who they wanted to interact with in a way they felt most comfortable. By noting these types of conversations within my observational diary I was able to form a deeper understanding of the everyday within the nursing home and, whilst there was limited time to fully engage with my writings within the moment, they have been useful in informing after the events. I have also been able to employ the conversations to further enhance the themes discussed within this research.

Ethical approval and access

In the first instance, ethical approval was sought from the Company in which I was working at the time due to utilising one of their businesses. Following this, ethical approval was granted by the University of Chester on the 8th June, 2016. Due to a change in Company structure and my leaving where the nursing home was situated, further ethical approval was sought prior to going into the home. Further agreement was granted from both the Chief Nurse and Director of Nursing. This information was duly passed to the General Manager and the Regional Manager from head office. As outlined, when the research was first discussed, I was employed within the Company and thus all procedures outlined by the Company were followed. There was a certain naivety as a new researcher that this was sufficient ethical approval, especially when the website indicates:

> Social care research does not require review by the a social care flagged REC if it is reviewed by another committee operating in accordance with the Economic and Social Research Council's (ESRC's) framework for research ethics, unless the categories above apply or the research involves NHS patients, people who use services or people who lack capacity as research participants.

Other student research within the field of social care should ordinarily be reviewed by a university REC (UREC) (NHS Health Research Authority, para. 3)

This statement, combined with the University regulations of:

22 All research falling within paragraphs 22.1-22.7 below must be submitted to the relevant NHS Trust Research Ethics Committee before the research can begin. For information regarding access to patient records, reference should be made to paragraphs 133-136 below.

22.1 Patients and users of the NHS. This includes all potential research participants recruited by virtue of the patient or user's past or present treatment by, or use of, the NHS. It also includes NHS patients treated under contracts with private sector institutions.

22.2 Individuals identified as potential research participants because of their status as relatives or carers of patients and users of the NHS, as defined above.

22.3 Access to data, organs or other bodily material of past and present NHS patients.

22.4 Foetal material and IVF involving NHS patients.

22.5 The recently deceased in NHS premises. (University of Chester, 2018, pp. 8-9)

The residents, visitors and staff proposed within the sample would not be NHS related and it was not envisaged that the people interviewed would be lacking in capacity and informed consent would be appropriated. Moving forwards with the new knowledge of being embedded within research, it would always be appropriate to approach the Health Research Authority for guidance and potential application for ethics.

As Bowling (2000), Fetterman (1989) and, Harrowing, et al. (2010) are keen to note, it is ethically essential for informed consent from participants should be sought, within the study I have been involved in, this is a much more complex issue. The nursing home is not a sterile environment where the researcher 'does at' those being researched, instead this study was viewed as a joint effort to enable the voices of people experiencing this particular phenomenon of living, working and visiting a nursing home to be explored and heard. The setting is a busy and vibrant arena where a multitude of health care professionals, family, friends and staff negotiate the intricacies of living, visiting and working within it. However, it is important to remember that both residents and their relatives are a

potentially vulnerable population who may have issues with capacity. To undertake research with people who may have memory issues or a diagnosis of dementia the following description is useful:

To have capacity a person must be able to:

- understand the information that is relevant to the decision they want to make
- retain the information long enough to be able to make the decision
- weigh up the information available to make the decision
- communicate their decision by any possible means, including talking, using sign language, or through simple muscle movements such as blinking an eye or squeezing a hand. (Mental Capacity Act [MCA], 2005).

It is essential to consider that there may well be fluctuating capacity which is dependent upon potentially many things; the physical (infections for example), environmental (noise levels for example) and mental state (sundowners for example). The MCA 2005 Principle One is clear in stating you should always start from the assumption that the person has the capacity to make the decision in question. However, the useful checklist provided gave me specific guidance that would alert me to any concerns relating to capacity:

- Understand information given to them
- Retain that information long enough to be able to make the decision
- Weigh up the information available to make the decision
- Communicate their decision – this could be by talking, using sign language or even simple muscle movements such as blinking an eye or squeezing a hand. (SCIE, 2017, para 4.)

I liaised with as many people as possible regarding the interviewee resident's capacity immediately prior to engaging with the resident – the care staff and any family members who were present (MCA, 2005). This was then confirmed by the resident not only at the start of the interview but throughout to ensure time and decision-specific capacity. Many of the research questions themselves, as part of the conversation, were capacity orientated as outlined by Graham and Cowley (2015). For example:

- Who are the people you have contact with?
- How long have you been here?
- What the difference between living somewhere and visiting it is
- What activities do they undertake?
- Why did you choose to be here?

Ongoing consent (Harrowing, et al., 2010) was confirmed particularly with relatives and residents as there was a need to ensure that no coercion was in play. The act of formal conversations were captured as an audio recording.

To ensure that the tripartite of staff, visitors and residents were informed and able to ask questions or express viewpoints, I attended the usual residents committee meeting. This allowed for an introduction of a new face around the home and a full explanation of what was occurring. This enabled me to be transparent with information pertaining to the study as well as answer any questions which were forthcoming. I also left contact details should further questions arise between then and the study. Understandably, there were the questions posed around confidentiality however, the overwhelming feedback was full acceptance and a feeling of looking forward to telling their stories.

Permission to audio-record interviews was sought by both the interviewees in advance and immediately prior to the interview as well as from the Manager in charge of the nursing home on the given days I was there. A private area was sought and this was either the resident's bedroom (for interviews with residents or a family member) or the manager's office (for interviews with staff members).

Observation of working practices was also proposed. This was not participant observation instead I was positioned within public areas to observe the milieu that naturally occurred. This would be overt observation and the days that I would be present were advertised to all staff, residents and visitors through the home's normal channels of communications of email. On the day I was in the home there was a notice placed on the front door outlining that I was there. If anyone had any questions to just ask. It was advised that I would not be taking anyone's picture or names as part of the observation period to ensure privacy of individuals. As already explored, I have spent many years within the nursing home environment and indeed this specific nursing home so I felt that I had an in-depth understanding of the usual routine and the demands placed upon staff, residents and visitors alike. By not engaging with intimate care of the residents it was seen that a certain level of 'power' over this group of people

would be reduced. As outlined by Tulley (2008), there is a risk of dependency on the researcher if the interviewees believe that they will gain either an advantage or disadvantage by participating in a given way should the researcher be in a caring role. The decision to make myself a non-participant within the usual care routine is supported by the work of Adler and Adler (1987) who outlined that actually being part of the care work team can actually limit the extent of the observation being undertaken. By concentrating fully on the resident and situation in hand there may not be the ability to observe what is actually happening at the same time. By undertaking the observation only role I was able to notice the noise and activities which staff, visitors and residents experience whereas, if I had been caring directly for an individual resident, I may not have had the time to take the whole environment into account. There is a competing demand on a researcher's ability to take note of a multitude of layers when actively caring. This is not to demean the rich data that one can achieve from the personal care and the conversations that arise from those situations, however, it was deemed that those deeper conversations would be obtained in the interviews and the observation approach could be part of the wider concept of the nursing home environment. Indeed, some of the conversations that occurred within the interviews noted the environment as having impact upon an individual's well-being which supports the decision to observe the wider environment as part of the research process. The observation role, however, formulated some internal ethical dilemmas. Whilst data could be collected as to how a specific matter played out, any situation that potentially could have been to the detriment of the resident a case of action over in-action would be justified in order to maintain the participant's interests above those of data collection and research. As outlined by Lipson (1994) "The dilemma is not whether to reciprocate or intervene, but how to do it responsibly" (p. 351) so, despite undertaking an observation only approach, I had to make a decision on what care actually was and decisions on the need to act where there was nobody else in the immediate environment to do so.

Setting

The setting for this study was in a large, purpose-built nursing home in a large market town in England. It is owned by a large private for-profit company. It is duel-registered for both general and mental health for 65 years plus and has ten beds that can be utilised for younger physical and learning disabilities.

Study population

All staff within the nursing home were invited to participate. A poster was placed within the staff room with contact details for further information. The research aims were to consider the voices of all job roles that are utilised within the nursing home under study as this was envisaged to provide an information rich data gathering. There was the following breakdown of staff employed (see Table 10):

Table 10: Breakdown of staff employed within the nursing home

Role	Number	Gender	Interviewed
Activities	2	Female	1
Maintenance	2	Male	1
Housekeeping	5	Female	1
Laundry	3	Female	0
Registered Nurses	10	4 females 6 males	3
Care Practitioners	4	3 females 1 male	1
Care assistants	39	27 females 12 males	2
General Manager (Registered nurse)	1	Male	1
Deputy Manager (Registered nurse)	1	Female	1
Kitchen staff	4	2 females 4 males	1

The N of eligible participants was 71 and through the participants putting themselves forward for interview there were N 12, for a total response rate of 15.5%. As is the nature of qualitative research the sample is to reflect rather than represent a specific population, therefore, this sample covered the majority of job roles within the home and also a mix of male and female participants. As discussed within ethics, residents and their family were given free choice as to whether they would like to participate. Six residents and eight family members came forward and consented for interview.

Sampling

As the researcher, I need to be explicit about the voices utilised within this work. There was a need to ensure that the nursing home community involved were neither coerced into partaking or exploited (Harrowing, et al., 2010). Whilst all people interviewed were required to be a member of current staff, a resident or a relative of a current resident, which indicates a convenience sample, the work undertaken at the beginning of the research process to inform all people concerned of the study also supported a snowball sampling strategy. Indeed, there were many relatives and staff who contacted me whilst I was in the home requesting to be a part of the study. As outlined by Grbich (2003) this type of sampling allows for a potentially "invisible group" (p. 70) to be located. Although snowball sampling has the disadvantage of recruiting people within one network (Bowling, 2000) this was the positive within this study as the network I was interested in was solely the nursing home staff, residents and relatives.

The residents interviewed had been within the home between two and four years. All residents were female. The ages of the residents were between 68-99 years, with the mean age being 79.3. Overall, this population of residents was fairly representative of the statistics regarding male and female populace within nursing home settings (ONS, 2018a). The relatives had had their spouse/parent in between two and six years. There was one male relative (a husband) interviewed with the remaining being female.

Data analysis

As appropriated by Braun and Clarke (2006), the usage of reflexive thematic analysis (TA) within qualitative research allows for the rich and detailed complexity of data to be accounted for. They suggest that it is accessible to all and does not require the somewhat overly detailed theoretical or technical knowledge that can be demanded by other methods. There is an accessibility to TA that other, more complex, data analysis tools do not possess. That being said, there are obviously disadvantages to this process which will be given mind to. What Braun and Clarke (2006) and Nowell, et al. (2017) outline is that the use of TA can be beneficial in exploring the perceptions of differing research participants, highlighting likenesses and variances and creating unforeseen insights.

Reflexive TA is a way of constructing patterns or meanings as an output from the data rather than using predetermined themes and trying to code the information into set boxes (Braun, et al, 2019). The reflective TA process involves six phases:

1. Familiarization: My preliminary engagement with the data was done through my transcription of the interviews, as the process provided extended time with each interview, both listening to the audio of the participant, and in the writing of the transcript. In order to fully immerse within the data, all audio recorded formal conversations were transcribed verbatim and were listened to many times to ensure the capture of the whole narrative. During this transcription, I took notes of potential points of interest for the analysis, using these types of questions as a guide. These were recorded on the edges of the paper. Whilst the writing of transcriptions by myself was, at times, painfully slow, time consuming and somewhat demoralising due to these issues, on reflection it allowed me to fully submerse myself within the conversations, reflexively thinking about the field notes and links to other conversations. I believe that this time spent has added to the depth of description present within the work and my knowledge of their stories to share with others when discussing this research. I believe that the minute details of conversations have only added to the data analysis as well as potential understanding of the situation.

2. Generating initial codes: Following transcription, I systematically coded each interview. The organization of data was initially conducted broadly through inductive searching for patterns within the transcripts. Post-it notes were utilised on to flipchart paper to identify linkages and interpretations. These interpretations were processed continually and, parallel with the analysis, the reading of related literature was undertaken, thus enabling an increased understanding of the material. According to Thorne (2016), this reading of associated literature, alongside analysis, can give a deeper understanding of the phenomenon being studied.

3. Constructing themes: When reviewing my emergent themes, I employed the approach described by Braun, et al (2019) as "using codes as building blocks", sorting my codes into topic areas or "clusters of meaning" (p. 855). From this grouping of codes, I produced and developed a set of themes through visual conceptual mapping and continuous engagement with the data.

4 & 5: Revising and defining themes: the thematic analysis at this stage contained five themes. I noticed the first theme of "Death" was lacking focus on clarity and thus this was split into three sub-themes "Social Death", "Life As We Know it Death" and Death of Self".. These sub-themes were to explore the highly faceted part of the overall central concept. The theme "Environment" subsumed an initial theme of "Economics of Care" as this was deemed to be "thin" on evidence from the analysis and it became a part of the "Environment" theme. A theme for "Compliancy" was also rejected as this fit across all parts of the analysis and was subsumed into these.

6. Writing the report. As part of the thesis writing-up process, there was a need for me to take some time out from studies. As soon as I was back onto the programme, I was able to undertake a period of study leave. I revisited, at length, both what I had written to date and also reviewed all of my diary notes and transcripts. I then re-read the transcripts alongside the audio tapes to really take me back to the moment they had occurred. This was invaluable as I could review my original thoughts and, although most remained true to my initial thoughts, there were areas which I reconsidered – enough so that I removed around 4,000 words from the working thesis! There were conversations that I had

forgotten about or had not noted as overly important. Therefore, the analysis was reworked as it was necessary to encompass new thoughts. By having the time to review the transcripts, audio recordings and the field notes there was a re-ignition of excitement and a recognition, by myself, that there were some areas where relationships between themes and not just on themes had not been fully considered.

Field notes were taken throughout observation periods, any conversations were written as soon as practicable and a reflexive journal was maintained. Data analysis was a continuous process throughout the data-collecting period. Kirby and Mckenna (1989) advise that there is a need to live with the data and allow ample time for revising any analysis taken, especially within the first instance. Whilst they suggest one to two weeks, I have found that a longer period improved and really focussed my analysis.

There is overlap between the themes that, at first, I did not address but I came to realise that the conversations and observations were part of a greater map which, due to its subject matter, was complex and there were always going to be connections. Nothing within human life is separate, there are connections at all times. At the beginning of Chapter Six, Figure three outlines the interconnectedness yet complexity that lies between the themes. Within the map there are obvious overlaying ideas that have been assigned to each overarching theme. These ideas are where the content of the conversations indicated it was best placed however, it is important to note that these did overlay into different themes. Chapters six to nine endeavour to clarify the themes that emerged both as separate entities and then as a connected whole.

Within a qualitative study there is a need to support the legitimacy of its findings to the wider community (Nowell, et al., 2017) which is usually supported by establishing the validity and reliability of such research (Bowling, 2000). Lincoln and Guba (in Loh, 2013) refined the concept of trustworthiness by introducing the notions of credibility, transferability, dependability and confirmability to work analogously alongside that of reliability and validity which is preferred by quantitative researchers. The use of trustworthiness is a pragmatic choice as it is important for this

research to be accepted and be found useful by the healthcare community, especially those with a

vested interest in ageing care.

Figure 3: Trustworthiness criteria and techniques for establishing them. (Adapted from Lincoln & Guba in Loh (2013, p. 5).

Criteria	Techniques	Those adopted
Credibility (internal validity)	1) Prolonged engagement 2) Persistent observation 3) Triangulation (sources, methods, investigators) 4) Peer debriefing 5) Referential adequacy (archiving of data) 6) Member checks	1)Within research role over 300 hours spent within the home 2)Varied observations over different shift patterns and over the two different units 3) Observation – different shifts, units, staff interviews (environmental triangulation), constant feedback between interviewer and interviewees 4) Critical friends 5) Not undertaken. All data analysed 6) Formally and informally undertaken. Within interviews and once analysis had progressed
Transferability (external validity)	7) Thick description	7) Background information has been provided to promote understanding of relevance, denotations and intentions that support social interactions "describing and interpreting observed social action (or behaviour) within its particular context" (Ponterotto, 2006, p. 543).
Dependability (reliability)	8) Overlap methods (Triangulation of methods) 9) Dependability audit - examining the process of the inquiry (how data was collected; how data was kept; accuracy of data)	8) As 2 9) An intellectual audit trail undertaken which has assisted the Author "in reflecting on how his/her thinking evolved throughout all phases of the study" (Carcary, 2009).
Confirmability (objectivity)	10) Confirmability audit - examines the product to attest that the findings, interpretations & recommendations are supported by data	10) As 9
All 4 criteria	11) Reflexive journal (about self & method)	11) Positionality stated within thesis. Choice of research domain, question, methodology, data collection, data

		analysis (Daly, 2007) have all been explored

Chapter summary

This chapter has justified the methodology and methods utilised to research the experience of the tripartite who reside, work and visit the nursing home environment. I have explored how I will use Marxism and ethnography to understand the lived experience of how commodified people experience and respond to this type of institutionalization. To meet the aims of the research proposed, a qualitative inductive approach is supported by the use of ethnography as a suitable framework as this is the emic viewpoint which insists that the insider's perception of reality is core. The qualitative theoretical framework has been examined; ethical rigour has been explained; sampling techniques described and the demographics of participants defined. Thematic analysis has been considered and the complexity and inter-reliability of the themes has been explored.

Chapter 6.

Introduction

As highlighted within the previous chapter, a conceptual map was completed that aimed to identify the overarching themes. Whilst undertaking this it became very apparent that whilst there were clear themes there was also inter-connectedness that linked themes to each other. This inter-connectedness demonstrated the inherent complexity that is based within social constructs. However, as identified by Braun and Clarke (2021), convergence, as well as divergence, is welcomed as qualitative research is not about sameness. My research was about giving a voice to others and welcomed the complexity that this method would offer. The conversations with the tripartite offer a rich and persuasive insight to the lived experience of living, visiting and working within the nursing home. The following Figure 3 is a conceptual map of themes that came from the data analysis undertaken and the following themes (chapters six to nine) provides evidence to support the identification of themes as well as the voices of those interviewed to support them.

Figure 4: Conceptual map of themes
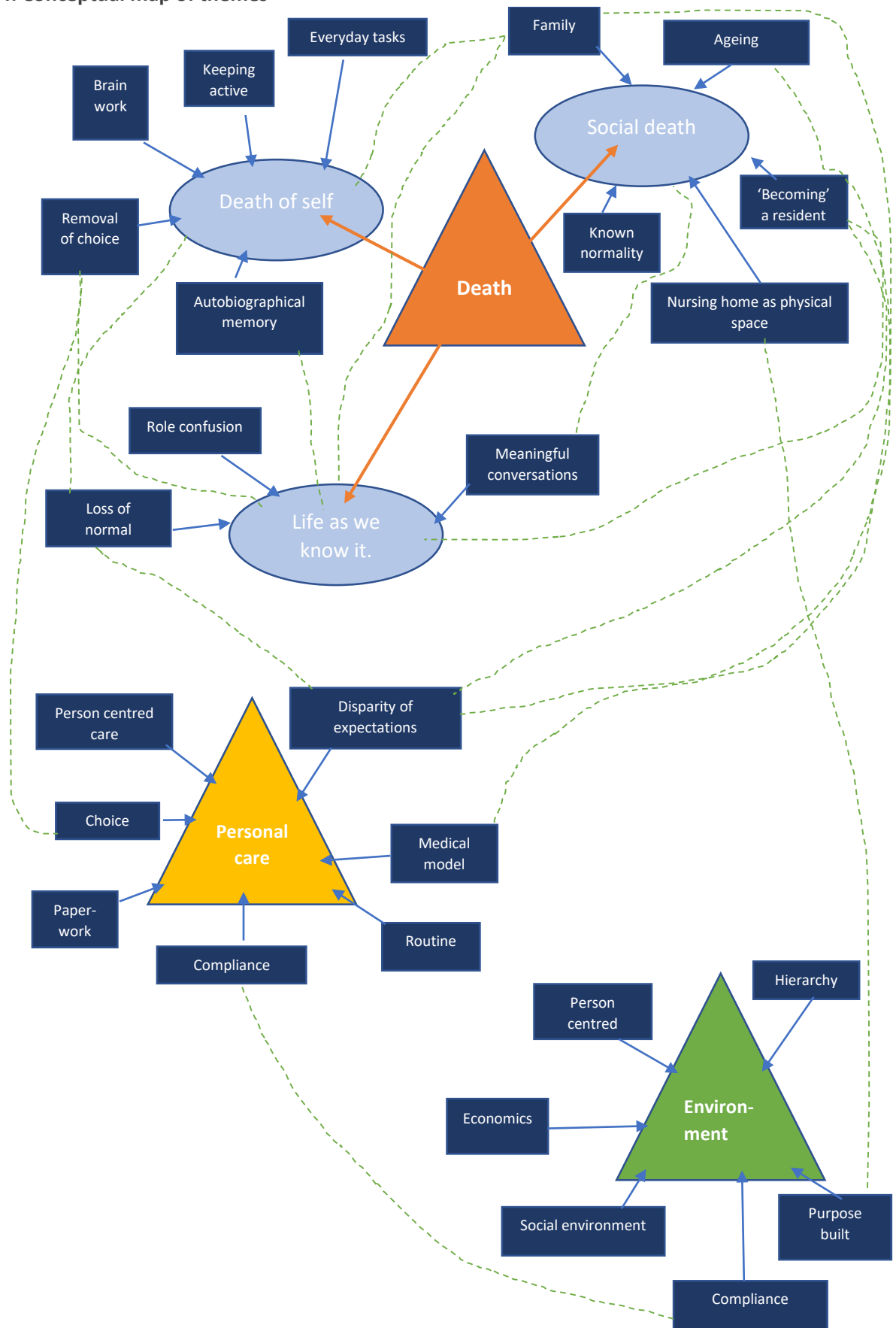
Theme 1: Death
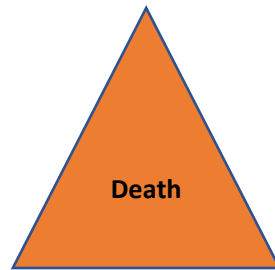
Introduction

> ...attention must be directed to the things we become after we have died in one of the many social senses and capacities in which death can come to us. ... a process of sifting and sorting occurs which the socially dead come to be effectively hidden from us. (Lemert & Branaman, 2002. p. 19).

Being situated within a nursing home and, through the structure of the tripartite, two things become apparent. Firstly the vulnerability of those who are being cared for, in the sense of physical vulnerability, which will lead to death and secondly, the movement towards and ultimate decay of their social death. What happens within the structure of the care home means that the social death, which is linked to ideas of community, belonging, self-worth and autonomy, become even more precarious because of the institutionalization of the individual through the nursing home. Therefore, the theme of death consisted of the following sub-themes: 'Death of self'; 'Social death' and; 'Life as we know it death'.

Sub-theme one: *"he didn't know what he was doing and sometimes he wasn't like my husband at all"*

Death of self

Now, a lot of people say oh happy days …not happy in the way you were when you were younger but more cont... more contented you know… you know? [resident conversation].

What became clear within this sub-theme is human integrity or the act of belonging to oneself. This human experience of being oneself is integral to the therapeutic nature of the reflective Marxism approach undertaken. Memories of past actions go towards constituting personal identity. Some residents see it within their power to maintain their 'self' which this excerpt from a resident conversation purveys:

I like a challenge, I've just finished my code word which makes my brain work and then I usually write a letter or I have Radio Shropshire on, now my sight is going so I've, well I've….now it's getting worse I can't read a book. You see I got the, I got the, I can't read without [shows me the very large magnifying glass]. *Of an evening I can watch television for a couple of hours, especially Strictly Come Dancing* [interviewee laughs] *Ed Balls* [laughs again] *he's … oh dear oh dear* [laughs again].

The declining ability of people living with dementia to communicate with others about the present and its relationship with the past has led some researchers to postulate an "internal loss of self". Cohen and Eisdorfer (1986) commented that "the victim of Alzheimer's disease must eventually come to terms with...the complete loss of self" (p.22) whilst others have suggested the "demented patient has no insight into his or her own state of helplessness...he forgets who he is himself' (Souren & Franssen, 1994, p.20). This suggestion appears to be borne out by one relative outlining;

…it started with the bank statements, so I took over. Then I couldn't go to the bank because I couldn't leave him alone. I cared for him in this state for at least eight years…he didn't know what he was doing and sometimes he wasn't like my husband at all.

Whilst this is true for those people living with dementia, it is also pertinent that older people with a loss of memory, which is not classed or formally diagnosed as dementia, can also express these feelings. There is a societal view that old people will have some level of memory loss and this, when internalised, can affect a person's self-esteem and eventually self-identity (Ballenger, 2006; Caddell & Clare, 2011; Davies & Nolan, 2003; Lorenz, et al., 2006) . There is also an inherent fear that they may be developing dementia which is pertinent for both the person and their family member (Imhof, et al., 2006). Staff themselves can naïvely partake in aiding a person's loss of self by inadvertently only adhering to the social norms of communication. As identified by Frogatt (2001), the decisions pertaining to care which an individual preferred were taken away from residents who had lost the ability to communicate in a traditional format, thus choice was diminished. This could be due to the busyness that staff within a nursing home work and it could also be due to lack of training in which the staff think that a failure to communicate is a failure to understand.

Historically, acadaemia has perceived the ageing population through a restricted biomedical deterministic model (Harding & Palfrey, 1997) where 'sufferers' are reduced to a catalogue of physical disabilities, cognitive deficits and behaviour disorders. According to Coyle (1999) there is a risk that devaluing a person, usually by the medical profession, can impact on notions of self and how an individual is able to control their fate. The 'loss of self', according to Ballenger (2006), reflects a postmodern bewilderment and suspicion regarding time-honoured conceptions of the consistency and rationality of time, space and selfhood. There is argument that through deep philosophical roots in science, dementia, ageing and its accompanying symptoms, come to represent an erasure of selfhood (Kantos, 2004). This concurs with what Foucault (1984) terms 'scientific classification' - the practice of making the body a thing. However, over the preceding decades this biomedical construct has been challenged by critical gerontologists, such as Fazio (2008); Kitwood (1997) and; Kelly (2010), who are more concerned with the subjective experience of older people, the nature of personhood and the self and, the socio-cultural context of the disease as well as concerning themselves with the issue of ageing. Caddell and Clare (2011) outline that it is currently unclear whether the self is affected

as a whole by dementia or whether different aspects of self are affected independently of each other. However, research that looks beyond the internal neuropathological decline and, instead addresses the role of external or social psychological factors that impact on identity, has begun to surface (Beard & Fox, 2008). This research identifies that the manner in which others interact with the person living with dementia can have a significant impact on the individual's own sense of well-being. In this respect, self-identity is considered to be constituted by and through social interaction (Beard & Fox, 2008).

Although the self is more than memory, over the previous decade a growing number of researchers have viewed autobiographical memory as a means of capturing the nature and functioning of the self. Indeed, Goffman (1961) comments that people, on admission, bring with them a "presenting culture…derived from a 'home world'' (p. 23). By connecting with our past and being able to integrate memories in a meaningful narrative, we are able to understand ourselves and, as a consequence, this impacts positively on a person's well-being and life satisfaction but, the structure of a nursing home makes this increasingly difficult. One resident shared their memories of seeing an aeroplane for the first time:

> *Do you know, you won't believe this honestly, I can remember I lived in Aberystwyth in Wales as a girl and I can remember I'd never seen an aeroplane err, and it was in the 1920's and the headmistress said one day erm, you're all going to go out into the playground this morning because there's going to be an aeroplane flying over. It must have been one for the first flights, it was something she knew, that aeroplane was due and I can remember looking up and seeing it. It must have been one of the early records and she knew that aeroplane was coming.*

This except was followed by laughing about how strange that must seem to todays children where aeroplanes are commonplace. What this demonstrates is the invaluable sharing of information across time and generations that, should people actively engage with older people, the information gleaned can impact on an understanding of the other person and their viewpoints. It is somewhat difficult to imagine today how awe-inspiring this sight must have been in a world where technology is all around

us and again, this underlined the therapeutic nature of the conversations. This conversation happened within the nursing home and the place itself could be an important variable factor of how the conversation occurred. Life is so busy today and what I saw about the visitors within the nursing home was the active engagement in meaningful conversation with their loved ones. The staff were taking care of physical needs and thus the family had the time to engage with their loved ones on an emotional and psychological level, allowing the sharing of stories to be heard. In fact, throughout my time observing for this research and also through the experience of my career, conversations were the great leveller within the nursing home. These conversations were between many different people crossing different relationships – from casual encounters through to parents and children. What was important was the reminiscing that occurred, mainly of a life well lived. Meaningful conversations can only enhance a person's sense of self and self-esteem and I would suggest that the ability of a nursing home to provide space for such conversations to occur is essential for well-being.

If autobiographical memory, or autonetic awareness (Fivush, 2011) is crucial to the construction of the sense of identity and the feeling of self-continuity, what happens to sense of identity in people living with dementia? Autobiographical memory contributes to the aspect of identity by accessing, remembering and reflecting on personal memories, and thus we define and establish personal identity. These personal memories are socially grounded in that we know our personal identity by knowing how we relate to others and the social groups around us (Fivush, 2011). There is an identified need to recreate the fragmented personality of the person living with dementia through the elicitation and validation of personally significant autobiographical memories. If self-identity is partially a social construction - how one perceives the self is a reflection of an understanding or interpretation of meaning that is derived through interactions with others - how others respond to a person influences how well the public self is maintained. Douglas and Douglas (2004) identified within their study that the removal of independence and choice inevitably led to feelings of loss of control. This loss of control eradicates personal identity due to power being removed from an individual and placed in the hands of another, in this case the staff of the nursing home.

Sub-theme two: *"we did have a lot of friends but I came to realise they were dying off!"*

Social death

If you were at home, nothing would be perfect…I'm trying to keep up with what life is going to be like for the future because now it's all press… I can't …I've got some DVDs to put on my … my son had to show me last night and I can't …I'm more nervous …I won't even have a mobile phone [resident conversation]

The very act of 'becoming' a resident within a nursing home can include a major interruption of the person's world including the not inconsiderable altering of relationships with friends and family. Whilst I have used the term 'becoming', Froggatt (2001) names this process as "Sequestration" (p. 320) and indicates that it is a "process of setting apart or separating out" (p.320). Froggatt (2001) identifies that this separation of the aged is as way of ensuring that society is not exposed to death as the general population do not need to have death as part of their personal consciousness. As in the title quote from a resident, there is an acknowledgement of the physical death that occurs of friends but once this happens a person's own life appears to inextricably change. Those people who are part of your life, with whom memories are made and shared, relationships made which are dependent upon each other in various ways are meaning making to people. The need to have friendships and conversations appears to be essential in the conservation of identity and to maintain social links. According to Goffman (1961), this admission to an institution of any sort purveys onto the admittee a sense of "mortification" (p. 24). The process of becoming a resident places an automatic, and unseen and possibly unrealised, barrier between the resident and the outside world which, according to Goffman (1961) is merely the first stage of mortification. Goffman (1961) goes on to suggest that any of the residents past history is no longer meaningful through the act of "role disposition" (p. 24). By removing those who are aged into nursing homes there is a separation imposed between those near to death and those who do not need to be aware of it. By removing people from their 'normal' or

current lives this inevitably enacts a social death occurring on behalf of the individual being uninvolved from society. This idea is further voiced within the work of Mor, et al. (1995) who identified that once a person was institutionalised, they would disengage with their known social life and underscored that continued social engagement was imperative to an individual's quality of life. This act of sequestration (Froggatt, 2001) also potentially enables the ignoring of society towards ageing and the inevitable death that will occur. This inability to accept the ageing process can lead to the social marginalization of some of the most vulnerable members of our society. However, as one resident put it when we talked around having friends prior to coming into the nursing home: *"Well yes, we did have a lot of friends but I came to realise they were dying off! Things were already changing; they wouldn't stay the same".* However, it must not be forgotten that the nursing home itself can be viewed as a community and as a resident stated *"This is my family now".* The resident was keen to point out this this new family had grown with her experience over the two years she had been within the nursing home and she herself had had to be an active participant within this process. This natural affinity for all people towards community-making is often in conflict with the institutional 'rules' of the nursing home.

There are different ways in which the decision for a person to be admitted into a nursing home can be made. There is the personal choice *"I started to get tired in the kitchen… I only lived two doors away from my son but I couldn't keep bothering him all the time".* Although this outlines that it was the person's choice the resident quantified this with *"…her* [daughter] *and her brother could look around together"* which could suggest that the resident was almost seeking permission from the children. This situation could also be viewed as the resident having great insight to the feelings of guilt that a child can experience when placing a loved one in a nursing home and the resident does cover this *"I'm glad we made the decision* [the interviewee and her spouse] *because I think it's very hard if the children made the decision to put their parents….but if the parents make the decision its easier for the family".* In this instance the resident was admitted to the nursing home with her husband, who was living with dementia. Although they had separate rooms the resident outlined that they had been together within the nursing home for five months and

…in the end it was the way I wanted it to be. He passed away. The resident went on to explain *There was no difficult decision as we were both 95* [years old]*, if we were 85* [years old] *I might have tried but in five more years we were going to be a 100* [years old]. We then both laughed at the concept of 85 years being young!

Social and personal identity are not necessarily distinct identities but can be considered opposite ends of a continuum with each influenced by the other as well as by outside forces (Basting, 2003) with the usefulness of the self being equated with a role within society. Sabat and Harre (1992) proposed that personal identity persists far into the end stage of dementia, whereas social identity, which requires interaction with others in order to be materialised, can be diminished, and even lost over, the course of the illness. Haslam, et al. (2009) postulate that in many social contexts, people define their sense of self in terms of group membership and reciprocally the group provides a person with stability, meaning, purpose and direction and thus has a positive implication for the individual's health. On a social level, people living within a nursing home environment can easily lose their social networks and run the risk of isolation and solitude or 'social death' (Sweeting & Gilhooly, 1997), have greater difficulty in accessing support services, suffer from poor self-image and may experience discrimination (Naue & Kroll, 2008). One resident outlined that since admittance she did not have as many visitors as when she was at home *"I don't want…I'm quite content … no…yes…"*. It is key here to highlight that social isolation and loneliness are usually conjoined as a concept but, according to Beneito-Manotagut, et al. (2018) whilst they are entwined with each other, each is a separate issue.

Mor, et al. (1995) identified, that the act of socially engaging with individuals or groups has to be insitu to be taken advantage of in the first place. As far back as 1951, Parsons (in Mor, et al. 1998) identified that those people who were in a nursing home were often obliged to assume the persona of a 'sick person'. This persona of a 'sick person' may assist the newly admitted resident into compliance within the regimen of abdicating care to another person, in this case somebody deemed a professional but this can also detract from those very social interactions that are seen to give life meaning. Further to this, within the nursing home environment there is a risk of individual residents spending a majority of their time within their rooms leading to a further layer of social isolation or within communal spaces

where there may be limited social interaction. By adopting the 'sick person' role (Parsons, in Mor et al, 1995) an individual's ability to recognise engagement with others as beneficial can be, lost, especially should the reason for being admitted to a nursing home be due to a cognitive deterioration.

Observation diary:

10.10 am: Resident lounge area. EF unit. Female resident walked in by female nurse. Moved another resident without asking to allow view of television (How did nurse know she wanted to see television? Didn't ask if she could see television. Didn't ask if she wanted to watch this specific programme).

10.15 am: Female resident bought in by two female care assistants in a chair. Chair placed in front of resident that was walked in five minutes earlier. All residents moved back to facilitate capacity and view of television, therefore, placed around the edge of the lounge.

Whilst there was interaction with the residents and between the staff there was a concentration on the resident receiving the care at the time, not on other residents that may have been impacted by their decisions and actions.

The resultant focus of where a person is living, due to age or disability, has become the focal point rather than the interactional or experiential aspects of living life to the full as an older person. With the added diagnosis of the illness or disability that has placed the individual within a nursing home, can immediately impose the role of 'patient' and, with this, comes the connotations of 'helpless', 'disability', 'needs care' and so on. As demonstrated within the next observation diary, there was a view that the nursing home itself was a place of safety, where a relative could be cared for due to an uncontrollable desire to walk. Whilst this is usually viewed as undesirable there is also a need to consider that behaviour in and of itself can be communication. Rather than exploring this there is a need to place an undesirable label upon the behaviour and seek to control it. For individuals who have a formal diagnosis, these labels may be in sharp discord with how they view themselves which, in turn, can make social interactions stagnant and frustrating.

One of the consequences, to an individual living within a nursing home, is that of being positioned as a member of a socially undesirable group causing stigmatization. As Goffman outlines; "...an individual

who might have been received easily in normal social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us" (p.15). As already discussed, in chapter two, the stigma of diagnosis and isolation are not only physical symptoms of aging but, are often reinforced by the perception that society has of the older person and nursing homes in general. As the excerpt below demonstrates, there is a desire to explain away stigmatising behaviours but, by doing this the person themselves can become part of the stigmatising process. As outlined by Riedy (1993); "If a person is seen simply in terms of their undesired difference, or stigma, then they are unlikely to have high expectations held about them…" (p. 11) with Coleman (1986) outlining; "I have intimated that 'stigmatized' and 'non-stigmatized' people are tied together in a perpetual inferior/superior relationship. This relationship is key to understanding the meaning of stigma" (p. 221). By the relative explaining away the behaviours the inferior/superior (Coleman, 1986) relationship is cemented and thus another level of stigma is introduced.

> Observation diary:
>
> 12.05pm: Resident lounge. EF unit. There are three female relatives visiting in the lounge and there is a conversation around the decline of their relatives and their patterns of behaviours. The relatives talk about their fears of losing their relative through wandering behaviours prior to their admission to the nursing home. Statements like "They didn't know what they [the relative] were doing". There is talk around feelings of guilt for leaving them in a nursing home. All utilised terms of [endearment? Possibly guilt?] "darling" and "love her".

By utilising a Social Constructionist approach, we can see that we are not solely who we think we are, but also who others believe us to be - we can come to learn about ourselves through the reactions of others. Throughout both the observations and the interviews there was a certain 'playing to the audience' that I ascertained. Relatives visiting would posture around the social spaces, ensuring that they came across as funny, caring and likeable. It appeared important to them that staff knew them and there was a certain deference preferred from the staff towards them. Residents were observed being quite cheeky with some of the staff in an effort to be 'liked' and staff were seen to be

encouraging a caring façade when relatives were around. In applying this to the field of dementia care we, as care workers, could potentially socially position those we care for in an unfavourable way. By not embracing or by disregarding what the person with dementia is attempting to communicate to us, either verbally or non-verbally, we (in ignorance?) potentially thrust an undesirable self on to that person. This process of marginalization towards the older person is important to focus on and, by providing an environment and care that promotes the individual in a holistic way, focussing on the whole person rather than by an institutionalised and task orientated approached, it can be suggested that individuals' self-esteem, engagement and overall health and well-being can be improved.

Part of the nursing home's ethos is to provide meaningful activities which enables conversations with others and the promotion of relationships. One resident outlined the following in regard to activities when asked if she participated with them:

> *I try to. They're very good, there's usually a programme and now we've got another erm, what do they call it?...activities that err…I've got some Christmas cards they've done for me you know and they had a competition and years ago I used to do a bit of art work. They put my one into the competition, yeah, and so, they did and they were kind enough… the one helper she was an art teacher and she's made from this one copy she's made me about a dozen Christmas cards with that picture on them.*

Another resident outlined that their favourite activity was to *"sit and listen to music. We had a singer in last Tuesday and do you know, even the people with very bad dementia they started and music gets through".* These conversations were borne out within my observations within the home.

Observation diary:

10.15: Residents lounge. MH unit. Arrived on to unit to a lovely "warm" smell. One R [resident] stirring cake mixture in a bowl in living area. At large kitchen table, three people are involved in different aspect of cake making. Carer speaking to each person in the room about cakes and how they get made, reminiscing about baking at home. Carer asks Resident "Are you OK?" "No, I'm not, I'm buggered" he laughs. Resident, washing up, asks Carer "Where's the tea towel?" Carer gives the tea towel which is black and white checked and Resident says "I don't think much of this tea towel, my mothers were spotless!"

Within this sub-theme of 'social death' there arose the interesting subject of nurses who had decided, for whatever reason, to leave the NHS. This, in effect, risked becoming a 'professional social death' due to the pervading perceptions among the profession that nursing home staff are somehow less qualified or lacking in ability compared to their colleagues working within the public sector. As one registered nurse outlined:

> *I get upset and very defensive when people that I've worked with at the hospital, I don't do face book any more but people made out and made comments about nursing homes and when there was all of that in the media a couple of months ago and then when we got praised, you know, by the residents for our being caring and all that I put on Facebook well you know this proves that not all nursing homes - I'll get me own back I thought (laughs). I hate it, I hate it. Their attitude [deep intake of breath] then when we send people into hospital that's another thing I notice, they have a go at us, you're not doing this or that hasn't been done but they don't realise how hard it is to request for a GP to come out. They think it's a cushy number. It isn't a cushy number. You're fighting to to to get a GP to actually come out and see the resident, you know?*

Haslam, et al. (2009) suggested that there is a risk to an individual's sense of well-being if a person believes that they belong to a group that is seen as in some way inferior to others, again linking into Goffman's overview of stigma (1963). Whilst this idea can also be assigned to residents and relatives coming to a nursing home, my personal experience has been that this superiority from staff employed by the NHS is real and can, indeed, effect the feelings of stigmatization on nurses who work within a different environment. Conversely, another registered nurse outlined that there was purpose in her decision to work, not only in elderly care, but within a nursing home:

> *When I went into nursing… my aim was to stay with the elderly because I just feel that they have a raw deal of life and I just think that they should have a good one to, you know, end it. …my main drive was to look after the elderly. There's a lot, isn't there, there's a lot of elderly and I just [pause] that was where my heart was. I just want to love them, caress them, some of them are alone, have no children or no husband or wife so I just wanted to love them really. I know you're not supposed to get attached but you do, that's the way I am. I, I, I was the type of person who didn't really want to go up the ladder really, I wanted to be a nurse on a level, to be hands on with the elderly.*

Whilst there could be some criticism, in today's society, around the words used within this heartfelt description of why nursing the elderly was where the nurse's heart lay, when sitting in front of her I

was touched by her sincerity and desire to nurse within this speciality. However, when she talked around her wish to remain hands on, there was a conundrum in my mind. Firstly, does it always mean that the higher you progress in nursing, the less time you have with patients? If so, what impact should this have on our nurse training as the management skills required at high level leadership are merely touched upon within current degree nurse training. There is also the impact that nurses, who are experienced within care, move up the ladder, which leaves less experienced nurses to care for the patients. With the current furore around Nursing Associates being a part of a widening health care workforce surely these experienced care workers should be embraced to support the less experienced newly qualified staff nurse.

It is important to recognise that not all staff within the nursing home felt their employment there as a social death, in fact it was a positive choice for them to work there and classed other places as a 'social death' environment, for example a member of kitchen staff outlined:

> *I didn't like it there, no* [a large activity centre catering for children] *…you weren't really cooking it was just mass delivery of food. Here I can know all of my residents and there is time to care about what I do.* There was a feeling that the skills she had were really valuable and she was able to utilise them to the full *you've got the whole variety of catering, you know? So, you go right down the bakery route, which is one of my favourites. I love patisserie work erm, you know, I love everything I do.*

I also interviewed an unregistered care worker who had worked within the nursing home for over a decade. When asked about her length of employment, she outlined that she *"loved it here. No two days are the same"*. She went on further to outline that her roles had changed over the years, from working in the kitchens to now being a Care Practitioner. This is a programme of education that I led on whilst employed within the Company. The role was designed to provide a richer skill mix of staff due to the prevalent issues of registered nurse recruitment and retention. This aspirational rise within the employment ranks had suited her as she could not afford to undertake her pre-registration nurse training, in either time or money, due to having young children. This programme of education had enabled her to remain within her workplace whilst gaining skills that would enhance her role and thus

the care provided to residents as she outlined: *"I really have a career here…it's brilliant"*. The ability of a large Company had enabled funding and design of the programme which a smaller nursing home company may not have been able to provide. Whilst labour power is the property of the individual, there is a need to sell this labour to a capitalist employer who owns the means of production, in this case a nursing home to provide care. Naturally, without an individual's own means of production they have no way of earning a wage. This is the crux of the matter – the company invented this role and training and it is not transferable to any other care provider. Thus, should this unregistered care worker want to move on, the qualification would be defunct. The wages paid to this role of worker within the company is lower than if they had supported the worker to undertake a recognised qualification but there is an expectation that the work they produce is at the same level. A company working a capitalist system obtains surplus value as the wages are lower than the value of the service provided (Harvey, 1983). According to Cohen (2013) an "…institution [in this case the nursing home] serves the ideological needs of capital for complicit and docile workers" (p. 9). Whilst this seems an overly deterministic view, when Marxist theory is applied to this particular situation it would appear that labour power is at play.

Sub-theme three: *"The problem was, I didn't know where it was all going"*

Life as we know it.
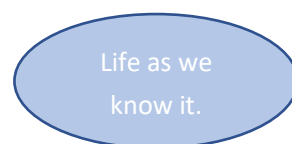
The skip was on the driveway for a month and I kept looking at it. How was I supposed to know what to put into it… these were my memories, with my wife (spouse interview).

This sub-theme was borne out of conversations with not only residents within the nursing home but also their relatives. Whilst there was an 'understanding' that the move into the nursing home (either from a residents or family member's perspective) was required due to being unable to care within a

domestic home environment, family members were filled with guilt due to their perception of failure. These feelings of guilt were manifested in different ways but it was apparent that there was a need to grieve over the end of a life as known. These were feelings that emerged and could be expressed through the structure of the tripartite. There was almost a fear over what the next stage of life would be – both for the family members as well as the resident themselves. In my experience, many family members want to be given certainties in regard to time; a much asked question was 'how long?' This 'how long' could be attributed to length of stay, until a resident died, until a treatment worked, until a doctor came but it was all about the waiting for something to happen. It was interesting to uncover how relationships had been altered due to the admittance of their relative to the nursing home and if the relative had needed to embrace a new role - that of 'visitor'. In my experience, the role of 'visitor' is a difficult one as I have both been the nurse dealing with visitors and, as my Grandmother and my Aunt had been nursed until their deaths within this nursing home, a visitor. Whilst undertaking observations many residents and relatives came to have an informal conversation with me. These were captured, in written form, immediately after the event to allow for a clear description. One such conversation was with a female resident who was going out on a trip:

> Informal conversation:
>
> We were chatting about the trip she is going on today "Well it gets you out of the place. No need to do my sewing now". We then started talking about why she was in the nursing home:" All my daughter's doin" (that she is in a nursing home). "I never wanted to end up in a nursing home but it's OK". (She then went on to tell me she's been a resident for around 12 months). "There's plenty [of people] to talk to here but there's nothing like old friends". "I'd like to think I'll go home, up the road, but it's my walking."

Within this sub-theme there was a strong emphasis not only on loss of self, as identified above within the informal conversation, but also on loss of the relative as they were. Many residents remained married (not widowed) and their spouse visited regularly. Many relatives that visit had been the person's carer and this gave a different slant to the habitualization of role. One relative was extremely adept at communicating their feelings of loss due to their spouse's deterioration from Alzheimer's disease:

> Spouse: *My biggest problem was I didn't know where it was all going. I didn't have…. I have had a lot of information since which would have been great to have had because* [pause] *as* [daughter's name] *will tell you, I failed my wife.*
>
> Daughter: *"Dad, you tried to look after her in the best way you could because you were worried and, and, there is that issue like of washing and cooking and things like that that if someone does it and gets it badly wrong you flood the house, or you set something on fire.*
>
> Spouse: *But if you set the table wrong, it doesn't matter.*
>
> Daughter: *You didn't fail her. You wanted to do things for her…*

This spouse was concerned that by doing things for his wife he had actually deskilled her and advanced her journey with dementia. There needed to be reassurance from both myself and his daughter at this point. His daughter pointed out to me that *"he's been living through this, day after day, as Mum wouldn't let him out of her sight"*. The impact on the whole family and specifically the carer's health emotionally, physically and psychologically is great. There appeared to be a need to learn a whole new language – one of medications and medical jargon – whilst learning to be part of a healthcare system that was not always supportive or explanatory. As the daughter outlined:

> *When they came to do the sectioning meeting they were amazed that Dad had managed for so long, and to keep her safe and to keep her healthy, well-presented and everything like that and I think he, because he's not been on anyone else's journey, he doesn't realise that it could be far worse than that or different to that. You know…"*

The wording used by the daughter to describe how specialists had come into a home and expressed amazement on how well a loved one was actually being cared for, despite the overwhelming mental health needs, alludes to a health system that is potentially acting too late. By this I mean that the health service acted when a person's health had reached a critical point rather than prior to this crisis where support could have been offered. There was a need for the family members to catalogue symptoms of the descent of their loved one into illness and the daughter was able to list the medications utilised, what the side-effects of each one were and how her mother had displayed some of them. There was talk of individuals, who were excellent in their support, within their dementia journey to date but this was couched in the terms of 'despite' the healthcare system rather than

'because of'. Through a desire to look after the wife the husband explained *"I even tried locking the doors"* to stop the wandering behaviour that potentially could bring risk to health and safety. It was pointed out by the daughter that the *"social worker said you can't do that"* but that left the husband bemused as he was merely trying to keep his wife safe, not captive. Whilst the daughter outlined: *"Whilst it's been a rough journey, we've managed it the best we can".* The husband interjected *"But that doesn't take away the feeling of guilt".* Out of all the conversations that I had whilst undertaking this research, this interview affected me the most, in an almost guttural way. It really made me consider the raw pain of losing somebody whilst trying to do everything within your power to keep them safe. There is an important point raised within this conversation in regard to the provision that is required to reduce stigma and maintain the support of both the person and their family. This tendency towards stigma is intensified within older people's care due to the capitalist structures that surround decision making. The rules and legislation that govern care are not person-centred and do not allow consideration for individual circumstances. As Reidy (1993, p.29) outlines;

> There's a difference between the artificial support network of a therapist and the support provided by family or friends. You're paying those people to be your support. It's not normal. The system needs to create natural supports. The system thinks of itself as, 'We're what people need to get well.' What people need is family, friends and the community.

Successive governments have chosen not to invest in the social care sector which has led to a reduction of staff and thus specialist expertise within domiciliary settings. This is an area that came about within this theme; that of the adjustment of a spouse to having their partner admitted to a nursing home. There were areas of anxiety that I had not considered over my personal career which the relatives were concerned over. These included ongoing transport issues where the spouse was a driver but, due to advancing age, was considering giving this up. However, keeping their licence was their only option as how else were they to visit. One relative talked about how they adjusted themselves to having their loved one go into the nursing home:

With great difficulty because I was living in a house full of memories [pause] and err [pause] I obviously realised that I've got to move and err I didn't want to move and it was only my family saying that, you know, this is silly. The daughter interjected with *Well it's a four bedroomed house, it hadn't been the family home for ever because we moved around a horrendous amount during my life time and your life time so it wasn't like this was the house I had grown up in, it wasn't but it was the last home mum and dad had shared and therefore it was…it was just too big and you weren't, you've had a couple of bouts where you haven't been brilliant on your feet, you developed , erm… labyrinthitis and things like that and we just sort of tried to say, you know, you need to look at something where you're on one level but you're actually amongst other people and things like that.*

This conversation identified to me that whilst the spouse was obviously dealing with emotional angst the daughter was having to ensure that both parents were looked after and that social engagement was a cornerstone to this. Neighbours, according to one visitor interview, were really important as there was a shared history and support was viewed as being close at hand *"they're just there, over the garden fence"*. Although the proximity of others is just as close (if not closer) within the nursing home space there are no familiar ties between people, no shared history. These ties are broken if a spouse feels it necessary to move. This is a large emotional burden for family members to take on and there is no real support for this as all of the focus is upon the relative being actually cared for, with the medical need. A daughter of a resident outlined:

I was apprehensive [about her mother being admitted to the nursing home] *but I could see the writing on the wall, I could see which way things were going to go. There was relief as it would take things out of Dad's hands and I felt that it would make Mum safer because I felt she was becoming increasingly unsafe walking round as she was getting less steady on her feet and as we now discovered, she had broke her hip…so it was relief really. Then you have to adjust to this.*

This is an area which needs further examination in the future.

There were conversations discussing relatives maintaining their care role "*Some may help in regards of assisting with feeding food and drink. We have a few husbands and wives that sort of come in at mealtimes and they make sure they do come in at mealtimes so that they can feel useful and be able to assist them with their meals".* This comment around "so they feel useful" could be dualistic – it could be around their own need and identity to feel useful. Whilst the perception of the staff may

have been around a spouses or family members need to feel useful, there were a couple of conversations that outlined that there was another reason for people to visit and get involved with care, that of monitoring:

Informal conversation:

A female relative arrived to visit her husband. She is obviously well known to the care staff as all greeted her by name. She came over and introduced herself and proffered to tell me "her journey to today". Her husband has been in the nursing home for over five years and ensured that I knew that the care had been "from bad to good". It felt that she was really ensuring that I knew that the nursing home had improved considerably. New management structures were now in place and there was a definite shift towards excellence in resident care and ensuring that relative's views were very much taken into consideration. Many sentences were commenced with "I'm not complaining but..." however this was tempered by the fact that care was improving. She informed me that she used to visit daily as she was so scared of what might happen if she didn't. Now she only visits two or three times a week. She ended her conversation with me by looking at her husband across the room, with tears in her eyes and said "He's not the man I married. It's tragic".

This was confirmed by one spouse telling me about how there was a fear that his wife would not be fed or cared for appropriately when he was not there: *"I still come in every day. I have to come in to make sure they're looking after her. Now it's become a habit. I come in probably six days a week".* This could be assigned to feelings of guilt for leaving a loved one in someone else's care but there is also an undercurrent of 'ownership' at play. By neither the resident or relative feeling ownership of; the plan of care, the potential decisions of why the person came to be in a nursing home or, the day-to-day humdrum of life, this can lead to power, authority and control issues which, in and of themselves are stigmatising (Reidy, 1993). As an adjunct to a visitor role, an interviewee, who was admitted to the nursing home, thus a dual visitor and resident role, with her husband after caring for him 24 hours a day felt the liberation of being relieved of duties at night but continued to care during the daytime

When I said goodnight, I knew the carers would look after him until breakfast time. It's a very hard decision to make for anybody but it's universal". The resident also outlined that *"A lot of the visitors, their spouses, had Alzheimer's and such like, you know, they just go to sleep…so, like err, only yesterday we had a death where one of the ladies who visits her husband, he died, so another lady who's a daughter is going to buy a card and we'll send it to the family.*

This particular resident benefitted from the conversations with other people's visitors and perhaps viewed herself as both resident and visitor. This was interesting to observe, as naturally a spouse was in the same age bracket of their loved one whilst their children were quite regularly classed as 'old' being over the age of 65 years. As one resident outlined *"My daughter's 70* [years old]*, my son's 68* [years old] *so, you know, it wasn't being fair on them* [to care for the interviewee and her spouse]. Therefore, there was a real sense of shared social and local history shared between visitors and this was born out in the myriad of conversations that were heard whilst undertaking observations within the nursing home. Whatever the viewpoint, this mix of people to engage with assisted the resident in her sense of personal and social identity.

As Mor, et al (1995) outline, there is a need for both physical and cognitive functioning to be in place to engage fully within the realms of social interaction and this was borne out within my time at the nursing home where many of the visitor's spouses were unable, due to cognitive ability, to engage in meaningful conversations of 'life before' so the majority of the conversations were between the visitors, comparing histories and discussing the town in which many of them had lived for many years. There was always hand holding and talk of the spouse as part of the conversation but I wonder whether the conversations visitors had within the nursing home held back the feelings of isolation and loneliness that they too were experiencing due to being a member of the aged society.

According to Holmgren, et al. (2012), each grade of nursing home staff imbibes a certain code of conduct when dealing with visitors. As one registered nurse explained: *"It's very scary for them* [the relatives]*, leaving their loved one in care, with us".* This registered nurse went on to explain that as the person who took the main interest in a relatives care was usually a female and it was important to *"*[take into account that] this *generation were at home cooking and cleaning and doing, like, the hard work, and they expect us, like, to be the same (laughs)".* This indicates a matriarchal dominance over care and family that lingers throughout time.   One non-registered care worker identified that there

was a need for both staff and the resident and relatives to *"get used to us and we have to get used to them".* This was not always an easy task as a non-registered care worker outlined:

> *We have difficult relatives and we have relatives that appreciate everything we do and I don't think it makes any difference whether they are male or female* [relatives] *I think it's sometimes that relatives feel guilty that their relative's in here* [there was a rising inflection to the end of this sentence, almost as though the interviewee was asking me a question or was unsure if I agreed]. *Also, if they're going away, they can become more difficult but we deal with that on a day-to-day basis* [laughs].

There are obvious feelings of guilt that a relative must feel when leaving their loved one in the care of others which come from feelings of resentment and pessimism due to the admission of a loved one (Davis & Nolan, 2003). This situation is not helped due to the identification of what Coyle (1999) identifies as relatives being made to feel "incompetent" (p.112) by those with medical knowledge. This is not necessarily a particular staff member behaving in a way to engender this thought, instead it is a feeling that a person places upon themselves due to the stress of coping with a situation, a sense of failure that they could not cope with their relative and feelings of selfishness. In my working experience, this has certainly been an area which residents can also manipulate in order to 'punish' a relative.

To end this theme of death, I think it is pertinent to read the words of one resident who wanted to impose on me what the future, for us *"young uns"* could be like and how this will impact on the next generation of older people:

> *Well for the future. What I do think, people have got to adjust…get their priorities right in world affairs. You know they don't save for the future like we used to. Yes. But they expect that when they get to their old age the state will look after …well we used to have to put by money for our old age …look after…I think the time has come that err the government can't carry on like it. I think people have got to realise they've got to save. You know, once upon a time a child would have a money box and save their …there's no, no sort of saying to children…. Yeah. You lose the value of money* [when everything is on a card]*, Yes, that's what I would like to change, for people to ask how much is that? I say to my Granddaughters or the mothers of them never be ashamed to say to the children you can't afford it. There are times we had to say no to our parents and children because we knew there wasn't the money. But nowadays, it's expected to spend a couple of thousand on a wedding dress and the next minute they're saying they can't afford a*

house. Values have gone and people's priorities have changed. That is the one thing I would like to change.

Chapter summary

This chapter has explored death through the lived experience of the tripartite. The physical ending of life was not the main sub-theme, rather the loss of life upon admittance to a nursing home was key whether that be a family member, a resident or staff. The self is reviewed against a multiple of theories as well as engaging with the biomedical deterministic opinion that the ageing population is often viewed through. The admission procedures to a nursing home are explored with regard to how this enacts a social death. Again, this can be viewed through the tripartite in various ways, each as important to the individual as the other. The relationships between family and resident are discovered with the feelings of guilt and fatalism explored. Throughout this chapter the narratives of the interviewees are central to the exploration and are detailed in their presentation.

Chapter 7.

Theme 2: Personalization of care and expectations.
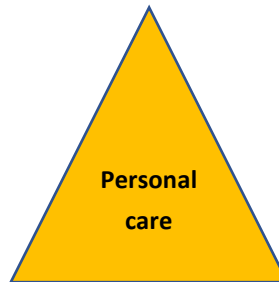
I honestly can't think there's anything …the world isn't perfect, you can't expect everything to be perfect all the time, you know sometimes you press the red button because you want help and they're all out, you know they, they, do the best they can. Yes…yes…yes (resident interview).

Introduction.

In the first instance care, as a notion, needs to be explored. Gilligan (1982) offers an explicit description of care by saying: "The idea of care is thus an activity or relationship, of seeing and responding to need, taking care of the world by sustaining the web connection so that no one is left alone" (p. 62). Care is relationship-based at its core, that there is a need for meaningful interactions to occur and, without these, there is just 'doing' at another person. There is an interdependence on both the giver and receiver of the care in question and through this care, in its truest form, will occur. This chapter is an exploration of the tensions that this sometimes causes within the tripartite.

Analysis and findings.

From the data analysis undertaken, all grades of care staff specifically talked around the need for person-centred care and were keen to distance their work from the term institutionalization. A non-registered care worker explained that this home was different to other homes within the town due to:

> *Erm… just what we think, we think about how we look after someone, that, erm, person-centred care is fantastic. Everyone gets a choice, they get choices whether they want to get up or not to get up, if they want to … what they want to eat, if they want to go out on day trips they go out, mainly at least once a week they've got day trips going on, always plenty for them to do.*

If the definition of person-centred care is "about focusing care on the needs of individual. Ensuring that people's preferences, needs and values guide clinical decisions, and providing care that is respectful of and responsive to them" (Heath Education England, 2019. Para. 2), it is important to uncover staffs' ideas of what person-centred care means to them. A non-registered care worker explained:

> *We just all do it naturally [laughs] you don't even think about it. You go into someone's room and you automatically ask them if it's OK, whether they want to get up that morning, what they want to wear, if they want to put make-up on, if it's a lady erm or even if it's a gentleman, I don't know [laughs]. Erm, so it just comes naturally and obviously as we get taught it through the training the girls do it day to day and they don't even have to think about it.*

This theme is concurrent with previous research undertaken by Killet, et al. (2013) of which I was a part of the focus groups and Vaismoradi, et al. (2015). This concept of person-centred care was seen to empower residents by staff interviewed and is consistent with the findings of Bridges, et al. (2013) who outlined that therapeutic potential is achieved for relationship-based partnerships through in-depth knowledge of an individual's personal choices for care. There were however misnomers around routine and coping with the fluidity which could result, as one registered nurse stated *"in a state of chaos".* Staff were happy to call some of their work routine but were very definite in that fact it was not institutionalized *"There is a little bit of routine, yeah, but every day is different. You know, it's not regimental".* The fragile ideas of person-centred care, based on contextual knowledge and empathy, are in constant tension with practical work constraints inherent within a nursing home community. There was some insight around the complexities that this entailed with a registered nurse saying:

> *Care rounds and positioning. I don't like that. It's like the old days. I know they have to be repositioned but* [pauses to think]. *How do we go about that?* [questioning self]. *How do we go about that?* [questioning me]. *It's a difficult one* [pause], *I don't know.*

This indicated that the routine was still there and, could be considered to be institutional but, this dichotomy could not be altered. The registered nurse went on to say:

My friends from [previous workplace] *came to see where me and* [another person employed] *were working and, err, they said the thing is...it's a nice home but at four o'clock, the party was still going on and all the residents were pushed back. It's sad, innit?*

What the registered nurse was explaining was that there was routine which was always adhered to as four o'clock is when people would need to be re-positioned and potentially taken out of their wheelchair. It did not matter what was going on around and there was no adjustment in place**.** That the registered nurse was also demonstrating was her conflicted position within this structure. This structure of work parallels what Goffman (1961) suggests institutionalism is; there is a timing to the steps that need to be undertaken in order for inmates to get dressed in a morning. What was interesting was that this same registered nurse went on to say *"That's what I love, over there on* [name of dementia unit]*, there's no real routine".* This indicates that there is a possible difference within the provision of care between a general unit and a dementia specific unit where disruptions of routine are not viewed as important. This is interesting as it would indicate that the personalization of care is much more at the forefront of staff behaviour when nursing people with dementia than those with physical illness or perhaps disruptions to the routine were not viewed in the same way. It raises questions around whether personalization is dependent upon your majority population illness (medically led), upon staff perceptions (staff led) or, indeed, around the population of visitors and their perceptions at the time (relative led). Ideally, however, these are erroneous paradigms of care as what we should be attempting to strive for is true person and relationship centred care. When discussing the best part of a care worker's day there was an attempt (I believe unintentionally) to hide the routine medicalization of a task by grounding it in the appeal of implicit communication:

…I'd say first medication round coz I get to be able to see everybody. I get to go into all their rooms whereas obviously during the daytime [I spend more time] *with certain patients than others erm…but yeah, the medication rounds* [registered nurse].

Throughout the interviews undertaken and relative to this theme was resident voice and whether residents were an integral part of the conversations around what their care looked like. Resident choice is an area which is within the promotional material for the Company, that staff interviewed talked around and which is central to many of the policies that surround care in its entirety. According to Vaismoradi, et al. (2015) the ability of a resident to be a part of their own care planning is essential for the maintenance of well-being, retaining autonomy and what they termed "Participation in living" (p. 117). Naturally, there was an affirmative if a direct question around resident choice was asked but even through the general conversations there was an innate desire to place the resident at the centre of their own care and provide choice wherever possible. For example, a member of kitchen staff stated *"when I sit down with them* [the resident] *erm….we do the basic stuff and we do ask the residents a lot, erm, we ask them what they would like at the residents meeting…its whatever residents want really".* Many care staff highlighted that there was always opportunity for residents and relatives to advise on likes and dislikes in relation to personal care, eating and drinking, activities and so forth however, it would appear that there is a need to document everything for seemingly two reasons. Firstly, the documenting on progress forms and care plans acted as a communication strategy between all members of the care team. Secondly, and more around the potentially litigious environment than an effort to promote person-centred care, was the school of thought that *"if it isn't written down it isn't done"* [registered nurse]. It was suggested that if the CQC could not see that care is planned appropriately and reviewed regularly, that the nursing home was unsafe. A non-registered care worker outlined the paperwork that is expected to be completed on a daily basis:

> *Repositioning charts, bed rails charts, food and fluid charts, then they have a chart to say they've* [care worker] *checked everything in that person's room before they've left, so they say if the room's tidy, wardrobe's tidy. As a nurse obviously you've got erm, all your evaluations, care plans that we have to update each day for the resident of the day. So, they have to be, all care plans have to be checked to makes sure that obviously we're providing the care that that person requires. Then medication (laughs) so the list is endless (laughs).* I then asked if she felt all of these charts were person-centred. *Yes.*

It appears to be dogmatic to get care staff to sign to say that they are leaving a residents room in a clean and tidy state and I was interested in how these forms were completed and questioned the non-registered care interviewee about the structure and ownership of them. She outlined that the repositioning chart had left and right sides indicated on them and this was essential to alert the next person, who could be different, which side they have been on. I explored with her that surely the person could see which side they were on just by looking but she outlined that there was no way around the filling in of the chart to show repositioning had occurred should a question be asked or a complaint raised about the standard of care. Again this demonstrates the conflicted position that staff are structurally placed within in the context of nursing homes. This conversation supported what the registered nurse had previously indicated and the idea of a litigious culture.

I asked if all of the forms completed would tell staff anything that they did not know:

> [a long pause]. *Err* [another long pause] *you learn a lot by their….especially their erm care plans because obviously the residents I tend to work with on what sort of side* [the two different units within the home] *and then the other side if I'm doing an update for that person that maybe I don't know, looking it up and looking at families have filled in like, erm, what they used to enjoy, you sort of get a lot from, whether they still enjoy that now how and whether you can sort of interpret that into bringing into their care here* [non-registered care worker].

When I suggested that if time spent completing documentation could be spent implementing and providing high quality person-centred care there would be no cause for complaint I was met with derision! This derision was a consequence of the conflicting idea of care whilst having to meet the needs of an institution which needs to meet the demands of the regulator in order to make money. The wider care team, such as the kitchen staff also talked about the record keeping that was required with files on each person identifying food likes and dislikes and any allergies. On interviewing a member of kitchen staff, she outlined that despite all of these records *"If I sat down with my deputy, I could probably go through the needs of 92 per cent of what everybody likes, err, down to where that person doesn't like carrots".* On further conversation, the member of kitchen staff outlined that there were at least eight different forms she had to complete from recording temperatures throughout the

whole of the process – in the kitchen, in the dumb waiter, on the units, on receipt of food, fridge and freezer temperatures – to date labelling. The kitchen staff member highlighted that the paperwork she completed was not legislative but, instead, enforced on her by Company policy. When questioned whether this paperwork she had to complete was more or less than within her previous roles (she had worked in hotels, restaurants and her own business) the answer was a resounding yes and outlined that previously she had cooked for around 700-800 people per day and nothing had to be documented as rigorously as within the home. Whilst discussion ensued about the time this extra paperwork took, she quantified with *"…but at the end of the day we've got people here that are probably the poorly people, they need a lot more …making sure that they're doing OK".* What all of this paperwork work demonstrates is that there are restraints on staff to work within policies that have the structural deficit of being black and white. The policy is decisive and not open to discussion or mediation. The policy is structured around tasks rather than the muddiness that goes around relationship building. There is a cultural disconnect between nursing homes and domestic homes and yet, according to the marketing literature, this is what nursing homes are led to be. The very fact that all choices have to be documented, for apparent litigation reasons, moves a culture of care away from being personable and resident-centric to an exercise of ticking the boxes to meet the requirements of governing bodies.

The care itself was not the only area to be documented. In the GM's office there are a number of notice boards which contain various memorandums, emergency phone numbers and Company information but what was interesting was the guidance given to all GMs to follow – a Manager's daily checklist, containing 19 activities; a weekly checklist, containing 11 activities and; a monthly checklist containing nine activities. The daily activities list contained inexplicable activities such as "Walk around home regularly in the day…" and "Talk to any relatives visiting the home" (confidential, refer request for reference to author). If there is a need to remind a GM to undertake such activities, I wonder about the calibre of the GMs employed. Surely, these types of activities are natural responses and not competencies that need to be instructed on.

Whilst there was discourse around the unhelpfulness of external agencies upon diagnosis of a physical or mental impairment prior to admittance there was also idealization of the NHS and the staff employed there. This is similar to the discussion in sub-theme two 'social death' where there was a glorification attached to working within the NHS and working externally to this panacea of healthcare somehow made the registered nurse less qualified. However, this idealization was added to by the same registered nurse articulating that this wrong glorification existed stating that:

> *I think, I think the qua... I feel awful saying this...I think the quality of the carers was so different to the quality of carers in the hospital. Does that sound bad?* When asked why she thought this was *Because they get lower pay. I said to* [name of staff member] *and was told they get paid peanuts, so it's up to us* [nurses] *to teach them and to make them better carers. Yeah... Do you think I've said the wrong thing?* [There was a need for reassurance towards the interviewee at this point].

Throughout conversations with both staff and visitors there was a view that external agencies had not been helpful in the portrayal of nursing homes and the care that was expected. There were unrealistic expectations provided by these agencies which, eventually, could lead and had led to disillusionment for relatives and subsequent issues between themselves and the nursing home staff. This was borne out with one non-registered care worker outlining that *"relatives can expect the resident to start walking again when the resident hadn't walked for years. They think we can perform miracles!"* Obviously, this can cause further anguish for the relatives which, in turn, does not help the basis of trust and relationship between themselves and the staff within the nursing home. As many residents are admitted following an acute admission to hospital it could be what McLean (2006) proffers in that nursing homes can be "contrived constructs that inaccurately reflect reality and promote other vested interests" (p. 928). The vested interest in this case may well be to reduce the phenomena of bed blocking, which is a key policy concern (Gaughan, et al., 2014) which highlights the rising issues surrounding the lack of care for our aged population. With government targets to be met, there is a real push for hospitals, social workers and doctors to tick the box that an older person is in the correct care setting. Ultimately, within the current system, these issues are unresolvable, it can only be

managed pragmatically but, by idealising the nursing home offering there is a risk of subjugating the older person and their relatives into making a decision to move.

Through discussion with the nursing home staff there was discourse around how residents and their families were admitted (inducted) into nursing home care and how expectations were managed. It appeared that this was not thought about in any depth and it was not an output process which could be learnt and standardized, it was more around dealing with the situation that confronts you. One registered nurse outlined: *"Err....how do we do it?* [a minute's pause whilst thinking]. *How do we do it? It's a hard one to say really".* Following further discussion, the registered nurse identified that *"Relatives thought there would be one to one care but that doesn't happen does it?* [Relatives thought] *standards are going to be exceptional, erm, but they're not are they?",* and this standard was deemed both unachievable and unrealistic. As previously noted, there is a cultural disconnect between the idea of 'home' and 'homeliness' to what marketing offers around a 'home away from home' to the actual reality. There is an imaginary ideal of care homes, commonly perpetuated through films, where older people live in harmony, free to do whatever they please which, is not what a nursing home is. People who reside within a nursing home are commonly aged, frail and living with multiple co-morbidities and this facet is hard to look upon when admitted to a home. This mismatch of expectations was similar to the findings from Bridges, et al. (2013) who identified that organizational factors impeded therapeutic relationships due to staff availability and number of staff employed and on duty at any one time. A member of non-registered care staff highlighted that there was a disparity between the resident and the relative's expectations: *"…maybe not the residents themselves, relatives most definitely. Erm, I think they expect everything to happen straight away…they kind of expect that we can provide miracles (laughs) but they don't understand that, obviously, we have to go through the process.* The kitchen staff were included within the admittance procedure but outlined *"I don't go and see then the first day they're here…it's too much…it's too dramatic for them. I have the paperwork from the assessment so I have everything I need. The second day I go down, I introduce myself, I ask them what they like, what they don't like and things like that.* With relatives outlining that there was

"apprehension" due to their relative being admitted it would appear that there needs to be much more focus on a therapeutic orientation where expectations can be viewed by both residents and their relatives but also managed in a more coherent way by the nursing home staff. This, in turn, could assist with the feelings of guilt that are inherently a part of admitting a loved one to a nursing home and thus decrease the anxiety that can contribute to complaints when a person is first admitted.

What is interesting within this theme is the lack of resident voice around their own expectations of the care they wanted to receive. This anomaly, in itself, would be an area for focussed future research but, for the purposes of this current research I will explore why this may be. There appears to be, from a resident's perspective, a desire for "family" and company as the main precept for care requirements. Many residents talked about the staff and other residents "becoming family". Activities programmes were talked about and how "staff made sure it was something I wanted to do". For those residents who spoke to me it appears that the reduction or eradication of loneliness is what good care looked like for them. The feeling of belonging to something bigger than oneself, to feel purposeful. As already discussed within Chapter 6 "Social death" and "Life as we know it death" many friends or a spouse had died or moved away, children could be far away and thus social interactions were reduced. These vulnerable older people were perhaps self-stigmatising (Haslam, et al, 2009) due to a reduced function of physical or cognitive abilities. This would go against the literature that advises that being placed within the nursing home environment can cause acute loneliness (Hanratty, et al, 2018). It is my belief that a more focussed and nuanced investigation with potential (and current) residents thoughts on nursing home care should be undertaken based upon this work that has identified little in the form of residents preference for care.

Chapter summary

In the chapter, care as a notion and more specifically, person-centred care, has been explored through utilising the narratives from the tripartite interviews and the absence of voice from a resident

perspective has been explored. The routine and possible links to total institutionalization have been discussed alongside the consideration of resident voice on impacting care. The issues of compliance have been raised through the discussions on a mounting excess of paperwork that has to be completed to demonstrate the safety of a home. Admittance to the home has been discussed alongside the management of expectations.

Chapter 8

Theme three: Environment and business policy.
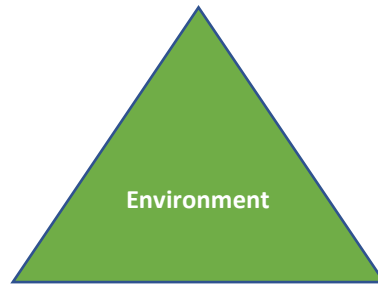
Introduction

Vaismoradi, et al. (2015) make a heartfelt plea at the end of their research paper, putting out a rally cry of: "The question is why the nursing home becomes institutionalized to the point that the 'home' aspect of the nursing home is forgotten and the older people lose their meaning of life" (p. 119). Vaismoradi, et al. (2015) believe that nursing homes, in and of themselves, are institutional and this is due to the organizational demands placed upon staff. The collective norm and rules of organizational requirements do not allow for individual decision-making and thus resident choice and holistic care is somewhat diminished. There could, however, be a much simpler but bigger question: why do we make it so difficult for older people in our society to live well? Age Uk (2019, p. 2) state that "We consider people to be living in poverty when their resources are not enough to meet their basic needs and also to allow them to take part in society" which indicates that it is not just financial poverty that the ageing society is in the midst of. This chapter will review evidence about whether resolving these, and other related issues, within the current context of the neo-liberal attitudes towards care homes, is ever going to be achievable.

Analysis and Findings

Meeting basic needs and being allowed to take part in society is wider than financial expectations, it is about those areas not traditionally measured, such as; self-esteem, travel, connectedness and communication. Given the chronic history of marginalization as a result of poverty and ageing it may be difficult to conclude that policy decisions, which do not address these issues in terms of adequate resources, indicate a distaste for allowing any purchase within a neo-liberal order. This is consistent with the recent history of policy. In the white paper *Our Health, Our Care, Our Say* (DHSC, 2006) set out exciting plans for the thorough integration of health and care systems but not how this could be realistically funded if they were to be achieved. Moving forwards, the Dilnot report (2011) gave a damning report on the state of the social care sector and how a costs cap should be in place. It is only in the DHSC (2021) policy paper *Build Back Better: Our Plan for Health and Social Care* that the core recommendations of both previous reports have been truly addressed and, for funding, this will not be in place until 2023. What this new care cap concentrates on is moving the older person into a care home, rather than their own home, again supporting the capitalist structures surrounding social care.

As outlined by McLean (2006), there is a question around the commoditization of nursing homes. McLean (2006) questions whether we can continue to call nursing homes a community when the ethos behind the business is a commodity. McKnight (1995) reveals stronger views and was resolute in stating that "the commodified substitute can never produce care as genuine care is the product of consenting commitment of citizens to one another, anything less is counterfeit" (p. 12). However, nursing homes are a business and thus the care staff are commodities within the nursing home market. Therefore, as a business, the nursing home works along institutionally defined care models where staffing ratios, care tasks and such like are objectively measured within a cost-based analysis model. Whilst, as within any type of business, there are instances of less than satisfactory behaviours, through my observations I have witnessed what McKnight (1995) and McLean (2006) deem genuine community care consisting of conversations that are not around the functional acts of toileting and

feeding, the effort to preserve a person's identity, whether they be the resident or the relative with an acknowledgement of the life before admission to the nursing home.

The ideology of the term 'Home' is an important part of a nursing home. As discussed earlier, under the concept of home, where the emphasis is the converse to death – life - and this is permeated throughout the organizations promotional material; for example: 'We strive to make life … as stimulating and fulfilling as possible and are committed to ensuring independence, dignity and choice in every aspect of daily life.'; 'Everyone has different interests and abilities, so what can be considered a 'meaningful activity' will be different for each individual' and 'Our home is renowned for its charm, elegance and character, but above all its distinct home-from-home feel'. One resident outlined that her children had *"looked for information on the computer"* and the reason this one was chosen was because *"it was built as a nursing home. The windows are big, there's no stairs, no steps up".* This decision to select a 'built for purpose' nursing home is reminiscent of the findings provided by Douglas and Douglas (2004) who outlined within their study that there was a need for the built environment to be supportive to people using them rather than entirely purposeful for the needs of the medical staff. The geographical location was important to residents with one resident outlining that one of the reasons the nursing home was chosen was because *"there wasn't miles to travel"*. This promotional material, for obvious reasons, does not relate the possible limited duration of living within a nursing home and on careful reviewing of the company's website there is no option to search for palliative or end of life care. There is also no information on any of the individual home's online pages that discuss end of life. Whilst this may well be due to the marketing precept the literature itself may not give an honest or true portrayal of what a nursing home actually undertakes. Within my long career within this sector, I have personally witnessed caring and compassionate deaths with many referrals from GPs, community and hospitals for exactly the purpose of end of life care. What this indicates is not a duplicity by private providers of care but a precarious balance between being both a perceived home and a place of nursing care. This ambiguity of discourse could be seen to both purvey the image of home as well as supporting (and even encouraging) sequestration (Frogatt, 2001).

Alternatively, it could be due to what Frogatt (2001) identifies as the "transitional state" (p.326) where there is no finite identification of when death will occur. Instead, with people living longer with treatment available for complex co-morbidities, it is becoming more difficult to identify end of life within the ageing population without a diagnosis such as cancer. This transitional state (Frogatt, 2001) becomes just as important as the potential to prepare for dying, therefore, the living aspect is fundamentally required and should be as specifically and carefully planned as expected death

In response to this, Kitwood (1990) proposed that caregivers can, and should, modify their interactional styles in order to maintain and replenish identity in dementia. According to a plethora of researchers including Cohen-Mansfield, et al. (2006); Kitwood (1990) and; Small, et al. (1998), the conceptualisation of dementia as a dialectical interplay between neurological and social-psychological factors places particular emphasis on the role of the environment in influencing the quality of life for people living with dementia. Their research has indicated that agitated behaviours frequently signal discontent that may be a result from a devaluing environment and misunderstandings by the care giver.

Observation diary:

08.40: Dining room. MH unit. Female resident shouts out generally to other residents who are sitting down "Come on you lazy lot, get out of bed". Turns to a resident and says "Give him a kick, lazy bugger". No member of staff intervenes in this.

According to Small, et al. (1998), the nursing home context has been frequently cited for its non-facilitative social environment. Rates of social interaction are low and, any interventions to increase these rates may not be accompanied by an increase in the quality of interactions. Indeed, this was witnessed within some of the observations undertaken:

Observation diary:

10.30 am: Resident lounge. EF unit. Care assistant brings in a female resident in a chair. Moves another resident (in silence) to facilitate his residents chair. Leaves with no response to female resident bought in or any other resident.

12.30 pm: Care Assistant asks a resident if he wants to go to the dining room for lunch. Resident answers "yes". Resident has his sock on his hand. Care assistant asks if he wants

to keep the sock on his hand. The resident replies "yes". Care assistant asks for the sock, resident gives it, and care assistant puts it back on the resident's foot anyway.

8.50 am: Cleaner, wearing latex gloves, moves through the resident's breakfast area with a carpet sweeper. Residents are eating breakfast at this time. No interaction between cleaner and residents.

According to McLean (2006) and supported by Bridges, et al. (2013), the desire to move towards a person-centred model of care is unachievable in the most part due to the economics of the business policy, governmental policy and the structure of the concrete buildings where our ageing communities live. This is absolutely consistent with all of the date I have I have looked at. Care work and person-centred relationships are formed not only through interactions within nursing home communities but also guided (and enforced?) by regulatory frameworks such as the CQC. There was some friction around the concept of personalised care for a resident whilst needing to appease relatives. For example, there was a relative who wanted to make the decision for their mother over what she could eat whereas the resident was deemed as having capacity and thus her choices were informed. This raised a discussion around who the customer actually was. As discussed within the demographics of an ageing population, with reduced LA funding, many people are providing top-ups to the nursing home. This can be mainly from relatives of the resident rather than the resident themselves which produces this dichotomy of who the customer is. Within the conversation with a member of kitchen staff, where this comment originated from, pointed out *"If I was a resident of 96 years old and I was told I couldn't have a bit of cake coz I'm a bit chubby…well then…erm…there's something wrong".* This juxtaposition between paying and care received is common and this commoditization plays a part of the problem when discussing the differences between how the NHS is viewed and how nursing homes are labelled. We all pay for the NHS through general taxation which is supplemented by National Insurance contributions (The Kings Fund, 2019c) but this is not viewed as paying for a service. This is not a new phenomenon with Killett, et al. (2013) outlining "a negative and hostile approach to the care home sector" (p. 42). Killett, et al. (2013) report attributed much of this negativity to monetary pressure, an ideologically based desire for all care to be provided within the person's home and

societal ageism. These pressures have been escalating over recent years and, as previously outlined, the funding of social care is becoming much more of a government policy minefield. These attitudes and beliefs on and of themselves can impact upon nursing homes in a multitude of ways. With a consistent diatribe of negativity directed at nursing homes instead of social policy which, as a whole, encourages distrust from the wider populace. Recruitment of staff can be affected as who would want to work in such places of disrepute. There is an increased consciousness of fear placed upon potential residents and their families that can only engender further feelings of guilt of not being able to care for their loved one within their own home. There has been many an occasion where people have said to me that they did not think nursing homes were 'like this' as they expected a kind of poor house institution.

The nursing home where the research is situated is part of a national chain that sits outside of the publicly-financed NHS. Through the provision of care for older people, there is a need to make a profit for shareholders. For this to happen, there is a need for high occupancy of beds, low usage of agency staff which can be dependent upon an external facing high reputation for quality of care. An interview with a member of kitchen staff outlined that there was some disagreement with some policies that are placed upon them *"I have relatives in every week, every day* [for lunch]*"* and when questioned around recompense for these meals *"they do, they do have to pay. We do a flat charge of two pounds fifty in this home. Erm…. At the end of the day, my Company won't like me saying this but, they are pensioners".*

Whilst management of the running of individual homes is tasked to the GM there is an infrastructure in place that leads, manages and governs the strategy, clinical, business and health and safety aspects of the business. The Company espouses their GM's "set the standards when it comes to person-centred care. From leading your team and balancing budgets to spending time with residents, you'll use your leadership skills and nursing background to make your home a place we can all be proud of" (confidential, refer request for reference to author). It was interesting to talk to all of the research

participants about their knowledge of the wider company and what, if any impact this had on them on a daily basis. Care staff were not aware of the management structure outside of the home environment, the reporting systems in place or even who the Managing Director was. However, the Company, of which I was a part of, truly believed that the Mission, Vision and Values were an integral part of each persons lived experience of working within the Company.

There was an indication that good leadership within the home was paramount to the execution of good and excellent care and overall, this was embodied by the fairly new GM with a non-registered care worker outlining that the current GM:

> *…gets all the staff involved whether they're the head of unit or right down to just a carer who has just started…..wants everyone to be involved the same and he's constantly asking everyone what, where they want to go, if they want to do their NVQs, if they want to do nursing….Erm, and he's always asking our opinion on things, which I think helps coz you feel like you're part of the team whereas we've never, sort of, been part of the management.*

The importance of leadership also came through conversations with relatives who identified that:

> *…in the regimes they were all unsure of what they were doing. Where you have systems where you have people there who are well 'it's not my job' and they're all griping as they feel that the management isn't managing properly then therefore the* [sighs]*. What happens is that you feel you don't want to ask people as they all look permanently stressed and busy and if you do say they all want to go home or be somewhere else. … and it depended which staff were on. There were some staff who were very good but there were others and a lot of patients to get up and therefore it was, that was tough.*

The word 'regimes' is crucial within the above interview. This lends itself to feelings of routinization and almost that of dictatorship or authoritarian leadership at best. Another relative outlined:

> *it just goes to show that with the wrong leadership in place, the culture that is created, the ethos that is created, the care that is given just doesn't happen and yet the same people, more or less, with the right people in place can actually do what they innately can do because they are being led properly. They know where the limits are, they know what their jobs are…they can come on and do what their jobs should be.*

This excerpt eloquently supports a similar view by Killett, et al. (2013) who identified within their report that leadership was the crux to achieving the quality of care required to meet expectations.

This view of 'well-led' is a crucial part of the CQC (2020) inspection and evidence must be provided to them on how a registered care home meets this. Spilsbury, et al. (2015) outline that leadership and the culture this facilitates within a nursing home is perceived to be an imperative influence on both staff well-being and the quality of care proffered to residents. Spilsbury, et al. (2015) go on to identify that this specific area and the concepts of leadership and culture are not well defined and are missing from the wider UK literature base.

Chapter summary

This chapter has reviewed the concept of home that was discussed within chapter three and I have discussed it in relation to the nursing home where the research was undertaken in. Both the Company literature and residents views on the nursing home have been discussed. The Company's business model and wider governmental policy have been reviewed in an effort to ascertain how it impacts upon the care within a nursing home setting. Older persons care has been discussed in regard to these policies and debate has ensued as to whether person-centred care can be achieved within the dogma of compliance and policy; all of the data that I have analysed in the course of this thesis indicates that the answer is no. By merely playing about with new policy, which is very similar to past policies, with no real thought as to resources, in an arena where the cultural attitudes are rooted in only seeing value in something you can commodify has fundamentally got to change. Whilst there are certainly pockets of great person-centred care given by individuals, this is in spite of and not because of the structures they are working within. Leadership has been highlighted by the tripartite as an essential component for the execution of good care.

Chapter 9

Discussion of interplay between themes

Introduction

This study has explored the experiences of the tripartite membership of resident, family and staff who all worked, lived or visited the nursing home. It was undertaken through semi-structured interviews, observation and conversations. Data analysis revealed three overarching themes: death, with three sub-themes; personalization of care and; environment and business policy. This chapter will engage with the complexity of the interplay between the themes. In order to make sense of the milieu presented, key people and the themes have been visually represented (see figure five below).

Figure 5: Interplay between themes
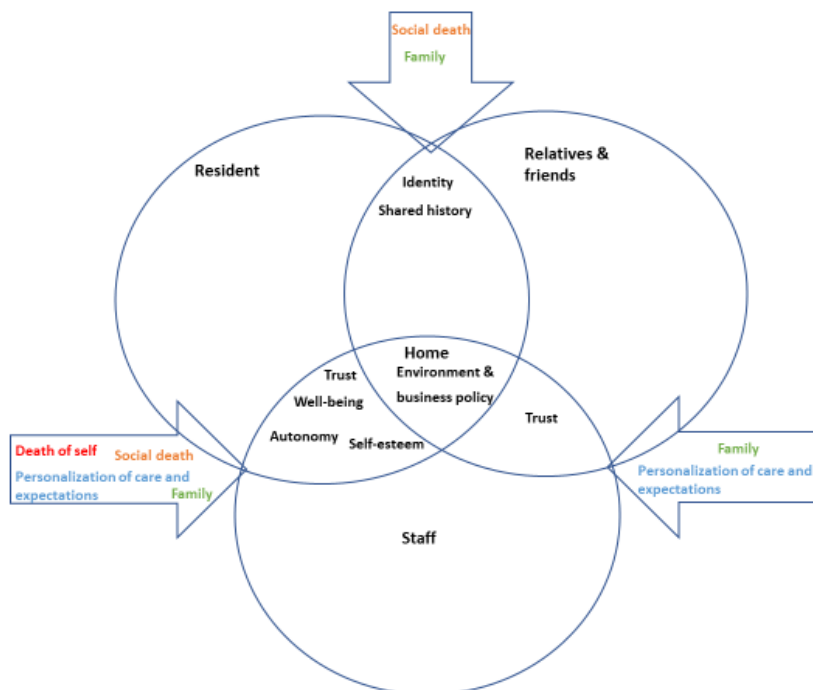
Interplay

As seen in figure 4, the nursing home is the central body that all tripartite members revolve around; some for living, others for work or visiting. Through the observations undertaken, the home appears busy with a lot of activity, conversation exchanges and movement but the residents, on an individual basis, have very much a routine with indications of passive activity - sleeping, eating, and waiting for relatives and activities. What these activities could represent are the final throes of control. Residents can make decisions around these activities for example; to sleep or not, what time to go sleep, what choice they want off the menu. These behaviours are hugely different to the context in which such behaviours take place outside of the nursing home in the sense that 'out there' in a capitalist society they are non-productive. Whilst admittance to a nursing home has commodified their being, with the lack of control and autonomy they become a husk of the person they once were, which makes these small decisions paramount to individuals as a way of exerting control and engendering a sense of community. This is conversant with other studies such as Kolanowski and Buettner (2008) and Nakrem (2015) with Ostlund (2010) suggesting that television is also a positive way to maintain an older person's social engagement and sense of well-being. Although Ostlund's (2010) study, undertaken in Sweden, provides sound evidence in the promotion of some types of passive activity to maintain a sense of freedom.

There is also a sense of the familiar being important that permeates through the conversations. As one resident outlined:

> *I don't think of it as a nursing home, I think of it as a care home but there is an awful lot of dementia here but, at the time, after my husband's funeral I had to go for a medical to my doctor and he said don't you think you could…you'd be better off in a care home that didn't take dementia …err….a residential home? But I said no, I said I'm happy there, I know the staff and the staff are so wonderful…yes… you know you can talk to any of them, it's like a family.*

The interdependence between appropriate interpersonal communication and personal well-being in ageing is often a precarious process and is sometimes neglected within older person's care.

Impoverished social interactions reduce a person's access to opportunities for self-assertion in communication with another person. There is a risk that care workers' conversations may become reduced to addressing mainly the tasks of care giving such as 'here is your breakfast'. Instead, the goal should be positive freedom - freedom to achieve certain ends; as a form of empowerment that allows an individual to fulfill her potential and to achieve a particular vision of self-realization. The fact that people come into care work to care brings an inherent risk of caring too much. By this I mean care workers can, through the best of caring intentions, position people living in nursing homes as helpless and confused. Nursing care is inherently based on intersubjectivity - the nurse/patient relationship - requiring human interaction in the process of care delivery. If care workers view "dysfunctional" behaviours as indicating helplessness and confusion rather than seeing them as presentational cues to the person's preferred persona, there is a lost opportunity to assist in co-constructing the preferred persona.

Family

The desire to belong to a family is something that, despite the constraints that operate within a care home was something that persisted for all of the tripartite members. This was not considered a theme in its own right, instead is was a central thread that really held the tripartite together. There were comments from staff such as: '*They're like my little family, you know? When I have my days off, I think about them'* and '*I can phone a relative up...and they trust you, you know? They trust us'*. These were reciprocated by the residents with observations such as: '*This is my family now'* and, when I asked one resident what was the best thing about living within the nursing home, the answer was: '*You're part of a family'.* The notion of family is often inexorably linked to a person having feelings of belonging, identity and trust which, also links with the concept of home (Wreder, 2008). This is a similar theme that was raised by Saarnio, et al. (2017) in their research looking at "at-homeness" (p. 43) where they suggested that these types of relationships were imperative for ensuring that the

residents accepted the admittance to a nursing home. Interestingly, residents' spouses and children did not convey staff or the nursing home itself within family notations, the term family remained denoted their loved one alone which is similar to the findings of Wreder (2008) and Holmgren, et al. (2012). The fact that family and friends were allowed to visit whenever they wanted was seen by visitors as a real positive for the home. This freedom of accessibility mirrors what Wiersma and Dupuis (2010) found within their study when discussing the boundaries of family within a long-term care setting. Family members articulated that they felt they still have a say over the care of their loved one – power had been retained to some extent, which is important for the maintenance of identity for both the family and the resident themselves.

Total Institutions

Whilst there were discussions around the routinization of care it was apparent that, for the staff, this was not classed as institutionalized. There was a real desire for person-centred and relationship-focussed care to be upheld but, due to the numbers of people being cared for, a routine also needed to be in place to ensure that the required care was given to all. This links to what Goffman (1961) describes as staff attempting to "manage the daily living activity of a large number of persons in a restricted place with small expenditures of resources" (p. 50). There will never be a ratio of one to one care within nursing homes which leads to a dichotomy between fully personalised care and that of routinization. However, whilst this routinization mirrors the features of a total institution to some extent, there was little to suggest surveillance or forced changes to the self (Goffman, 1961).

In chapter three, I discussed the use of Mali's (2008) tool to examine the concept of total institutions. In Figure six, I have adapted this to highlight against both Mali's (2008) and Goffman's (1961) descriptions what the findings are for this study. It can be seen that this nursing home could not be classed as a total institution and many of the characteristics are missing which would indicate such labelling. What does remain is that the nursing home itself, although based within a community setting

and inviting friends, family and the wider community in via different means, remains as an 'other'

place, a place where older people are placed and almost hidden away.

Figure 6: Dimensions and variables of total institutions (adapted from Mali, 2008., p. 436)

Dimensions of the total institution	Variables of the total institution	Research findings
Isolation from the outside world	1.Contact with the outside world 2. Visits by friends, relatives and acquaintances 3. Defining life 'inside' and 'outside' the institution	Contact is actively encouraged. Resident trips are organised. Open visiting times are in operation. Family and friends invited for lunch. As a way of keeping contact with life prior to admittance, resident are actively encouraged to bring their own furniture into their rooms. Indeed, many rooms had photographs of loved ones around their rooms.
Process of mortification	4. Admission procedures 5. Personnel's assistance in solving residents' problems 6. Personnel's assistance in adjusting to institutional life	Whilst the residents I spoke to had adjusted to nursing home life and there was some consideration from staff on the admission procedure itself there was room for improvement regarding helping family to adjust. Staff tend to unconsciously lead residents to be come dependent upon them. This is seen with the little things like overly-assisting them with the activities of daily living. There was a difficulty from staff in describing how residents were assisted in adjusting to their admission. It was a "we just do it" approach rather than a thought out procedure.
Strict control of authorities over the individual's life	7. The way of entering a room 8. Respect for the privacy of residents 9. Calling residents by their names 10. Way of communication with residents	As with any place where there are numbers of people living together and sharing space there are issues with other residents observing particular care to another. For example: asking a resident if they wish to use the bathroom, utilising the hoist to move a resident from one place to another. However, through observations, staff always knocked prior to entering a room and appeared to speak to residents and family using their preferred name.
Comprehensive care for all aspects of an individual's life	11. Residents access to information on the performance of services, events in the home	Posters are placed around the home and there is a monthly news sheet. There is a residents and family meeting which is regularly held. A full life story is in place and residents, where able, input into their own care plans which

		deal with choice around the activities of daily living.
Bureaucratisation of life	13. House rules 14. Residents rights 15. Adjustment to institutional life	Whilst there are some fixed points within the day, overall there is flexibility to address the individuality of the resident. There is a comments and suggestions book placed within the lobby of the nursing home. When I looked within this there were some suggestions of a low level such as the coffee was out of stock. However, mainly, there were compliments to staff.
Non-everyday life	16. Stage of independent care 17. Performance of activity of the home environment in the institutions 18. Consideration of individual wishes, interests and needs of residents	There is a mixture, as expected, of different stages of independence of residents within the home. Routines were flexible to accommodate personal choice. As resident turnover is quite low, the staff knew the likes and dislikes of individual residents and were able to cater for them. There was no set 'bedtime' however, there was an observation that staff were much more task and routine focussed in a morning when needing to get people up. The afternoons felt much more relaxed and there was opportunity for those conversations that were relationship focussed rather than task/routine focussed.
Disciplinary system	19. Violations of the house rules and their sanctions	There was nothing noted within the observations. Within the interviews some staff noted that relatives could come into conflict with staff, certainly more than residents ever did. This was put down to some unrealistic expectations from family members. However, staff were keen to state that any conflict was always discussed and usually there was a constructive solution agreed upon.
Spending of free time	20. Employment activities 21. Influence of the activities on adjustment to institutional life	Activities organisers are employed within the home and there appeared to be a full activities programme which was on offer. There were quite a few activities on offer for those residents her were more able and fewer for those who were not. There were trips out on offer but staff were part of the decision process to suggest who would go on these trips due to the need to have a mix of more and less-abled people due to staffing and transport. Residents

		were able to visit their relative's homes but the relatives need to be able to care for them there.
Secondary adjustments	22. Ways of adjusting to institutional life 23. Withdrawal into oneself 24. Search for a sense of life in the institution	Whilst Goffman (1961) talks about situational withdrawal, intransigent lines, colonisation and conversion, these were not noted within the home. However, conversant with Mali (2008) it was noted that the residents interviewed were non-critical of living within the nursing home. Staff did discuss that some residents did become withdrawn when first admitted but they talked about supporting such residents and giving them time to adjust.
The world of residents - the world of staff	25. Relationship between staff and the residents 26. An involvement cycle	From the interviews undertaken, staff were clear that they had an emotional involvement with both residents and their families. This was often 'taken home' with them and they thought about particular residents even when not on duty. From the observations undertaken, all residents were treated with respect at all times.
Atmosphere and culture of the institution	27. Atmosphere and culture of residents 28. Atmosphere and culture of staff.	Staff displayed virtues such as kindness, care, commitment, friendliness and humanity towards both residents and family. The staff gave thought to the best care they could provide residents and were relationship-focussed. Residents, overall, were keen to underline that the staff were caring and did their very best.

Chapter summary

This chapter has noted that the nursing home cannot be classed as a total institution by comparing the findings to Goffman (1961) and the defined characteristics. There are, however, areas that could be acted upon to make the adjustments to nursing home living easier on both residents and relatives.

It has also highlighted the complexity of the themes by highlighting the interplay that moves between themes and introducing that of family as a thread that goes across many boundaries.

Chapter 10

Recommendations

Introduction

Salsberg and Quigley's (2017) study confirms that there remains a need to reframe sickness to health care within the rhetoric around older people and their requirements from a healthcare system, coupled with a necessity of educating the wider population on societal prejudice and discriminations to an ageing population. There remains what Kahn (1999) outlines as the nursing home symbolising "the eventual outcome of their struggle with old age" (p. 130). The nursing home remains a place where people are put to die or to be placed within for being deviant to the norm that society accepts. Social care is also where criticism is apportioned in regard to poor quality of care, including abuse, malnutrition and a high incidence of falls (Eldh, et al., 2019). There has been an intention from the current Conservative government to "fix" adult social care. The Build Back Better (DHSC, 2021) policy document outlined the introduction of a cap on lifetime care costs. The Health and Social Care Levy (HM Revenue & Customs, 2021) is proposed to raise £30.3 billion as a way of protecting health and social care bodies however, the majority of this levy raised money is signposted for the NHS, with £5.4 billion going to social care. With the increasing demand on social care services this is only an increase on current spending of 1.8 percent (Bottery, 2021). With fiscal issues constructing a bleak future for social care it should be noted that in order to challenge embedded beliefs on what a nursing home is and, assumptions about the people who reside and work there, there needs to be a radical break with the current neo-liberal care culture otherwise these beliefs will continue to be perpetuated. This will be difficult as there is a current societal norm that has a blindness to an ageing society. Rather than embrace ageing as a part of life where we can celebrate longevity, there is a cultural belief which has pre-defined old age as physical decline, illness and mental deterioration. There is a need for

intergenerational awareness that allows for a shift in the understanding and appreciation of the conception of ageing.

Integrated care and parity of esteem

As per other research studies (Spilsbury, et al., 2015), there remains a need for effective inter-agency partnerships as inter-agency working continues to be limited due to neo-liberal structures and policies. A realization of the full patient journey - from birth to death – needs to be understood and planned for within wider policies. Nursing home staff need to be a part of the wider dialogue concerning partnership working as well as being noted as an integral part of the healthcare family. The most recent white paper is from December 2021 and entitled "People at the Heart of Care" (DHSC, 2021). This paper (DHSC, 2021) outlines a 10-year ambition for the transformation of support and care within England whilst acknowledges the challenges currently in play in regards to integrated care. Whilst the Build Back Better (DHSC, 2021) proposes reforms that have real potential in improving access to care, the People at the Heart of Care (DHSC, 2021) does little to build upon these proposals. There is an intention that a further White paper is required on the integration of health and care services but this is not imminent.

There needs to be the same consideration for nursing home staff's ongoing professional learning and development as there is for staff working within the NHS. Collaboration between health and social care organizations need to promote true person-centred care. However, in order for this to occur this whole policy and ideological edifice needs to radically change. This will also assist in raising the value of those care workers who have chosen to work within the social care setting. There is currently a lack of coordination between services which leads to the biomedical approach rather than a relationship focus to person-centred care. The DHSC (2021) do outline that there will be monies available for better training of staff, a commitment to ongoing continuous professional development but, what is notable

absent, is a plan for the recruitment and retention of social care staff so it is envisaged that a recruitment crisis within the social care sector is somewhat inevitable.

Routinization

Resident's acceptance of their admittance to the nursing home is always precarious in relation to their risk of institutionalization and this is an area where the tripartite are conscious of but unable to change. This is because of where power lies within the system and this is not with the residents themselves, nor is it necessarily with those who work or even run the institution**.** This power resides within the regulatory processes and the institution's policies and procedures. Residents, relatives and staff have no choice but to abide by these regulations or compliancy becomes an issue**.** This is an element of their freedom which they are aware of but powerless to stop being reduced. This supports the earlier research by DeForge, et al. (2011) and Wiersma and Dupuis (2010) who outlined that residents themselves place themselves within the structures of an organization thus becoming institutionalised. There is a conformity that occurs but I suggest that it applies to the whole tripartite and not just residents (Wiersma & Dupuis, 2010). There was a routinization of care, although, as discussed within the previous chapter, this falls short of Goffman's (1961) description of total institutions. However, there is evidence of residents and relatives being in a set place which was pre-determined by the institution – mealtimes were spent in the dining room and visitors were received within the public areas, for example. Whilst there is no doubt that choice was offered to residents regarding tasks within tasks with the choice of meal, what to wear and where to sit wherever possible, these choices were always predicated as the routines were structured and determined by the home itself. Whilst Wiersma and Dupuis (2010) outline that "residents become institutional property….residents did not have a say over their own bodies" (p. 288) my research indicates that choice was not limited, wherever possible, and both through interviewing and observations, staff were

person-centred and relationship-focussed in their approach to care. There were interactions between staff and residents that were not merely about "care encounters" (Wiersma & Dupuis, 2010, p. 289):

Observation diary:

11am: Lounge area. Care assistant enters. Sits in a chair next to a male resident. Talks about residents previous job (surgeon) and asks meaningful questions of him. Lasts around 10 minutes

08.45am: Lounge area. Care assistant enters. Chats to a resident about their child's birthday the day before. Asks resident about their memories of their children's birthdays. Discussion ensues around how birthdays have changed over the years.

These types of conversations, and there were many observed, whilst occurring within the workplace, were not always within a direct care encounter. The conversations were borne out of a desire for human connectedness rather than an institutionalised interaction. These types of conversations were echoed within staff and relative interactions. Whilst I was observing within the lounges, conversations around family and friends were heard that were not based around surface tripartite interactions. There was a genuineness felt within the conversations of relationships that had been built up around the discursive nature of personhood rather than merely a disembodied notion of care. However, the emotional support of family when a relative is placed within a nursing home is under-researched.

There is a need to engage further with the current conceptualizations of care at a deeper and philosophical level. It can only assist organizations and staff that care for the elderly to be aware of how easy it is, at the point of care, to go one of two ways, that of institutional or meaningful. The care that residents are in nursing homes for inevitably involves the withdrawal of interaction. By ensuring that the interaction is humanised, meaningful, person centred and based fully upon resident choice, the less routinized and institutional care will be. Routinization of care could be replaced with an affirmation of dignity, personhood (Kitwood, 1997), power and control. This withdrawal of humanity is consonant with the commodification of all entities and meaning within a neo-liberal dynamic.

Compliancy

The inevitability of health and social care sitting within a legislative context means that the issue of compliancy sometimes carries with it a dynamic that reduces, or overtakes, any 'real' care involvement. Compliancy, whilst pivotal in shaping long-term care, can be seen to be obstructive in tolerating the fluidity of needs from this patient group. There is a frustration with some of the stringent requirements that the CQC have in place with the amount of reporting and paperwork being discussed most frequently within the interviews. For an individual nursing home or organization to survive there is an anxiety to meet the ongoing compliance and regulatory demands placed upon them which enforces a care structure that is highly commercialised. There is a risk of a two-fold event within nursing homes should compliancy be the fundamental structure by which to care for people. Firstly, there is a risk of a culture of compliancy that organizations become embroiled in which leads to the second issue, that of being afraid to care. Staff can feel that they are being watched to some extent which promotes a culture of fear and recrimination. This supports the earlier work of De Forge, et al. (2011) who researched staff's views on compliance within Canadian nursing homes. Nakrem (2015) highlights that the rigid requirements of compliancy can be an obstacle to the care home organization's ability to provide individualised care. Personal experience suggests that this is true as there have been times when I was expected or requested to undertake a task that was a requirement rather than potentially being in the best interests of a resident. For example, we had a well-known homeless person admitted for palliative care. He had been on the streets for many years and resided outside on the post office building by the air vents for warmth. When he was admitted to the home, he had his own room, a clean bed, his own bathroom, all of the things you would expect from a nursing home. However, he continuously tried to take the mattress off the bed and place it next to the radiator. This was what was normal for him, this was his choice and we ensured that he was comfortable and safe to meet his wishes. We were reported by a visitor for having somebody who was obviously unwell, lying on the floor of his room. We subsequently had an unannounced inspection and were strongly guided that this was not appropriate. Whilst we, as a care team, knew we were

fulfilling the patients' needs and wishes and the inspector probably agreed on a personal level but the issue of the legislative framework and need for compliance overtook the wishes of the resident. Compliance did not take into account the persons wishes and that there is a need for flexibility. Whilst there were no stories heard through the interviews that outlined the rigidity of compliance, there were instances of staff feeling unable to adjust their way of working due to the perceived obstacles put in place by policies and procedures based upon compliancy requirements.

Leadership within the care service is critical in ensuring the quality of service offered to older people and their families. Good leadership will only assist with the attrition of staff with Skills for Care (2020) advising that care homes with less turnover of staff have higher CQC ratings. With staff who are better trained, paid appropriately and retained can only lead to true co-production.

Expectations versus reality

We are in a situation because of the refusal to think about getting old. It is not on the agenda of a capitalist neo-liberal country to consider the inevitable fact that the place that you hold within this competitive world is not going to last forever. Whether this non-consideration is to do with ignorance or fear, it is an ideological refusal to engage with the reality which means that, if you go into a nursing home, there is a yawning gap which needs to be negotiated between the two worlds or 'normal' and 'nursing home'. This affects not only the people living in the nursing home but, potentially to a greater extent, the family visitors. This yawning gap can initially be addressed by the careful consideration of how a resident, and their family, are inducted into the home. There is standardized and routinized care that is in place, for reasons such as time and staff availability. If the reasons for this are fully explained, this would reduce the angst that can be demonstrated by relatives. There is an increasing need to engage with residents and families in a meaningful way to encourage empowerment and ownership of life choices.

In regard to staffing, there is a need to ensure that the positive outcomes of working within long-term care are available. The recruitment and retention of staff within social care is one of the leading issues within health services worldwide (Eldh, et al., 2019) and never more so than within the social care sector with 7.8 percent or 122,000 vacancies within England alone (Skills for Care, 2019a). The most current estimations for staff turnover within nursing homes is 31.5% (Skills for Care, 2019b) which, by any standards, is a frightening statistic, especially when the older generation are now outnumbering the younger. The data in this thesis has clearly demonstrated that whilst social care is seen as a Cinderella service, in this nursing home there is a commitment to personalised care and engagement with older people.

Compassion and understanding was demonstrated by care staff to both residents and family. Eldh, et al. (2019) talk about "establishing kinship with the older people" (p. 367) but this seems quite a cold terminology. A philosophical love was apparent throughout my observations and underpinned the dialogue within the interviews. This is a type of love that understands the contingent conditions. These conditions, different in each person, are difficult yet, through philosophical love, these can be accommodated by using "humanity to its maximum" (Hide, 2018, p. 8). I observed staff engaging with residents on an individual level and, there appeared to be a family-like relationship between the whole tripartite. As stated by Hide (2018, p.18) "Love forms the foundation of meaningful relationships and enables human beings to care about what happens to themselves and the people around them". For meaningful relationships to be built between staff and both residents and visitors, there needs to be a mutual trust. However, as Roche (2020) states "Love and solidarity are basic human needs that are consistently frustrated by capitalism" (p. 36) so within the structures that staff operate, this can be difficult to undertake and is not judged within compliancy requirements.

Covid-19

The Covid-19 pandemic coincided with the writing of the final parts of this work and statistics and information arising from this global pandemic have confirmed the general conclusions from my thesis which are; the under-resourcing of social care, a disregard for the care of older people and staff being under increasing pressures to care for people within structures not designed to support them. In line with these conclusions, deaths within care homes have risen to 159% higher to prior to the pandemic (The Health Foundation, 2020). The Health Foundation (2020) confirms that deaths within the care home setting outweigh those within other settings. However, deaths within care homes were not reported on from the beginning of the pandemic. There were a myriad of reasons for this but it appears to be because of the marked difference in priority between the NHS and the social care sector.

With the pandemic being a new and emerging danger to all, there were obviously specifics that were not known. In February 2020, there was guidance from Public Health England that face masks do not prevent the spread of respiratory infections and thus staff were not encouraged to wear them. Public Health England (2020) advised the following: "Currently there is no evidence of transmission of COVID-19 in the United Kingdom. There is no need to do anything differently in any care setting at present" (para. 18). Whilst this advice was withdrawn on the 13th March, 2020, the transmission had already occurred and would go on to infect over 40% of all care home settings within England (Booth, 2020).

On the 12th March 2020 Public Health England ceased testing within the community which, included care settings. Despite the knowledge that Covid-19 was particularly dangerous to those over the age of 65 years with co-morbidities (DH&SC and Public Health England, 2020), in an attempt to free up hospital beds, elderly patients were transferred to care homes without being tested for Covid-19. The testing for patients awaiting to be discharged did not come into force until the 16th April, 2020. Testing for staff has also proven to be a misnomer and even though scientific advisors such as Grassly, et al. (2020) have identified that weekly routine testing of health care workers reduces the transmission rate of Covid-19 by between a quarter and third, the government policy was to only test care home

staff and the residents living within the care home only when the person is symptomatic. Eventually, lateral flow tests were planned to be dispatched but again, there was an uneven distribution within care homes compared to the NHS (Booth, 2020).

Staff working within the care home setting were already positioned as marginalized compared to their NHS counterparts and now they are feeling the extra strain from a lack of resources and equipment. There have been issues over the supply of personal protective equipment (PPE) and some commentators have noted that some care workers have been victimised due to their working within care (Maben & Bridges, 2020). Staff are working in an environment of fear – fear of the illness, fear of recriminations, fear for their families and loved ones. It seems wholly out of touch for Public Health England to suggest that care home staff live-in for four weeks (Booth, 2020). Frustration is playing a part in undermining care home staff's morale. This frustration is due to a lack of their voices being heard at a higher level and a perceived discrimination towards them and their residents. There is currently a need to work in a different way than before, there is a need for creativity on behalf of the staff to nurse residents in a way that is safe for all involved whilst maintaining person-centeredness at the core. However, unless an entirely different method to this current neo-liberal approach to care is planned and undertaken, this is unlikely to happen. In lieu of this we can already see a new compliance has entered the already compliance-centric environment – that of social distancing.

Whatever the future may bring in regard to this pandemic there will need to be long-term recovery (Maben & Bridges, 2020) factored in. There will be a need for economic recovery but the longer terms effects on staff, residents and their families need to be considered, but will the space for this recovery also include the space to address the longer term effect. Whilst this is a time for recovery, the social care sector must take the initiative to work on public perception, which has altered more in these last few months due to the increased media coverage of this sector. There were outcries on the perceived discrimination between NHS staff and those who work within social care. This is an opportunity to

continue to raise the awareness of the public about this valuable sector of health care provision and

the time is now to ensure parity between all divisions of the health care service.

Chapter 11
Conclusion

Introduction

This thesis set out to explore the lived experience of the significant tripartite who come together in the unique setting of the nursing home. This arena indicates a tripartite who have a rich lived experience to share as these are individuals put together, through little choice of their own and who have little control over their lives. They live separately but come together within the arena of the nursing home, which is the end of the neo-liberal road of usefulness. The context of the nursing home has never been more valuable in today's society where there is an accelerating ageing population with an increase of complex co-morbidities. The process of considering the immediate pressures to ageing care and new knowledge of life working, living and visiting a nursing home has led to the formation of an important and original contribution to knowledge. This new knowledge has potential for not just the nursing sector but also spans other health care disciplines, fiscal interests and social policy as a whole.

Personal growth

My positioning as a registered nurse with history within the nursing home sector has both supported my research question and has enabled me to ask questions that researchers, not deeply rooted within the discipline, may have not perceived. I realised that there was a need for me to ensure perspective on my own analysis of the data. By taking some reflective time away from the data and then revisiting it allowed me to reflexively search for the voices that needed to be heard. I have been able to reflect, not only on the data, but make sense of my history as a nurse by utilising a Marxist lens thus

understanding that peoples agency was limited by the extent to which the free market dominated and pre-determined their choice.

Contribution to knowledge

Within the current literature there is a scarcity of evidence which utilises the tripartite of resident, visitor and staff to examine the lived experience within a nursing home setting. This thesis has not only contributed to this increasingly important area of health care but it has also highlighted the desperate state of social care today. We are all growing older and how we want to be looked after is for all of us to act upon now, before it is too late. This research does not represent tangential perspectives on policy: on the contrary, it goes deep into the lived experience of being within a nursing home as a member of the tripartite. The essentially commodified characterization of the individual as constrained by the forces of capitalistic policy detracts from the personalization of care and promotes stigmatization of the tripartite which will only serve a neo-liberal agenda rather than provide excellence in care, now and in the future, to this vulnerable population.

Parameters

The parameters of the study were organised around the length of time undertaken to gather observational data. Organizational events or variations to care that occur infrequently may have been missed. Despite my self-awareness of the possible subjectivity that I would bring to this research study my interpretations mays have caused some bias in the findings. Due to my experience within the sector under study there is a risk that my observations and thoughts related to analysis have been influenced by my professional knowledge. There were occasions where I really had to concentrate and understand that what was happening within an observation or interview was not everyday life, or to be accepted and not challenged. By not discussing the everyday or the accepted way of doing things

there would be a limited chance of widening understanding of the lived experience within a nursing home and no hope of challenging the current accepted culture to change and adapt.

There have been some emergent patterns in the data which are theoretically important however, the small sample size reduces the ability to generalise the results to a larger population. However, the themes which have emerged through this research are realistically applicable to other nursing home settings. It is envisaged that people interested in older people's care and the staff who work within this sector can take the themes and question their own practices as a minimum.

Conclusion

This study has given a unique insight into the lived experience of the resident, visitor and staff within a nursing home. It is imperative that future researchers within this field will consider the importance of all voices within the nursing home setting and utilise a tripartite approach to future work. This study makes a strong contribution to the existing literature on nursing home lives in general and, importantly, this research adds to the scarcity of literature on applying Goffman (1961) and his work on total institutions to nursing homes of today. There are recommendations for practice as well as further study. Some of these recommendations echo what researchers have been suggesting for a long time whilst others are new and based upon contemporary issues that nursing homes are facing today.

All the statistical evidence points to a future where there is an ageing population with increasingly complex co-morbidities which will be situated within the reality of a decreasing younger population. Whilst we are aware of the proposed demographics there is little definite known about the needs and expectations of this growing elderly population, all we have is current data and information that could be transposed and, suppositions based on current trends. From this research, a greater understanding of the interplay between the tripartite of resident, family and staff within a nursing home setting has

been provided but it has also highlighted complex differences between the preferences and expectations of each group.

It is crucial that the organizations that provide care are flexible to the upcoming demands of an ageing population. There is a need to provide a standard of care that meets expectation of the resident and their family whilst apportioning adjustments to meet the needs of regulation. This is no easy task due to the ingrained culture within nursing homes and the lack of resources that the social care sector has at its disposal.

Relationship-based care is a way of ensuring that resident's physical and psychological needs are best met whilst allowing for empowerment for their own decision-making. There is value in ensuring that family members are included within the relationship which will assist in their own emotional well-being.

There is also a need for a sustainable and integrated workforce. There needs to be a cultural change to the way in which staff are acknowledged as providing an important and integral area of care within the cradle to grave belief of health care. Accompanying this is the need to reframe social care within societal understandings. This will be a complex undertaking due to the ingrained social misconceptions that abound.

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Appendix 1: The doctoral journey through study.

PR7001. Research Methods for Professional Enquiry.

Assignment title: Component 1- discussion of the philosophy and theory of selected methodological paradigms appropriate to a given research question arising from practice. Component 2 – Research report on the application of a selected research methodology to a small scale enquiry within a practice/professional setting.

Component one considered the preceptorship process within the company I worked and how the efforts of recruitment and retention of inductees via an organizational socialisation approach worked within a case study approach of five new recruited preceptees. Within this initial assignment at the very beginning of my doctoral journey I was reacquainted with research terms and remained firmly ensconced within the qualitative paradigm.

Component two considered the work of Bourdieu (1977) and the notion of habitus in regard to the socialisation process of preceptees. I undertook a narrative analysis on the transcripts from interviews. The themes that occurred were around the academic experience and the social experience.

PR7002. Social Theory and Education. Key Issues and Debates.

Assignment title: Component 1 – a review essay of selected readings in social theory. Component 2 – an essay examining and discussing implications of applying selected theories to your professional context.

A tentative step into the world of phenomenology and hermeneutics was undertaken within this assignment to look at the Cavendish Report (2013) from the perspective of the social care workforce. Wenger's (2000) work was utilised in regard to the community of practice that health care workers belong to and the prejudices that social care staff encounter against those that work for the NHS. There was an attempt to use Gadamer's (2004) work of fusion of horizons concept the guide the review of the Cavendish report and applied each of the concepts aligned with this to discuss issues arising.

PR7003. Policy Analysis for Integrated Services

Assignment title: Oh Matron – From Hattie to here.

This assignment investigated how policy had impacted on the nursing profession throughout the years. Health policy was analysed and regarded through a lens of current instability within the nursing profession which has a diverse workforce and how it had impacted on the rhetoric around the ideology that surrounded the NHS. An archaeology of the nursing was undertaken which explore the origins of nursing through to how each government had impacted upon the HNS with their individual social policies. This work concluded with how I had played a part in the new discourse around the nursing family as part of the government's Trailblazer groups.

PR7005. Creativity in practice.

Assignment title: The Chair

This assignment explored the use of creativity within my scope of professional practice. At this time, I worked within a care company which had specialised dementia units. I explored the meaning of creativity between and amongst people living with dementia. This assignment was in two parts- firstly a creative output with a second part of writing about the process.

I adopted the extended phase model of Cropley and Cropley (2008) to elucidate my personal creative journey. "The Chair" was the final output of the creative process. The chair was symbolic of an older person – sourced from a charity shop (old and thrown away), removed from a set (taken away from family) and sanded down (removal of past identity). The poem "Kate" was then placed on the underside of the chair seat as an invitation for a person to use the The Chair as a way of asking what they see within a dementia unit. Black and white photographs, taken from within a dementia unit, were then placed onto the chair. The photographs were black and white to denote the bleakness that people think exist within nursing homes. There were then coloured words inviting people to sit and explore "What do you see". The letters were taken from newspapers and magazines as a representation of people's perceptions that people living with dementia use other people's words. Overall, the assignment was about creative moments linking all people together – residents, staff and visitors. This assignment was adapted and was submitted for submission to The Journal of Dementia Care. It was published in the journal, along with the photographs in the July/August 2016 edition. Please see Appendix 2.

PR8001. Thesis in Context

Assignment title: Revolution or Evolution: Redefining Care and Aligning the Social Care Workforce for a New Healthcare Landscape

Following on from a presentation outlining the precept of the proposed thesis, this research project assignment outlined the precis. Critical ethnography was discussed as a methodology for the thesis which was to: explore the ideology of care within a nursing home; the role of nurses and health care workers; how the care home can meet the challenges of an adequate care workforce and; the care home environment being positively promoted as essential part of the wider healthcare arena. Data collection was proposed and the issue of co-creation of evolving knowledge between myself and the participants was explored.

PR8002: Institutions, Discontinuities and Systems of Knowledge.

Assignment title: Do you know me? Studying the self in people with dementia

This assignment utilised in-house audits that, in part, evaluated the type and quality of communication that occurs during "normal" working practice within one of our dementia units. There was a concentration on the results for the maintenance of identity for people living with dementia and the inclusion of this group within a society. The assignment considered the concepts of self and personal identity as well as investigating the negative regard in which people living with dementia have within society.

Appendix 2: Published work
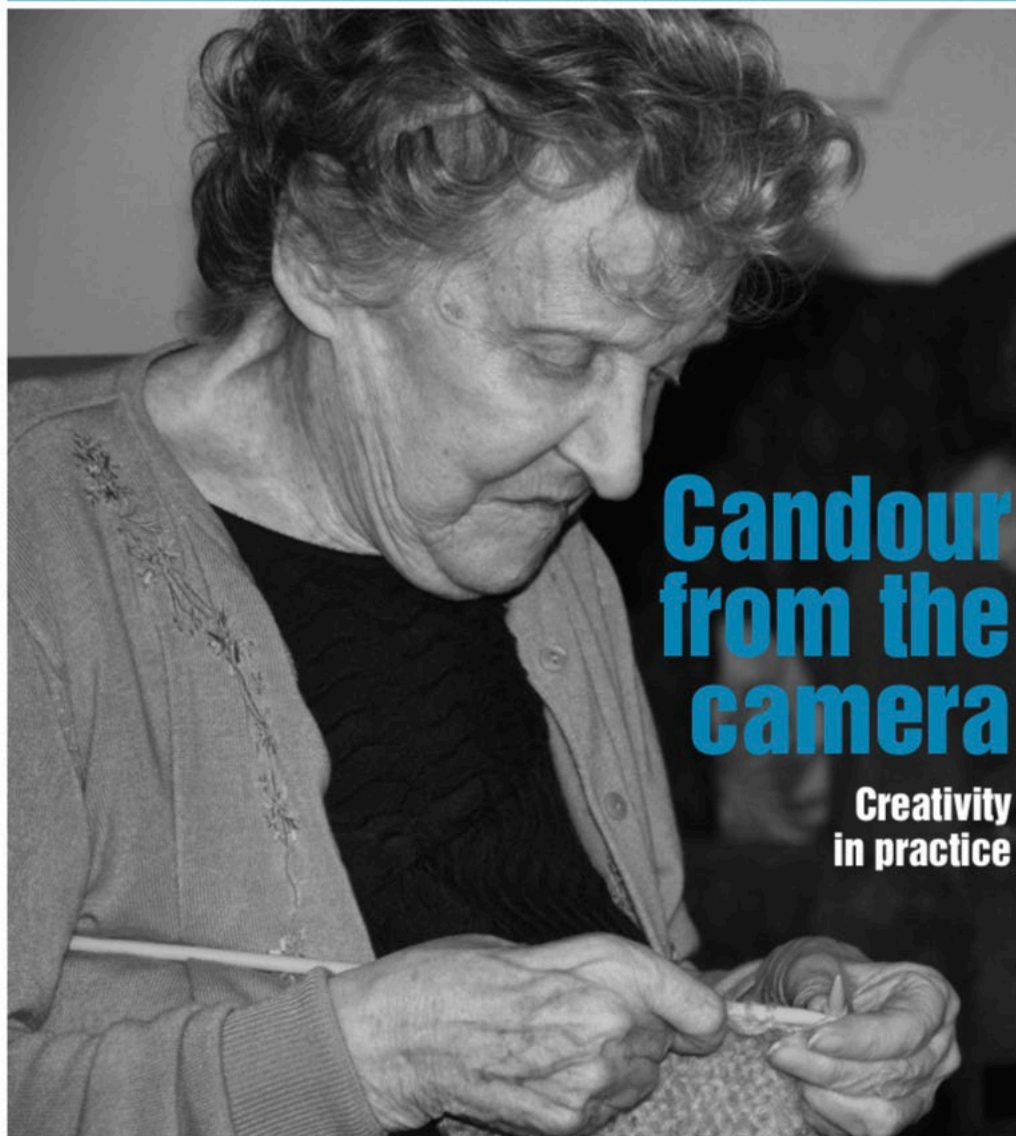
Candour from the camera

Creativity in practice

Also inside this issue: ■ Dementia among gypsies and travellers ■ Sensory stories ■ Learning from Japan: social projects with business links

We can all act as agents of creative change.

Kate Mansfield-Loynes, Trish Morris-Thompson and Di Marks-Maran

Kate Mansfield-Loynes was formerly head of trainer development at Barchester Healthcare and is now senior lecturer at the University of Chester; Trish Morris Thompson is director of quality and clinical governance and chief nurse at Barchester Healthcare; and Di Marks-Maran is honorary professor of nursing, Kingston University and St George's University of London.

Dementia research has primarily focused on a cause and cure. Although there is a recent interest in the subjective experiences of people living with dementia, such studies tend to be marginalised in the scientific community. But account should be taken of the deterioration of verbal abilities, memory and abstract thinking as dementia progresses, and attention given to developing alternative and effective interventions to work creatively and therapeutically.

The first part of this article briefly explores creativity and dementia, especially in care homes. The second part presents a case example of how one member of staff in a care home setting used photography to observe, from sitting in a chair and photographing residents in a dementia unit. The intention was not to draw out creativity from the residents but rather to observe through photographs what it was like to live with dementia.

Of people living in care homes 80% have a form of dementia or severe memory loss (Alzheimer's Society 2013). Exploring ways to understand and work through the resultant emotions and distress associated with dementia is essential to the enhancement of the wellbeing and fulfilment of those who live with it.

In the literature many authors have offered definitions of creativity, but one that seems appropriate to nursing practice is from Cropley and Cropley (2008): *"Creativity requires doing things differently from the way they are usually done or even defying the norms of society"* (p 360). This definition is not based on individual genius or arts and crafts, but refers to undertaking a usual process differently. Creativity in dementia care practice can be found in progressive dementia care units where one can observe care assistants and nurses creatively interacting and working. Killick and Allan (1999) argue that arts in dementia should fall into the creative leisure activity category, *"generating a sense of enjoyment and satisfaction"* (p35) while enabling emancipatory potential (Radley & Bell 2007).

Odell-Miller et al (2006) emphasised the potential of art for non-verbal communication and Hirsch and Meckes (2000) suggested that art empowers others through treating the person holistically rather than just the illness. If the person living with dementia is unable to fully participate in art, even engaging as a passive observer of a creative activity inspires hope and restores optimism (Rockwood Lane 2005). For people with dementia the creation of artwork is a means of expressing emotion rather than the production of great works of art; all people living with dementia can partake. The lead author (Kate Mansfield-Loynes) has recently worked closely with the dementia specialist team in Barchester Healthcare to formulate a range of training programmes linked to person-centred care in dementia, specifically in Barchester's "Memory Lane" dementia homes.

Creativity and care

In these Memory Lane units creativity involves the ability to produce something that is both original and appropriate for the goal for which it was designed (Mumford 2003), in this case individualised care for the person with dementia. For people with dementia there is no textbook that explains their thoughts and feelings. In the Memory Lane units, staff 'go with the flow' with residents, every

behaviour displayed being taken as a manifestation of something the resident is attempting to communicate to those around them. Staff continually do things differently for each resident. When people walk into a Memory Lane unit it might appear that staff and residents are behaving outside the norm as a way of providing care that is person-centred, encompassing respect, encouraging independence, supporting personal choice, maintaining dignity and finding ways to ensure enjoyment and fulfilment.

Memory Lane communities practise what Csikszentmihalyi (1996) terms "sociocultural validation". The creativity of these communities is communicated – and this communication is crucial – through research-based practice and home design, and then what has been created is evaluated by residents and their families and by staff. When the results are positive this evaluation provides sociocultural validation, which can also be demonstrated by simply sitting with a new resident to listen to what they are seeing and feeling. According to Csikszentmihalyi (1996), if it is not communicated it cannot be effective creativity, no matter how innovative. Interest has grown recently in how creative pursuits can regulate emotional processing in dementia. Rockwood Lane (2005) suggested that creativity can "heal by changing a person's physiology and attitude from one of stress to one of deep relaxation" (p122). Mimica and Kim (2011) postulated that art therapy may be of benefit for people living with dementia as a way of reducing stress-related behaviours. Riley et al (2009) made similar suggestions through the creative use of music with people with dementia. So it looks as though creativity could play a role in reduced medication, improved stress-relieving practices, behaviour modification and enhanced person centred care by *offering pleasurable, engaging and meaningful self-expression* (Harlan 1990, p103).

Unfortunately, according to Beard (2011), studies have demonstrated that individuals with dementia in long-term care settings spend the majority of their time in passive care rather than engaging in creative activities. However, it must be said that the relationship between dementia and creativity is inherently complex. Palmiero et al (2012) say that:

 • creativity diminishes over time in dementia

 • creativity may nevertheless help people to express their own emotions and wellbeing

 • the right hemisphere of the brain and, in particular, the prefrontal cortex, appear to be essential for creativity.

 Creativity is not a panacea for all people living with dementia, but it does have the potential to offer ways of expression where gesture, movement and vocalization make communication sense. In a dementia setting creativity can be viewed as an expression of the most internal states that cannot be expressed in any other way (Palmiero et al 2012). Creative endeavours stimulate the hypothalamus and activate the autonomic nervous system, which balances and maintains blood flow, heart rate and hormone level (Rockwood Lane 2005)

Case example: creativity in practice

This case example is told in the first person as it is Kate Mansfield-Loynes' personal account of her project. The project was designed to photograph dementia from the perspective of the residents in one of the Memory Lane care homes, or in other words, by sitting in a chair and photographing how residents and staff communicate with each other, often in creative ways. The photography project was undertaken as an assignment about creativity in my doctoral studies and was done with the permission of everyone concerned and in keeping with the care home's policies. The aim was to display the resulting photographs in the care home.

In thinking about how to undertake the project, I happened across the idea of a chair. The work of Cropley and Cropley (2008) on the extended phase model of the creative process was adapted and enlarged upon by myself for this project. This is shown in figure 1. I added the extra column on the right hand side of figure 1 (creative approach). As outlined by Cropley and Cropley (2008) this process can look simplistic, but it has enabled me to put my cluttered ideas into an order that illuminated my thought processes. Many of the phases have double and even triple-looped as the process advanced.

Creative process

"The Chair" was where I sat to take the photographs. I chose this particular chair as a metaphorical representation of common misconceptions of older people in care homes. The chair in the photographs was sourced from a charity shop (i.e. it was old and thrown away), it was taken from a set of three (it was taken away from its 'family'), and it was sanded down (removal of past identity often associated with dementia).

A poem was placed on the bottom side of the chair. This poem, "Kate", (in Bornat (2005), reproduced almost in full on p27 opposite) has unknown origins but probably dates back to the 1970s. The story about which the poem was written is that of an old person who is dying. On clearing out her personal belongings, the poem is found. The verses contrast her identity from her past life lived with a present identity defined by mental and physical frailty. Due to the length of the poem, I only used the first verse. Again, my decision to place it on the bottom side of the chair was metaphorical as the poem focuses on the hidden person; it acts as the opposite of what I would like people to do with regard to people with dementia – to sit and see, as I was doing in this photography project.

The photographs were taken in black and white to portray the bleakness that is often envisaged when imagining residents living in care, but also to portray the tendency to see dementia in black and white terms. Following the advice in Davis Basting (2009) I wanted people to engage with the photographs and appreciate that dementia is not black and white; the experience of memory loss is, in fact, shades of grey. Davis Basting argues that we need to be in touch with the grey and "keep our eyes and hearts open for moments of grace" (p156).

My original intention, agreed with the care home, was to sit in one position for a couple of hours and take a photograph every minute. However, this is not what happened! When I arrived, many of the residents were excited to be the focus of attention and those who didn't have the ability to remember I was coming soon took an interest in the large camera. I was invited by them to "come with me" and "look at this," so I did. It would have been unfair to everyone for me to remain the impartial viewer of their day. In the end, this was a great decision as I had enlightening conversations, viewed residents' own works of art and became part of their world for a brief moment in time. This was made all the easier by the welcoming staff.

My aim was to deal with the ideas of memory, dignity and transience in a direct and powerful manner in a medium that portrays individuals in an honest light. Throughout the photographs (shown on p25 and the front cover of this issue) there are many symbolic activities employed by the residents in the construction of meaning, not only about their world but about themselves (Bruner 1990). For example, the lady with a seemingly random tattered pile of magazines and papers had in fact carefully sorted through them, selected the ones she preferred and carried them with her, guarding them with her very being. The essential human need for togetherness and touch was captured in a moment between two residents. The need to create 'something' themselves was witnessed through residents knitting, a pastime now but essential in their younger days to clothe their children. What emerged from the

photographs was an understanding that people with dementia and staff caring for them demonstrated their own creativity in their day to day activities and in the way they communicated with each other.

Relational art

Relational art is "[a] system of encounters which takes being together as a central theme, the 'encounter' between beholder and picture and the collaborative elaboration of meaning" (Borriaud 1998). While I appreciate that "The Chair" is just a chair and it only works as a piece of art if people engage with the photographs and its format, it can be argued that it is fused with the real life experiences (Bishop 2004) that occur every minute of every day in the Memory Lane units. This links with Gillick (2010) who argues that the presence of an audience is an essential component of art. As Gillick puts it: *My work is like the light in a fridge, it only works when there are people to open the fridge door. Without people, it's not art – it's something else – stuff in a room* (Gillick 2010, p 26).

I had hoped that the photographs would act as an inspirational piece, highlighting creativity and excellent care, and making a space for new thoughts and critical speculation on dementia care in general.

Artefacts as a creative outlet

In the Memory Lane units, a variety of dementia-specific mixed or miscellaneous activities are employed including doll therapy, multi-sensory experiences and combination therapies. Regardless of the type of creative activity, flexibility must be part of it. People living with dementia are individuals and do not become a homogeneous group just because of a dementia 'label'. As Goldsmith says: *There is something about engaging with people with dementia which is very humbling. They draw us into a world in which we recognise the limitations of our own power and competence. We are forced to face up to parts of ourselves that we often prefer to remain hidden, and they invite us to respond to them in ways which take us by surprise* (Goldsmith 2005, p10).

Human memory is inherently complex, but creative moments can link preserved function if the right set of circumstances or the right stimulation is provided. Artefacts placed around the home can be as simple as newspapers and knitting wool, as demonstrated in the photographs. They can serve as a catalyst to enable past associations and as an outlet for creative expression so that people can be heard and valued. Potential opportunities for creative expression are numerous but often neglected. Flexibility is required instead of a 'one size fits all' mentality. The photographs demonstrate how this creative expression can be captured and how stimulated people can be by it. When people are allowed to *live with* dementia, utilising various life-enriching creative activities rather than exclusively fighting against the condition, it can become a manageable disability rather than a social death sentence. As nurses and carers we can act as agents of creative change.

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We can all act as agents of creative change

Creativity in nursing practice can offer innovative ways to people with dementia of expressing emotion and generating a sense of enjoyment and satisfaction. **Kate Mansfield-Loynes**, **Trish Morris-Thompson** and **Di Marks-Maran** explain, using the example of a unique photographic project.

Kate Mansfield-Loynes was formerly head of trainer development at Barchester Healthcare and is now senior lecturer at the University of Chester; Trish Morris-Thompson is director of quality and clinical governance and chief nurse at Barchester Healthcare; and Di Marks-Maran is honorary professor of nursing, Kingston University and St George's University of London.

> The intention was to observe through photographs what it was like to live with dementia